National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[A] Who has a legal right to advocacy?

NICE guideline NG227

Evidence reviews underpinning recommendations 1.1.1 and 1.1.2 in the NICE guideline

November 2022

Final

Disclaimer

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ISBN: 978-1-4731-4782-9

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Key theme

- Who has a legal right to advocacy?

Introduction

The aim of this review is to lay out who has a legal right to advocacy. Legal right to advocacy is also called statutory advocacy because entitlement exists in law (statute).

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Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are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	Legal right to advocacy

Methods and process

The process for identifying, adopting and adopting 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

Existing recommendations relevant to who has a legal right to advocacy were identified from 10 NICE guidelines ([CG90] Depression in adults: recognition and management, [CG136] Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services, [NG53] Transition between inpatient mental health settings and community or care home settings, [NG86] People's experience in adult social care services: improving the experience of care and support for people using adult social care services, [NG93] Learning disabilities and behaviour that challenges: service design and delivery, [NG96] Care and support of people growing older with learning disabilities, [NG108] Decision-making and mental capacity, [NG150] Supporting adult carers, [NG181] Rehabilitation for adults with complex psychosis, [NG189] Safeguarding adults in care homes). The audiences for these guidelines included: people with the condition or users of a services and their families and carers; health and social care professionals, practitioners and providers; service managers; commissioners, local authorities and safeguarding adult boards; and other staff who come into contact with people using services (for example, education, voluntary and community sector, welfare, criminal justice, clerical and domestic staff). Only NG86, NG96, NG108 and NG189 specifically listed advocates among their target audiences.

Formal consensus

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

Five documents were identified for this review (Lawson 2020, Macadam 2013, Mercer 2020, Newbigging 2012, Ridley 2018).

One document each focused on people detained under the Mental Health Act 1983 (Newbigging 2012), those who have duties to commission and arrange advocacy services for safeguarding adults (Lawson 2020), people who use social care services (Macadam 2013), and independent advocacy services (Mercer 2020). One document (Ridley 2018) included 3 different populations: African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; and children and young people receiving advocacy services.

Excluded studies

Formal consensus

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

Summary of included studies

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

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

Document	Population	Evidence base
Lawson 2020	Those who have duties to commission and arrange	Briefing generated by a series of conversations with 28 advocates

Document	Population	Evidence base
Briefing report England	advocacy services for safeguarding adults	from 18 advocacy providers across England, covering 33 local authority areas
Macadam 2013 Scoping review England	People who use social care services	Systematic scoping review and call for evidence with content analysis
Mercer 2020 Scoping review England	Independent advocacy services commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the Mental Health Act) ii) NHS CHC (adults) iii) Children and Young People's CC iv) Personal Health Budgets; v) Personal Wheelchair Budgets	Non-systematic scoping exercise including data from: Freedom of information requests to identify what services were commissioned, by whom and to which groups; advocacy survey for advocates to identify what advocacy providers are delivering; semi-structured telephone interviews with Independent Advocacy providers; review of legislation and guidance to identify current provision and identify gaps
Newbigging 2012 Research report England	People detained under the amended Mental Health Act 1983, who were eligible for support from IMHA services, including people with and without capacity and children under the age of 16	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Ridley 2018 Review of 3 qualitative studies England	African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; children and young people receiving advocacy services	Comparative analysis and synthesis of findings from 3 qualitative studies (including service user, advocate, professional and commissioner perspectives); data collected through focus groups and/or interviews

CC: continuing care; IMHA: Independent Mental Health Advocate; NHS CHC: NHS Continuing Healthcare

See the full evidence tables for documents included in the formal consensus process in appendix B.

Summary of the evidence

Existing NICE guidelines

A total of 10 existing recommendations related to who has a legal right to advocacy were identified from the 10 NICE guidelines. The committee agreed 1 recommendation should be adapted and 9 recommendations should not be used in this guideline.

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

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

Formal consensus round 1

Three documents (Macadam, 2013; Mercer, 2020; Ridley 2018) were assessed using the Risk of Bias in Systematic reviews (ROBIS) checklist and 2 included documents (Lawson 2020; Newbigging, 2012) were assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative research. See the results of the quality assessment in the evidence tables in appendix B and quality assessment tables in appendix C.

The committee were presented with 13 statements in round 1 of the formal consensus exercise; responses were received from all 12 committee members. At the time that round 1 voting for this scope area occurred, there were 12 committee members appointed. An additional committee member was appointed between the first and second round of voting; therefore, 13 committee members were eligible for voting during round 2. Ten of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Three statements had between 60% and 80% agreement. Two of these were included for the discussion with the committee as the comments related to how the statements might inform recommendations rather than the content of the statements; the remaining statement was re-drafted for round 2. No statements had <60% agreement.

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

Formal consensus round 2

The committee were presented with 1 statement in round 2 of the formal consensus exercise; responses were received from 11 of 13 committee members. This statement reached ≥80% agreement and was included for the discussion with the committee.

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

Economic evidence

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

The committee's discussion and interpretation of the evidence

The outcomes that matter most

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

The quality of the evidence

Existing NICE guidelines

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

Formal consensus

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

The quality of 3 documents (Macadam, 2013; Mercer, 2020; Ridley, 2018) were assessed using the ROBIS checklist for systematic reviews. One document (Macadam, 2013) was judged to have unclear risk of bias because insufficient details were provided to enable a judgement to be made. Two documents (Mercer, 2020; Ridley, 2018) were judged to be at high risk of bias.

