National Institute for Health and Care Excellence

Draft for consultation

Advocacy services for adults with health and social care needs

[C] Information about effective advocacy and signposting to services

NICE guideline number tbc

Evidence reviews underpinning recommendations 1.3.1 to 1.3.6 in the NICE guideline

June 2022

Draft for consultation

These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

Disclaimer

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

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

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Information about effective advocacy and signposting to services

Key theme

- Information about effective advocacy and signposting to services

Introduction

The aim of this review is investigate keys issues around information about advocacy services and signposting to advocacy services.

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	Information about effective advocacy and signposting to services

Methods and process

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

Declarations of interest were recorded according to NICE’s 2019 conflicts of interest policy (see Register of Interest)

Effectiveness evidence

Included studies

Existing NICE guidelines

Existing recommendations relevant to information about effective advocacy and signposting to services were identified from 16 NICE guidelines ([CG102] Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management, [CG145] Spasticity in under 19s: management, [CG149] Neonatal infection (early onset): antibiotics for prevention and treatment, [NG11] Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, [NG22] Older people with social care needs and multiple long-term conditions, [NG53] Transition between inpatient mental health settings and community or care home settings, [NG62] Cerebral palsy in under 25s: assessment and management, [NG74] Intermediate care including reablement, [NG76] Child abuse and neglect [NG86] People’s experience in adult social care services: improving the experience of care and support for people using adult social care services, [NG97] Dementia: assessment, management and support for people living with dementia and their carers, [NG108] Decision-making and mental capacity, [NG150] Supporting adult carers, [NG181] Rehabilitation for adults with complex psychosis, [NG189] Safeguarding adults in care homes; [PH28] Looked after children and young people). The audiences for these guidelines included: people with the condition or users of a services and their families and carers; health and social care professionals, practitioners and providers; service managers; commissioners, local authorities and safeguarding adults 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, 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.

Two documents were identified for this review (National Development Team for Inclusion [NDTi] 2020a, Newbigging 2012).

One document focused on advocates across multiple areas of statutory and non-statutory advocacy (NDTi 2020a) and one document focused on people detained under the amended Mental Health Act 1983 (Newbigging 2012).

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
NDTi 2020a Report on survey findings England & Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 435 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers
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

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

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

Summary of the evidence

Existing NICE guidelines

A total of 17 existing recommendations related to information about effective advocacy and signposting to services were identified from the 16 NICE guidelines. The committee agreed that 3 recommendations should be adapted and 14 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

The 2 included documents (NDTi, 2020a; 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 5 statements in round 1 of the formal consensus exercise; responses were received from 12 of 13 committee members. All 5 statements reached ≥80% agreement in round 1 and were included for the discussion with the committee.

See appendix G for the statements that were rated by the committee and results of round 1, which are provided in Table 9.

Formal consensus round 2

As all the statements reached ≥80% agreement during round 1, a second round of rating was not performed.

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 the benefits and harms section and appendix F.

Formal consensus

The quality of the 2 documents (NDTi, 2020a; Newbigging, 2012) was assessed using the CASP checklist for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations. The second document (NDTi, 2020a) 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

Making information available

Statement 1 highlighted the importance of advocacy organisations having a shared commitment to ensuring their services are known about. The committee acknowledged that the statement had been extracted from a document judged to be of lower quality. However they were in full agreement with the statement and because their own knowledge and experience chimed with the point being made they concluded it would be important to make a recommendation on that basis and that the benefits of doing so outweighed any risks of excluding the statement altogether. The committee agreed to reword statement 1 as there is a duty on local authorities to make information available about the care and support services in their area. In the committees' experience, this is happening very inconsistently despite it being a legal requirement according to the Care Act (2014), which means it can be difficult for people to find out about care and support services, including advocacy. The committee agreed to also incorporate statement 3 in this recommendation. Statement 3 is about the need for accessible promotional materials to promote IMHA services and how to access them. Therefore, the committee agreed to reword statement 1 to ensure that local authorities make information and advice about care and support services for adults in their area publicly available.

Receiving information about independent mental health advocates (IMHAs)

Statement 5 covered health authorities and NHS trusts ensuring qualifying patients and carers receive information about independent mental health advocates (IMHAs). The committee agreed that this statement should be broadened to cover all people with a legal entitlement to advocacy, not just those eligible for IMHA services, and to clarify that this is also a responsibility of local authorities. The committee agreed about the importance of applying this more broadly because in their experience the benefits are needed (e.g. people being aware of their entitlements) across the wider population of people requiring advocacy services. It is a legal duty for local authorities, health authorities, NHS Trusts and advocacy services to provide all people entitled to advocacy with information; however, in the committees' experience this does not happen consistently. Furthermore, the committee agreed that if people who are legally entitled to advocacy are not provided with information about their entitlement to advocacy services, they likely would be unaware of their entitlement and unable to access services, as advocacy services are not widely known about. The existing recommendation from the 2010 NICE guideline on Looked-after children and young people [PH28] about ensuring that all young people know their entitlements to services was also used to inform this recommendation. In the committees' experience, young people tend to be poorly served. Ensuring that young people know their entitlements to services is a legal requirement; however, this does not happen consistently. The scope of this guideline only includes young people who are accessing adult services, so the wording of the recommendation had to reflect this.

