National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[E] Enabling and supporting effective advocacy

NICE guideline NG227

Evidence reviews underpinning recommendations 1.5.1 to 1.5.4, 1.5.7, 1.5.8, 1.5.9, 1.5.11 to 1.5.16, 1.4.5 and 1.1.2 in the NICE guideline

November 2022

Final

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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Contents

Enabling and supporting effective advocacy

Key theme

- Enabling and supporting effective advocacy (for example, time, approach, environment, including virtual and non-face-to-face services)

Introduction

The aim of this review is to identify ways to enable and support effective 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 review 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	Enabling and supporting effective advocacy (for example, time, approach, environment, including virtual and non-face-to-face services)

Methods and process

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

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

Effectiveness evidence

Included studies

Existing NICE guidelines

Existing recommendations relevant to enabling and supporting effective advocacy were identified from 6 NICE guidelines ([CG120] Coexisting severe mental illness (psychosis) and substance misuse: assessment and management in healthcare settings, [NG86] People's experience in adult social care services: improving the experience of care and support for people using adult social care services, [NG108] Decision-making and mental capacity, [NG150] Supporting adult carers, [NG189] Safeguarding adults in care homes; [PH28] Looked after children and young people). 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, welfare and criminal justice domestic staff). Only NG86, NG108 and 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.

Three documents were identified for this review (Lawson 2017, Newbigging 2012, Ridley 2018).

One document focused on people detained under the Mental Health Act 1983 (Newbigging 2012). One document focused on those who have duties to commission and arrange advocacy services for safeguarding adults (Lawson 2017). One document (Ridley 2018) focused on 3 different populations: African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; and children and young people receiving advocacy services.

Excluded studies

Formal consensus

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

Summary of included studies

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

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

Document	Population	Evidence base
Lawson 2017 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
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
Ridley 2018 Review of 3 qualitative studies England	African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; children and young people receiving advocacy services	Comparative analysis and synthesis of findings from 3 qualitative studies (including service user, advocate, professional and commissioner perspectives); data collected through focus groups and/or interviews

IMHA: Independent Mental Health Advocate; LGA: Local Government Association; NHS: National Health Service

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

Summary of the evidence

Existing NICE guidelines

A total of 9 existing recommendations related to enabling and supporting effective advocacy were identified from the 6 NICE guidelines. The committee agreed all 9 recommendations should be adapted for use 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

One included document (Lawson, 2017) was assessed using AGREE II, 1 document (Ridley, 2018) was assessed using the Risk of Bias in Systematic reviews (ROBIS) checklist and 1 included document (Newbigging, 2012) was 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 11 statements in round 1 of the formal consensus exercise; responses were received from 12 of 13 committee members. Eight of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Two statements had between 60% and 80% agreement and were re-drafted for round 2. One statement had <60% agreement and was 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 2 statements in round 2 of the formal consensus exercise; responses were received from 12 of 13 committee members. Both statements reached ≥80% agreement and were included for the discussion with the committee.

See appendix G for the statement that was rated by the committee and results of round 2, which are provided in Table 11.

Economic evidence

Economic consideration 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. Therefore, some domains of ROBIS may be less relevant for these documents and they would not have followed reporting guidelines for systematic reviews. The AGREE II instrument is intended for use assessing the quality of systematically developed clinical practice guidelines, including assessments of methodological rigour and transparency. 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 1 document (Lawson, 2017) was assessed using the AGREE II instrument. High quality documents were defined as those where any two domains scored ≥ 70%. The document was not deemed to be high quality. The included document scored 22% for stakeholder involvement and 4% for applicability. The document scored 8% for rigour of development and 0% for editorial independence. Overall, the document did not provide sufficient information on the stakeholder involvement in the development of the document. There was some mention of potential tools provided but no information on the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the document. 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 document scored 61% for scope and purpose, and 22% 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 1 document (Ridley, 2018) was assessed using the ROBIS checklist for systematic reviews. The document was judged to be at high risk of bias because of a lack of clear reporting or an absence of reporting about eligibility criteria. Other concerns related to insufficient information on study selection, lack of critical appraisal of included papers, and an absence of testing the robustness of the review findings.

The quality of 1 document (Newbigging, 2012) was assessed using the CASP checklist for qualitative research. The document was judged to have minor methodological limitations.

Benefits and harms

Identifying the need for advocacy and allowing sufficient preparation time

The committee agreed with the existing recommendation from the 2010 NICE guideline on looked-after children and young people [PH28] that children and young people need to have enough notice of planned changes and review meetings to arrange advocacy support. However, the committee agreed the recommendation should be broadened to include all populations needing advocacy support, because in their experience the benefits, such as people being able to effectively participate in decision making, are needed across the wider population of people requiring advocacy services. Furthermore, the committee agreed that several steps were needed to ensure that not only do people have enough notice of planned changes to arrange an advocate, but that there is sufficient time to appoint and meet with an advocate to ensure that the support is effective. These steps are discussed in detail below.

Further details about the committee's decisions to adopt or adapt existing NICE recommendations in the area of enabling and supporting effective advocacy are given in appendix F.

Firstly, the need for advocacy should be identified as early as possible and a referral made to advocacy services without delay. 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 effectively participate in decision making. The Care Act (2014) specifies that the local authority must consider whether people would have substantial difficulty in understanding, retaining and considering information, and communicating their views, wishes or feelings at the point of first contact. If they are likely to have substantial difficulty in any of these areas and do not have an appropriate person to support them, an independent advocate must be appointed. Whilst legislation notes under which circumstances someone is legally entitled to an advocate, the committee agreed that referral should happen as early as possible once determined that they are legally entitled to an advocate and the need for advocacy had been identified, regardless of the circumstances.