Methodological limitations included a lack of clear reporting or an absence of reporting about eligibility criteria. Other concerns related to insufficient information on study selection, lack of critical appraisal of included papers, and an absence of testing the robustness of the review findings.

The quality of 2 documents (Lawson, 2020; Newbigging, 2012) were assessed using the CASP checklist for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations. The second document (Lawson, 2020) was 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 agreed that the legislation covering statutory entitlement to advocacy is very complex and difficult for people to understand, in part because statutory entitlement is covered by different acts depending on circumstances. Due to the complexity of the legislation and the fact that it can change over time, the committee agreed it would be most useful to refer to the guidance supporting each Act of Parliament as well as the legislation itself (e.g., Care and support statutory guidance: issued under the Care Act 2014, Mental Capacity Act 2005 Code of Practice, Mental Health Act 1983: Code of Practice) rather than make their own recommendations about entitlement to advocacy. They agreed that having all the relevant legislation signposted in one place would make it easier for people to find the relevant information, including relevant legislative updates such as the forthcoming implementation of Liberty Protection Safeguards.

The committee were aware of legislation that specifically references the provision of advocacy support for people making, or intending to make complaints (the 2012 Health and Social Care Act amendment to the 2007 Local Government and Public Involvement in Health Act, and the NHS Complaint Standards in the 2021 update to the NHS Constitution.). It places the duty on local authorities to provide a service rather than an individual right to advocacy support, so in this sense is slightly different than the duties set out in the legislation described in the paragraph above. They therefore dealt with this separately by recommending that local authorities ensure appropriate arrangements for independent advocacy services to provide assistance to people intending to make complaints, as described in the Health and Social Care Act 2012.

Statements not used in this review

As the committee agreed not to make their own recommendations about entitlement to advocacy, there were a number of statements (Statements 1, 2, 3, 4, 7, 8, 9, 10, 11, 12 and 13) carried forward to committee discussions that were not used to inform recommendations. Furthermore, statement 5 which covered the duty of local authorities to ensure advocacy is provided to people who are the subject of a safeguarding enquiry was not used to inform a recommendation as the content is covered by the reference to the statutory guidance. Statement 6 emphasised that paid relevant person’s representatives should provide support to people subject to Deprivation of Liberty Safeguards (DoLS) authorisations to understand restrictions and their rights in matters relating to DoLS. This was not used to inform a recommendation as the legislation does not specify that paid relevant person’s representatives should help people understand restrictions and rights, so this is not a legal entitlement.

Existing recommendations not used in this review

Similarly, the existing recommendations about entitlement to advocacy from the NICE guidelines on people’s experience in adult social care services [NG86], service user experience in adult mental health [CG136], depression in adults [CG90], decision making and mental capacity [NG108], rehabilitation in adults with complex psychosis and related severe mental health conditions [NG181], and transition between inpatient mental health settings and community or care home settings [NG53] were not used in this guideline as the content is covered by the statutory guidance referred to in the recommendations.

The existing recommendations from the NICE guidelines on learning disabilities and behaviour that challenges: service design and delivery [NG93] and care and support of people growing older with learning disabilities [NG96] were also partly covered by the reference to the statutory guidance, as far as the minimum requirements for providing independent advocacy and partly covered by recommendation 1.2.1 about who else would benefit from advocacy (see evidence review B). The existing recommendation about organisations working with adults with health and social care needs from the NICE guideline on safeguarding adults in care homes [NG189] was used to inform recommendation 1.4.1

about how training should be used to raise awareness among health and social care practitioners about the role of advocacy. The existing recommendation from the NICE guideline on supporting adult carers [NG150] also addressed the concept of minimum requirements, so this aspect was already covered by the reference to statutory guidance. However, this recommendation was also used to inform recommendation 1.3.2 about local authorities, health authorities, NHS trusts and advocacy services providing information about advocacy entitlement to all people who are legally entitled to advocacy.

Cost effectiveness and resource use

The recommendations bring together statutory guidance and any resource impact would be as a result of becoming compliant with legal requirements. The committee considered that the statutory guidance highlighted by the recommendations is largely being adhered to in almost all settings and any increase in resource use would be very small.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 and 1.1.2.

References – included studies

Existing NICE guidelines

National Institute for Health and Care Excellence 2009

National Institute for Health and Care Excellence (2009). Depression in adults: recognition and management (Clinical Guideline 90). Available at: https://www.nice.org.uk/guidance/cg90/resources/depression-in-adults-recognition-and-management-pdf-975742636741

National Institute for Health and Care Excellence 2011

National Institute for Health and Care Excellence (2011). Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (Clinical Guideline 136). Available at: https://www.nice.org.uk/guidance/cg136/evidence/full-guideline-pdf-185085613

National Institute for Health and Care Excellence 2018

National Institute for Health and Care Excellence (2018). Decision-making and mental capacity (NICE Guideline 108). Available at: https://www.nice.org.uk/guidance/ng108/evidence/full-guideline-pdf-6542486605

National Institute for Health and Care Excellence 2016

National Institute for Health and Care Excellence (2016). Transition between inpatient mental health settings and community or care home settings (NICE Guideline 53). Available at: https://www.nice.org.uk/guidance/ng53/evidence/full-guideline-pdf-2606951917

National Institute for Health and Care Excellence 2018

National Institute for Health and Care Excellence (2018). People’s experience in adult social care services: improving the experience of care and support for people using adult social care services (NICE Guideline 86). Available at: https://www.nice.org.uk/guidance/ng86/evidence/full-guideline-pdf-4731854077