Providing information about advocacy services and how to access them

The committee agreed that the existing recommendations from the 2018 NICE guideline on Dementia: assessment, management and support for people living with dementia and their carers [NG97] and the 2021 NICE guideline on Safeguarding adults in care homes [NG189] should be combined because both focused on providing information about how advocates can help people. Further details about the committee's decisions to adopt or adapt existing NICE recommendations in the area of information and signposting are given in appendix F. The existing recommendation from the 2018 NICE guideline [NG97] was about offering people diagnosed with dementia and their family members or carers oral and written information explaining how advocacy services can help and how to contact them. The existing recommendation from the 2021 NICE guideline [NG189] was about care homes telling residents how advocates can help them with safeguarding enquiries and the eligibility criteria for advocacy services. The committee agreed that the recommendation should be broader than these populations and cover providing information about advocacy services and how to access them to everyone who is legally entitled to an advocate. Further, in the committees' experience, providing people who are not legally entitled to advocacy but who may benefit from advocacy services with information is also very important but this is not happening consistently. In the committee's experience, if a service that is publicly funded is provided, there is also a duty to provide this information to facilitate accessing these services. Currently, it is difficult for people to know what advocacy services are available, especially for non-statutory advocacy services. The committee agreed that providing information about such services should increase knowledge and uptake of non-statutory advocacy. Therefore, they recommended that information is provided whether or not people are legally entitled to advocacy services.

Providing information in a variety of formats

The committee discussed that information needed to be provided in a variety of formats, including other methods of communication such as braille and sign language in addition to, or instead of, oral and written information, in order to ensure information is accessible. The Accessible Information Standard (NHS England 2017) requires provision of information in accessible formats. The committee's experience is that this often does not happen for information about advocacy services. Providing people with information in a variety of formats and languages would promote a person's independence and ensure that the information received is reputable, as they would not have to rely on others interpretation of the information. Further, in the case of those legally entitled to advocacy services, this would ensure that people actually have their legal rights, as the right to the information is not being upheld if the person receiving it cannot understand the information. Finally, the committee were concerned that there was a risk of inequalities in access to both statutory and non-statutory advocacy services if information isn't provided in a variety of formats, such that those with communication difficulties would be less able to access services.

Providing information to people placed out-of-area

The committee agreed to reword the existing recommendation from the 2020 NICE guideline on Rehabilitation for adults with complex psychosis [NG181] about explaining the advocacy support available for people who are placed in out-of-area rehabilitation services to make it broader so it does not just apply to people accessing rehabilitation services. The committee agreed about the importance of applying this more broadly because in their experience the benefits of people being aware of which advocacy services are available to them are needed across the wider population of people requiring advocacy services. In the committees' experience, this is not happening currently and there is often confusion about who should be providing advocacy services when people are placed out-of-area and who is responsible for providing information about this. The committee agreed that it is the organisation who is placing the person out-of-area that should be responsible for providing the information and made a recommendation to highlight this. In order to ensure a broader and more equitable reach they also agreed the recommendation should not be narrowly focussed on information in written formats, as in the existing recommendation on which this was based. The committee did not make a recommendation about who should provide the advocacy service in these situations as there is variation in the legislation about who has this responsibility.

Information at each key point of interaction

The committee agreed, based on their knowledge and experience, to add a recommendation about providing information about advocacy at each key point of interaction with health and social care in case they want to take it up. The committee agreed that some people might want to take up an advocate even after they initially declined it. It is therefore important that this is information is offered repeatedly, so the person has the information and ability to have access to an advocate when they want to.

Statements that were not used to inform new recommendations

There were two statements carried forward to committee discussions that were not used to inform recommendations. Statement 2 was not used to inform recommendations because this issue will be addressed by recommendations made about providing information in a variety of formats. Statement 4 was not used to inform recommendations because, as explained above, it is not within the scope of NICE guidelines to tell advocacy services to promote themselves. However, the committee agreed that this issue will be addressed by the recommendations made above about providing eligible individuals with information and local authorities publicising the services available in their area, as well as recommendations about training practitioners to understand who is entitled to advocacy (see evidence review J).

Existing recommendations not used in this review

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

Cost effectiveness and resource use

Currently there are inconsistencies in providing information about advocacy services across different areas. The majority of recommendations are legal requirements and all advocacy services should be providing some level of information and signposting. There may be some change in practice for those not fully compliant with statutory requirements. For example, providing information in a range of formats, whilst a legal requirement, is not always done and there will be an associated cost to achieving this recommendation.

Providing information and signposting to individuals in out-of-area services will be a change in practice as there is currently variation and confusion about who should provide this service. It is not thought however that stating the responsibility should be with the referring organisation will lead to any increase in resource use.