Secondly, once an advocate had been appointed, there needs to be adequate time for people to prepare with their advocates ahead of meetings. This was also supported by two existing recommendations from the 2018 NICE guideline on people's experience in adult social care services [NG86]. Given the potential for restrictions to peoples' rights, freedom and individual liberty and the serious consequences of the decisions being made, proper preparation and consideration is needed to ensure the best outcome for the individual. However, in the committees' experience this is not happening consistently enough at present. The committee agreed that it is difficult to specify how much time is needed as it is dependent on the circumstances and needs of the individual, for example if they need an interpreter. However, giving the person enough time to prepare with their advocate should give them maximal opportunities to be involved and participate in meetings and decision-making and enable them or their advocate to communicate the outcomes they want to achieve. For example, people need to agree with their advocate what will be communicated during the meeting, and by who. The committee agreed that it is equally important that there is enough time for the advocate to build up trust with the person they are supporting and to get to understand their communication needs, wishes, and preferences where the advocacy is non-instructed. The committee acknowledged that advocates might need to take additional steps, such as talking to family members and carers, to develop an understanding of the person's likely wishes, feelings and desired outcomes in these cases. One of the existing recommendations from the 2018 NICE guideline on people's experience in adult social care services [NG86] also covered ensuring people had enough time to meet with their advocates after meetings to ensure they have understood the outcome. The committee agreed that it is considered good practice to check that the person understood the outcome and is able to express their feelings about it and raise any further concerns; however, this does not happen consistently. The committee discussed that it may not always be possible for people to understand the outcome, for example in cases of non-instructed advocacy where people lack capacity, but that advocates should ensure that they are supported to understand the outcome as far as is possible.

Rearranging meetings

While the committee agreed that the recommendations above should ensure people have enough time to appoint an advocate and prepare with them ahead of meetings, in the committees' experience a lack of time to prepare often occurs because of poor planning, other urgent commitments and competing demands, and service pressures. Also, advocates may be unavailable due to periods of absence. Therefore, the committee agreed it was important that people are given the opportunity to rearrange meetings if they did not have enough time to prepare with their advocate. In a case when a person is unable to instruct their advocate to rearrange a meeting, the advocate will need to decide whether to request a rearrangement or not. Similarly, where people are unable to instruct their advocate to attend meetings, the people arranging the meeting should invite the advocate, or advocates may need to invite themselves. In the committee’s experience even when advocacy is non-instructed it is important that the person has enough time to build up trust with the advocate, so the person can clearly communicate with the advocate, which should help to build more effective advocacy.

Involving a person’s advocate in discussions

The committee agreed that the existing recommendation from the 2018 NICE guideline on decision making and mental capacity [NG108] about involving an Independent Mental Capacity Advocate (IMCA) in the process until a decision has been made should not be limited to IMCAs but should equally apply to any type of advocate. The committee agreed to broaden this recommendation, because in their experience the benefit of advocates having sufficient time to consider and challenge decisions and outcomes, should be experienced equally by people, regardless of the type of advocate they have. The existing recommendation was that the IMCA should stay involved until the decision has been implemented fully. However, this is not a requirement in the Mental Capacity Act (2005). Instead, the committee agreed that the decision needs to be communicated with the individual and advocate and sufficient time provided for them to consider the decision and outcome and to have the opportunity to challenge these. The committee also agreed that the wording of ‘instructed’ should be removed from the recommendation as this recommendation should also apply for non-instructed advocacy. In the committees’ experience, this is required in practice but does not always happen and therefore there is no opportunity to challenge the decision. The committee agreed that it is important for a person to understand the agreed outcome so that they can raise any further concerns they might have.

Facilitating advocacy

The committee agreed that the existing recommendation from the 2011 NICE guideline on Coexisting severe mental illness (psychosis) and substance misuse: assessment and management in healthcare settings [CG120] about healthcare professionals working collaboratively with the voluntary sector should be reworded to focus the recommendation on working with advocacy services specifically and should have a broader focus than people with psychosis and substance misuse. The committee agreed about the importance of applying this more broadly because in their experience the benefit of enabling effective advocacy through health and social care practitioners working collaboratively with advocacy services even after referral, are needed across the wider population of people requiring advocacy services. Further, the committee agreed that this recommendation did not provide enough detail about how this should be done so based on the committee’s experience they expanded the recommendation to include examples of how health and social care practitioners should facilitate advocacy. In the committee’s experience, health and social care practitioners are often busy and may sometimes assume that once they have made a referral that their job is completed; however, their ongoing support is necessary to enable effective advocacy to take place. There are also variations in practice about how well health and social care practitioners are currently facilitating advocacy. The examples given in the recommendation are based on the committee’s experience of actions that would help facilitate advocacy. The existing recommendations from the 2021 NICE guideline on Safeguarding adults in care homes [NG189], about practitioners building effective working relationships with advocates, and the 2010 NICE guideline on Looked after children and young people [PH28], about ongoing contact with advocates, were also incorporated into this recommendation. Specifically, the committee agreed that building good relationships should be encouraged at the start of the process by practitioners and advocates engaging in dialogue on the different roles and how they will work together.

Remote communication

Further, the committee agreed, based on their experience, that more support is needed to enable people to communicate remotely with their advocate. The committee were aware of instances when people have not been supported to access remote systems and this has led to meetings not going ahead. The committee agreed that effective advocacy services cannot be delivered if advocates are unable to meet with a person and resources are being used inefficiently if meetings are unable to go ahead or have to be rescheduled.

Raising concerns

The committee agreed that the existing recommendation from the 2020 NICE guideline on Supporting adult carers [NG150] about social care practitioners recognising the contribution of advocates if carers choose to have one should be broadened so that it covers recognising the contribution of advocates for all people accessing advocacy and to provide more detail about the required action. Based on the committees' experience it is important to apply this more broadly, because the benefits of the advocacy role being carried out more effectively are needed across the wider population of people requiring advocacy services. Therefore, the committee agreed to reword the recommendation so that health and social care professionals ensure that all concerns raised by the person, or on their behalf, are understood, responded to, and recorded. The committee agreed this is essential to ensure that the advocacy role is being carried out effectively and appropriately.