National Institute for Health and Care Excellence 2018

National Institute for Health and Care Excellence (2018). Learning disabilities and behaviour that challenges: service design and delivery (NICE Guideline 93). Available at: https://www.nice.org.uk/guidance/ng93/evidence/full-guideline-pdf-4788958429

National Institute for Health and Care Excellence 2018

National Institute for Health and Care Excellence (2018). Care and support of people growing older with learning disabilities (NICE Guideline 96). Available at: https://www.nice.org.uk/guidance/ng96/evidence/full-guideline-pdf-4792236013

National Institute for Health and Care Excellence 2020

National Institute for Health and Care Excellence (2020). Supporting adult carers (NICE Guideline 150). Available at: https://www.nice.org.uk/guidance/ng150/resources/supporting-adult-carers-pdf-66141833564869

National Institute for Health and Care Excellence 2020

National Institute for Health and Care Excellence (2020). Rehabilitation for adults with complex psychosis (NICE Guideline 181). Available at: https://www.nice.org.uk/guidance/ng181/resources/rehabilitation-for-adults-with-complex-psychosis-pdf-66142016643013

National Institute for Health and Care Excellence 2021

National Institute for Health and Care Excellence (2021). Safeguarding adults in care homes (NICE Guideline 189). Available at: https://www.nice.org.uk/guidance/ng189/resources/safeguarding-adults-in-care-homes-pdf-66142030079941

Formal consensus

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]

Macadam 2013

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]

Mercer 2020

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]

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]

Ridley 2018

Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 23(4), 280-292

Other

Department of Health 2015

Department of Health (2015). Mental Health Act 1983: Code of Practice. Available at: https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983 [Accessed 15/02/2022]

Department for Constitutional Affairs 2007

Department for Constitutional Affairs (2007). Mental Capacity Act 2005: Code of Practice. Available at: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice [Accessed 15/02/2022]

Department of Health and Social Care 2022

Department of Health and Social Care (2022). Care and Support Statutory Guidance. Available at: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#independent-advocacy [Accessed 15/02/2022]

Health and Social Care Act 2012

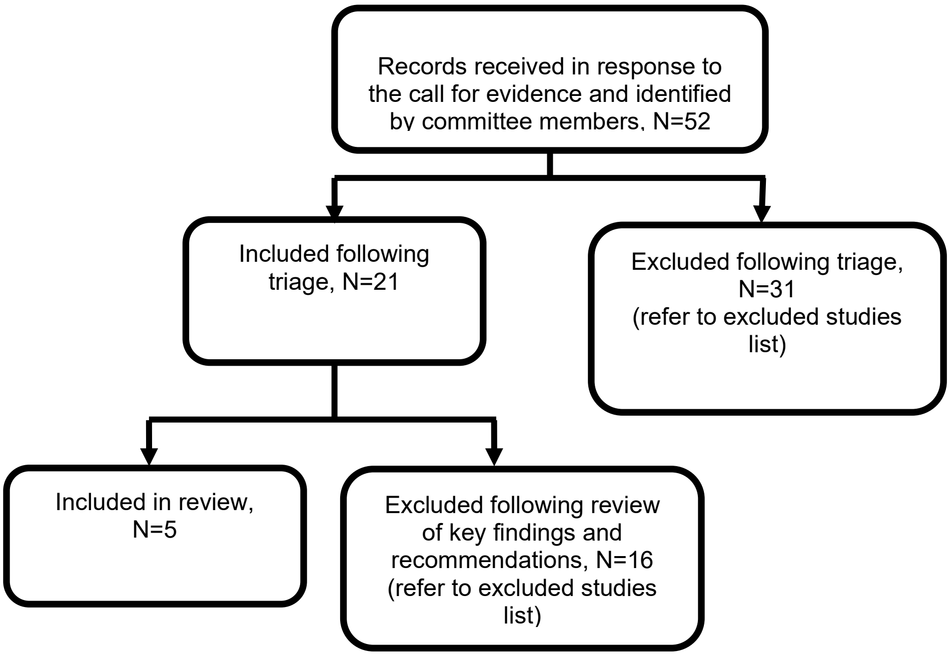
Health and Social care Act, 2012 (c.7). Available at: https://www.legislation.gov.uk/ukpga/2012/7/contents [Accessed 09/02/2022]

Appendices

Appendix A Study selection for formal consensus process

Study selection for scope area: Who has a legal right to advocacy?

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Who has a legal right to advocacy?

Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
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** • Advocacy is statutory right for some people who are subject of safeguarding concerns.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to support strengthening the role of all types of advocacy in safeguarding adults, specifically in Making Safeguarding Personal by generating multi-agency conversations based on the briefing and stimulating local action to address some of the core messages that emerge from this. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18 advocacy providers across England, covering 33 Local Authority areas.