Providing information about non-statutory advocacy services, which is currently not a legal requirement, will not require any additional resource use and can be provided alongside and included on other information sources already provided. There may be an increase in resource use from an increase in people using non-statutory advocacy services. This is discussed in more detail for the recommendations around providing non-statutory advocacy services (see evidence review G).

Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.1 to 1.3.6.

References – included studies

Existing NICE guidelines

National Institute for Health and Care Excellence 2012

National Institute for Health and Care Excellence (2012). Neonatal infection (early onset): antibiotics for prevention and treatment (Clinical Guideline 149). Available at: https://www.nice.org.uk/guidance/cg149

National Institute for Health and Care Excellence 2015

National Institute for Health and Care Excellence (2015). Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management (Clinical Guideline 102). Available at: https://www.nice.org.uk/guidance/cg102/resources/meningitis-bacterial-and-meningococcal-septicaemia-in-under-16s-recognition-diagnosis-and-management-pdf-35109325611205

National Institute for Health and Care Excellence 2015

National Institute for Health and Care Excellence (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NICE Guideline 11). Available at:

https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-pdf-1837266392005

National Institute for Health and Care Excellence 2015

National Institute for Health and Care Excellence (2015). Looked after children and young people (Public Health Guideline 28). Available at: https://www.nice.org.uk/guidance/ph28/resources/lookedafter-children-and-young-people-pdf-1996243726021

National Institute for Health and Care Excellence 2015

National Institute for Health and Care Excellence (2015). Older people with social care needs and multiple long-term conditions (NICE Guideline 22). Available at: https://www.nice.org.uk/guidance/ng22/resources/older-people-with-social-care-needs-and-multiple-longterm-conditions-pdf-1837328537797

National Institute for Health and Care Excellence 2016

National Institute for Health and Care Excellence (2016). Spasticity in under 19s: management (Clinical Guideline 145). Available at: https://www.nice.org.uk/guidance/cg145/resources/spasticity-in-under-19s-management-pdf-35109572514757

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 2017

National Institute for Health and Care Excellence (2017). Cerebral palsy in under 25s: assessment and management (NICE Guideline 62). Available at: https://www.nice.org.uk/guidance/ng62/resources/cerebral-palsy-in-under-25s-assessment-and-management-pdf-1837570402501

National Institute for Health and Care Excellence 2017

National Institute for Health and Care Excellence (2017). Intermediate care including reablement (NICE Guideline 74). Available at: https://www.nice.org.uk/guidance/ng74/resources/intermediate-care-including-reablement-pdf-1837634227909

National Institute for Health and Care Excellence 2017

National Institute for Health and Care Excellence (2017). Child abuse and neglect (NICE Guideline 76). Available at: https://www.nice.org.uk/guidance/ng76/resources/child-abuse-and-neglect-pdf-1837637587141

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). Dementia: assessment, management and support for people living with dementia and their carers (NICE Guideline 97). Available at: https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109

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 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

National Development Team for Inclusion 2020a

National Development Team for Inclusion (2020a). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021]

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]

Other

NHS England 2017

NHS England, Accessible information standard, 2017. Available at: https://www.england.nhs.uk/ourwork/accessibleinfo/ [Accessed 25/11/2021]

Care Act 2014

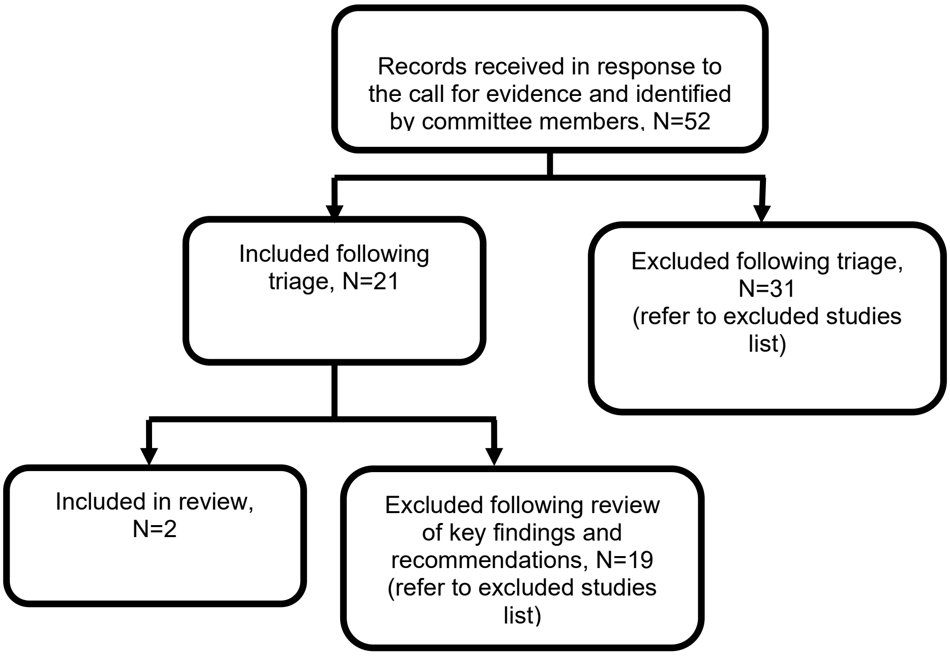
Care Act 2014, c. 23. Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 21/09/2021]

