National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[G] Partnership working and relationships with families and carers, commissioners and providers

NICE guideline NG227

Evidence reviews underpinning recommendations 1.4.3, 1.7.1 to 1.7.11, 1.11.7, 1.11.13 and 1.11.14 in the NICE guideline

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Key theme

- Partnership working and relationships with families and carers, commissioners and providers

Introduction

The aim of this review is to identify ways in which advocacy providers can work in partnership with families, carers, commissioners and providers.

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

Summary of the inclusion criteria

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

Table 1: Summary of the inclusion criteria

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Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are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

Methods and process

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

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

Effectiveness evidence

Included studies

Existing NICE guidelines

No existing NICE recommendations were identified for this scope area.

Formal consensus

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

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

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

Excluded studies

Formal consensus

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

Summary of included studies

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

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

Document	Population	Evidence base
Lawson 2017 Report National	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing including qualitative discussions with advocates from across England to determine the enablers and barriers to involvement of advocacy in safeguarding adults

Document	Population	Evidence base
Lawson 2020 Briefing Multiple areas	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing including qualitative discussions with advocates from across England to determine the enablers and barriers to involvement of advocacy in safeguarding adults
NDTi 2014b Report of an evidence review International	People living with disabilities	Report describing the findings of an evidence review on independent advocacy for: Young disabled people at transition; Disabled parents whose children are subject to safeguarding procedures; Disabled people when entry to residential care is a possibility; Disabled people are victims or alleged perpetrators of anti-social behaviour.
NDTi 2016a Framework England	Providers and commissioners of independent advocacy	Framework produced to measure and demonstrate the impact that independent advocacy has for individuals, the health and social care sector, wider community, and on the advocacy sector itself. Includes a toolkit as a detailed resource and practical guide for advocacy organisations to develop their understanding of how to define, measure, analyse and report on impact and outcomes achieved.
NDTi 2020a Report on survey findings England & Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 435 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers
NDTi 2020b Report on survey findings Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 72 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers
Newbigging 2011 Systematic Review National (England, Wales, and Northern Ireland)	African and Caribbean men using mental health services.	Systematic literature review, a national survey on the provision of advocacy (n=391 providers of mental health advocacy services), focus groups with African and Caribbean men (n=25), and case

Document	Population	Evidence base
		studies (22 people including 7 service users, 6 commissioners, 4 mental health service providers and 5 experts in the field).
Newbigging 2012 Mixed methods: literature review, qualitative research (focus groups and interviews), case studies England	Patients detained under the amended Mental Health Act 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Roberts 2012 Survey England	People living with learning disabilities	3 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies; provides information on, for example, funding and also discusses gaps in advocacy provision and barriers to accessing services
SERIO 2021 Service evaluation England	Veterans and their families	Report of an independent three-year evaluation of The Veterans' Advocacy People, a service targeted at veterans, and their families from each of the service arms, which aims to provide open and flexible advocacy support. Includes qualitative interviews
Turner 2012 Brief report England	People living with learning disabilities	2 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies (no detailed methods reported); provides advice and suggestions on actions for commissioners and advocacy groups to provide robust evidence on the effectiveness and reach of advocacy services

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

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

Summary of the evidence

Existing NICE guidelines

No existing NICE recommendations were identified for this scope area.

Formal consensus round 1

Two included documents (Lawson, 2017; NDTi, 2016a) were assessed using the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE II), 1 document (Newbigging, 2011) was assessed using both the Risk of Bias in Systematic reviews (ROBIS) checklist and the Critical Appraisal Skills Programme (CASP) tool for qualitative research as it included both a systematic literature review and a survey with qualitative components, and 8 included documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi, 2020b; Newbigging, 2012; Roberts, 2012; SERIO, 2021; Turner, 2012) were assessed using the CASP tool for qualitative research. See the results of the quality assessment in the evidence tables in appendix B and quality assessment tables in appendix C.

The committee were presented with 81 statements in round 1 of the formal consensus exercise; responses were received from 12 of 13 committee members. Seventy-five of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Five 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 8.

Formal consensus round 2

The committee were presented with 5 statements in round 2 of the formal consensus exercise; responses were received from 12 of 13 committee members. Three statements reached ≥80% agreement and were included for the discussion with the committee. Two statements had between 60% and 80% agreement and were discarded.

Economic evidence

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

The committee's discussion and interpretation of the evidence

The outcomes that matter most

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

The quality of the evidence

Existing NICE guidelines

No existing NICE recommendations were identified for this scope area.

Formal consensus

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

The quality of 2 documents (Lawson, 2017; NDTi, 2016a) were assessed using the AGREE II tool. High quality documents were defined as those where any two domains scored ≥ 70%. The documents scored an overall rating of 29% and 34% and were therefore not deemed to be high quality. The included documents scored 22% and 28% for stakeholder involvement; both scored 4% for applicability; 8% and 10% for rigour of development and 0% and 17% for editorial independence. Overall, the documents did not provide sufficient information on the stakeholder involvement in the development of the document. It was unclear whether the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the document were considered. The methods used to formulate and update the recommendations, and details on whether a systematic process had been used to gather and synthesise the evidence, were not clearly described. Declaration of any bias or competing interests from the document development group members were not reported.

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

The quality of 8 documents were assessed using the CASP tool for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations. Seven documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi, 2020b; Roberts, 2012; SERIO, 2021; Turner, 2012) were judged to have serious methodological limitations because of insufficient detail relating to participant recruitment, data collection and data analysis. Other concerns related to the lack of adequate consideration for the relationship between researcher and participants, and lack of consideration regarding ethical issues.

Benefits and harms

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

Liaising with family members and carers

Based on their knowledge and experience the committee agreed to add a recommendation about advocates liaising with family members and carers when the person wants them to do so. In the committee's experience, families and carers commonly report that advocacy services are not working cooperatively with them, when it should be in the best interest of the person to do so. Advocates working cooperatively with family members and carers can be beneficial to the person and their care, however this is not happening consistently. The committee agreed that working together could help to gain an understanding of the persons' views, preferences, and desired outcomes, which is particularly important when people may not be able to communicate this effectively themselves. In the committee's experience, family members can also be helpful in providing guidance to the advocate into how to develop relationships with the person, particularly in the case of learning disabilities and communication challenges. Advocates working with family members and carers can also be important to help clear misunderstandings and negative feelings in relationships between family members if they do not understand what is happening.

Advocacy providers being familiar with local support services

Statement 11 covered partnerships between advocacy providers, commissioners and wider support services. The committee agreed to base a recommendation on this statement and shared a view that it would be important to specify that advocacy providers need to be aware of other local support services. This is to ensure they can provide people using advocacy with information about other local support. The committee agreed it was important to state this in the recommendation to help with understanding and ultimately aid its implementation. In the committee's experience, it is a vital part of advocacy to be aware of other services in the area but it does not happen consistently. It is important to have consistent and up to date knowledge among advocacy providers.

Safeguarding adult boards working with advocacy providers

Statement 14 covered Safeguarding Adults Boards (SAB) engaging with advocacy providers and commissioners. In the committee's experience, advocates could help raise awareness of issues and the extent of issues that the safeguarding board might be unaware of, which in turn could support better care and safeguarding. Safeguarding boards engaging with advocacy providers could raise the profile of advocacy, lead to less variation and support effective advocacy. Therefore, the committee agreed to reword the statement so that safeguarding adult boards should think about ways of working with advocacy providers to inform their strategic plan and annual report for example by having them as board members, giving providers the opportunity to feedback on services.

Ensuring information is available

Statement 16 covered the need to make sure commissioners are included in development and awareness raising about advocacy. In the committee's experience, it can be difficult for people to find information about who the advocacy provider in their area is. This information should be on council websites as local authorities are required under the Care Act 2014 to make information about care and support services, including advocacy services, publicly available. However, the committee agreed that people who require advocacy are unlikely to be looking on council websites so they may not find this information. Therefore, it is important that additional steps are taken to ensure people who may benefit from advocacy are provided with the relevant information (see evidence review C for recommendations about information about effective advocacy and signposting to services). The committee agreed that the best way for commissioners to be involved in raising awareness is by supporting advocacy providers to make this information available. One way of doing this would be by allowing time in contracts for advocates to provide people with information, as opposed to only covering the time needed for actually delivering advocacy. The committee agreed that providing information is an integral part of providing advocacy services, as people would otherwise not know about the services available to them.