Study details	Population	Recommendations/key findings	Quality assessment
			6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?** Valuable - the authors discuss issues arising in relation to providing advocacy services in relation to safeguarding adults and provide suggestions on how to address the key issues. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.
Full citation Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services,	People who use social care services	**Key findings** • Some advocacy is statuary – some people have legal right to an advocate in some	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?**

Study details	Population	Recommendations/key findings	Quality assessment
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] **Country/ies where the study was carried out** England **Study type** Scoping review **Study dates** 2013 **Source of funding** No sources of funding reported		defined circumstances. Statuary advocacy includes: ○ IMCA (Supporting people who have lack of capacity to make specific decisions). ○ IMHA (Supporting people detained under MHA or people who are subject of Community Treatment Orders). • Local authorities have duty to provide advocacy services for looked-after children and children in need.	Probably yes – No full protocol available but pre-defined criteria are supplied. **1.2 Were the eligibility criteria appropriate for the review question?** Yes. **1.3 Were eligibility criteria unambiguous?** Probably no. The scope of documents considered relevant for the review is outlined but the authors note that there were some deviations from the parameters but provide minimal information about this. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** Yes – Restrictions were minimal. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** Yes. ***Concerns regarding specification of study eligibility criteria*** Low concern – Considerable effort to clearly define review question and specify eligibility criteria, has been made. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** Yes. **2.2 Were methods additional to database searching used to identify relevant reports?** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
			2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible? Yes. **2.4 Were restrictions based on date, publication format, or language appropriate?** No (restricted to English). **2.5 Were efforts made to minimise errors in selection of studies?** Yes. ***Concerns regarding methods used to identify and/or select studies*** Low concern. **3.1 Were efforts made to minimise error in data collection?** No (Data collection likely conducted by one researcher). **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Yes. **3.3 Were all relevant study results collected for use in the synthesis?** No information. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			3.5 Were efforts made to minimise error in risk of bias assessment? No information. ***Concerns regarding methods used to collect data and appraise studies*** Unclear concern (Insufficient details provided). **4.1 Did the synthesis include all studies that it should?** No information. **4.2 Were all predefined analyses followed or departures explained?** No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information. **4.5 Were the findings robust, e.g. as demonstrated through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			Concerns regarding the synthesis and findings Unclear concern (Insufficient detail provided). ***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
Full citation 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] **Country/ies where the study was carried out** England **Study type**	Independent advocacy services commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the MHA). ii) NHS Continuing Healthcare (adults).	**Key findings** • Advocacy under the Care Act 2014 – supporting people who may have substantial difficulty to be involved in their Care and Support Assessments, Care and Support Planning, Care and Support Reviews as well as supporting people who are subject to Section 42 safeguarding enquiries, where there is no other appropriate individual available to provide support and representation. • IMCA – supporting people who don't have appropriate friends and family to consult	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Probably no - There was no evidence of eligibility criteria but pre-specification of objectives the scoping exercise are provided. **1.2 Were the eligibility criteria appropriate for the review question?** No information - Eligibility criteria were not provided. The scoping exercise included a freedom of information request, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance which appear to be conducted by the authors themselves.

Study details	Population	Recommendations/key findings	Quality assessment
Report of a scoping exercise (including freedom of information requests, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance) **Study dates** January to March 2020 **Source of funding** Commissioned by NHS England and NHS Improvement	iii) Children and Young People's Continuing Care. iv) Personal Health Budgets. v) Personal Wheelchair Budgets.	and who lack the mental capacity to make decisions about where they live, serious medical treatment, DoLS and safeguarding. • Paid Relevant Person's Representative – supporting people subject to DoLS authorisations, to understand restrictions and their rights and supporting them in all matters relating to the DoLS. • Independent Mental Health Advocacy – supporting people who are subject to the MHA 1983, to understand and promote their rights under the Mental Health Act and more generally, understand their care and treatment and express their views. • NHS Complaints Advocacy – supporting people thinking about or making complaints about NHS services.	**1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the types of study, population, interventions, comparators and outcomes. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information - Restrictions applied on the basis of sources of information were not clearly described. ***Concerns regarding specification of study eligibility criteria*** High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the scoping exercise. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** No information – No systematic searches appear to have been conducted **2.2 Were methods additional to database searching used to identify relevant reports?** No information – Additional database searching appears not to have been conducted. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?**

Study details	Population	Recommendations/key findings	Quality assessment
			No information. **2.4 Were restrictions based on date, publication format, or language appropriate?** No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information. ***Concerns regarding methods used to identify and/or select studies*** High concern - There is insufficient information reported however it appears as though some eligible studies are likely to be missing from the scoping exercise. **3.1 Were efforts made to minimise error in data collection?** No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** No – study characteristics were not reported. **3.3 Were all relevant study results collected for use in the synthesis?** Probably no – Unclear whether all relevant study results were included. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No - Study quality was not formally assessed.

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

Study details	Population	Recommendations/key findings	Quality assessment
			Concerns regarding the synthesis and findings Unclear concern - There is insufficient information reported to make a judgement on risk of bias. ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes. **Risk of bias** – High concern.
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**	Patients detained under the amended MHA 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	**Recommendations** • Through full policy implementation, government needs to continue to recognise the value of advocacy to a highly vulnerable group of people for whom the experience of detention under the MHA can be frightening, bewildering and isolating. Having a voice in this process is vital and support recovery.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MHA 1983. To identify the factors that affect the quality of IMHA services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
Mixed methods: literature review, qualitative research (focus groups and interviews), case studies **Study dates** 2010 to 2012 **Source of funding** Department of Health			Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how IMHA services and service users were identified is explained, in addition to identification of carers and family members, mental health staff and commissioners. **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)**

Study details	Population	Recommendations/key findings	Quality assessment
			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. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Minor limitations.
Full citation Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 23(4), 280-292. **Country/ies where the study was carried out** England **Study type** Qualitative meta-synthesis **Study dates** Not reported **Source of funding** No sources of funding reported	*Study 1*: African and African Caribbean men with experience of mental health services. *Study 2*: Adults and children who were subject to compulsion under the MHA 1983, and therefore eligible for (but not necessarily accessing) an IMHA under the 2007 MHA. *Study 3*: Children and young people receiving	**Key findings** • English adoption and Children act supported children in care and care leavers with making complaints; 2005 MCA: Right to IMHA for individuals deemed to be lacking capacity; Right to IMHA was introduced to protect rights of people detained under MHA; Local authorities have duty to provide independent advocacy for people using social care who require support with decision making and lack appropriate support	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** No information - There was no evidence of pre-specification of objectives and eligibility criteria. **1.2 Were the eligibility criteria appropriate for the review question?** No - Eligibility criteria were not provided. However, the included studies appear to have been selected due to being research studies previously undertaken by the authors on independent mental health advocacy. **1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the population. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided.