Appendices

Appendix A Study selection

Study selection for scope area: Information about effective advocacy and signposting to services

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Information about effective advocacy and signposting to services

Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
Full citation National Development Team for Inclusion (2020a). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England and Wales **Study type** Survey (open and closed ended questions) **Study dates** June 2020 **Source of funding** No sources of funding reported	Advocates (across multiple areas of statutory and non-statutory advocacy)	**Key findings** • Shared commitments by advocacy organisations to ensure people’s access to effective advocacy. Advocacy organisations have committed to: ○ Make sure their advocacy services are known about, accessible, person-centred, and provide effective advocacy whether through remote tools or face to face meetings.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)** Yes – to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic's impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place. **2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)** Can't tell – insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)** Can’t tell – limited information on methods of data collection and no other details provided.

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. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable – the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.
Full citation Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard:	Patients detained under the amended MHA 1983, who	**Key findings** • Methods on how participants learnt about IMHA services	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021] **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research (focus groups and interviews), case studies **Study dates** 2010 to 2012 **Source of funding** Department of Health	are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	and how to access them included: ○ Need for accessible promotional materials in a range of formats available from a range of mental health services. ○ Promotion by staff and appropriateness of referral to IMHA services. ○ The responsible health authority/NHS Trust ensures that all qualifying patients and their carers receive information about entitlement to IMHA and the IMHA providers in their area. • Practical steps to improve access: leaflets or posters were reported to be useful but relying only on such materials was reported to be inadequate.	Yes – to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MHA 1983. To identify the factors that affect the quality of IMHA services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes – how IMHA services and service users were identified is explained, in addition to identification of carers and family members, mental health staff and commissioners. **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

Study details	Population	Recommendations/key findings	Quality assessment
			Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes – the authors describe the analysis process and sufficient data are presented to support the findings. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes. **10. How valuable is the research?** Valuable – the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Minor limitations.

1 *CASP: Critical Appraisal Skills Programme; IMHA: Independent Mental Health Advocate; MHA: Mental Health Act; NHS: National Health Service*

Appendix C Quality Assessment

Quality assessment tables for scope area: Information about effective advocacy and signposting to services

Existing NICE guidelines

Table 4: AGREE II quality assessment of included guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Neonatal infection (early onset): antibiotics for prevention and treatment (Clinical Guideline 149)	2012	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	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 description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	98

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
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				available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.				
Looked after children and young people (Public Health Guideline 28)	2015	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views of the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are	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 recommendation	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate	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

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				guideline will be updated is provided though the methodology for this procedure is unavailable.				
Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management (Clinical Guideline 102)	2015	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions	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

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				provided though the methodology for this procedure is unavailable.				
Older people with social care needs and multiple long-term conditions (NICE Guideline 22)	2015	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these.	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

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				for this procedure is unavailable.				
Cerebral palsy in under 25s: assessment and management (NICE Guideline 62)	2017	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.	83 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. Very few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the	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.	96

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Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NICE Guideline 11)	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	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.	71 Descriptions of barriers and facilitators 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 some detail given on the potential resource implications of applying the recommendations. There are identification criteria	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.	94

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Child abuse and neglect (NICE Guideline 76)	2017	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	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.	92 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There is economic consideration, which is reported clearly. The	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.	96

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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 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 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 resource implications of	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

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Dementia: assessment, management and support for people living with dementia and their carers (NICE Guideline 97)	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.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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

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Spasticity in under 19s: management (Clinical Guideline 145)	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.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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

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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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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

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Intermediate care including reablement (NICE Guideline 74)	2017	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 audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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

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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)	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 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 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 resource implications of	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

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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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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

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Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Supporting adult carers (NICE Guideline 150)	2020	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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 %**
				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.		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 %**
Safeguarding adults in care homes (NICE Guideline 189)	2021	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of	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 %**
				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.		applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		

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

Formal consensus

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**
NDTi 2020a	2020	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

CASP: Critical Appraisal Skills Programme

Appendix D Excluded studies

Excluded studies for scope area: Information about effective advocacy and signposting to services

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 Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021]	No key findings or recommendations relevant to Information about effective advocacy and signposting to services
Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services, NIHR School for Social Care Research Scoping Review. Available at: https://www.ndti.org.uk/assets/files/SSCR-scoping-review_SR007.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Information about effective advocacy and signposting to services
Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of advocacy delivery in relation to Personal Health Budgets and other health funded support. Available at: https://www.ndti.org.uk/assets/files/Advocacy-Health-Funded-Support-Report-pdf.pdf [Accessed 07/05/2021]	No key findings or recommendations relevant to Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
National Development Team for Inclusion, Empowerment Matters (2014). Advocacy QPM: Advocacy Code of Practice, revised edition, 2014. Available at https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf [Accessed 25/11/2021]	Publication has no evidence base
National Development Team for Inclusion. (2018). Advocacy QPM: Assessment Workbook.	Publication has no evidence base

Study	Reason for Exclusion
Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]	
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 Information about effective advocacy and signposting to services
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished	No key findings or recommendations relevant to Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
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 (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 (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 Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
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	Publication is based on a book/book chapter.