Auditing and monitoring advocacy services

Based on their experience, the committee made recommendations about health and social care providers auditing and monitoring advocacy services. In the committee's experience, there is wide variation in referrals for statutory advocacy, demonstrating that non-compliance with legal duties is common. Health and social care providers auditing and monitoring advocacy services in addition to commissioners (see evidence review K) may help to identify any gaps in complying with duties to refer earlier or recognise things that could be missed if only commissioners were monitoring this as their auditing and monitoring is likely to be more fine-grained and will occur earlier in the process. The committee also recognised the importance of health and social care providers developing actions plans to improve compliance in order to address any issues found during monitoring and bring advocacy services up to the standard required by the legislation. Further, the committee agreed that including the numbers of referrals in their corporate performance information would help to highlight obvious discrepancies between the amount of advocacy commissioned and the number of people supported.

Safeguarding concerns

Statement 7 focused on empowering staff to report and act on concerns. The committee acknowledged that the statement had been extracted from a document judged to be of lower quality. However they were in full agreement with the statement and because their own knowledge and experience chimed with the point being made they concluded it would be important to make a recommendation on that basis and that the benefits of doing so outweighed any risks of excluding the statement altogether. In the committees' experience, identifying and acting on safeguarding concerns is a crucial part of the advocacy role that is being implemented inconsistently. The committee agreed that advocacy providers ensuring that advocates know when and how to report and act on safeguarding concerns would help empower them to act on concerns and, therefore, should increase the protection of individuals who are at risk of abuse.

In the committee's experience, there is variation in the quality of safeguarding. Therefore, the committee agreed that additional guidance was needed for advocacy services on how they should ensure that advocacy staff are delivering effective safeguarding in order to maintain a high and consistent standard. The committee agreed, based on their experience, that robust internal guidance is needed to ensure that everyone is working in a consistent way and to the required standard. Similarly, it is important that services have a safeguarding lead so that it is clear who has the overall responsibility for this and that there is a point of contact for when people need additional guidance and support. The committee were aware that a safeguarding lead is already part of many local safeguarding policies but agreed to emphasise the need for this role to help prevent poor practice. In the committee's experience, keeping detailed, contemporaneous and accurate records is part of good practice but it is not happening consistently. This is crucial not only for carrying out the safeguarding role itself but also for enabling the tracking and monitoring of concerns, systems for learning from adverse events and the sharing of information with other agencies, such as safeguarding adult boards. In turn, these are necessary to ensure that concerns are addressed in a timely manner and do not escalate, and to safeguard against similar issues occurring in the future. As described above for advocacy support more broadly, the committee agreed that it was important that advocates are involved throughout the process in order to ensure that people understand the outcome and have the opportunity to challenge any decisions or raise further concerns they might have. Finally, the committee agreed that training and supervision is required to ensure that people are performing the role in a consistent way, and to a high standard (see evidence reviews I and J for further recommendations about training).

Making complaints

Statement 10 focused on making complaints procedures and guidance available and accessible to people. The committee acknowledged that the statement had been extracted from a document judged to be of lower quality. However they were in full agreement with the statement and because their own knowledge and experience chimed with the point being made they concluded it would be important to make a recommendation on that basis and that the benefits of doing so outweighed any risks of excluding the statement altogether. The committee agreed that it was important that people know how to make complaints about advocacy services but were aware of existing recommendations on assisting people to make complaints in the NICE guidelines on people's experience in adult social care services [NG86], patient experience in adult NHS services [CG138] and service user experience in adult mental health [CG136]. Therefore, the committee agreed to cross-refer to the existing guidelines rather than make a new recommendation and to move this recommendation to the area of legal right (see evidence review A)

Continuity of care

The existing recommendation from the NICE guideline on people's experience in adult social care services [NG86] covered commissioners and managers in all settings ensuring there is continuity in care. This recommendation relates to statement 25 in improving access to advocacy (see benefits and harms section in evidence review D), which 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 to combine the existing recommendation and statement 25 to inform recommendation 1.4.5 in improving access to advocacy (see benefits and harms section in evidence review D).

Statements that were not used in this guideline

There were a number of statements carried forward to committee discussions that were not used to inform recommendations. Statements 1 and 2 were not used to inform recommendations as the concept of mental health service providers and commissioners supporting the delivery of IMHA services are covered by the recommendation discussed above about how health and social care practitioners should facilitate advocacy and these statements did not provide any additional information about how this should be done. Statements 4 and 5 were not used to inform recommendations because they did not provide enough detail to inform what action should be taken. Statement 8 was not used to inform a recommendation as the committee did not think the action in the statement was the responsibility of advocacy services. Statement 6, which is about the advocacy sector focusing on developing staff to recognise situations where there is potential abuse, was covered in the recommendation 1.9.3 (see evidence review I), so an additional recommendation was not made based on this statement. Statement 9 which is about the advocacy sector engaging with and including people so that advocacy and safeguarding services are influenced by the people using it was not used to inform a recommendation as the concept of co-production is covered by recommendation 1.8.5 in planning and commissioning (see evidence review H). Statement 11 which is about the views of advocacy providers informing development of safeguarding services across organisations was not used to inform recommendations as the concept of working with and/or informing other services is covered by recommendation 1.7.3 in partnership working (see evidence review G).

Existing recommendations that were not used in this review

There were a number of existing NICE recommendations that the committee neither adopted nor adapted for the section on enabling and supporting effective advocacy. The reasons behind their decision making are given in appendix F.

Cost effectiveness and resource use

How well effective advocacy is enabled and supported varies across different areas. There will be areas where for there to be sufficient time and availability to allow for preparation then additional hours of work will be needed which may require employing additional advocates or extending the hours of current ones. Having an advocate involved from the beginning may help to streamline processes and require less resources later in the processes, for example by avoiding needing to revisit issues. Recommendations should also allow for advocacy to happen earlier. There is unlikely to be any resource impact to this but costs will be incurred earlier.