Developing protocols to facilitate effective advocacy

Statement 31 addressed the need for protocols for referrals between mental health professionals and Independent Mental Health Advocate (IMHA) services. The committee agreed that protocols for referral are important but that the need for these would apply to all types of advocacy, not just IMHAs. This was supported by statement 60, which covered issues about boundaries being raised when advocates and mental health professionals work together. Furthermore, in the committee's experience other protocols are also needed to facilitate effective advocacy, such as protocols for how advocacy services and other organisations should engage with each other and resolve disputes. The committee agreed these protocols are required as advocates need to be on the side of the people they are supporting and independent from other services. However, they do need to work closely with other services in order to deliver safe and effective advocacy. This tension can be difficult to balance in practice so it is important that there are policies in place to guide this. The committee agreed that having protocols that have been developed jointly should also help enable positive working relationships between different services. Furthermore, the committee mentioned that engagement protocols are stated in the Advocacy Quality Performance Mark (2018).

Commissioners working collaboratively with other local commissioners and commissioning bodies

Statements 41, 42 and 49 covered commissioners of advocacy services working collaboratively with NHS and other commissioners and commissioning bodies both locally and in other geographical areas. In the committee's experience, working together is important to ensure the commissioning is effective, with a long-term view that considers the future commissioning and provision of services. Working together should also improve consistency and quality of advocacy services across different areas, while reducing the likelihood of gaps occurring between geographical areas and for people that fall between different parts of the health and social care system. The statements were combined for ease of reference and to avoid unnecessary duplication as the committee agreed the purpose of collaboration would be the same in all instances. The committee agreed that explaining what working collaboratively should aim to achieve would help readers understand the purpose of this and how to implement it and, therefore, clarified this in the recommendation.

Risk assessments and safety plans

Statement 55 covered positive relationships reflecting the understanding that mental health professionals can support advocacy services by keeping alert to the safety of the advocate. The committee agreed that as worded the statement runs at risk of stigmatising people using advocacy services. In the committee's experience, it is important that advocates are protected where there is a risk as there is a potential for harm if this does not happen, which could also lead to ineffective advocacy if people do not feel safe. Risks are not always clearly communicated. The committee agreed that sharing the relevant elements of individual risk assessments and safety plans with advocates would help ensure the safety of both advocates and those using advocacy services, as currently risks are not always communicated clearly. The committee also agreed that this recommendation should apply to all practitioners working with advocates and people using advocacy services, as opposed to just mental health professionals, as there may be risks that need communicating outside of mental health settings.

When and how advocates are able to access a person's records

Statement 73 covered mental health services ensuring there is a policy and understanding of access to notes. In the committee's experience, it is essential that advocates have the information they need in order to support the person they are advocating for, without infringing upon information that they want to keep private. However, the committee agreed that this is necessary in all instances where people are being supported by an advocate, not just for people within mental health services. Furthermore, the committee agreed that advocates having access to notes would also be beneficial for safeguarding reasons, for example by helping the advocate to identify if people's rights are not being upheld. In the committee's experience, advocates do not always know that they can access notes and health and social care providers may not routinely share information, so there is inconsistency in whether advocates are able to access information about the person they are supporting. The committee were aware that there is legislation governing the sharing of information, such as the Data Protection Act (2018). Therefore, the committee agreed that health and social care providers and advocacy providers need to ensure that their staff understand when and how advocates are able to access a person's records in line with legislation, but did not include details about what information can be shared and when in the recommendation.

Working in partnership with commissioners of mental health services

Statement 77 covered those commissioning IMHA services working in partnership with commissioners of mental health services, so that the impact of IMHA provision on mental health service development can be understood and maximised. In the committee's experience, commissioners of IMHA services working in close partnership with commissioners of mental health services would help to ensure that services are co-ordinated and that there is a good interface between IMHA services and mental health services. This partnership may also help to identify any gaps in services and give the opportunity for commissioners of one service to input into commissioning decisions made by the other, which in turn may improve the quality of both services.

Working in partnership to ensure culturally appropriate advocacy

Statements 79 and 80 covered various suggestions for providing mental health advocacy for African and Caribbean men and statement 81 highlighted the importance of black community and voluntary sector services working in partnership with mainstream mental health advocacy services. The committee agreed that the common theme across these statements was working in partnership with other organisations to deliver culturally appropriate advocacy so focused their recommendation on this and included examples from the statements. The need for culturally appropriate advocacy was also supported by the expert witness testimony (see evidence review F) that mainstream advocacy provision: has a narrow focus that fails to take account of broader issues relevant to minority communities (such as welfare issues and social disadvantage), only has a superficial understanding of equality and diversity, and does not include adequate representation of advocates from Black, Asian and Minority Ethnic communities. Specifically, support for integrating or co-locating with black community and voluntary sector services came from testimony that such organisations can play a critical role in building social capital and addressing social disadvantage. This testimony also supported increasing the diversity of staff within advocacy services as people from Black, Asian and Minority Ethnic communities have expressed a preference for advocates who share their gender, language, and culture, which the committee agreed can be important for increasing understanding of individuals' circumstances and the issues that are important to them. Therefore, a lack of diversity may be a barrier both to people accessing services and to building trusting relationships, which helps improve the effectiveness of advocacy and may be particularly important to people from Black, Asian and Minority Ethnic communities who may lack trust in services. Reflecting on the wider issues relevant to Black, Asian and Minority Ethnic communities highlighted above, the committee agreed that the recommendation should not be limited to IMHAs and mental health advocacy, as it is important that all advocacy is culturally appropriate. The committee agreed that equality is still an issue within advocacy and this recommendation could help to reduce these inequalities.

Advocacy providers liaising with and facilitating the regulator

The committee were aware that regulators may need the input of advocates in order to monitor the Mental Health Act. One of the areas that could be looked at as part of the monitoring is access to advocacy. Monitoring involves visits to institutions and interviews with staff, including IMHA. The committee agreed that advocacy providers should liaise with and facilitate the regulator in carrying out their role, including in inspecting regulated services., therefore the committee agreed to add a recommendation covering this.

Highlighting areas for improvements

Statement 1 covered advocacy services increasing awareness of the issues facing particular groups of people. The committee agreed that the role of advocacy services is to identify issues and report these to other relevant services not, for example, about the running of general awareness campaigns. This is consistent with statements 24, 25, and 35, which covered advocacy organisations committing to harnessing insight and expertise and highlighting gaps in service provision to commissioners. Further, there were several statements related to sharing information with other organisations to highlight areas for improvements identified under the area of monitoring services, so the committee agreed to combine these statements with those to make a single recommendation (see evidence review K). Statements 8 and 9 covered commissioners and service managers acting on trends and themes for service change and improvement that are identified by advocacy services. As with the above statements, related statements were identified under the area of monitoring services, so the statements were combined to avoid unnecessary repetition (see evidence review K).

Working in partnership when implementing an outcome reporting system

Statement 5 was about everyone involved with advocacy working in partnership when implementing an outcome reporting system. The committee agreed to reword and combine this statement with statement 22 about advocacy services identifying and recording what the advocate is working with a person to achieve in terms of outcomes under the area of effective advocacy to make a single recommendation (see evidence review F).

Ensuring advocates can work effectively with a variety of backgrounds

Statement 2 covered that advocacy services should develop connections and exposure to a variety of people and ways of working with them. The committee agreed that training and support was the most appropriate way to ensure advocates can work effectively with a variety of backgrounds. Therefore, the statement was combined with existing recommendations and statements identified under the area of training for advocates (see evidence review I) to inform recommendation 1.9.1.

Agreeing on outcomes to be achieved

Statement 6 and 7 covered advocacy providers and commissioners working together where possible so there is agreement on outcomes to be achieved and how they are reported. The committee agreed to combine these two statements due to the commonality between them. In the committee’s experience, it is important to have agreed outcomes so that there is a shared understanding of what constitutes an effective advocacy service. It is important to report outcomes in a consistent way to aid the monitoring and comparability across advocacy services. In the committee’s experience, this is not happening consistently. Statement 33 from effective advocacy (see evidence review F) about advocacy outcomes needing to be identified and recorded for services was also used to inform this recommendation. The committee agreed to move this recommendation under the area of monitoring services (see evidence review K).

Understanding advocacy and the role it plays in protecting rights

Statement 18 covered commissioners needing to understand advocacy and the role it plays in protecting individuals’ rights and promoting wellbeing. The committee agreed it is important that commissioners have training so that they understand what they are commissioning, including the value of advocacy and why it is important. As the committee agreed that training was the best way to address this issue, they combined the statement with existing recommendations and statements identified under the area of training and skills for practitioners (see evidence review J) to inform recommendation 1.10.3.