Study	Reason for Exclusion
Right to Be Heard: Context, Values and Good Practice. Jessica Kingsley Publishers: London, UK.	
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Older People's Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, Vol. 23(4), 280-292.	No key findings or recommendations relevant to Information about effective advocacy and signposting to services
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 Information about effective advocacy and signposting to services
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 (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). 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	Publication has no evidence base

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

Study	Reason for Exclusion
commissioning/what-good-imha-service-looks-like/ [Accessed 16/02/2022]	
Strong, S. (2012). User-led organisation leadership of support planning and brokerage. The International Journal of Leadership in Public Services, 8(2), 83-89.	Publication is based on case-studies.
Taylor & Francis Production Disability and Rehabilitation (IDRE). My Life Tool (self-management tool): www.mylifetool.co.uk	Publication has no evidence base
Teeside University (2015/2016). UTREG Online Module Specification: Advocacy - Evolution, Equality and Equity. Unpublished.	Publication has no evidence base
Townsley, R., Marriott, A., Ward, L. (2009). Access to independent advocacy: an evidence review, Office for Disability Issues. Available at: http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-exec-summary-standard.pdf [Accessed 16/02/2022]	Not published in the last 10 years
Turner, S. & Giraud-Saunders, A. (2014). Personal health budgets: Including people with learning disabilities	Publication is based on case-studies.
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 Information about effective advocacy and signposting to services
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 review question.

Appendix E Research recommendations – full details

Research recommendations for scope area: Information about effective advocacy and signposting to services

No research recommendations were made for this scope area.

1 # Appendix F Existing NICE recommendations

2 Table 7: Existing NICE recommendations for scope area: Information about effective advocacy and signposting to services

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Ensure all young people know their entitlements to services and how to access them, including independent advocacy if needed.	**Looked after children and young people [PH28] – 1.47.5** Impact: Evidence from 4 studies indicates that interventions for improving the transition outcomes can be effective. In 1 study the focus was transitional housing support, which provided evidence of positive outcomes for housing, employment and substance misuse. Similarly, 2 studies focused on life-skills coaching indicated positive outcomes in respect of uptake of social and support services. Lastly, 1 study focused on transition support for pregnant and parenting young foster care woman where participation was associated with positive changes across a range of domains. The current recommendation does not provide specific details on the type or duration of interventions to support young people preparing for independence from foster care. It does indicate leaving care service should include support, for example, through safe and settled accommodation, training in life skills, opportunities for continuing education and substance misuse advice. This is a potential topic which could be covered by an updated guideline. The comment from 1 topic expert that there are no recommendations relating to older looked after young people who may be in supported lodgings would require evidence to support a recommendation. Currently, the guideline provides recommendations on moving to independent living.	**Adapted** The recommendation was used to inform recommendation 1.3.2 about local authorities, health authorities, NHS trusts and advocacy services providing people with information about their entitlements to advocacy. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review 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.
Care homes should tell residents: how advocates can help them with safeguarding enquiries that they may have a legal right to an advocate, and what the criteria for this are.	**Safeguarding adults in care homes [NG189] – 1.18.12** Rationale and Impact: 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.	**Adapted** The recommendation was combined with the recommendation below from NG97 and was broadened to cover	Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should provide everyone who would benefit from advocacy (whether

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	The evidence showed that residents benefit when they are involved and kept informed throughout the safeguarding process. The evidence also emphasised the value that residents place on support from family, friends or advocates in helping them achieve their desired outcomes. However, the committee had some concerns about the quality of the data, which had some methodological limitations as well as questionable relevance (it was not always clear whether findings related specifically to care home settings). The committee therefore also used the Making Safeguarding Personal framework and the Care Act 2014. These sources highlight the importance of involving people fully as possible in decisions and giving them the information and support they need to participate. The committee recognised that there should be a clear difference and understanding of the roles of the practitioners and independent advocate involved in safeguarding. Although the practitioner might be acting in the best interest of the person, they may be operating within the constraints of their role. It is only the independent advocate who acts according to instruction from the person. Residents will often need emotional and practical support while an enquiry is taking place. In addition, they may need this support to continue afterwards, and their needs should be reassessed after the enquiry.	providing information to everyone, whether or not they are legally entitled to an advocate. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	or not they are legally entitled to it) with information about: • what advocacy services are available to them • how an advocate could help them • how to access and contact advocacy services.
At diagnosis, offer the person and their family members or carers (as appropriate) oral and written information that explains: • how the following groups can help and how to contact them: ○ advocacy services	**Dementia: assessment, management and support for people living with dementia and their carers [NG97] – 1.1.6** Trade-off between benefits and harms: The committee agreed with the finding in the evidence that advocacy and voluntary support services are important for people living with dementia and the committee agreed that the advocacy and voluntary support service recommendations from the previous guideline should be retained (informing people about the services that are available).	**Adapted** The recommendation was combined with the recommendation above from NG189 and was broadened to cover providing information to everyone who is legally entitled to an advocate.	Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should provide everyone who would benefit from advocacy (whether or not they are legally entitled to it) with information about: • what advocacy services are available to them