There will be some changes in practice required in order to involve advocates until decisions have been communicated, these should not result in further costs but rather re-organisation of resources. There might also be some resources associated with rearranging meetings; however this might result in meeting time being used more effectively, thus resulting in less challenging of decisions and using resources more efficiently.

Having the same advocate throughout when people transition between different types of advocacy may have some upfront costs associated with moving or employing multi-skilled advocates where these are not currently used. This should however lead to more efficient use of resources through reducing the number of handovers needed and time needed for people to build relationships with new advocates and duplication of work. This should also help provide a better quality service.

No extra resources are expected in order for health and social care practitioners to facilitate advocacy, as this should be within the role requirements already. In cases where this is currently not happening, it may require a change in ways of working rather than constituting additional tasks that require extra resources. Advocates using digital platforms as necessary and health and social care providers supporting people to communicate with their advocate remotely, is not expected to require any additional resources, as the systems required to do this were widely implemented during the COVID-19 pandemic. However, in the committee's experience, ensuring people can use such systems at times agreed with their advocate may require better organisation and planning. Better use of such systems may, where it will not reduce the quality of service, replace in-person meetings saving on travel costs and time.

Ensuring that local authorities and health and social care providers are auditing and monitoring referrals and including the number of referrals in public facing information is not expected to require additional resources, as services will already have processes for collecting and sharing information in place. For services not already doing this it will result in a change in what is being collected and reported.

The committee did not expect there to be a resource impact associated with ensuring advocates know how and when to act on safeguarding concerns and how to deliver effective safeguarding as, in their experience, a number of these practices are already happening. However, they agreed the recommendation was important for improving consistency and quality of services.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.5.1 to 1.5.4, 1.5.7, 1.5.8, 1.5.9, 1.5.11 to 1.5.16, 1.4.5 and 1.1.2.

References – included studies

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Formal consensus

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Care Act 2014

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Mental Capacity Act 2005

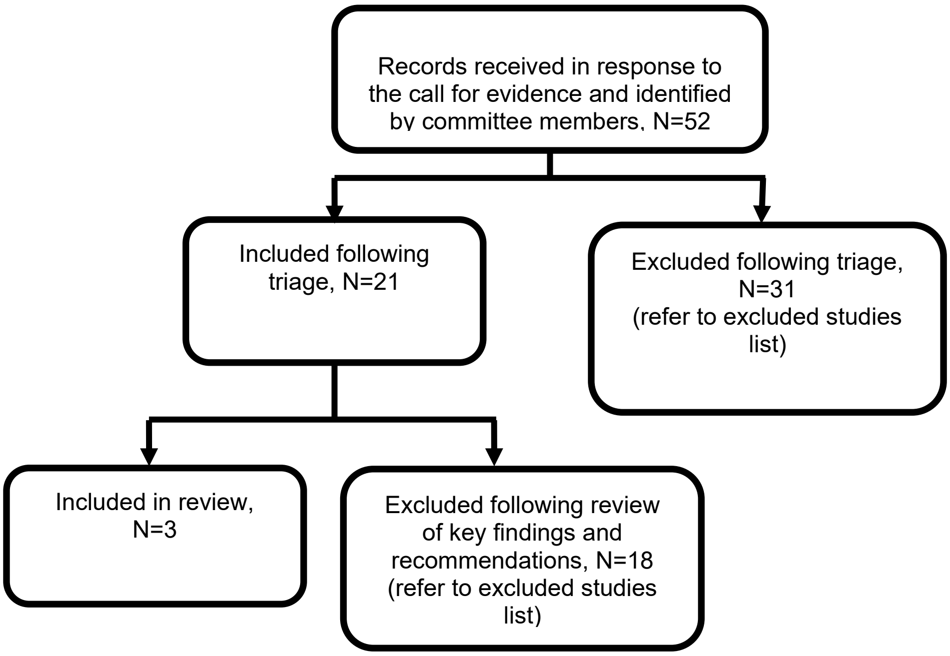
Mental Capacity Act, 2005 (c.9). Available at: http://www.legislation.gov.uk/ukpga/2005/9/contents [Accessed 23/02/2021]

Appendices

Appendix A Study selection for formal consensus process

Study selection for scope area: Enabling and supporting effective advocacy

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Enabling and supporting effective advocacy

Table 3: Evidence tables

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/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England **Study type** 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 no 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%

Study details	Population	Recommendations/key findings	Quality assessment
			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. **Overall rating** 29.19%
Full citation Newbigging, 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. 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 **Source of funding** Department of Health	Patients detained under the amended MHA 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	**Recommendations** • Through full policy implementation, government needs to continue to recognise the value of advocacy to a highly vulnerable group of people for whom the experience of detention under the MHA can be frightening, bewildering and isolating. Having a voice in this process is vital and support recovery.	**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 MHA 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
			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 3 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
			Overall methodological limitations (No or minor/Minor/Moderate/Serious) Minor limitations.
Full citation Ridley, J., Newbigging, K., Street, C., (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 23(4), 280-292 **Country/ies where the study was carried out** England **Study type** Qualitative meta-synthesis **Study dates** Not reported **Source of funding** No sources of funding reported	*Study 1*: African and African Caribbean men with experience of mental health services. *Study 2*: Adults and children who were subject to compulsion under the MHA 1983, and therefore eligible for (but not necessarily accessing) an IMHA under the 2007 MHA. *Study 3*: Children and young people receiving advocacy services.	**Key findings** • English adoption and Children act supported children in care and care leavers with making complaints; 2005 MCA: Right to IMHA for individuals deemed to be lacking capacity; Right to IMHA was introduced to protect rights of people detained under MHA; Local authorities have duty to provide independent advocacy for people using social care who require support with decision making and lack appropriate support	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** No information - There was no evidence of pre-specification of objectives and eligibility criteria. **1.2 Were the eligibility criteria appropriate for the review question?** No - Eligibility criteria were not provided. However, the included studies appear to have been selected due to being research studies previously undertaken by the authors on independent mental health advocacy. **1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the population. **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***

Study details	Population	Recommendations/key findings	Quality assessment
			High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the review. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** 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 – No search strategy provided. **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 - There is insufficient information reported. **3.1 Were efforts made to minimise error in data collection?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results? Probably yes – Summary of key service user characteristics in each study in Table I. **3.3 Were all relevant study results collected for use in the synthesis?** Probably yes – Lines of enquiry from study participants in Box 1. **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.