Monitoring access to and take up of advocacy by different populations

Statement 33 covered commissioners working with advocacy groups to ensure that advocacy organisations meet the needs of people living with learning disabilities. The committee agreed it was important that organisations are meeting the needs of all people in the local community, not just people living with learning disabilities, as the committee were aware that there is a wide range of people who may benefit from advocacy support (see evidence review B). There are a number of recommendations made in this guideline (for example recommendations 1.6.1, 1.6.2 and 1.6.12 in effective advocacy, see evidence review F, and recommendation 1.9.1 in training for advocates (see evidence review I) that will help to ensure services can meet diverse needs. However, the committee agreed that monitoring access to and take up of advocacy by different populations would help to identify if there are groups of people that are not accessing or taking up the offer of advocacy services. This information would help to identify inequalities in access and areas where improvement is needed. The committee agreed this is important as they were aware of wide discrepancies in how advocacy is commissioned in different areas, with some areas only commissioning statutory advocacy services rather than being responsive to local needs. The committee agreed that this recommendation is about commissioners monitoring access and take up and it was therefore included in the section of the guideline on monitoring services and collecting data (1.11.7).

Availability of the advocate

Statement 62 covered service providers thinking about the availability of the advocate when planning and scheduling meetings. The committee agreed that for people who have a statutory right for advocacy, if advocates are not able to attend meetings, then their right to advocacy support is not being upheld. However, this is also crucial for non-statutory advocacy to ensure that people can have their voices heard at meetings and when decisions are being made. This recommendation was also supported by statement 64 as it covered IMHAs reporting positive experiences and encouragement from the clinical team for them attending meetings. The committee agreed that this recommendation was better suited under the area of enabling effective advocacy (see evidence review E).

Facilitating access to IMHA support

Statement 74 stated the need for mental health services to recognise the unique role IMHAs can play and how this is complementary to and not an alternative to legal representation. In the committee’s experience, there are sometimes misconceptions that people do not require an IMHA if they have legal representation, whereas the reality is that having legal representation does not fulfil, or negate, the legal entitlement to advocacy (see evidence review A). The committee agreed that the statement did not make it clear what action readers of the guideline should take. Therefore, the committee recommended that mental health services must continue to facilitate access to IMHA support even if the person who has been detained has legal representation. They agreed that this recommendation should be under the area of ‘improving access’.

Statements that were not used in this review

There were a number of statements carried forward to committee discussions that were not used to inform recommendations. Statement 21 which covered advocacy organisation aiming for greater cooperation with other agencies was not used to inform a recommendation as the concept of cooperation is covered by several recommendations in this key-theme and this statement did not provide any additional information about how this should be done.

A number of statements were not used to inform recommendations because their concepts were already covered by recommendations in the area of effective advocacy (see evidence review F). Statement 17 is covered by recommendation 1.6.3 about learning what matters to the person receiving advocacy support. Statement 23 is covered by recommendation 1.6.15 about advocacy services working with each other to promote best practice. Statement 27 is covered by recommendation 1.6.8 about advocacy providers keeping the same advocate working with a person. Statement 28 is covered by recommendation 1.6.1 about advocacy organisations ensuring that their services are accessible. Statement 39 is covered by recommendation 1.6.6 about promoting equality and equity of access. Statement 43 is covered by recommendation 1.6.5 about advocacy providers including people with lived experiences in their organisation. Statements 59 and 68 are covered by recommendation 1.6.2 about advocacy being person centred. Statement 54 and 72 are covered by recommendation 1.5.8 about service providers providing facilities for private discussion in enabling and supporting (see evidence review E). Statement 61 is covered by recommendation 1.6.2 and 1.6.9 about advocacy providers maintaining independence. Statement 67 is covered by recommendation 1.6.2 about advocacy providers ensuring that they are person-centred. Statement 69 is covered by recommendation 1.6.2 about advocacy being person-focused and in addition recommendation 1.8.7 about service specifications, service costs and contracts with advocacy service providers being person-centred in planning and commissioning (see evidence review H). Statement 70 is covered by recommendation 1.6.12 about providing culturally appropriate advocacy. Statement 71 is covered by recommendation 1.5.7 under enabling effective advocacy (see evidence review E) about practitioners facilitating advocacy. Statement 78 is covered by recommendation 1.7.9 in this review about commissioners of IMHA services working in partnership with commissioners of mental health services.

Statement 13 was not used to inform a new recommendation as the committee agreed that training is how you will ensure practitioners understand statutory duties to refer people to advocacy support and this concept is covered in recommendation 1.10.1 (see evidence review J). Statement 4 was not used to inform a recommendation because the committee agreed that there was not enough information provided on how good working relationships could be enhanced. However, the committee also agreed that statement 4 is covered by recommendation 1.10.3 about training in the role and function of advocates under training and skills for practitioners (see evidence review J) and by recommendation 1.5.7 about facilitating advocacy by building good working relationships with advocates and other supporting people under enabling and supporting effective advocacy (see evidence review E). Statement 26 was not used to inform recommendations because there was not enough information provided about what action should be taken to ensure access. However, the committee agreed that access to advocacy would be improved by the recommendations made under the area of improving access (see evidence review D) and recommendations 1.6.1 and 1.6.2 under effective advocacy (see evidence review F). Statement 30 was not used to inform a recommendation as the committee agreed that the actions required to address the concepts in the statement were covered by recommendation 1.10.1 about advocacy awareness training in training and skills for practitioners (see evidence review J) and recommendation 1.3.3 about giving information to everyone who would benefit from advocacy in information about effective advocacy (see evidence review C).Statement 32 was not used to inform recommendations as it was covered by recommendation 1.10.3 about addressing misconceptions that could lead to negative working relationships in training and skills for practitioners (see evidence review J). Statement 56 was not used to inform a recommendation as the concept is covered in recommendation 1.10.1 about ensuring that practitioners have training in advocacy awareness in training and skills for practitioners (see evidence review J). Statement 65 covered that there can be confusion between IMHA and IMCA; the committee agreed this issue would be addressed by recommendation 1.4.5 about commissioners and advocacy providers making it easier to access advocacy in improving access to advocacy (see evidence review D). Statement 66 was not used to inform a recommendation as the concept was covered by recommendation 1.10.1 about ensuring that practitioners have training in advocacy awareness in training and skills for practitioners (see evidence review J) and by recommendation 1.3.2 about providing information to people who are legally entitled to advocacy in information about advocacy (see evidence review C). Statement 69 was not used to inform a recommendation as the concept was covered by recommendation 1.8.5 about local authorities and commissioners involving people who use independent advocacy services in planning and commissioning (see evidence review H). Similarly, statements 50, 51, 52, 53, 63, 75 and 76 were not used to inform recommendations as their concepts were already covered in recommendation 1.5.7 about how health and social care practitioners should facilitate advocacy (see evidence review E).

Statements 12, 15, 19, 22, 29, 34, 36, 37, 38, 40, 44, 45, 46, 47, 48, and 57 were not used to make recommendations as these did not provide sufficient detail to inform what action should be taken. Finally, statement 20 was not used to inform a recommendation as the commission of individualised solutions would only apply to a small number of people in high risk situations and therefore, was not generalizable to the wider population covered by this guideline.

Cost effectiveness and resource use

Currently there is variation in the level of service provided in regards to partnership working and relationships with families and carers, commissioners and providers. The committee highlighted that a number of the recommendations are legal requirements which advocacy services in almost all areas are already following so no resource implications are expected.

The recommendations should enable services to respond to people more quickly allowing advocacy services to intervene before the any needs escalate avoiding costly interventions such as residential care. It should also improve services, reduce repetition and complaints and make services more efficient. The committee believed that more effective partnership working would lead to cost savings for these reasons.

Allowing for dedicated time for sharing information with and seeking information from family members and carers may increase the total amount of time needed. However, having dedicated time for this may reduce the need for collecting information later, often over a longer period of time and through multiple contacts. Missed information may lead to inappropriate referrals or suboptimal advocacy leading to wasted resources from using services which may not best meet needs.

There will be some cost from setting up protocols. This should be limited and it is likely these protocols will serve a large population and will need minimal intervention to keep updated. Downstream costs will therefore be small.

There would some initial upfront costs from collaboration of services where these are not already set-up to establish the processes but this is expected to lead to the avoidance of duplication of effort and resources and be ultimately more efficient and cost saving. Advocacy providers working together with local support services to ensure they are familiar with what these services can offer, should already be regular practice but does not happen consistently. In the committee’s experience, it is not expected to have an impact on resource implications, but rather some advocacy organisations will need to reorganise their resources.

Making sure the correct and up to date information is used should avoid people trying to contact disbanded services or trying to contact them outside of operating hours and should reduce costs even if initial upfront investment is needed. This will speed up access to advocacy, avoid duplication and avoid people losing contact with advocacy services where their needs may escalate. Ensuring that service providers consider the availability of the advocate when planning and scheduling meetings is expected to lead to more productive meetings with less revisiting of decisions, thus expected to lead to a more efficient use of resources, cost savings and should not require any resource input.