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
		See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	• how an advocate could help them • how to access and contact advocacy services.
Offer parents and carers contact details of organisations that provide parent support, befriending, counselling, information and advocacy. They may signpost families to other sources of help.	**Neonatal infection (early onset): antibiotics for prevention and treatment [CG149] – 1.1.9** Rationale and Impact: The committee decided that some of the information and support recommendations in the previous version of the NICE guideline on neonatal infection for the families of babies with early-onset infection were also applicable to the families of babies who may develop late-onset infection.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Not applicable
Offer children and young people and their parents or carers: information about and access to further care immediately after discharge, and contact details of patient support organisations including meningitis charities that can offer support, befriending, in-depth information, advocacy,	**Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management [CG102] – 1.5.2** In making their recommendations, the GDG highlighted children and young people who experience disability as a result of having bacterial meningitis or meningococcal septicaemia as a priority for receiving follow-up care and support to minimise health inequalities associated with their disabilities	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
counselling, and written information to signpost families to further help, and advice on accessing future care.		See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	
Offer contact details of patient organisations that can provide support, befriending, counselling, information and advocacy.	**Spasticity in under 19s: management [CG145] – 1.1.11** Other considerations: Supporting the child or young person and their parents or carers The GDG noted that management of spasticity involves a long-term commitment for the child or young person and their family or carers, and that the network team has an important role to play in providing ongoing support throughout development. In particular, the group noted that the network team should ensure the timely provision of equipment associated with particular interventions, should play a central role during transition and should provide children and young people and their parents or carers with contact details of patient organisations which can provide support, befriending, counselling, information and advocacy.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Not applicable
Practitioners should tell people about advocacy services as a potential source of support for decision-making, including: • enabling them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs	**Decision-making and mental capacity [NG108] – 1.1.7** Other considerations: Recommendations 1.1.7 and 1.1.9 are based on discussions about the evidence in SDM3 and SDM4 describing ways in which people can be successfully supported to participate in decision making. On the basis of the evidence the committee noted that there are principles and tools (e.g. talking mats and signing) which could be applicable to people living with dementia or with a learning disability. The committee acknowledged that there are ways of enabling people to participate in decision making, even where they are experiencing substantial difficulty and that this would not be limited to learning	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
- facilitating their involvement in decisions that may be made, or are being made under the Mental Capacity Act 2005.	disabilities and dementia. They discussed other means of support (beyond those cited in the research) and agreed, on the basis of their expertise and then supported by expert testimony (EW LS) that it is appropriate to recommend advocacy as a means of providing the kind of support which is valued by people engaged in decision making	See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	
When providing support to family members or carers (including siblings): - explain how to access family advocacy	**Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11] – 1.3.3** Other considerations: Although carers' assessments and NICE-recommended interventions should be readily accessible for all carers, the GDG noted from the review of carer experience that these options were often not available to carers of people with a learning disability and therefore considered that recommendations in this area were needed to improve carers' experience.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence 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 recommendations: There was no evidence in this area, but there is a legal responsibility on local authorities to provide access to independent advocacy, in line with the Care Act 2014 and the Mental Capacity Act 2005. The committee agreed by consensus that it was important to inform carers about their right to support from advocacy services and the circumstances in which they would apply. To build on this and ensure that advocates (or other representatives) can give meaningful support to carers, the committee agreed that practitioners should recognise the voice and	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	role of advocates. In the committee's view this does not always happen in practice. The committee also noted the important role of advocacy as set out in the Mental Capacity Act 2005.	See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	
When people are placed in out-of-area rehabilitation services, provide an explanation in writing to the person (and their family or carers, as appropriate): the advocacy support available to help them.	**Rehabilitation for adults with complex psychosis [NG181] – 1.4.3** Why the committee made the recommendations: In the committee's experience, many potential users of rehabilitation services and their families and carers are unaware of what services are available and how to access them. This was also reflected in the qualitative evidence.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Not applicable