Study details	Population	Recommendations/key findings	Quality assessment
			4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies? Yes – Qualitative synthesis appears appropriate. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** Not applicable – Qualitative synthesis. **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** Not applicable – Qualitative synthesis. **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*** 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 emphasising results on the basis of their statistical significance?** Not applicable.

Study details	Population	Recommendations/key findings	Quality assessment
			Risk of bias – High concern.

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; CASP: Critical Appraisal Skills Programme; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MCA: Mental Capacity Act; MHA: Mental Health Act; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Appendix C Quality Assessment

Quality assessment tables for scope area: Enabling and supporting effective 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 %**
Coexisting severe mental illness (psychosis) and substance misuse: assessment and management in healthcare settings (Clinical Guideline 120)	2011	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 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	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 recommendati	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.	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.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				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 methodology for this procedure is unavailable.	ons are summarised as flow charts.	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.		
People's experience in adult social care services:	2018	100 The overall objective of the guideline, the	100 The guideline development group included a	96 Systematic methods were used to search for evidence and	100 The recommendations are	96 There is description of the facilitators	100 The funding body has been stated and	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
improving the experience of care and support for people using adult social care services (NICE Guideline 86)		health question covered by the guideline, and the population to whom the guideline applies are specifically described.	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 of the guideline are clearly defined.	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, and each recommendation is linked to a key evidence description. The	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.	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. There are details given on the potential resource implications of	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 %**
				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.		applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Decision-making and mental capacity (NICE Guideline 108)	2018	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	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	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 recommendati	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 recommendati	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	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			development. The target users of the guideline are clearly defined.	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, 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	ons are grouped together in one section. The description of recommendati ons are summarised as flow charts.	ons 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. There are details given on the potential resource implications of applying the recommendati ons. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.	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 %**
				procedure is unavailable.				
Supporting adult carers (NICE Guideline 150)	2020	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. The guideline describes how the guideline development group linked and used the	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 resources to facilitate application and there are directions on	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 %**
				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.		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.		
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	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and	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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the	97

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
		specifically described.	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.	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, 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	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.	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. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation	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 %**
				available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		and monitoring or auditing criteria.		
Looked after children and young people (Public Health Guideline 28)	2015	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 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	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	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	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.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				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 methodology for this procedure is unavailable.	summarised as flow charts.	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.		

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 procedure for updating have been provided.	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

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**
Ridley 2018	2018	High concern	Unclear concern	High concern	Unclear concern	High 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**
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

CASP: Critical Appraisal Skills Programm

Appendix D Excluded studies

Excluded studies for scope area: Enabling and supporting effective 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.
Chatfield, D., Lee, S., Cowley, J., Kitzinger, C., Kitzinger, J., Menon, D. Is there a broader role for independent mental capacity advocates in critical care? An exploratory study. Nurs Crit Care. 2018 Mar;23(2):82-87	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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 is based on case studies
Feeney, M., Evers, C., Agpalo, D., Cone, L., Fleisher, J., Schroeder, K. (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. Health Expectations, 23, 722-730.	Non-UK based (International)
Harflett, N., Turner, S., Bown, H., National Development Team for Inclusion (2015). The impact of personalisation on the lives of the most isolated people with learning disabilities. A review of the evidence. Available at: https://www.ndti.org.uk/assets/files/Isolation_and_personalisation_evidence_review_final_02_06_15.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
Healthwatch (2015). Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. Available at: https://www.healthwatch.co.uk/sites/healthwatch	Publication is based on case studies

Study	Reason for Exclusion
.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	
Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 44(2), 219-230.	Publication is based on case studies
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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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 Enabling and supporting effective advocacy
Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of advocacy delivery in relation to Personal Health Budgets and other health funded support. Available at: https://www.ndti.org.uk/assets/files/Advocacy-Health-Funded-Support-Report-pdf.pdf [Accessed 07/05/2021]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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 Enabling and supporting effective advocacy
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished	No key findings or recommendations relevant to Enabling and supporting effective advocacy
National Development Team for Inclusion (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Available at: https://www.ndti.org.uk/assets/files/Reasonably-adjusted_2020-12-30-150637.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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 (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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy

Study	Reason for Exclusion
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 Enabling and supporting effective advocacy
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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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. (2018/2019). The Quality Performance Mark Advocacy standards. Assessment Workbook Quality Performance Mark. A National Development Team for Inclusion programme	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., 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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Sadd, J., Machin, K., et al. (2015). Independent Mental Health Advocacy – The Right to Be Heard: Context, Values and Good Practice. Jessica Kingsley Publishers: London, UK.	Publication is based on Book/book chapter.