Study details	Population	Recommendations/key findings	Quality assessment
	advocacy services.		**1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information - Restrictions applied on the basis of sources of information were not clearly described. ***Concerns regarding specification of study eligibility criteria*** High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the review. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** No information – Searches appear not to have been conducted. **2.2 Were methods additional to database searching used to identify relevant reports?** No information – Additional database searching appears not to have been conducted. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information – No search strategy provided. **2.4 Were restrictions based on date, publication format, or language appropriate?** No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			Concerns regarding methods used to identify and/or select studies Unclear concern - There is insufficient information reported. **3.1 Were efforts made to minimise error in data collection?** No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Probably yes – Summary of key service user characteristics in each study in Table I. **3.3 Were all relevant study results collected for use in the synthesis?** Probably yes – Lines of enquiry from study participants in Box 1. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No - Study quality was not formally assessed. **3.5 Were efforts made to minimise error in risk of bias assessment?** Not applicable – study quality was not formally assessed. ***Concerns regarding methods used to collect data and appraise studies*** High concern - Some bias may have been introduced through the data collection and no risk of bias assessment completed. **4.1 Did the synthesis include all studies that it should?** No information.

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

Study details	Population	Recommendations/key findings	Quality assessment
			No. **C. Did the reviewers avoid emphasising results on the basis of their statistical significance?** Not applicable. **Risk of bias –** High concern.

CASP: Critical Appraisal Skills Programme; DoLS: Deprivation of Liberty Safeguards; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MCA: Mental Capacity Act; MHA: Mental Health Act; NHS: National Health Service; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews; s117: section 117

Appendix C Quality Assessment

Quality assessment tables for scope area: Who has a legal right to advocacy?

Existing NICE guidelines

Table 3: AGREE II quality assessment of NICE guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Depression in adults: recognition and management (Clinical Guideline 90)	2009	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline. is reported in detail. The views from the target audience were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are	92 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	98

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.	summarised as flow charts.	resources to facilitate application and there are directions on how users can access these. There is economic consideration, which is reported clearly. The potential resource impact of applying the recommendations has not been reported. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Service user experience in adult mental health:	2011	100 The overall objective of the guideline, the	89 The guideline development group included a	96 Systematic methods were used to search for evidence and	89 The recommendations are specific	67 Descriptions of barriers and facilitators are	100 The funding body has been stated and there is an	90

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
improving the experience of care for people using adult NHS mental health services (Clinical Guideline 136)		health question covered by the guideline, and the population to whom the guideline applies are specifically described.	range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The	and unambiguous but a small number of recommendations lack identification of the intent or purpose of the recommended action. The different options for management of the condition or health issue are clearly presented, though in a few cases, the description of options and the populations most appropriate to each option are not given. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are	vague. Feedback from key stakeholders were obtained. There is description of how the recommendations can be put into practice but there is no implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There is little to no detail given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation	explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.	summarised as flow charts.	and monitoring or auditing criteria.		
Decision-making and mental capacity (NICE Guideline 108)	2018	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views of the target audiences were included in guideline development. The target users of the	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how recommendations can be put into practice and	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				procedure is unavailable.				
Transition between inpatient mental health settings and community or care home settings (NICE Guideline 53)	2016	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	94 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. Some views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	98

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
People's experience in adult social care services: improving the experience of care and support for people using adult social care services	2018	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
(NICE Guideline 86)		specifically described.	reported in detail. The views of the target audiences were included in guideline development. The target users of the guideline are clearly defined.	has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are	presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	were obtained. There is a clear description of how recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.	guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.				
Learning disabilities and behaviour that challenges: service design and delivery (NICE Guideline 93)	2018	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views from the target audience were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Care and support of people growing older with learning disabilities	2018	100 The overall objective of the guideline, the health question covered by the	100 The guideline development group included a range of individuals from	96 Systematic methods were used to search for evidence and have been reported transparently. The	100 The recommendations are specific and unambiguous,	96 There is a description of the facilitators and barriers and how these	100 The funding body has been stated and there is an explicit statement reporting the	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
(NICE Guideline 96)		guideline, and the population to whom the guideline applies are specifically described.	relevant professional groups, and information about their profession and discipline is reported in detail. The views from the target audience were included in guideline development. The target users of the guideline are clearly defined.	criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by	and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to	funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		assess guideline implementation and monitoring or auditing criteria.		
Supporting adult carers (NICE Guideline 150)	2020	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	97

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Rehabilitation for adults with complex psychosis (NICE Guideline 181)	2020	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. Views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations,	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Safeguarding adults in care homes (NICE Guideline 189)	2021	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly.	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendation	96 There is a description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group	97

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				guideline will be updated is provided though the methodology for this procedure is unavailable.				