The committee strongly agreed, after hearing expert testimony, the need for culturally appropriate advocacy that meets local needs. The committee made a range of potential actions that could be undertaken to better achieve this but acknowledge they may have a resource impact and evidence around cost effectiveness was limited. The committee however highlighted NICE Principles 9 and 10 which discuss some examples of when recommendations with limited of cost effectiveness. Principle 9 that NICE guidance should support strategies that improve population health as a whole, while offering particular benefit to the most disadvantaged especially protected characteristics under the Equality Act of 2010. Principle 10 highlights that again recommendations can go against usual decision rules when the fairness of society can be improved. Given the strong expert testimony around inequality for some groups it was considered that any decrease in the efficient use of resources would be more than compensated by the reduction in inequality and increase in the fairness of society. The bullet points in the recommendations are also only suggestions, given the lack of economic evidence for the effectiveness of these recommendations and it can be up to individual service providers to decide how best to achieve the objective of the recommendation.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.4.3, 1.7.1 to 1.7.11, 1.11.7, 1.11.13, 1.11.14. Other evidence supporting these recommendations can be found in the evidence review on monitoring (see evidence review K).

References – included studies

Formal consensus

Lawson 2017

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

Lawson 2020

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

NDTi 2014b

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

NDTi 2016a

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

NDTi 2020a

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]

NDTi 2020b

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]

Newbigging 2011

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

Newbigging 2012

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

Roberts 2012

Roberts, H., Turner, S., Baines S., Hatton, C. Advocacy by and for adults with learning disabilities in England. Advances in Mental Health and Intellectual Disabilities, 6(1), 26-32, 2012.

SERIO 2021

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

Turner 2012

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]

Other

Care Act 2014

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

Data Protection Act 2018

Data Protection Act 2018 (c.12). Available at: https://www.legislation.gov.uk/ukpga/2018/12/contents/

NDTi 2018

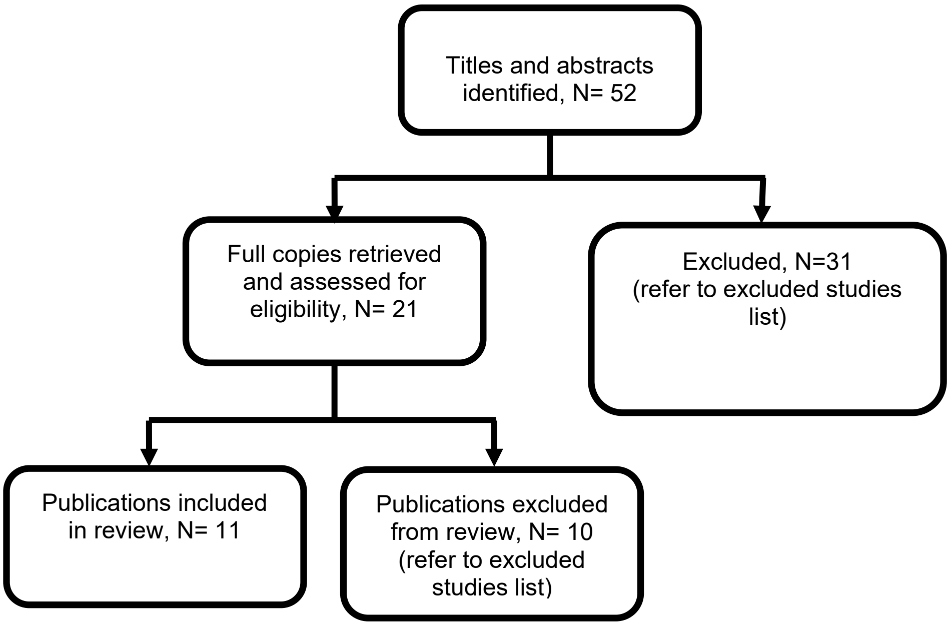
National Development Team for Inclusion (2018). The Advocacy Quality Performance Mark version 4. Available at: https://qualityadvocacy.org.uk/

Appendices

Appendix A Study selection

Study selection for scope area: Partnership working and relationships with families and carers, commissioners and providers

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Partnership working and relationships with families and carers, commissioners and providers

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/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England **Study type** Report/Review **Study dates** 2017 **Source of funding** No sources of funding reported.	Those who have duties to commission and arrange advocacy services	**Recommendations in relation to partnership working and relationships with families and carers, commissioners and providers** • Commissioners need to understand advocacy and the role it plays in protecting individual rights and promoting wellbeing. Commissioners should work alongside providers, acknowledging their expertise • Commissioners should establish effective communication and working relationships with providers in order to facilitate working up flexible and personalised solutions for individuals. • Commissioners should avoid placing a cap on the number of hours an advocate can support an individual. To truly involve the person as envisaged under the Care Act (2014) requires more time. This is particularly so for people with substantial	**Quality assessment using AGREE II** **1) Scope and Purpose** 61% Overall objective and population are described. Health question is not specifically described but alluded to **2) Stakeholder involvement** 22% Target users are defined but not information on guideline development group and views and preferences from population has been included. **3) Rigour of development** 8% Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and procedure for updating have been provided. **4) Clarity of presentation** 22% Recommendations are not always specific and easily identifiable. No mentioning of different options for management. **5) Applicability** 4% Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided.

Study details	Population	Recommendations/key findings	Quality assessment
		difficulty, complex needs or who may lack capacity in relation to safeguarding protection and decisions. Commissioners must ensure that service specifications cover issues of competency and training for advocates including those set out above and should consider the funding implications of this.	**6) Editorial independence** 0.0% No funding body and competing interest have been identified. **Overall rating** 29%
Full citation Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England **Study type** Qualitative (Focus group discussions) **Study dates** 2020 **Source of funding** No sources of funding reported.	Those who have duties to commission and arrange advocacy services	**Key findings in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** • Advocacy organisations need to rebuild relationships and raise awareness about the roles on ongoing basis • Fundamental to develop strong working relationships between advocacy providers and social workers, social care practitioners, commissioners, safeguarding leads and SAB, in order to ensure the understanding of statutory duties to refer people for advocacy support. • Advocates agree that when they were able to build mutually supportive working relationships, they were more likely to:	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to support strengthening the role of all types of advocacy in safeguarding adults, specifically in Making Safeguarding Personal by generating multi-agency conversations based on the briefing and stimulating local action to address some of the core messages that emerge from this. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell – insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
		○ Get appropriate time referrals ○ Be kept up to date and included in communications ○ Support safeguarding processes effectively ○ Ensure people have full opportunities for engagement in processes ○ Ensure people's views and wishes were considered in decision making • SAB (Safeguarding Adults Board) want to make sure they hear about local issues in these environments by engaging with advocacy providers as well as commissioners of advocacy • Relationship commissioners have including with providers and with SABs needs to be central focus in developing advocacy's part in MSP (making safeguarding personal) • Need to make sure commissioners are included in development and awareness raising about advocacy Views of people who use services and their carers will maximise effectiveness of independent advocacy and inform improvements in safeguarding	Yes – to some extent. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18 advocacy providers across England, covering 33 Local Authority areas. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No – the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?** Valuable – the authors discuss issues arising in relation to providing advocacy services in relation to safeguarding adults, and provide suggestions on how to address the key issues. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** **Serious limitations.**

Study details	Population	Recommendations/key findings	Quality assessment
Full citation National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished **Country/ies where the study was carried out** England **Study type** Briefing Note/Survey **Study dates** 2014 **Source of funding** No sources of funding reported	People living with disabilities	**Key findings in relation to partnership working and relationships with families and carers, commissioners and providers (Delivering Advocacy)** • Co-location (eg shared office space, advocates based with other services, or working in partnership with other service providers across locality area) • Strong partnerships between advocacy providers, commissioners and wider support services across the spectrum of public services and local agencies (such as health, social care, education, employment support, community action).	**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 summarise the findings of the survey to highlight what good advocacy for disabled people should look like. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Can't tell – Survey included over 200 advocacy providers but no more information was included. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Can't tell – Insufficient information regarding the survey. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell – insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – insufficient detail on data collection **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No – the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
			Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are clearly discussed but researchers do not discuss credibility of their findings. **10. How valuable is the research?** Valuable – the authors discuss issues in delivering advocacy for disabled people and highlight key areas to improve on as well as providing a summary as to what 'good' advocacy should look like. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** **Serious limitations.**
Full citation National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Framework **Study dates** 2016	Providers, commissioners and users of independent Advocacy	**Key findings in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** • When implementing an outcome reporting system it is important to work as an organisation – everyone should be involved (managers, advocates, contact centre staff, business support, board members, people who access the service, and commissioners/funders) • Providers and commissioners should work together where possible so there is agreement on outcomes to be achieved and how they will be reported	**Quality assessment using AGREE II** 1) **Scope and Purpose** 22% Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided. 2) **Stakeholder involvement** 28% Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear. 3) **Rigour of development** 10% Health benefits have seemingly been considered when describing recommendations. No information regarding systematic methods, criteria for selection, strengths and limitations, and methods for formulating recommendations have been provided. Links between recommendations and evidence are not clear. No information on external reviews and no information on updating has been provided. 4) **Clarity of presentation**