Study	Reason for Exclusion
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.	No key findings or recommendations relevant to Enabling and supporting effective advocacy
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case studies
Older People's Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	Publication is based on case studies
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case studies
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]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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:	Publication has no evidence base

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

Study	Reason for Exclusion
Taylor & Francis Production Disability and Rehabilitation (IDRE). My Life Tool (self-management tool): www.mylifetool.co.uk	Publication has no evidence base
Teeside University (2015/2016). UTREG Online Module Specification: Advocacy - Evolution, Equality and Equity. Unpublished.	Publication has no evidence base
Townsley, R., Marriott, A., Ward, L. (2009). Access to independent advocacy: an evidence review, Office for Disability Issues. Available at: http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-exec-summary-standard.pdf [Accessed 16/02/2022]	Not published in the last 10 years
Turner, S., Giraud-Saunders, A. (2014). Personal health budgets: Including people with learning disabilities, Think Local act Personal. Available at: https://www.thinklocalactpersonal.org.uk/_assets/Reports/TLAPIncludingLD.pdf [Accessed 16/02/2022]	Publication is based on case studies
Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Enabling and supporting effective advocacy
Varley, P. (2021). The Veterans' Advocacy People: Final Evaluation and Social Return on Investment Analysis	No key findings or recommendations relevant to Enabling and supporting effective advocacy
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
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. Available at: https://www.voiceability.org/assets/download/STOMP-2021B.pdf [Accessed 16/02/2022]	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: Enabling and supporting effective advocacy

No research recommendations were made for this scope area.

Appendix F Existing NICE recommendations

Table 9: Existing NICE recommendations for scope area: Enabling and supporting effective advocacy

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Ensure the child or young person has enough notice of any planned change to arrange for an advocate to support them in their review meeting.	**Looked after children and young people [PH28] – 1.13.5** Evidence statement E5.9: Seven studies (1 [++] and 6 [+]) provide evidence that preparation and support for leaving care is an important issue for looked-after children and young people. In order to improve the process of leaving care, looked-after children and young people said they needed: • improved and more timely preparation for independent living prior to leaving care to improve this transition • a network of support to provide ongoing practical help and emotional support after leaving care • greater and more appropriate information and advice about entitlements to help to make better use of services available to them on leaving care • a higher level of financial support and more advice for managing finances to prevent serious financial problems for care leavers • access to better quality and more appropriate housing. Evidence statement C3.5: The evidence gathered in all sites and across the professional groups strongly suggests that the most important factors in influencing looked-after children and young people's health and wellbeing outcomes are stability and consistency. The child or young person's placement is of paramount importance and the characteristics of a quality placement are good matching of carer and child at the point of placement. Good matching is characterised by the matcher having robust and detailed information about the child, their characteristics and preferences so that they can match these against the lifestyle and characteristics of the foster carers at the point of matching. The matching process is also aided by timely planning, with the child and carers experiencing introductory meetings and agreeing to the time frame for the planned move. Additional characteristics of a quality placement are thought to be the consistent approach that the carer brings to the relationship, having commitment, staying power and demonstrating unconditional positive regard for the child. In summary, the quality of the relationship between the carer and child is crucial. Alongside	**Adapted** Recommendation was broadened to include all populations needing advocacy support and all steps involved in ensuring people have sufficient time to appoint and meet with an advocate (taking into account existing recommendations below from NG86 and NG108). See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Health and social care practitioners and other referrers should: • identify the need for advocacy as early as possible and • make a referral to an advocacy service without delay.

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	this, stability of school placement and consistency in key workers are also thought to be highly influential in promoting health and wellbeing in looked-after children and young people.		
If a third party or advocate is supporting someone to give their views, ensure that enough time has been allowed for them to do it.	**People's experience in adult social care services: improving the experience of care and support for [NG86] – 1.1.8** Evidence statement RQ4.7: Supporting decision making for people who lack capacity: This evidence statement is based on a small amount of evidence from one mixed-methods study of medium level quality that people who lack capacity can be supported in participating in decisions. Redley et al. (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found that, in over half of their cases, people who lacked capacity were supported in participating in decisions made on their behalf. The study found that people who lack capacity can be supported in participating in decisions. Other considerations: Recommendation 1.1.8 was based on RQ4.7, which found that time limits to advocacy interviews is a barrier to enabling people to express their wishes. Again, the Committee considered the resource implications of ensuring sufficient time with advocates. However, this was balanced against the potential for particular groups, particularly people with learning disabilities or people who may lack capacity, to be excluded from giving their views and experiences in the absence of support.	**Adapted** This recommendation was combined with recommendation 1.3.2 below from NG86. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Advocacy providers should aim to support continuity by offering people the same advocate for different types of advocacy (for example, statutory advocacy in line with the Care Act 2014, IMHA and non-statutory advocacy). If this is not possible, they should ensure that systems for handover are in place that do not need a new referral.
People who are supported by an independent advocate during care and support needs assessment and care planning should have enough time with their advocate: • for preparation before the assessment or care planning session • to ensure they have understood the outcome afterwards.	**People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86] – 1.3.2** Evidence statement RQ4.7: Supporting decision making for people who lack capacity: This evidence statement is based on a small amount of evidence from one mixed-methods study of medium level quality that people who lack capacity can be supported in participating in decisions. Redley et al. (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found that, in over half of their cases, people who lacked capacity were supported in participating in decisions made on their behalf. The study found that people who lack capacity can be supported in participating in decisions. Other considerations: Recommendation 1.3.2 drew on Guideline Committee expertise and experience in the use of advocacy. Following stakeholder consultation, the Guideline Committee noted that advocacy involvement should be at every stage of the process to be effective, and revised this	**Adapted** This recommendation was combined with recommendation 1.1.8 above from NG86. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Advocacy providers should aim to support continuity by offering people the same advocate for different types of advocacy (for example, statutory advocacy in line with the Care Act 2014, IMHA and non-statutory advocacy). If this is not possible, they should ensure that systems for handover are in place that do not need a new referral.