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

Formal consensus

Table 4: ROBIS quality assessment of included systematic reviews

Domains (Low concern/High concern/Unclear concern)						
Systematic review reference	**Year**	**Study eligibility criteria**	**Identification and selection of studies**	**Data collection and study appraisal**	**Synthesis and findings**	**Overall risk of bias**
Macadam 2013	2013	Low concern	Low concern	Unclear concern	Unclear concern	Unclear concern
Mercer 2020	2020	High concern	High concern	High concern	Unclear concern	High concern
Ridley 2018	2018	High concern	Unclear concern	High concern	Unclear concern	High concern

ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Table 5: CASP quality assessment of included qualitative studies

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

CASP: Critical Appraisal Skills Programme

Appendix D Excluded studies

Excluded studies for scope area: Who has a legal right to advocacy?

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

Table 6: Excluded studies and reasons for their exclusion

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

Study	Reason for Exclusion
.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	
Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 44(2), 219-230.	Publication is based on case-studies
Lawson, J. (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]	No key findings or recommendations relevant to Who has a legal right to advocacy?
National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished.	No key findings or recommendations relevant to Who has a legal right to advocacy?
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished.	No key findings or recommendations relevant to Who has a legal right to advocacy?
National Development Team for Inclusion (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Available at: https://www.ndti.org.uk/assets/files/Reasonably-adjusted_2020-12-30-150637.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?
National Development Team for Inclusion (2014). The impact of advocacy for people who use social care services: a review of the evidence, NDTi Insights. Available at: https://www.ndti.org.uk/assets/files/Insights_19_Impact_of_Advocacy_FINAL.pdf [Accessed 11/02/2022]	No key findings or recommendations relevant to any scope area
National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?
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 Who has a legal right to advocacy?
National Development Team for Inclusion (2020). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?

Study	Reason for Exclusion
National Development Team for Inclusion (2020). Valuing voices in Wales: Protecting rights through the pandemic and beyond. Available at: https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report [Accessed 07/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?
National Development Team for Inclusion. (2018). The Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). The Easy Read Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/The-Advocacy-Charter-Easy-Read.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). Advocacy QPM: Assessment Workbook. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion, Empowerment Matters (2014). Advocacy QPM: Advocacy Code of Practice, revised edition, 2014. Available at https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf [Accessed 25/11/2021]	Publication has no evidence base
Newbigging, K., 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.	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 a book/book-chapter.
Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. Health Expectations, 16(1), 80-104.	No key findings or recommendations relevant to Who has a legal right to advocacy?
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Older People's Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the	Publication is based on case-studies

Study	Reason for Exclusion
power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?
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]	No key findings or recommendations relevant to Who has a legal right to advocacy?
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services, easy read version. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence and University of Central Lancashire (2015). Flowchart for Open Access IMHA. Available at: 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	Publication has no evidence base

Study	Reason for Exclusion
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]	
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a briefing for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/briefing/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a report for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/report/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). Commissioning Independent Mental Health Advocacy (IMHA) services in England: 10 top tips for commissioners. https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/10-top-tips.asp [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). What does a good IMHA service look like? (Self-assessment tool) Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/what-good-imha-service-looks-like/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Making a difference: measuring the impact of Independent Mental Health Advocacy (IMHA). Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022]	Publication is based on case-studies
Strong, S. (2012). User-led organisation leadership of support planning and brokerage. The International Journal of Leadership in Public Services, 8(2), 83-89.	Publication is based on case-studies
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

Study	Reason for Exclusion
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
Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who has a legal right to advocacy?
VoiceAbility (2021). STOMP and STAMP: Stopping the over medication of children, young people and adults with a learning disability, autism or both.	Publication has no evidence base
VoiceAbility (2021). Preventing over-medication. STOMP top tips for advocates: How you can help to stop the over-medication of people with a learning disability, autism or both	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: Who has a legal right to advocacy?

No research recommendations were made for this scope area.

Appendix F Existing NICE recommendations

Table 8: Existing NICE recommendations for scope area: Who has a legal right to advocacy?