Inform people about, and direct them to, advocacy services.	**Older people with social care needs and multiple long-term conditions [NG22] – 1.5.4** Evidence statement ES37 – Extent of social isolation living in communal environments compared to when living alone: A good quality qualitative paper (Blickem 2013 +) reports that older people who live in communal environments are as likely to feel isolated and lonely as those remaining in their own homes. Granville (2020 +) also confirms that people in care homes who maintained a network of	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	friends and family retained 'more of their own sense of identity and have more meaning in their lives' (p69) Other considerations: The recommendations here drew on and expert witness testimony as well as Guideline Committee consensus. The Guideline Committee discussed the lack of good research evidence concerning the availability, effectiveness and cost effectiveness of different interventions to reduce social isolation and facilitate social contact for people in care homes. The expert witness testimony provided a range of examples of how this has been delivered successfully elsewhere which the Guideline Committee felt strongly should inform recommendations. They agreed that care homes should promote a culture which reflects the interests and needs of their clients, allowing them to live the life they choose, so far as possible. They also noted that this should involve everyone being able to access information about the cost of care home services so they can make informed decisions about their support. Guideline Committee members also gave examples, from their own experience, of how care homes can improve residents' experience and facilitate social contact both in and outside the home. Expert witness testimony highlighted examples of creative uses of care home space and innovative ways to involve members of the wider local community in the life of the care home.	See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	
A senior health professional should ensure that discussions take place with the person being admitted to check that: • they have understood the information they were given at admission • they know they have a right to appeal, and that information and advocacy	**Transition between inpatient mental health settings and community or care home settings [NG53] – 1.3.14** Evidence statement HA1: There is good evidence from 1 mixed methods study (Katsakou 2011 ++/++) and 1 cross-sectional study (Bindman 2005 +/+) that people admitted to mental health units may feel coerced into accepting admission, whether or not they are formally admitted under the Mental Health Act. There is also evidence (Bindman 2005 +/+) that people do not necessarily know whether they are voluntary or involuntary patients, and may suspect they will be	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
can be provided to support them to do so if they wish - they understand that any changes to their legal status and treatment plans will be discussed as they occur.	sectioned if they do not cooperate. Although most felt they needed help, they held alternative treatment to be preferable and less restrictive, and did not feel respected or cared for. Those not reporting a sense of coercion felt included in the admission and treatment process, respected and cared for (recs 1.3.13, 1.3.14). Evidence statement HA 6: There is good quality evidence from 2 good qualitative studies (Katsakou et al. 2011 ++; Valenti et al. 2014 ++), and from 1 literature review (Van Den Hooff 2014 +), that people who are involuntarily admitted under the Mental Health Act value freedom, safety and respect from staff. These values could be supported by improved: - involvement in, information about, and explanation of decisions and treatment - being listened to - having some concessions to freedom of movement and activity - staff showing respect to people and listening and responding to patients' concerns sense of safety, being protected and being cared for by staff (recs 1.3.13, 1.3.14). Other considerations: The GC took into account the fact that people did not necessarily know whether they had been admitted as a formal or informal patient – and that the distinction may be misleading if people felt they would be 'sectioned' if they did not cooperate. Information about legal status and rights was felt to be important, but the GC recognised that the person may not be able to take it in at admission, and hence needed reiteration and follow up. This needed to be overseen or delivered by a practitioner ('senior health professional') who was competent to explain the Mental Health Act (as not all staff may have adequate knowledge). Ideally, this discussion might take place within the context of a developing 'therapeutic relationship'. Accessible written information – possibly a video - might also be useful (recs 1.3.13, 1.3.14).	See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Provide information about local support and advocacy groups to the child or young person and their parents or carers.	**Cerebral palsy in under 25s: assessment and management [NG62] – 1.6.8** Consideration of clinical benefits and harms: The Committee also mentioned that resources varied locally and over time. Resources that were available one year may not be available the following year. The Committee agreed that it was very important for people with cerebral palsy and their parents and/or carers to get support from advocacy groups. The Committee mentioned that local authorities also had the responsibility of supporting people with disability and their families; and that they should enable access to support groups to people with cerebral palsy.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Not applicable
When assessing people for intermediate care, explain to them (and their families and carers, as appropriate) about advocacy services and how to contact them if they wish.	**Intermediate care including reablement [NG74] – 1.3.5** Other considerations: Recommendation 1.3.5 is based on guideline committee consensus in the context of discussions around the review about information, advice, advocacy, training and support. The group discussed how access to advocacy is important throughout the intermediate care process and for people from all local communities. The group discussed the resource implications to ascertain whether it is achievable for everyone being assessed for intermediate care to be told how to access advocacy services. However, members cited requirements of the Care Act and agreed this recommendation should therefore be made.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Give families information about local services and resources, including advocacy that they may find useful.	**Child abuse and neglect [NG76] – 1.5.5.** Evidence statement ES4 – Acceptability of home visiting services provided to families at risk of abuse and neglect: There were 6 studies of moderate evidence quality. This evidence statement is based on a good amount of moderate quality evidence comprising 1 US RCT (Silovsky et al. 2011 +) and 5 US qualitative studies (Allen 2007 +, Domian et al. 2010 +, Krysik et al. 2008 +, Paris 2008 +, Stevens et al. 2005 +). This evidence suggested that caregivers and parents value home visiting services provided at the early help stage. One moderate quality US RCT (Silovsky et al. 2011 +) found significantly higher levels of satisfaction with services for parents allocated to a home visiting intervention compared to those allocated to standard community mental health services. The 5 qualitative studies (Allen 2007 +, Domian et al. 2010 +, Krysik et al. 2008 +, Paris 2008, Stevens et al. 2005 +), showed that caregivers and parents value: a positive and trusting relationship with the home visitor; the personal qualities of the home visitor, for example being ‘caring’ or ‘a friend’; having a home visitor who is perceived as knowledgeable, in particular having had experience of having children; provision of practical support, such as provision of household support and making links to community services; and provision of support in the home, Child abuse and neglect (October 2017) 262 of 613 meaning that transportation is not required. Consideration was given to the applicability of US evidence. However, it was judged that factors affecting parental satisfaction were likely to be similar in the US and UK. Other consideration: Recommendation 1.5.5 was based on ES4 and highlights the role that practitioners working at the early help stage can have in helping families to make use of universal community resources that are available to them. Reference to advocacy was added based on consultation feedback.