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	recommendation to include assessment, planning, implementation and review stages.		
Commissioners and managers in all settings should ensure that there is continuity in care and support for people, including: - using the same independent advocate where possible.	**People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86] – 1.4.7** Evidence statement V2: Consistency of care. This evidence statement is based on some evidence of overall medium level quality. In the first of 4 studies (Cameron et al. 2016 ++) tracked a group of homeless women and women at risk of homelessness to determine how their service needs (including social care needs) changed over this time. The second study (Katz et al. 2011 +) examined the views of what older people with high support needs value in their lives, and within services. The third study (Goodman et al. 2013 +) aimed to explore how older people with dementia discussed their priorities and preferences for end-of-life care. The fourth study (Cook et al. 2006 +) aimed to draw on older people's narratives to illuminate the experience of living in a care home. The studies found that consistency of care delivery is important to adults who receive home help and improves relationships between carers and their clients, which impacts positively on quality of care. Other considerations: Recommendations 1.4.7 and 1.4.8 were based on evidence statement V2*, that people appreciate consistency in aspects of their care. The Committee acknowledged that practicalities of providing care meant that it was not always possible for the same individuals to deliver a person's care. The recommendation therefore focuses on ensuring that there is good handover between staff members, and that levels of skill and knowledge Adult social care: improving people's experience (February 2018) 385 of 423 across the staff team are consistent. The Guideline Committee also noted that consistency did not mean rigidity of care offered and that people's needs and preferences may change over time. The evidence related to people who were receiving care at home. The Guideline Committee agreed that this experience was relevant to other settings.	**Adapted** This recommendation was combined with recommendation 1.4.7 in improving access to advocacy (see evidence review D). See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Advocacy providers should aim to support continuity by offering people the same advocate for different types of advocacy (for example, statutory advocacy in line with the Care Act 2014, IMHA and non-statutory advocacy). If this is not possible, they should ensure that systems for handover are in place that do not need a new referral.
When an Independent Mental Capacity Advocate has been instructed, they should be involved in the process until a	**Decision-making and mental capacity [NG108] – 1.5.16** Evidence statement BIA11. There is a small amount of evidence that independent mental capacity advocates believe there can be a lack of clarity regarding how long they should work with someone who lacks capacity. The quality of the evidence is good. Redley et al. (2009 ++) report that advocates	**Adapted** Recommendation was broadened as this process should not just	Health and social care practitioners should involve a person's advocate in all discussions with the

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
decision has been made and implemented fully.	were sometimes unclear regarding the point at which their involvement should cease, particularly in relation to cases where a change in accommodation was the key issue. Advocates reportedly believed that they should be involved in a case until a decision had been made and fully implemented. They also expressed concern that they rarely received responses to or even an acknowledgement of their report. Other considerations: Recommendation 1.5.16 was based on BIA11 which reported that Independent Mental Capacity Advocates believe there is some lack of clarity about their role, including the length of time for which they should be involved in a case. The committee noted that Independent Mental Capacity Advocates are contracted for a set number of hours regardless of the complexity of the decision or the needs of the individual. They discussed whether the evidence showed that there was a problem with time-limited involvement of Independent Mental Capacity Advocates. Some members felt that arbitrary cut-offs to the involvement of Independent Mental Capacity Advocates can limit their effectiveness so the group agreed this recommendation based on the view that the IMCA role should be expanded. The committee wished to emphasise the point an Independent Mental Capacity Advocate has to remain involved in a case until a decision is made as full involvement allows them to check whether the decision has been implemented.	apply to IMCAs but to any type of advocate. Recommendation was also adapted as the committee agreed the most appropriate action is for advocates to be involved until the decision has been communicated and the individual has had the opportunity to challenge the decision, rather than until the decision has been implemented fully. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	person until a decision has been made and explained to the person, and they have had a chance to challenge the decision if they want to.
Promote ongoing contact with valued friends, professionals or advocates where this enhances and promotes emotional wellbeing and self-esteem.	**Looked after children and young people [PH28] – 1.24.2** Evidence statement E5.5: The significance for looked-after children and young people of contact with their birth families was revealed in 11 studies (1 [++]; 10 [+]). Studies reported that: • many have a strong desire to maintain contact with their birth families • maintaining contact with birth families is important for supporting their self-identity • they felt that social workers and care providers can obstruct their efforts to maintain contact with their families, and were resentful of this • a lack of contact causes significant emotional upset • contact with birth families is a complex issue. Although an overwhelming majority [of participants] saw it as positive, not all felt the same.	**Adapted** This recommendation was combined with recommendation 1.1.24 below from CG120 to include an example of how health and social care practitioners should facilitate advocacy. See the Benefits and harms section of The committee's discussion and interpretation of the	Health and social care practitioners should facilitate advocacy, for example by: • respecting the advocate's independence • sharing information appropriately with advocates and anyone else supporting the person and building good working relationships with them

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	Evidence statement E5.18: There was evidence in 2 (+) studies on parents' views about maintaining contact with their children. Parents specifically stated that: • they wanted to maintain continuity in contact with their children • they wanted to be a source of support to their children • they needed support from professionals while their children are in care in order to have useful contact with them.	evidence in this review for more information.	• encouraging and supporting ongoing contact between the person and their advocate • giving the person privacy to talk to their advocate • supporting people to understand about advocacy and to ask for the advocacy that they would want or ask for it on their behalf if appropriate • responding to advocates in a timely manner • supporting any communication needs, such as arranging an interpreter.
Healthcare professionals in primary care and secondary care mental health services, and in specialist substance misuse services, should work collaboratively with voluntary sector organisations that provide help and support for adults and young people with psychosis and coexisting substance misuse. Ensure that advocates from such organisations are included in the	**Coexisting severe mental illness (psychosis) and substance misuse: assessment and management in healthcare settings [CG120] – 1.1.24** From evidence to recommendations: When working with people with psychosis and coexisting substance misuse, the GDG thought that a number of safeguarding issues were important and needed recommendations. In addition, the GDG felt that voluntary sector organisations had an important role to play in lives of people with psychosis and coexisting substance misuse, therefore, recommendations were made about collaborative working.	**Adapted** This recommendation was adapted to focus on advocacy services specifically, have a broader focus than people with psychosis and substance misuse, and to include examples of how health and social care practitioners should facilitate advocacy.	Health and social care practitioners should facilitate advocacy, for example by: • respecting the advocate's independence • sharing information appropriately with advocates and anyone else supporting the person and building