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
All organisations involved with safeguarding adults in care homes should: • understand the role of advocacy in relation to safeguarding, and that the advocate is the only person who acts solely according to instructions from the resident • think about the resident's needs and know when to refer people for advocacy • involve an independent advocate for the resident, when this is required by the Care Act 2014 and Care Act 2014 statutory guidance or the Mental Capacity Act 2005 • ensure that anyone supporting the resident as an informal or independent advocate has been identified in line with the resident's statutory rights to advocacy under the Care Act and the Mental Capacity Act	**Safeguarding adults in care homes [NG189] – 1.8.11** Why the committee made the recommendation: The committee used qualitative themes from research evidence on responding to and managing safeguarding concerns in care homes, and support and information needs for everyone involved in safeguarding concerns in care homes. The evidence showed that residents benefit when they are involved and kept informed throughout the safeguarding process. The evidence also emphasised the value that residents place on support from family, friends or advocates in helping them achieve their desired outcomes. However, the committee had some concerns about the quality of the data, which had some methodological limitations as well as questionable relevance (it was not always clear whether findings related specifically to care home settings). The committee therefore also used the Making Safeguarding Personal framework and the Care Act 2014. These sources highlight the importance of involving people fully as possible in decisions and giving them the information and support they need to participate. The committee recognised that there should be a clear difference and understanding of the roles of the practitioners and independent advocate involved in safeguarding. Although the practitioner might be acting in the best interest of the person, they may be	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the concept of understanding the role of advocacy in relation to safeguarding and knowing when to refer people are covered by recommendations 1.8.13 and 1.10.3. The concept of involving an independent advocate as legally required is covered by recommendations 1.1.1 and 1.3.2. See the **Error! Reference source not found.** section of **Error! Reference source not found.** review as well as evidence review C, H and J for more information.	Not Applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	operating within the constraints of their role. It is only the independent advocate who acts according to instruction from the person.		
Local authorities must, in line with the Care Act 2014, provide independent advocacy to enable people to participate in: • care and support needs assessment and • care planning and • the implementation process and review • where they would otherwise have substantial difficulty in doing so	**People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86] – 1.3.1** Other considerations: Recommendation 1.3.1 highlighted the statutory duty within the Care Act 2014 to provide advocacy. Although the Committee noted that there is already a duty to provide this, they thought access to advocacy was very important to people's experience of services, and the extent to which assessment and care planning processes are able to fully understand a person's individual needs and preferences.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by the Care Act 2014 and the Care and Support statutory guidance referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
When detaining a service user under the Mental Health Act (1983; amended 1995 and 2007): • ensure they have access to an Independent Mental Health Advocate (IMHA).	**Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services [CG136] – 1.8.5** Evidence to recommendations: The review of qualitative evidence and surveys suggest that some people do not have their rights properly explained to them, and some do not realise they are, in fact, detained under the Mental Health Act (HMSO, 2007); consent to treatment is largely ignored when a person is detained under the Mental Health Act, and there are reports of service users finding healthcare professionals patronising and petty in their approach. Overall, the experience of being detained is, at least for some, a traumatic one, with a loss of dignity and	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by the Mental Health Act 1983 and its Code of Practice referred to. See the **Error! Reference source not found.** section of **Error! Reference**	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	respect and a feeling of not being cared for; with little account taken of how disoriented the detained person is, and how disorienting the environment of many wards continue to be. For some service users, they are simply being detained. On reviewing the aspirations and the key problems the guidance group focused attention on some broad issues that apply across all points on the care pathway, but were of particular importance to detention under the Mental Health Act. Health and social care professionals should ensure that they can understand and apply the principles of the Mental Capacity Act (2005)	**source not found.** in this review for more information.	
A decision to use ECT should be made jointly with the person with depression as far as possible, taking into account, where applicable, the requirements of the Mental Health Act 2007. Also be aware that: • if informed consent is not possible, ECT should only be given if it does not conflict with a valid advance decision, and the person's advocate or carer should be consulted.	**Depression in adults: recognition and management [CG90] – 1.10.4.5** Evidence to recommendations: The review of ECT for the updated guideline found relatively little additional data to update the reviews undertaken for the original NICE TA (NICE, 2003). There were no new data comparing ECT with sham ECT, antidepressants, or combination treatment in the acute phase and limited new data in the continuation phase after acute treatment. Integrating the evidence for ECT with that for other treatments for depression it is evident that many people with depression have a poor response to treatment. In addition the definition of the severity of depression has altered between the previous guideline and this guideline update so that many patients previously defined as severely depressed would now be included in the moderate severity category. For this reason, while ECT is still not recommended as a routine treatment for moderately severe depression, it is presented as an option in those with moderate depression who have repeatedly	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by the Mental Health Act 1983 and its Code of Practice referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	not responded to both drug and psychological treatment.		
As a minimum, independent advocacy must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007	**Decision-making and mental capacity [NG108] – 1.1.8** Adapted from the NICE guideline on learning disabilities and behaviour that challenges: service design and delivery [NG93] – see below for underpinning evidence (NG93; 1.2.8]	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by all the guidance referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Local authorities should provide information to carers about how to access advocacy support services. Access to advocacy services should meet the requirements of the Care Act 2014 and the Mental Capacity Act 2005.	**Supporting adult carers [NG150] – 1.5.6** Why the committee made the recommendation: There was no evidence in this area, but there is a legal responsibility on local authorities to provide access to independent advocacy, in line with the Care Act 2014 and the Mental Capacity Act 2005. The committee agreed by consensus that it was important to inform carers about their right to support from advocacy services and the circumstances in which they would apply. To build on this and ensure that advocates (or other representatives) can give meaningful support to carers, the committee agreed that practitioners should recognise the voice and role of advocates. In the committee's view this does not always happen in practice. The committee also noted the important role of advocacy as set out in the Mental Capacity Act 2005.	**Adapted** This recommendation was used to inform recommendation 1.3.2 (see evidence review C). See the **Error! Reference source not found.** section of **Error! Reference source not found.** in evidence review C for more information.	Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should provide everyone legally entitled to advocacy (including young people who are using adult services) with information about their entitlement to advocacy and what this means.

