National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[B] Who else would benefit from advocacy and how do we identify them?

NICE guideline NG227

Evidence review underpinning recommendation 1.2.1 in the NICE guideline

November 2022

Final

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Who else would benefit from advocacy and how do we identify them?

Key theme

- Who else would benefit from advocacy and how do we identify them?

Introduction

The aim of this review is to identify those who would benefit from advocacy aside from those with a legal right to advocacy.

Recommendations about advocacy have been made in a number of existing NICE guidelines. However, these have identified a lack of evidence relating to advocacy that would meet inclusion criteria for standard evidence reviews. Therefore, it was agreed that recommendations for this guideline would be developed by adopting and adapting advocacy-related recommendations from existing NICE guidelines, using a formal consensus 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Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are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	Who else would benefit from advocacy and how do we identify them

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 who else would benefit from advocacy and how do we identify them were identified from 12 NICE guidelines ([CG136] Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services, [CG142] Autism spectrum disorder in adults: diagnosis and management, [CG155] Psychosis and schizophrenia in children and young people: recognition and management, [NG11] Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, [NG21] Home care: delivering personal care and practical support to older people living in their own homes, [NG43] Transition from children's to adults' services for young people using health or social care services, [NG53] Transition between inpatient mental health settings and community or care home settings, [NG86] People's experience in adult social care services: improving the experience of care and support for people using adult social care services, [NG119] Cerebral palsy in adults, [PH28] Looked after children and young people, [PH50] Domestic violence and abuse: multi-agency working, [PH52] Needle and syringe programmes).The audience for these guidelines included: health and social care professionals, non-clinical staff, people with the condition or users of a service and their families and carers, commissioners and providers, service managers, and other staff who come into contact with people using services (for example education, voluntary and community sector, criminal justice, clerical and domestic staff). Only NG86 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.

Eight documents were identified for this review (Harflett 2015, Macadam 2013, National Development Team for Inclusion [NDTi] 2012, Newbigging 2012, Ridley 2018, Roberts 2012, SERIO 2021, Turner 2012).

Four documents focused on people living with autism and/or people living with learning disabilities, including those who are most isolated (Harflett 2015, NDTi 2012, Roberts 2012, Turner 2012) and 1 document each focused on people who use social care services (Macadam 2013), veterans and their families (SERIO 2021) or people detained under the amended Mental Health Act 1983 (Newbigging 2012). One document (Ridley 2018) included 3 different populations: African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; and children and young people receiving advocacy services.

Excluded studies

Formal consensus

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

Summary of included studies

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

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

Document	Population	Evidence base
Harflett 2015 Narrative review England	Most isolated people with learning disabilities	Literature review
Macadam 2013 Brief report England	People who use social care services	Systematic scoping review and call for evidence with content analysis
NDTi 2012 Report England	People with learning disabilities and people with autism	Systematic review with content analysis, call for evidence and meetings with experts by experience, family carers and professionals
Newbigging 2012 Research report England	People detained under the amended Mental Health Act 1983, who were eligible for support from IMHA services, including people with and without capacity and children under the age of 16	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Ridley 2018 Review of 3 qualitative studies England	African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; children and young people receiving advocacy services	Comparative analysis and synthesis of findings from 3 qualitative studies (including service user, advocate, professional and commissioner perspectives); data collected through focus groups and/or interviews
Roberts 2012 Survey England	People living with learning disabilities	3 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies; provides information on, for example, funding and also discusses gaps in advocacy provision and barriers to accessing services
SERIO 2021 Service evaluation	Veterans and their families	Report of an independent three-year evaluation of The Veterans' Advocacy People, a service targeted at veterans, and their

Document	Population	Evidence base
England		families from each of the service arms, which aims to provide open and flexible advocacy support. Includes qualitative interviews
Turner 2012 Brief report England	People living with learning disabilities	2 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies (no detailed methods reported); provides advice and suggestions on actions for commissioners and advocacy groups to provide robust evidence on the effectiveness and reach of advocacy services