Study details	Population	Recommendations/key findings	Quality assessment
Source of funding Esmee Fairbairn Foundation		- Trends and themes for service change and improvement identified by advocacy services need to be acted upon by commissioners and service managers	56% Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to. **5) Applicability** 21% Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing criteria are provided. **6) Editorial independence** 17% Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided. **Overall rating** **34%**
Full citation National Development Team for Inclusion (2020a). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England and Wales **Study type** Survey (open and closed ended questions)	Advocates (across multiple areas of statutory and non-statutory advocacy)	**Key findings in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** - Some advocates hoped the advocacy sector would continue to push for greater cooperation to “share experience and good practice (at advocate level not just managers)”, “ensure we remain a valued support by policymakers and those in power”, and “to work in partnership/coproduction with outside agencies […] to raise awareness of people’s rights […] to access advocacy services.” (p.19)	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)** Yes - to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic's impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place. **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)**

Study details	Population	Recommendations/key findings	Quality assessment
Study dates June 2020 **Source of funding** No sources of funding reported.		**Recommendations in relation to Partnership working with families and carers, commissioners and providers (delivering advocacy)** • Shared commitments by advocacy organisations to ensure people's access to effective advocacy. Advocacy organisations have committed to: ○ Harness our insight and expertise to influence policy and practice, at an individual level through challenging decisions, and at the wider level of systemic change.	Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** **Serious limitations.**
Full citation	Advocates (across multiple	**Key findings in relation to what does effective advocacy**	**Quality assessment using CASP qualitative studies checklist**

Study details	Population	Recommendations/key findings	Quality assessment
National Development Team for Inclusion (2020b). Valuing voices in Wales: Protecting rights through the pandemic and beyond. Available at: https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report [Accessed 07/04/2021] **Country/ies where the study was carried out** Wales **Study type** Survey (open and closed ended questions) **Study dates** June 2020 **Source of funding** Age Cymru	areas of statutory and non-statutory advocacy)	**look like? (Delivering Advocacy)** • 85% of advocates reported that people's human rights were not being fully upheld during the pandemic; health and social care services reduced, non-compliance with legal duties, severe ongoing restrictions on people's liberty and private and family life. • Reduced referral rates: "Referrals to advocacy are much lower and indicate rights to advocacy not observed." (p.9) and "Lower admissions to wards. Some wards stopped referring for a while thinking, despite assurances to the contrary, that IMHA was suspended by the CA2020…." (p.9)	**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic's impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
			Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** **Serious limitations.**
Full citation Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. Health Expectations, 16(1), 80-104. **Country where the study was carried out** UK (England, Wales, and Northern Ireland) **Study type** Systematic literature review and national survey **Study dates** 2011	African and Caribbean men using mental health services.	**Key findings in relation to partnership working and relationships with families and carers, commissioners and providers (Delivering Advocacy)** • Evidence suggested that mental health advocacy could be provided as an integral part of wider BCVS mental health service, as a discrete casework advocacy service managed by a BCVS mental health service or through employing African and Caribbean staff within general mental health advocacy services. • It was suggested that different types of advocacy services could be co-located, for example, an African and	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Yes – There were a clear protocol and pre-specification of objectives the review are provided. **1.2 Were the eligibility criteria appropriate for the review question?** Yes – Eligibility criteria seem appropriate for review question **1.3 Were eligibility criteria unambiguous?** Yes – Eligibility criteria were clearly defined **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** Yes – Restrictions seemed appropriate **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?**

Study details	Population	Recommendations/key findings	Quality assessment
Source of funding Social Care Institute of Excellence (SCIE)		Caribbean advocacy service located in community centre together with a general mental health advocacy service. • Evidence highlighted the importance of BCVS services working in partnership with mainstream mental health advocacy services and mental health services (McKeown 2002, Christie & Hill 2002). Such partnerships can increase uptake, ensure cultural sensitivity of provision and contribute to capacity building.	Yes – Restrictions applied on the basis of sources of information were clearly described. **Concerns regarding specification of study eligibility criteria** Low Concern - Considerable effort has been made to clearly specify the review question and objectives, and to pre-specify and justify appropriate and detailed eligibility criteria that have been adhered to during the review **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** Yes – Direct databases are all clearly identified. **2.2 Were methods additional to database searching used to identify relevant reports?** Yes – secondary reference search was undertaken. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information **2.4 Were restrictions based on date, publication format, or language appropriate?** No – Search was restricted to English language publications. **2.5 Were efforts made to minimise errors in selection of studies?** Yes – Two authors independently screened and searched data. **Concerns regarding methods used to identify and/or select studies** Unclear concern – Some information regarding search strategy is missing

Study details	Population	Recommendations/key findings	Quality assessment
			3.1 Were efforts made to minimise error in data collection? Yes – 2 authors independently data extracted. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Probably yes – Link to full study characteristics provided; however cannot access these. **3.3 Were all relevant study results collected for use in the synthesis?** Probably yes – Unclear whether all relevant study results were included **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** Yes – TAPUPAS standard was used to critically assess included studies. **3.5 Were efforts made to minimise error in risk of bias assessment?** Yes – Two reviewers independently critically assessed included papers and a third reviewer was used where there were discrepancies. **Concerns regarding methods used to collect data and appraise studies** Low concern – Insufficient information about study characteristics but risk of bias as assessed accordingly. **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? No information **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** No information **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No - The studies were evaluated for risk of bias but results were not incorporated into findings/conclusion **Concerns regarding the synthesis and findings** Unclear concern - There is insufficient information reported to make a judgement on risk of bias ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** Yes **B. Was the relevance of identified studies to the review's research question appropriately considered?** Yes **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes **Risk of bias** – Unclear risk of bias

Study details	Population	Recommendations/key findings	Quality assessment
			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 – Aims very clearly defined **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 – Recruitment strategy clearly defined and deemed appropriate. **5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)** Yes – Focus groups and national surveys were used. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)** Can’t tell – No information provided **7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)** Yes – Ethical issues were considered **8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)** Yes – Thematic analysis was used and clearly defined.

Study details	Population	Recommendations/key findings	Quality assessment
			9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings **10. How valuable is the research?** Valuable- Researchers also highlight that there is further need for research on the impact of advocacy on the use of mental health services, satisfaction with care, and mental health and broader social outcomes for African and Caribbean men and the relationship between different organizational models for provision and this range of outcomes. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** **No limitations**
Full citation Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021] **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research (focus groups and interviews), case studies	Patients detained under the amended Mental Health Act 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	**Key findings in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** • There was broad consensus in relation to the need for positive working cultures between advocates and mental health services. This could form part of the commissioning process or an engagement protocol, but would depend on whether there is mutual understanding and realistic expectations of each others' roles. • The organisational culture and attitudes of mental health professionals towards	**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)**

Study details	Population	Recommendations/key findings	Quality assessment
Study dates 2010 to 2012 **Source of funding** Department of Health		advocacy impacts on the support for the provision of IMHA services: • Some mental health professionals clearly welcomed the IMHA role in protecting the rights of service users under the Mental Health Act. • Some mental health professionals viewed the IMHA role as challenging, even irritating and inappropriate. • Positive relationships reflected an understanding of the needs for IMHA provision, its purpose and potential outcomes for qualifying patients. Relationships between IMHA services and advocacy partners took time to build and were facilitated by continuity of an advocate who was able to change roles from IMHA to generic advocate when necessary. The advocacy role was seen by some mental health professionals as being an extension of team-working. • Mental health professionals can support advocacy services by making IMHAs feel welcome, make sure rooms are available or a quiet space for meeting services	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. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes - the methods used were explicitly described and justifications for their use were provided, although saturation of data was not discussed. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** Yes - the authors acknowledged the potential for the quality of the data collection and analysis to be influenced by the researchers. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** Yes - ethical approval was received from the Cambridgeshire Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes - the authors describe the analysis process and sufficient data are presented to support the findings. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes. **10. How valuable is the research?** Valuable - the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research.