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Local authorities must, in line with the Care Act 2014, provide independent advocacy to enable people to participate in: • care and support needs assessment and • care planning and • the implementation process and review • where they would otherwise have substantial difficulty in doing so.	**Rehabilitation in adults with complex psychosis and related severe mental health conditions [NG181] – 1.6.7** Adopted from the NICE guideline on people's experience in the adult social care services [NG86] Committee's discussion – rationale and impact: The offer of independent advocacy is a key aspect of collaborative care-planning. A recommendation was identified in guideline NG86 which worded this well. The Care Act 2014 sets the requirement for advocacy to be offered to all vulnerable groups (including those in the current guidelines' population) and the wording of the existing recommendation was considered succinct for this requirement. As a result of the Care Act's broad application the committee did not consider it a problem that the evidence underlying the recommendation was based on a much broader population.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by the Care Act 2014 and the Care and Support statutory guidance referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Ensure that the person who will be subject to the [community treatment/ guardianship order] order has the opportunity to discuss why it is being imposed. Explain: • how to access advocacy (including their entitlement to an Independent Mental Health Advocate), and what this means.	**Transition between inpatient mental health settings and community or care home settings [NG53] – 1.6.11** Other considerations: The GC agreed by consensus that the use of CTOs should be considered within the principle of personalised care, and at all times the person made subject to the order should be aware of the reasons and potential benefits of the approach. The GC felt that there were negative ethical consequences if psychiatrists were using CTOs without proper explanation (see qualitative evidence). They appeared to see some benefit in people being uncertain about what might constitute a breach. People put on CTOs or guardianship orders and their carers should be enabled to understand why the order was imposed, what would happen if it was contravened, and when it would be reviewed (rec	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it covers statutory requirements which are covered by the Mental Capacity Act 2005 and its Code of Practice and the Mental Health Act 1983 and its Code of Practice referred to. See the **Error! Reference source not found.** section of **Error! Reference**	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	1.6.9). This should also be explained to carers and families providing support (rec 1.6.12).	**source not found.** in this review for more information.	
Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum, it must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007. (1.2.8)	**Learning disabilities and behaviour that challenges: service design and delivery [NG93] – 1.2.8** Other considerations: Consensus recommendation following on from discussions about the importance of the availability of advocacy to enable involvement in one's own care and decision making, but also that to be effective, advocates had to have specialist knowledge of navigating services for learning disabilities and behaviour that challenges. The view of the committee was that this could only happen if the commissioner made sure that independent advocates could demonstrate they had this specialist knowledge and skills in this area.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it partly covers statutory requirements, which are covered by all the guidance referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Offer independent advocacy whenever it is wanted or needed by a person with a learning disability. As a minimum, it must be offered as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007. (1.1.11)	**Care and support of people growing older with learning disabilities [NG96] – 1.1.11** Adapted from the NICE guideline on learning disabilities and behaviour that challenges: service design and delivery [NG93] – see above for underpinning evidence (NG93; 1.2.8]	**Recommendation not used in this guideline** This recommendation was not used in this guideline as it partly covers statutory requirements, which are covered by all the guidance referred to. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

AMHP: approved mental health professional; CTO: community treatment order; ECT: electroconvulsive therapy; HMSO: Her Majesty's Stationery Office; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RCT: randomised controlled trial; RQ: review question; TA: technology appraisal

Appendix G Formal consensus

Additional information related to scope area: Who has a legal right to advocacy?

Table 9: Formal consensus round 1 statements and results for scope area: Who has a legal right to advocacy?

Statement no.	Statement	Reference	Percentage agreement	Action taken
1	Advocacy services should provide support to people who may have substantial difficulty to be involved in their Care and Support Assessments, Care and Support Planning and Care and Support Reviews, where there is no other appropriate individual available to provide support and representation.	Mercer, 2020	90.00%	Carried forward to committee discussion
2	IMCAs should provide support to people who don't have appropriate friends and family to consult and who lack the mental capacity to make decisions about their care and support.	Mercer, 2020; MacAdam, 2013	90.00%	Carried forward to committee discussion
3	Local authorities have a duty to provide independent advocacy for people using social care who require support with decision making and lack appropriate support.	Ridley, 2018	91.67%	Carried forward to committee discussion
4	Advocacy services should provide support to people who are subject to Section 42 safeguarding enquiries, where there is no other appropriate individual available to provide support and representation.	Mercer, 2020	90.00%	Carried forward to committee discussion
5	Advocacy organisations have a duty to provide support to some people who are the subject of safeguarding concerns.	Lawson, 2020	63.64%	Redrafted for round 2
6	Paid relevant person's representatives should provide support to people subject to DoLS authorisations to understand restrictions and their rights in all matters relating to DoLS.	Mercer, 2020	90.00%	Carried forward to committee discussion
7	Advocacy services (for example, IMHAs) have a duty to provide support to people who are subject to the Mental Health Act 1983 to understand and promote their rights under the Mental Health Act.	Mercer, 2020; MacAdam, 2013; Ridley, 2018; Newbigging, 2012	100.00%	Carried forward to committee discussion
8	Advocacy services (for example, IMHAs) have a duty to provide support to people who are subject to the Mental Health Act 1983 to understand their care and treatment and express their views.	Mercer, 2020; MacAdam, 2013; Ridley,	90.00%	Carried forward to committee discussion

Statement no.	Statement	Reference	Percentage agreement	Action taken
		2018; Newbigging 2012		
9	IMHAs have a duty to provide support to people who are subject to Community Treatment Orders.	MacAdam, 2013	81.82%	Carried forward to committee discussion
10	Local authorities have a duty to provide advocacy services for looked-after children.	MacAdam, 2013	90.00%	Carried forward to committee discussion
11	Local authorities have a duty to provide advocacy services for children in need.	MacAdam, 2013	80.00%	Carried forward to committee discussion
12	NHS Complaints Advocacy services should provide support to people thinking about making complaints about NHS services.	Mercer, 2020	77.78%	Carried forward to committee discussion (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
13	NHS Complaints Advocacy services should provide support to people making complaints about NHS services.	Mercer, 2020	75.00%	Carried forward to committee discussion (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)

DoLS: Deprivation of Liberty Safeguards; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate.

Table 10: Formal consensus round 2 statements and results for scope area: Who has a legal right to advocacy?

Statement no.	Statement	Percentage agreement	Action taken
5	Local authorities have a duty to ensure advocacy is provided for people who are the subject of a safeguarding enquiry or Safeguarding Adult Review (SAR), where the person has ‘substantial difficulty’ in being involved in the process and where there is no other suitable person to represent and support them	80.00%	Carried forward to committee discussion

SAR: Safeguarding Adult Review