IMHA: Independent Mental Health Advocate; 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 21 existing recommendations related to who else would benefit from advocacy and how do we identify them were identified from the 12 NICE guidelines.. The committee agreed that none of the recommendations should 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

One included document (NDTi 2012) was assessed using AGREE II, 3 documents (Harflett, 2015; Macadam, 2013; Ridley, 2018) were assessed using the Risk of Bias in Systematic reviews (ROBIS) checklist, and 4 documents (Newbigging, 2012; Roberts, 2012; SERIO, 2021; Turner, 2012) were assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative research. See the results of the quality assessment in the evidence tables in appendix B and quality assessment tables in appendix C.

The committee were presented with 14 statements in round 1 of the formal consensus exercise; responses were received from all 12 committee members. At the time that round 1 voting for this scope area occurred, there were 12 committee members appointed. An additional committee member was appointed between the first and second round of voting; therefore, 13 committee members were eligible for voting during round 2. Nine of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Five statements had between 60% and 80% agreement and were re-drafted for round 2. No statements had <60% agreement.

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

Formal consensus round 2

The committee were presented with 5 statements in round 2 of the formal consensus exercise; 2 of the original statements was split into 2 statements and 2 statements were combined. Responses were received from 11 of 13 committee members. Four statements had between 60-80% agreement and were discarded. One statement reached ≥80% agreement and was included for the discussion with the committee.

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

Economic evidence

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

The committee's discussion and interpretation of the evidence

The outcomes that matter most

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

The quality of the evidence

Existing NICE guidelines

The quality of the existing NICE guidelines was assessed using AGREE II. Overall, the guidelines are of a very high quality (2 or more domains scored ≥90%) and are recommended for use. Some guidelines scored lower in stakeholder involvement because there were fewer experts by experience included in the committee group compared to other guidelines. A few guidelines 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 some of the documents identified by the committee and through the call for evidence was assessed using ROBIS and the AGREE II tool, which is explained in detail in the methods supplement for this guideline. ROBIS is intended for use in assessing the quality of systematic reviews but was also used for the purpose of this guideline to assess a number of reviews that were not intended by the authors to be systematic as it was the best available tool. The AGREE II instrument is intended for use assessing the quality of systematically developed clinical practice guidelines, including assessments of methodological rigour and transparency. Therefore, some domains of ROBIS and the AGREE II tool may be less relevant for these documents and they would not have followed reporting guidelines for systematic reviews. All supporting material published with documents was reviewed to inform quality assessment, however it was not feasible to contact the authors of each document. Therefore it is plausible that the documents may have scored lower on quality assessments than the underlying methodology would warrant had authors made their full methodology available or if more appropriate tools were available. The committee were aware of this in their discussions of the existing recommendations and statements extracted from documents identified from the call for evidence. Where shortcomings in the quality of documents impacted the committee's opinions about using the statements, this is described in the benefits and harms section below. On the whole however, where there was full committee support for a statement extracted from a lower quality document, the committee made the recommendation because their experiential knowledge corroborated the statement and strengthened the argument to use it as the basis for a recommendation.

The quality of 1 document (NDTi, 2012) was assessed using the AGREE II instrument. High quality documents were defined as those where any two domains scored ≥ 70%. This document was not deemed to be high quality. The included document scored 16% for stakeholder involvement and 8% for applicability. The document scored 19% for rigour of development and 0% for editorial independence. Overall, the document did not provide sufficient information on the stakeholder involvement in the development of the document. It was unclear whether the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the document were considered. The methods used to formulate and update the recommendations, and details on whether a systematic process had been used to gather and synthesise the evidence, were not clearly described. Declaration of any bias or competing interests from the document development group members were not reported.