Study details	Population	Recommendations/key findings	Quality assessment
		users, and keeping alert to the safety of the advocate, such as communicating basic information about wellbeing or risk prior to IMHAs seeing particular service users. For example, "Our staff should be courteous, polite, make sure they have open access to any areas they should have access to, you know, and give them explanations if there's things that have to be kept confidential or things that can't be shared". [Service user Involvement Worker] (p.164) • Negative relationships often reflected uncertainty or lack of achievement of desired outcomes, the extent to which mental health professionals understood that their service had an obligation to promote the advocacy service, and certain aspects of the way the IMHA service was delivered. • Occasionally there is resistance and conflict which can lead to problems in working relationships between IMHA and mental health services. • Balancing the desirability of having constructive working relationships with mental health services could be a challenge to some IMHAs, and	**Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Minor limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		advocacy services, who could be seen by service users as no longer being independent and too close to mental health professionals. For example, “slowly but surely we are becoming part of the statutory regime” (p.171). • Working together raised some issues about boundaries and the extent to which a valued close working relationship may become too enmeshed, and work against the principles of advocacy, such as advocacy co-opted. • The organisation of key meetings such as the Care Programme Approach (CPA) was seen to reflect the status of working relationships, with failure to consider advocacy thoroughly in the planning and attendance at meetings resulting in problems in staff-advocacy relations. • Lack of effective communication could make the advocacy role more difficult and place strain on the relationship with care teams. • IMHAs reported positive experiences and encouragement from the clinical team for them attending meetings.	

Study details	Population	Recommendations/key findings	Quality assessment
		• Carers were not always aware of IMHA services and voluntary sector providers drew attention to the potential confusion with IMCA. • Quality indicator 14 – Person-centred focus ○ IMHA services have a clear person-centred focus and the centrality of relationship to advocacy work is recognised in service specification and contracts. There is a tangible commitment to equality, equity of access and providing a culturally relevant approach. ○ IMHA services involve and work with mental health service users, to co-design, develop and monitor the provision of IMHA services. • Issues that potentially impacted on the quality of the relationship between the IMHA and advocacy partner included characteristics such as gender, ethnicity and shared cultural identity. • Quality indicator 1: ○ Those commissioning IMHA services work in partnership with commissioners of mental health services, so that the impact of IMHA	

Study details	Population	Recommendations/key findings	Quality assessment
		provision on mental health service development can be understood and maximised. ○ Work in partnership with health commissioners to ensure that the context within which IMHA services are operating is a supportive one. **Recommendations in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** • Mental health services need to consider how to provide a supportive context within which IMHA service can operate. This should include: • Care being taken to involve the IMHA in relevant meetings by timetabling key meetings and providing advance notice to the qualifying patients and the advocate. • Respect for the advocate role means ensuring that qualifying patients can contact and meet the IMHA service in private. • Ensure that there is a policy and understanding of access to notes. • Recognising the unique role that IMHAs can play and how this is complementary to, and	

Study details	Population	Recommendations/key findings	Quality assessment
		not an alternative, to legal representation. Having an explicit focus on improving relationships between mental health staff and the IMHA service and the importance of IMHA maintaining its independence.	
Full citation Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** December 2011 and January 2012 **Source of funding** Supported by the Department of Health.	A range of people including people living with learning disabilities	**Key findings in relation to partnership working with families and carers, commissioners and providers (delivering advocacy)** • 20 advocacy organisations (33%) worked with local authorities. For example, "We actively take part in consultations with our local council"; "We work closely with the local authority on the learning disability partnership board and with the various task groups". (p.23) • 12 advocacy organisations (20%) worked with other local advocacy groups. For example, "We work with other charitable organisations in the area which provide peer advocacy, as well as citizen advocacy". (p.23) • 6 advocacy organisations (10%) worked with charities such as Mencap.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how advocacy organisations and commissioners of advocacy services were identified is explained to some extent. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided.

Study details	Population	Recommendations/key findings	Quality assessment
		• Other groups or agencies mentioned by advocacy organisations included, for example, community services such as day services and community nurses or learning disability nurses; IMHAs and IMCAs; police and probation. • 67% of commissioners were to some extent engaged in collaborative working with other commissioners of advocacy: • 14 commissioners worked collaboratively with NHS commissioners. • 11 commissioners worked with other commissioners and commissioning bodies; some worked within their own local authority with other service commissioners (for example, mental health) while others were working collaboratively with commissioners from other boroughs. • Links with other organisations, including councils, police and schools (6 organisations). • Involving service users in the organisation, including as a user led organisation and involvement in the AGM or Board meetings (6 organisations).	**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide evidence on gaps in the provision of advocacy services and areas for further research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		Supporting parents with learning disabilities, including child protection issues (8 organisations). Fully including people with learning disabilities within the advocacy organisations (sometimes as paid self-advocates, sometimes as part of management committees or boards, thus giving people with learning disabilities a say in the direction of the organisation).	
Full citation SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at: https://www.vfrhub.com/wp-content/uploads/221/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research and social return on investment analysis	Military veterans and their families	**Key findings in relation to partnership working with families and carers, commissioners and providers (Delivering Advocacy)** • Advocates relayed the impact of their role with The Veterans' Advocacy People in terms of increasing their awareness of the issues faced by veterans and the size of the problem; developing connections and exposure to a variety of people and ways of working with them; making changes in how they respond to people and issues, or how they view circumstances. ○ "Other organisations are starting to understand advocacy. They're starting to value what we do. We are	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to assess the impact of advocacy on veterans and their families, and the wider social and financial impact. To enable a greater understanding within central and local government and across the military charity sector of any potential for investment in this area and lessons for practice in support for veterans and in the wider use of advocacy services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
Study dates 2018 to 2021 **Source of funding** No sources of funding reported.		getting the message out there, both at a senior level and on the ground." (p.22) • The benefits of a more joined-up system were discussed in terms of greater understanding of advocacy by other organisations and greater working relationships. ○ "It is very mutually beneficial because some of the issues they cannot deal with they pass the clients on to us [e.g. time-intensive benefits appeals], and vice versa. Some of the things that we cannot help with, we pass on to them. There is mutual benefit. There is a close bond. This partnership also benefits clients." (p.22) ○ "A very effective working relationship. We have go-to people we can contact immediately, can offer immediate and practical support for our members who are struggling and we can't do anything about it." (p.22)	Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors suggest strengths and limitations of the research and potential for unintended outcome consequences, and suggestions for further analysis relating to data monitoring. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
Full citation Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** December 2011 and January 2012 **Source of funding** Supported by the Department of Health.	A range of people including people living with learning disabilities	**Recommendations in relation to partnership working with families, carers, commissioners and providers (Delivering Advocacy)** • Advocacy organisations should highlight gaps in service provision to commissioners. • Most advocacy organisations collaborated with other groups or organisations, most commonly local authorities, although some described working with other advocacy groups. • Although advocacy organisations are not public bodies, they can be commissioned by public bodies and relationships between the two should take equality into consideration. For example, survey responses indicated that parents with learning disabilities and young people in transition may struggle to access advocacy. **Recommendations in relation to Partnership working with families and carers, commissioners and providers (delivering advocacy)** • Commissioners and advocacy groups should work	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes – how advocacy organisations and commissioners of advocacy services were identified is explained to some extent. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No – the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
		collaboratively to plan better services. • To ensure that advocacy organisations meet the needs of people living with learning disabilities, it is important for commissioners to work with advocacy groups who are well placed to tell commissioners what is needed. • One advocacy group (Your Say) highlighted the importance of a supportive commissioner for the group's development and as a conduit to the local Health and Wellbeing Board. • Collaborative working can also potentially increase the coverage of advocacy for people in protected groups. • Understand the potential of local, regional and national groups to strengthen and support advocacy, and support local advocacy groups to be part of the wider network.	No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable – the authors provide evidence on gaps in the provision of advocacy services and areas for further research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

AGM: annual general meeting; AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; BCVS: Black and community voluntary sector; CASP: Critical Appraisal Skills Programme; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MHA: Mental Health Act; NDTi: National Development Team for Inclusion; NHS: National Health Service; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews; SAB: Safeguarding Adults Board; TAPUPAS: transferability, accessibility, propriety, utility, purposivity, accuracy and specificity; UCLAN: University of Central Lancashire

Appendix C Quality Assessment

Quality assessment tables for scope area: Partnership working and relationships with families and carers, commissioners and providers

Formal consensus

Table 4: AGREE II assessment of included guidelines

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

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument

Table 5: ROBIS quality assessment of included systematic reviews

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

ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Table 6: CASP quality assessment of included qualitative studies

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

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**
NDTi 2014b	2014	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
NDTi 2020a	2020	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
NDTi 2020b	2020	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Newbigging 2011	2011	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Roberts 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable
SERIO 2021	2021	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Turner 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable

CASP: Critical Appraisal Skills Programme

Appendix D Excluded studies

Excluded studies for scope area: Partnership working and relationships with families and carers, commissioners and providers