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
care planning and care programming process wherever this is possible and agreed by the person with psychosis and coexisting substance misuse.		See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	good working relationships with them • encouraging and supporting ongoing contact between the person and their advocate • giving the person privacy to talk to their advocate • supporting people to understand about advocacy and to ask for the advocacy that they would want or ask for it on their behalf if appropriate • responding to advocates in a timely manner • supporting any communication needs, such as arranging an interpreter.
Practitioners involved in managing safeguarding concerns should build effective working relationships with advocates and other people supporting the resident.	**Safeguarding adults in care homes [NG189] – 1.8.13** Why the committee made the recommendations: The committee made the recommendations based on a limited amount of qualitative evidence on the roles and responsibilities of Safeguarding Adults Boards. There were a number of concerns with this evidence, around: • the methods used, for example in relation to data analysis and sampling strategies • the relevance of the themes in the evidence, as some of the studies were conducted in care settings other than care homes	**Adapted** This recommendation was combined with recommendation 1.1.24 above from CG120 to include an example of how health and social care practitioners should facilitate advocacy as the committee agreed	Health and social care practitioners should facilitate advocacy, for example by: • respecting the advocate's independence • sharing information appropriately with advocates and anyone

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	- adequacy, as the themes were based on relatively limited data. The evidence highlighted the challenges associated with partnership working, and the difficulties in communicating with care homes. The evidence also indicated that there may sometimes be confusion around: - lines of communication about safeguarding and safeguarding concerns - who is responsible for each part of the process - how and when care homes should be working with the local Safeguarding Adults Board.	building effective relationships should apply in all context, not just safeguarding. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	else supporting the person and building good working relationships with them - encouraging and supporting ongoing contact between the person and their advocate - giving the person privacy to talk to their advocate - supporting people to understand about advocacy and to ask for the advocacy that they would want or ask for it on their behalf if appropriate - responding to advocates in a timely manner - supporting any communication needs, such as arranging an interpreter.
If carers choose to have an advocate or representative to support them, health and social care practitioners should recognise this person's contribution and include them in discussions.	**Supporting adult carers [NG150] - NG150: 1.5.7** Why the committee made the recommendations: There was no evidence in this area, but there is a legal responsibility on local authorities to provide access to independent advocacy, in line with the Care Act 2014 and the Mental Capacity Act 2005. The committee agreed by consensus that it was important to inform carers about their right to support from advocacy services and the circumstances in which they would apply. To build on this and ensure that advocates (or other representatives) can give meaningful support to	**Adapted** This recommendation was adapted to make it apply to all people accessing advocacy, not just carers, and to provide more detail about the required action.	Health and social care practitioners responsible for decisions should ensure that all concerns that are raised, either by the person or the advocate on their behalf, are understood,

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	carers, the committee agreed that practitioners should recognise the voice and role of advocates. In the committee's view this does not always happen in practice. The committee also noted the important role of advocacy as set out in the Mental Capacity Act 2005.	See the Benefits and harms section of The committee’s discussion and interpretation of the evidence in this review for more information.	responded to and recorded.

GCG: guideline development group; IMCA: Independent Mental Capacity Advocate; NICE: National Institute for Health and Care Excellence; RQ: review question

Appendix G Formal consensus

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

Table 10: Formal consensus round 1 statements and results for scope area: Enabling and supporting effective advocacy

Statement no.	Statement	References	Percentage agreement	Action taken
1	The quality and impact of IMHA services are dependent upon the mental health provider context within which the service is delivered.	Ridley 2018	72.73%	Redrafted for round 2
2	The quality and impact of IMHA services are dependent upon distinguishing between how ready various locations or care teams are to engage with advocacy.	Ridley 2018	75.00%	Redrafted for round 2
3	The quality and impact of IMHA services are dependent upon the different types of social space that make involvement possible.	Ridley 2018	58.33%	Discarded
4	The quality of IMHA services is dependent on the quality of commissioning.	Newbigging 2012	83.33%	Carried forward to committee discussion
5	The quality of IMHA services is dependent on the organisation and management of the IMHA services.	Newbigging 2012	91.67%	Carried forward to committee discussion
6	The advocacy sector should focus on developing staff to recognise situations where there is potential for abuse/neglect.	Lawson 2017	91.67%	Carried forward to committee discussion
7	The advocacy sector should focus on empowering staff to report and act on concerns.	Lawson 2017	91.67%	Carried forward to committee discussion
8	The advocacy sector should focus on involving and engaging people and communities so that they are informed, empowered and connected to social networks in the wider community.	Lawson 2017	90.91%	Carried forward to committee discussion
9	The advocacy sector should focus on engaging with and including people so that advocacy and safeguarding services and strategies are influenced by the people who use them.	Lawson 2017	100.00%	Carried forward to committee discussion
10	The advocacy sector should focus on making complaints procedures and guidance available and accessible to people.	Lawson 2017	100.00%	Carried forward to committee discussion
11	The views of advocacy providers and those they support should inform development of safeguarding services across organisations.	Lawson 2017	91.67%	Carried forward to committee discussion

IMHA: Independent Mental Health Advocate

Table 11: Formal consensus round 2 statements and results for scope area: Enabling and supporting effective advocacy

Statement no.	Statement	References	Percentage agreement	Action taken
1	Mental health service providers should support the delivery of IMHA services.	Ridley 2018	91.67%	Carried forward to committee discussion
2	Mental health service providers should ensure that care teams engage with advocates to promote and support the delivery of IMHA services.	Ridley 2018	100.00%	Carried forward to committee discussion

IMHA: Independent Mental Health Advocate