The included document scored 83% for scope and purpose, and 33% for clarity of presentation. Generally, the overall aim, specific health questions and target population for the documents were described, but details were sometimes limited. The document did not present recommendations in a clear and concise structure and format.

The quality of 3 documents (Harflett, 2015; Macadam, 2013; Ridley, 2018) were assessed using the ROBIS checklist for systematic reviews. Two documents (Harflett, 2015; Macadam, 2013) were judged to have unclear risk of bias because insufficient details were provided to enable a judgement to be made. One document (Ridley, 2018) was judged to have high risk of bias because of a lack of clear reporting or an absence of reporting about eligibility criteria. Other concerns related to insufficient information on study selection, lack of critical appraisal of included papers, and an absence of testing the robustness of the review findings

The quality of 4 documents (Newbigging, 2012; Roberts, 2012; SERIO, 2021; Turner, 2012) were assessed using the CASP checklist for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations and 3 documents (Roberts, 2012; SERIO, 2021; Turner, 2012) were judged to have serious methodological limitations because of insufficient detail relating to participant recruitment, data collection and data analysis. Other concerns related to the lack of adequate consideration for the relationship between researcher and participants, and lack of consideration regarding ethical issues.

Benefits and harms

This area of the scope was concerned with establishing who would benefit from advocacy in addition to those with a legal right to advocacy and how those people should be identified. However, in the committee’s experience, it is a person’s circumstances or current situation that mean they may benefit from advocacy, rather than the characteristics of the person themselves, although there may be some populations that are more likely to experience situations where advocacy support would be beneficial. Therefore, the committee agreed that it was important to also consider when people would benefit from advocacy, rather than just who would benefit from advocacy.

The committee reviewed the existing NICE recommendations about populations for whom, or situations in which, advocacy support should be offered or considered (see Appendix F). They agreed that a common theme from these recommendations was the need for advocacy for people who would otherwise not be able to have their views heard about decisions that would have a substantial impact on their wellbeing or the wellbeing of people for whom they have caring responsibilities. However, the committee were concerned that adopting the existing recommendations, or adapting them into a list of when advocacy should be offered, may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. Therefore, the committee made a recommendation that defined the circumstances in which advocacy should be offered. They agreed it was beneficial in the interests of clarity to make a single recommendation encapsulating this information. The committee noted that, while the recommendation refers to decisions that will have a substantial impact on wellbeing, it is important that the cumulative impact of decisions be considered, alongside the importance of early involvement of advocates. In the committee's experience, advocacy is rarely available beyond that which is required by legislation. However, the circumstances in which people would benefit from advocacy support is wider than that covered by legislation and the provision of such support is necessary to enable people to participate in their care and decision making in a meaningful way.

None of the existing NICE recommendations or statements addressed the issue of how to identify people who will benefit from advocacy, other than those with a statutory entitlement. The committee therefore did not make a separate recommendation addressing this area. However they agreed that the way to identify these groups of people would be implied in the single recommendation about defining the circumstances in which advocacy should be offered. In other words people would be identified through recognising the circumstances described.

Statements not used in this review

There were a number of statements (Statements 1, 4, 8, 9, 10, 11, 12, 13 and 14) carried forward to committee discussions that were not used to inform recommendations because they covered populations for who, or situations where, advocacy support may be beneficial. Therefore, the committee agreed this content was covered by the recommendation outlined above. Similarly, statement 3, which covered providing advocacy services to everyone who needs it, was not used to inform recommendations as this did not provide any further detail about when this need may occur.

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 who else would benefit from advocacy. The reasons behind their decision making are given in appendix F.