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

Table 7: Excluded studies and reasons for their exclusion

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

Study	Reason for Exclusion
https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	
Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 44(2), 219-230.	Publication is based on case-studies
Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services, NIHR School for Social Care Research Scoping Review. Available at: https://www.ndti.org.uk/assets/files/SSCR-scoping-review_SR007.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Partnership working and relationships with families and carers, commissioners and providers
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 Partnership working and relationships with families and carers, commissioners and providers
National Development Team for Inclusion, Empowerment Matters (2014). Advocacy QPM: Advocacy Code of Practice, revised edition, 2014. Available at https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf [Accessed 25/11/2021]	Publication has no evidence base
National Development Team for Inclusion. (2018). Advocacy QPM: Assessment Workbook. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion (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 Partnership working and relationships with families and carers, commissioners and providers
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished	No key findings or recommendations relevant to Partnership working and relationships with families and carers, commissioners and providers
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 Partnership working and relationships with families and carers, commissioners and providers
National Development Team for Inclusion. (2018). The Advocacy Charter (Poster). Available at:	Publication has no evidence base

Study	Reason for Exclusion
https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]	
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 (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
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: Summary Report, University of Central Lancashire.	Summary of Newbigging 2012: No additional information reported
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 a book/book-chapter.
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Older People's Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, Vol. 23(4), 280-292.	No key findings or recommendations relevant to Partnership working and relationships with families and carers, commissioners and providers
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

Study	Reason for Exclusion
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 (2015). Commissioning Independent Mental Health Advocacy (IMHA) services in England: 10 top tips for commissioners. https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/10-top-tips.asp [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Flowchart for Open Access IMHA. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving access to Independent Mental Health Advocacy for providers of mental health services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a briefing for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/briefing/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a report for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/report/ [Accessed 16/02/2022]	Publication is based on case-studies

Study	Reason for Exclusion
Social Care Institute for Excellence, University of Central Lancashire (2015). Making a difference: measuring the impact of Independent Mental Health Advocacy (IMHA). Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). What does a good IMHA service look like? (Self-assessment tool) Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/what-good-imha-service-looks-like/ [Accessed 16/02/2022]	Publication has no evidence base
Strong, S. (2012). User-led organisation leadership of support planning and brokerage. The International Journal of Leadership in Public Services, 8(2), 83-89.	Publication is based on case-studies
Taylor & Francis Production Disability and Rehabilitation (IDRE). My Life Tool (self-management tool): www.mylifetool.co.uk	Publication has no evidence base
Teeside University (2015/2016). UTREG Online Module Specification: Advocacy - Evolution, Equality and Equity. Unpublished.	Publication has no evidence base
Townsley, R., Marriott, A., Ward, L. (2009). Access to independent advocacy: an evidence review, Office for Disability Issues. Available at: http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-exec-summary-standard.pdf [Accessed 16/02/2022]	Not published in the last 10 years
Turner, S. & Giraud-Saunders, A. (2014). Personal health budgets: Including people with learning disabilities	Publication is based on case-studies
VoiceAbility (2021). Preventing over-medication. STOMP top tips for advocates: How you can help to stop the over-medication of people with a learning disability, autism or both	Publication has no evidence base
VoiceAbility (2021). Preventing over-medication. STOMP top tips for advocates: How you can help to stop the over-medication of people with a learning disability, autism or both	Publication has no evidence base

Excluded economic studies

No economic evidence was considered for this scope area.

Appendix E Research recommendations – full details

Research recommendations for scope area: Partnership working and relationships with families and carers, commissioners and providers

No research recommendations were made for this scope area.

Appendix F Existing NICE recommendations

No existing NICE recommendations were identified for this scope area.

Appendix G Formal consensus

Additional information related to scope area: Partnership working and relationships with family and carers, commissioners and providers

Table 8: Formal consensus round 1 statements and results for scope area: Partnership working and relationships with family and carers, commissioners and providers