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee’s discussion and interpretation of the evidence in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to communicate and if they have any communication needs (in line with the Accessible Information Standard). This could include: • advocacy support	**People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86] – 1.1.5** LD4: People with learning disabilities and disempowerment This evidence statement is based on two studies, of overall medium quality. In the studies, some people highlighted that services should treat them equally, and give them the confidence to believe they had a legitimate right to services, which helps them feel valued and respected. The first study (Hoole and Morgan 2011 +) explored the lived experiences of people with learning disabilities as users of services. This study further noted that people with learning disabilities felt empowered when they were given accessible information, access to self-advocacy forums and travel training. The second study (Miller et al. 2008 +) explored outcomes important to people with intellectual disabilities. The studies found that people with learning disabilities feel disempowered and not ‘afforded the same rights’ as people without a learning disability. RQ4.7: Advocacy interviews: This evidence statement is based on a small amount of evidence of medium quality from one mixed-methods study that time limits to advocacy interviews is a barrier to delivering person-centred care. Redley et al (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found the timelimited nature of the interviews allowed to a person who lacked capacity was a barrier to getting to know them and to delivering a truly person-centred approach in helping their clients express their wishes. This study found that time limits to advocacy interviews is a barrier to delivering person-centred care. V1: Matching service users and care staff: This evidence statement is based on 1 study of medium level quality (Valdeep et al. 2014 +), which examined satisfaction with social care services among black and minority ethnic populations. The study found that matching (for example, on ethnicity, age and gender) was not perceived as essential to service users, who prioritise personalised care and being listened to.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee’s discussion and interpretation of the evidence in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	Other considerations: Recommendation 1.1.5 about supporting people to express their views, preferences and aspirations in relation to their care and support was based on evidence statements LD1, LD4, RQ4.7 and V1. The evidence included: a lack of support to listen to the complaints of residents with learning disabilities living in supported accommodation; time limits to advocacy interviews being a barrier to delivering person-centred care; and language being a significant barrier to receiving and accessing services. The Guideline Committee had wide-ranging discussions which included: the need to deal with people's complaints; acknowledgement of the significance of advocacy; and an awareness that certain groups such as people with dementia and people with learning disabilities are excluded from participating in local authority surveys. The Guideline Committee agreed that this recommendation should be broadened to all groups and settings. Additional detail on how to support people with different communication needs to express their views, preferences and aspirations by following the guidance set out in the Accessible Information Standard was added based on Guideline Committee consensus following stakeholder feedback.		
Named professionals should: • ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate.	**Dementia: assessment, management and support for people living with dementia and their carers [NG97] – 1.3.2** Trade-off between benefits and harms: People living with dementia who refuse assistance The committee noted that if the person does not have capacity to make decisions about their care, special consideration should be given to the individual's views, in line with the principles of the Mental Capacity Act. They noted that the term 'special consideration' has a specific meaning with the Act, and was therefore the correct term to include in the guideline. Related to this, they also felt it was important to inform people about the availability of local advocate services, and in particular their rights to an independent mental capacity advocate, should they meet the criteria for needing one.	**Recommendation not used in this guideline** This recommendation was not used in this guideline as the populations covered here are already covered by other recommendations about providing information. See the Benefits and harms section of The committee's discussion	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
		and interpretation of the evidence in this review for more information.	

GDG: guideline development group; IMCA: Independent Mental Capacity Advocate; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RCT: randomised controlled trial

Appendix G Formal consensus

Additional information related to scope area: Information about effective advocacy and signposting to services

Table 8: Formal consensus round 1 statements and results for scope area: Information about effective advocacy and signposting to services

Statement no.	Statement	References	Percentage agreement	Action taken
1	There should be shared commitments by advocacy organisations to make sure their advocacy services are known about.	National Development Team for Inclusion 2020a	91.91%	Carried forward to committee discussion
2	Leaflets or posters may be useful in improving access to advocacy, but should not be solely relied on.	Newbigging 2012	91.67%	Carried forward to committee discussion
3	There is a need for accessible promotional materials in a range of formats available from a range of mental health services to promote IMHA services and how to access them.	Newbigging 2012	100.00%	Carried forward to committee discussion
4	Staff should promote IMHA services and how to access them.	Newbigging 2012	100.00%	Carried forward to committee discussion
5	Health authorities and NHS Trusts should ensure that all qualifying patients and their carers receive information about entitlement to IMHA and the IMHA providers in their area.	Newbigging 2012	100.00%	Carried forward to committee discussion

IMHA: Independent Mental Health Advocate; NHS: National Health Service