Cost effectiveness and resource use

The provision of non-statutory advocacy services varies widely across areas and service providers. Whilst there are pockets of excellent provision, this is the minority and large numbers of areas have little or no provision beyond what is legally required. Where this is the case investment is going to be needed to expand the scope and range of services including the employment of additional advocates to cover these additional non-statutory cases. The committee highlighted that whilst there was not any identified economic evidence for this topic the recommendation did draw on a number of NICE guidelines where the use of non-statutory advocacy was thought to be both an effective and cost effective in the populations they covered, because it reduced or prevented the need for medical or other interventions. These recommendations are listed in Appendix F. They include recommendations in a very wide range of areas, including looked after children and young people, domestic violence and abuse services, home care, people transitioning between settings and adult mental health services. These guideline populations overlapped with a large proportion of the population covered by this guideline and the committee considered it reasonable that these results were generalised to this guideline. Whilst these recommendations will largely be reiterating current recommendations from NICE it is acknowledged a small proportion of the population for whom the recommendation of providing non-statutory advocacy services will be new.

The prominent justification for the previous recommendations was in reducing or preventing the need for medical or other interventions. This was particular true for complex interventions which would require longer hospitalisation or residential care and would be costly and have a large impact on an individual's quality of life.

In line with justification given for published NICE recommendations in other guidelines the committee particularly highlighted that for some people, had they not received non-statutory advocacy, their needs would eventually have escalated to a point where they would meet the threshold for statutory provision. These cases are not new costs but costs incurred earlier. Given the lower level of need for this group, the time needed for advocacy is likely to be significantly lower and unplanned hospital admissions and need for residential care is likely to be reduced. This should also lead to a higher quality of life through addressing needs earlier and preventing escalation. This reduction in time needed should also free up capacity in the statutory advocacy system although this may take a few years. This will reduce or potentially remove the need for longer term investment in services especially in regards to employing new advocates.

Recommendations supported by this evidence review

This evidence review supports recommendation 1.2.1.

References – included studies

Existing NICE guidelines

National Institute for Health and Care Excellence 2011

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

National Institute for Health and Care Excellence 2021

National Institute for Health and Care Excellence (2021). Autism spectrum disorder in adults: diagnosis and management (Clinical Guideline 142). Available at: https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909

National Institute for Health and Care Excellence 2016

National Institute for Health and Care Excellence (2016). Psychosis and schizophrenia in children and young people: recognition and management (Clinical Guideline 155). Available at: https://www.nice.org.uk/guidance/cg155/resources/psychosis-and-schizophrenia-in-children-and-young-people-recognition-and-management-pdf-35109632980933

National Institute for Health and Care Excellence 2016

National Institute for Health and Care Excellence (2016). 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). Home care: delivering personal care and practical support to older people living in their own homes (NICE Guideline 21). Available at: https://www.nice.org.uk/guidance/ng21/resources/home-care-delivering-personal-care-and-practical-support-to-older-people-living-in-their-own-homes-pdf-1837326858181

National Institute for Health and Care Excellence 2016

National Institute for Health and Care Excellence (2016). Transition from children's to adults' services for young people using health or social care services (NICE Guideline 43). Available at: https://www.nice.org.uk/guidance/ng43/resources/transition-from-childrens-to-adults-services-for-young-people-using-health-or-social-care-services-pdf-1837451149765

National Institute for Health and Care Excellence 2016

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

National Institute for Health and Care Excellence 2018

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

National Institute for Health and Care Excellence 2019

National Institute for Health and Care Excellence (2019). Cerebral palsy in adults (NICE Guideline 119). Available at: https://www.nice.org.uk/guidance/ng119/resources/cerebral-palsy-in-adults-pdf-66141606816709

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 2014

National Institute for Health and Care Excellence (2014). Domestic violence and abuse: multi-agency working (Public Health Guideline 50). Available at: https://www.nice.org.uk/guidance/ph50/resources/domestic-violence-and-abuse-multiagency-working-pdf-1996411687621

National Institute for Health and Care Excellence 2014

National Institute for Health and Care Excellence (2014). Needle and syringe programmes (Public Health Guideline 52). Available at: https://www.nice.org.uk/guidance/ph52/resources/needle-and-syringe-programmes-pdf-1996415046853