Statement no.	Statement	Percentage agreement	Reference	Action taken
1	Advocacy services should increase awareness of issues faced by particular groups of people.	91.67%	SERIO, 2021	Carried forward to committee discussion
2	Advocacy services should develop connections and exposure to a variety of people and ways of working with them.	83.33%	SERIO, 2021	Carried forward to committee discussion
3	Advocacy services should make changes in terms of how they respond to people and issues.	63.64%	SERIO, 2021	Re-drafted for round 2
4	Advocacy services should ensure a greater understanding of advocacy and greater working relationships.	72.73%	SERIO, 2021	Re-drafted for round 2
5	Everyone involved with advocacy (including people who access the service) should work in partnership when implementing an outcome reporting system.	100.00%	NDTi, 2016a	Carried forward to committee discussion
6	Advocacy service providers and commissioners should work together where possible so there is agreement on outcomes to be achieved.	100.00%	NDTi, 2016a; Newbigging, 2012	Carried forward to committee discussion
7	Advocacy service providers and commissioners should work together where possible so there is agreement on how outcomes will be reported.	100.00%	NDTi, 2016a	Carried forward to committee discussion
8	Trends and themes for service change and improvement identified by advocacy services need to be acted upon by commissioners.	90.91%	NDTi, 2016a	Carried forward to committee discussion
9	Trends and themes for service change and improvement identified by advocacy services need to be acted upon by service managers.	100.00%	NDTi, 2016a	Carried forward to committee discussion
10	Consider co-location (for example, shared office space) for advocates working in partnership with other service providers.	66.67%	NDTi 2014b	Re-drafted for round 2
11	There should be strong partnerships between advocacy providers, commissioners and wider support services across the spectrum of public	100.00%	NDTi 2014b	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
	services and local agencies (such as health, social care, education, employment support, community action).			
12	Advocacy organisations need to raise awareness about their roles on an ongoing basis.	100.00%	Lawson, 2020	Carried forward to committee discussion
13	It is fundamental that strong working relationships are developed between advocacy providers and others involved in advocacy to ensure the understanding of statutory duties to refer people for advocacy support.	100.00%	Lawson, 2020	Carried forward to committee discussion
14	Safeguarding Adult Boards (SAB) should engage with advocacy providers and commissioners to make sure they hear about local issues in these environments.	100.00%	Lawson, 2020	Carried forward to committee discussion
15	Relationship commissioners have, including with providers and with SABs, needs to be central focus in developing advocacy’s part in making safeguarding personal (MSP).	87.50%	Lawson, 2020	Carried forward to committee discussion
16	Need to make sure commissioners are included in development and awareness raising about advocacy.	90.91%	Lawson, 2020	Carried forward to committee discussion
17	Ensure the views of people who use services and their carers are captured to maximise effectiveness of independent advocacy and inform improvements in safeguarding.	100.00%	Lawson, 2020	Carried forward to committee discussion
18	Commissioners need to understand advocacy and the role it plays in protecting individual rights and promoting wellbeing.	100.00%	Lawson, 2017	Carried forward to committee discussion
19	Commissioners should work alongside providers, acknowledging their expertise.	91.67%	Lawson, 2017	Carried forward to committee discussion
20	Commissioners should establish effective communication and working relationships with providers in order to facilitate working up flexible and personalised solutions for individuals.	100.00%	Lawson, 2017	Carried forward to committee discussion
21	Advocacy organisations should continue to aim for greater cooperation with other agencies to raise awareness of people’s rights to access advocacy services.	90.91%	NDTi, 2020a	Carried forward to committee discussion
22	Advocacy organisations should share commitments to ensure people’s access to effective advocacy.	90.91%	NDTi, 2020a	Carried forward to committee discussion
23	Advocacy organisations should continue to aim for greater cooperation with other agencies by sharing experience and good practice.	81.82%	NDTi, 2020a	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
24	Advocacy organisations should commit to harnessing insight and expertise to influence policy and practice at an individual level by challenging decisions.	90.91%	NDTi, 2020a	Carried forward to committee discussion
25	Advocacy organisations should commit to harnessing insight and expertise to influence policy and practice at the wider level of systemic change.	100.00%	NDTi, 2020a	Carried forward to committee discussion
26	Advocacy services should work with care providers to ensure people have access to advocacy.	100.00%	NDTi, 2020b	Carried forward to committee discussion
27	Advocacy services should be flexible in the way they deliver services to ensure that continued support is provided to people.	90.91%	NDTi, 2020b	Carried forward to committee discussion
28	Advocacy services should utilise different approaches to communicating with people to ensure full access to advocacy remains in place.	100.00%	NDTi, 2020b	Carried forward to committee discussion
29	Health professionals work with IMHAs could be facilitated by location within a recovery-focused approach.	87.50%	NDTi, 2020b	Carried forward to committee discussion
30	Mental health professionals working with those on CTOs should receive training about their obligation to inform qualifying patients about IMHA services.	90.00%	NDTi, 2020b	Carried forward to committee discussion
31	Protocols for referrals between mental health professionals and IMHA services should be developed.	90.91%	NDTi, 2020b	Carried forward to committee discussion
32	Advocacy services should provide staff training that explicitly addresses the issues that enhance good partnership working between IMHAs and mental health professionals.	90.91%	NDTi, 2020b	Carried forward to committee discussion
33	Commissioners should work with advocacy groups to ensure that advocacy organisations meet the needs of people living with learning disabilities.	100.00%	Turner, 2020	Carried forward to committee discussion
34	Commissioners should support advocacy groups to be part of the wider network.	83.33%	Turner, 2020	Carried forward to committee discussion
35	Advocacy services should highlight gaps in service provision to commissioners.	100.00%	Turner, 2020	Carried forward to committee discussion
36	Advocacy organisations should collaborate with other groups or organisations.	91.67%	Turner, 2020	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
37	Advocacy organisations should collaborate with local authorities.	91.67%	Turner, 2020	Carried forward to committee discussion
38	Advocacy organisations should collaborate with other advocacy groups.	91.67%	Turner, 2020	Carried forward to committee discussion
39	Relationships between advocacy organisations and public bodies should take equality into consideration.	91.67%	Turner, 2020	Carried forward to committee discussion
40	Advocacy organisations should work collaboratively with other agencies and advocacy groups.	91.67%	Roberts, 2012	Carried forward to committee discussion
41	Commissioners of advocacy should work collaboratively with other local commissioners and commissioning bodies.	100.00%	Roberts, 2012	Carried forward to committee discussion
42	Commissioners of advocacy should work collaboratively with other commissioners and commissioning bodies from other geographical areas.	91.67%	Roberts, 2012	Carried forward to committee discussion
43	People who use services should be provided with the opportunity to be actively involved in advocacy organisation activities (for example, AGM or board meetings).	91.67%	Roberts, 2012	Carried forward to committee discussion
44	Advocacy organisations should work with local authorities.	91.67%	Roberts, 2012	Carried forward to committee discussion
45	Advocacy organisations should work with other local advocacy groups.	91.67%	Roberts, 2012	Carried forward to committee discussion
46	Advocacy organisation should work with charities.	90.91%	Roberts, 2012	Carried forward to committee discussion
47	Advocacy organisations should work with community services (day services).	91.67%	Roberts, 2012	Carried forward to committee discussion
48	Advocacy organisations should work with criminal justice services.	90.91%	Roberts, 2012	Carried forward to committee discussion
49	Commissioners of advocacy services should work collaboratively with NHS commissioners.	100.00%	Roberts, 2012	Carried forward to committee discussion
50	There is a need for positive working cultures between advocates and mental health services.	100.00%	Newbigging, 2012	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
51	The organisational culture and attitudes of mental health professionals towards advocacy impacts on the support of for the provision of IMHA services.	100.00%	Newbigging, 2012	Carried forward to committee discussion
52	Positive relationships reflected an understanding of the needs for IMHA provision, its purpose and potential outcomes for qualifying patients.	100.00%	Newbigging, 2012	Carried forward to committee discussion
53	Positive relationships reflected the understanding that mental health professionals can support advocacy services by making IMHAs feel welcome.	91.67%	Newbigging, 2012	Carried forward to committee discussion
54	Positive relationships reflected an understanding that mental health professionals can support advocacy services by making sure rooms or a quite space are available for meeting service users.	91.67%	Newbigging, 2012	Carried forward to committee discussion
55	Positive relationships reflected the understanding that mental health professionals can support advocacy services by keeping alert to the safety of the advocate (such as communicating basic information about wellbeing or risk prior to IMHAs seeing particular service users).	100.00%	Newbigging, 2012	Carried forward to committee discussion
56	Negative relationships often reflected uncertainty around the extent to which mental health professionals understood that their service had an obligation to promote the advocacy service.	90.00%	Newbigging, 2012	Carried forward to committee discussion
57	Negative relationships often reflected occasional resistance and conflict leading to problems in working relationship between IMHA and mental health services.	88.89%	Newbigging, 2012	Carried forward to committee discussion
58	There is a difficulty to develop constructive working relationships between IMHA and MH services that preserve the independence of these services.	54.55%	Newbigging, 2012	Discarded
59	IMHA may not be seen as independent by service users if they work closely with MH services.	66.67%	Newbigging, 2012	Re-drafted for round 2
60	Issues about boundaries could be raised when advocates and MH professionals work together.	83.33%	Newbigging, 2012	Carried forward to committee discussion
61	Working together raised issues about the extent to which a valued working relationship may become too enmeshed and work against the principles of advocacy.	63.64%	Newbigging, 2012	Re-drafted for round 2
62	Advocacy is not considered thoroughly when planning and attending meetings.	83.33%	Newbigging, 2012	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
63	Lack of effective communication could make the advocacy role more difficult and place strain on the relationship with care teams.	100.00%	Newbigging, 2012	Carried forward to committee discussion
64	IMHAs reported positive experiences and encouragement from the clinical team for them attending meetings.	100.00%	Newbigging, 2012	Carried forward to committee discussion
65	There can be confusion between IMHA and IMCA.	83.33%	Newbigging, 2012	Carried forward to committee discussion
66	Carers are not always aware of IMHA services.	90.91%	Newbigging, 2012	Carried forward to committee discussion
67	IMHA services should have a clear person-centred focus and the centrality of relationship to advocacy work is recognised in service specifications and contracts.	100.00%	Newbigging, 2012	Carried forward to committee discussion
68	The centrality of relationship to advocacy work should be recognised in service specifications and contracts.	90.91%	Newbigging, 2012	Carried forward to committee discussion
69	IMHA services should involve and work with mental health service users to co-design, develop and monitor the provision of IMHA services.	100.00%	Newbigging, 2012	Carried forward to committee discussion
70	Characteristics such as gender, ethnicity, and shared cultural identity potentially impact the quality of the relationship between the IMHA and advocacy partner.	91.67%	Newbigging, 2012	Carried forward to committee discussion
71	Mental Health services need to consider how to provide a supportive context within which the IMHA service can operate. IMHA should be involved in meetings by timetabling key meetings and providing advance notice to the qualifying patient and the advocate.	100.00%	Newbigging, 2012	Carried forward to committee discussion
72	Qualifying patients should be able to contact and meet the IMHA services in private.	100.00%	Newbigging, 2012	Carried forward to committee discussion
73	Mental health services need to ensure that there is a policy and understanding of access to notes.	100.00%	Newbigging, 2012	Carried forward to committee discussion
74	Mental health services should recognise the unique role the IMHA can play and how this is complementary to and not an alternative to legal representation.	100.00%	Newbigging, 2012	Carried forward to committee discussion
75	Mental health services need to have an explicit focus on improving relationships between mental health staff and IMHA service.	91.67%	Newbigging, 2012	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
76	Mental health services need to have an explicit focus on importance of IMHA maintaining independence.	91.67%	Newbigging, 2012	Carried forward to committee discussion
77	Those commissioning IMHA services should work in partnership with commissioners of mental health services, so that the impact of IMHA provision on mental health service development can be understood and maximised.	100.00%	Newbigging, 2012	Carried forward to committee discussion
78	Work in partnership with health commissioners to ensure that the context within which IMHA services are operating is a supportive one.	91.67%	Newbigging, 2012	Carried forward to committee discussion
79	Mental health advocacy could be provided as an integral part of wider black community and voluntary sector (BCVS) mental health service, as a discrete casework advocacy service managed by a BCVS mental health service or through employing African and Caribbean staff within general mental health advocacy services.	100.00%	Newbigging, 2011	Carried forward to committee discussion
80	Different types of advocacy services could be co-located, for example, an African and Caribbean advocacy service located in community centre together with a general mental health advocacy service.	100.00%	Newbigging, 2011	Carried forward to committee discussion
81	It is important that black community and voluntary sector services work in partnership with mainstream mental health advocacy services and mental health services to increase uptake, ensure cultural sensitivity of provision and contribute to capacity building.	100.00%	Newbigging, 2011	Carried forward to committee discussion

AGM: annual general meeting; BCVS: Black community and voluntary sector; CTO: Community Treatment Order; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MH: mental health; NHS: National Health Service; SAB: Safeguarding Adults Board.

Table 9: Formal consensus round 2 statements and results for scope area: Partnership working and relationships with family and carers, commissioners and providers

Statement no.	Statement	Percentage agreement	Action taken
3	Advocacy services should engage with specialist services to discuss their roles and enable them, where necessary, to make changes to improve the way in which they respond to specific populations and address their issues.	66.67%	Discarded
4	Advocacy services should work with other service providers to promote an understanding of each other’s roles and responsibilities, in order to enhance good working relationships.	91.67%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
10	Consider co-location (for example, shared office space) for advocates working in partnership with other service providers, if this is deemed appropriate and clear boundaries are set out to maintain the independence and confidentiality of advocacy services.	66.67%	Discarded
59	IMHAs should explain to people using services the reasons for working closely with mental health professionals but emphasise that they remain independent from mental health services.	100.00%	Carried forward to committee discussion
61	IMHA services should balance having constructive working relationships with MH services with maintaining professional boundaries and the independence of the IMHA service.	90.91%	Carried forward to committee discussion

IMHA: Independent Mental Health Advocate; MH: mental health