Formal consensus

Harflett 2015

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]

Macadam 2013

Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services, NIHR School for Social Care Research Scoping Review. Available at: https://www.ndti.org.uk/assets/files/SSCR-scoping-review_SR007.pdf [Accessed 06/04/2021]

National Development Team for Inclusion 2012

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]

Newbigging 2012

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

Ridley 2018

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

Roberts 2012

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]

SERIO 2021

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

Turner 2012

Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021]

Other

Mental Health Act (1983, amended 2007)

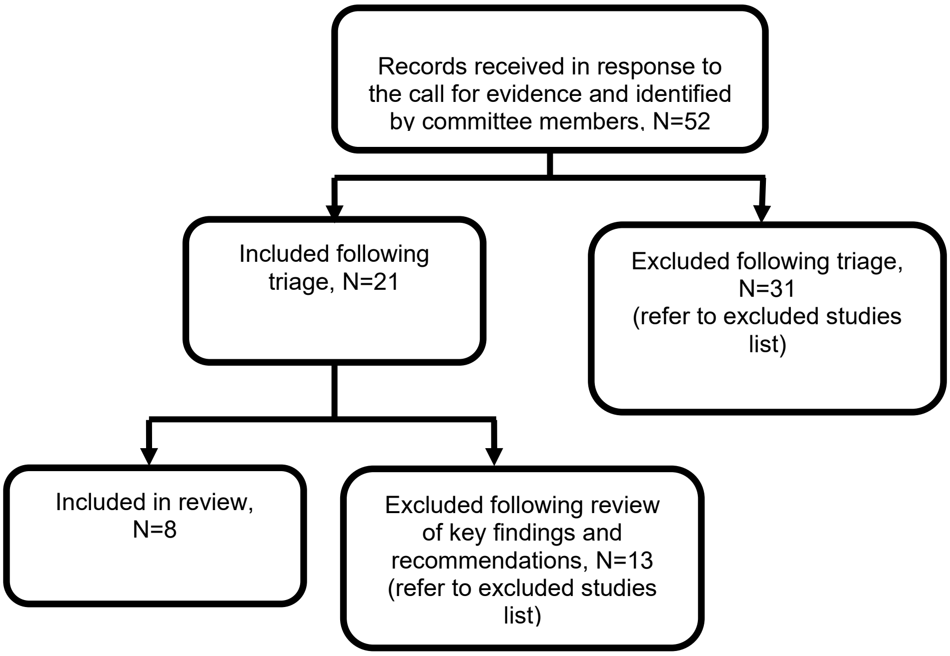
Mental Health Act 1983, amended 2007 (c. 20). Available at: https://www.legislation.gov.uk/ukpga/1983/20/contents [Access 15/11/2021]

Appendices

Appendix A Study selection for formal consensus process

Study selection for scope area: Who else would benefit from advocacy and how do we identify them?

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Who else would benefit from advocacy and how do we identify them?

Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
Full citation Harflett, N., Turner, S., Bown, H., National Development Team for Inclusion (2015). The impact of personalisation on the lives of the most isolated people with learning disabilities. A review of the evidence. Available at: https://www.ndti.org.uk/assets/files/Isolation_and_personalisation_evidence_review_final_02_06_15.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Review of evidence **Study dates** June 2015 **Source of funding** No sources of funding reported	Most isolated people with learning disabilities	**Key findings** • Access to advocacy recommended for adults with profound intellectual and multiple learning disabilities to ensure people who don't have family benefit from self-directed support.	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** - No information. **1.2 Were the eligibility criteria appropriate for the review question?** - Probably no (Insufficient information). **1.3 Were eligibility criteria unambiguous?** - Probably no (Insufficient details about eligibility criteria). **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** - No information. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** - No information. ***Concerns regarding specification of study eligibility criteria*** - Unclear concern (Insufficient information). **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?**

Study details	Population	Recommendations/key findings	Quality assessment
			- Probably yes (Used academic search engines but does not specify which ones). **2.2 Were methods additional to database searching used to identify relevant reports?** - No information. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** - No information. **2.4 Were restrictions based on date, publication format, or language appropriate?** - No information. **2.5 Were efforts made to minimise errors in selection of studies?** - No information. ***Concerns regarding methods used to identify and/or select studies*** - Unclear concern (Insufficient information provided). **3.1 Were efforts made to minimise error in data collection?** - No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** - No. **3.3 Were all relevant study results collected for use in the synthesis?**

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

Study details	Population	Recommendations/key findings	Quality assessment
			4.6 Were biases in primary studies minimal or addressed in the synthesis? - No information. ***Concerns regarding the synthesis and findings*** Unclear concern (Insufficient information). ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasising results on the basis of their statistical significance?** Yes **Risk of bias –** Unclear risk of bias
Full citation 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]	People who use social care services	**Key findings** Advocacy can be provided to those who are unable to personally instruct their advocate (Non-instructed advocacy). This may be because of the person's limitations in grasping concepts, or because they are unable to make others	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** - Probably yes – No full protocol available but pre-defined criteria are supplied.

Study details	Population	Recommendations/key findings	Quality assessment
Country/ies where the study was carried out England **Study type** Scoping review **Study dates** 2013 **Source of funding** No sources of funding reported		understand their wishes due to significant communication barriers	**1.2 Were the eligibility criteria appropriate for the review question?** - Yes. **1.3 Were eligibility criteria unambiguous?** - Probably no. The scope of documents considered relevant for the review is outlined but the authors note that there were some deviations from the parameters but provide minimal information about this **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** - Yes – Restrictions were minimal. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** - Yes. ***Concerns regarding specification of study eligibility criteria*** - Low concern – Considerable effort to clearly define review question and specify eligibility criteria, has been made. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** - Yes. **2.2 Were methods additional to database searching used to identify relevant reports?** - Yes. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?**

Study details	Population	Recommendations/key findings	Quality assessment
			- Yes. **2.4 Were restrictions based on date, publication format, or language appropriate?** - No (restricted to English). **2.5 Were efforts made to minimise errors in selection of studies?** - Yes. ***Concerns regarding methods used to identify and/or select studies*** - Low concern. **3.1 Were efforts made to minimise error in data collection?** - No (Data collection likely conducted by one researcher). **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** - Yes. **3.3 Were all relevant study results collected for use in the synthesis?** - No information. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** - No information. **3.5 Were efforts made to minimise error in risk of bias assessment?**

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

Study details	Population	Recommendations/key findings	Quality assessment
			Phase three **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** Yes **B. Was the relevance of identified studies to the review's research question appropriately considered?** Yes **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes **Risk of bias** – Unclear risk of bias
Full citation National Development Team for Inclusion (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Available at: https://www.ndti.org.uk/assets/files/Reasonably-adjusted_2020-12-30-150637.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Mixed Methods (Literature Review and Qualitative Research) **Study dates**	Adults with learning disabilities and adults with autism	**Key findings** • Advocacy should be available to everyone who needs it, especially people who are in residential settings, those who have few choices and those subject to legal restrictions.	**Quality assessment using AGREE II** 1) **Scope and Purpose** 83% Overall objective, population and description of the health are described. 2) **Stakeholder involvement** 16% Composition of the committee was alluded to but no specific information provided. Some views from the target audiences were included. Target users of the guideline were not defined. 3) **Rigour of development** 19% Systematic methods were attempted but not clearly enough defined. No or little information about criteria for selection, strength and limitations, and methods for formulating recommendations provided. Some health benefits have been considered when making recommendations. No explicit links to recommendations,

Study details	Population	Recommendations/key findings	Quality assessment
February 2012 **Source of funding** No sources of funding reported			and no procedure for updating guidelines have been included. 4) **Clarity of presentation** 33% Recommendations could be clearer and more specific. No different options are presented. Key recommendations are identifiable. 5) **Applicability** 8% Descriptions of barriers and tools are vague. No information regarding resource implications and auditing criteria were provided. 6) **Editorial independence** 0% No information regarding funding and/or potential conflict of interest were provided. **Overall rating** 36.02%
Full citation Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021] **Country/ies where the study was carried out** England	Patients detained under the amended Mental Health Act 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	**Key findings** • Some mental health professionals stressed that IMHA services were more pertinent for those qualifying patients who did not have support or were in conflict with family members. **Recommendations** • Consideration should now be given to extending the opportunity to access advocacy to informal patients in hospital.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MH Act 1983. To identify the factors that affect the quality of IMHA services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
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		• Consideration is given to extending IMHA provision to all in-patients, as recommended by NICE (National Institute for Health and Clinical Excellence, 2011) and introduced recently by the Welsh Government (Welsh Office, 2011a).	**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 3 Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes - the authors describe the analysis process and sufficient data are presented to support the findings.

Study details	Population	Recommendations/key findings	Quality assessment
			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.
Full citation Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 23(4), 280-292 **Country/ies where the study was carried out** England **Study type** Qualitative meta-synthesis **Study dates** Not reported **Source of funding** No sources of funding reported	• African and African Caribbean men with experience of mental health services • Adults and children who were subject to compulsion under the MH Act 1983, and therefore eligible for (but not necessarily accessing) an IMHA under the 2007 MH Act • Children and young people receiving	**Key findings** • Children and adults experiencing mental health problems at particular risk of having views and experiences dismissed, thus advocacy is consistent with recovery-focussed approaches.	**Quality assessment using ROBIS** **Phase two** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** No information - There was no evidence of pre-specification of objectives and eligibility criteria. **1.2 Were the eligibility criteria appropriate for the review question?** No - Eligibility criteria were not provided. However, the included studies appear to have been selected due to being research studies previously undertaken by the authors on independent mental health advocacy. **1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the population. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided.

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

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

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

Study details	Population	Recommendations/key findings	Quality assessment
			B. Was the relevance of identified studies to the review's research question appropriately considered? No. **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Not applicable. Risk of bias – High risk of bias
Full citation Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** December 2011 and January 2012 **Source of funding** Supported by the Department of Health	A range of people including people living with learning disabilities	**Key findings** • Commissioners stated that people living with learning disabilities were more likely to receive advocacy services from organisations providing services solely to people living with learning disabilities. • Advocacy organisations were asked whether they provided services to people with profound or multiple learning disabilities (PMLD): ○ 55 organisations (83%) ensured inclusion of PMLD. ○ 7 organisations described links with service providers. ○ 6 provided non-instructed advocacy in this area. ○ 4 organisations provided 1-to-1, professional or case advocacy. • Overall, mixed response in relation to the degree to which work with PMLD took place.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how advocacy organisations and commissioners of advocacy services were identified is explained to some extent.

Study details	Population	Recommendations/key findings	Quality assessment
		• Young people moving from school or college into adult life: ○ 53 organisations (80%) took steps to ensure young people were included in their services. ○ For example, work within and links to schools and colleges (13 organisations), engaging with local authority transitions or other services (8 organisations) and running specific transitions projects (6 organisations). • Older people: ○ 46 organisations (70%) took steps to ensure older people were included in their services, including making links to other service providers (5 organisations) and partnership work with or links to Age UK (3 organisations). • Transgender people: ○ 19 organisations (29%) took steps to ensure transgender people were included in services, although few examples of specific practice in this area were provided. • Gypsy and Traveller communities: ○ 15 organisations (23%) aimed to ensure services	**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide evidence on gaps in the provision of advocacy services and areas for further research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		were provided to these communities, but few examples of specific practice were provided. For example, work as part of a BME project (2 organisations), links with the traveller community (1 organisation) and links with traveller services (1 organisation). • Asylum seekers: ○ 12 organisations (18%) ensure services were provided to asylum seekers, but few examples of specific practice were provided. • Gaps in advocacy provision: ○ 56 advocacy organisations (82%) suggested gaps for parents with learning disabilities. For example, “We support parents that have a learning disability who are on the Child in Need or Protection registers. There is a big gap in this area as there is no provision to assist these”. (p.44) ○ “Different geographical areas place a different priority on Advocacy and on different groups of people – especially parents with a learning disability”. (p.44) ○ One organisation said there was a gap in relation to	

Study details	Population	Recommendations/key findings	Quality assessment
		people with caring responsibilities. ○ 6 organisations (11%) suggested a gap in relation to transition between children's and adult services. ○ 4 organisations (7%) stated that people with mild or moderate learning disabilities were less likely to receive advocacy support. For example, "Currently to access advocacy people need to be accessing a health or social service. There are a number of people with mild or moderate learning disabilities who do not qualify". (p.44) • Other examples of gaps were identified by at least 2 advocacy organisations: 1-to-1 citizen advocacy); BME population; Children's advocacy; Crisis advocacy; Lack of advocacy in certain geographical areas; Housing; Not enough support for volunteers to befriend people with learning disabilities or not enough volunteer advocates; Offenders or ex-offenders; Support to enter paid employment; People who are isolated and may live alone	

Study details	Population	Recommendations/key findings	Quality assessment
		without knowledge of advocacy services; People with PMLD or complex needs; People not eligible or qualifying for local authority services; Self-advocacy; Support on direct payments and personal budgets; Young people. • Organisations were asked about the involvement of family carers: ○ 6 organisations (10%) said that family members may be involved in some way in the provision of advocacy: ○ 'Advocates engage family carers in advocacy where possible.' ○ 'All our advocacy is done in conjunction with family carers.' ○ 'Our direct support is to adults with learning difficulties/disabilities, however as many of the partnerships are of a long term nature, it is inevitable that the advocates have contact with the family carers.' • Further research on family advocacy is needed, including the role of agencies in advocating for families, the role of families in acting informally as advocates and	

Study details	Population	Recommendations/key findings	Quality assessment
		links to self-advocacy and statutory advocacy.	
Full citation SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at: https://www.vfrhub.com/wp-content/uploads/2021/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research and social return on investment analysis **Study dates** 2018 to 2021 **Source of funding** No sources of funding reported	Military veterans and their families	**Key findings** Benefits for many clients in terms of onward referral to, and engagement with, an appropriate organisation that met their needs (for example, organisations providing social activities, provision of access to education or employment), or discussed access to other services, led to a sense of greater control of their life course.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to assess the impact of advocacy on veterans and their families, and the wider social and financial impact. To enable a greater understanding within central and local government and across the military charity sector of any potential for investment in this area and lessons for practice in support for veterans and in the wider use of advocacy services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
			No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?** Valuable - the authors suggest strengths and limitations of the research and potential for unintended outcome consequences, and suggestions for further analysis relating to data monitoring. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.
Full citation Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHA	A range of people including people living with learning disabilities	**Key findings** • Although advocacy organisations are not public bodies, they can be commissioned by public bodies and relationships between the two should take equality into consideration. For	**Quality assessment using CASP qualitative studies checklist** See Roberts 2012

Study details	Population	Recommendations/key findings	Quality assessment
L-ev-_2012-01.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** See Roberts 2012 **Source of funding** Supported by the Department of Health		example, survey responses indicated that parents with learning disabilities and young people in transition may struggle to access advocacy.	

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; NICE: National Institute for Health and Care Excellence; BME: Black and minority ethnic; CASP: Critical Appraisal Skills Programme; IMHA: Independent Mental Health Advocate; MH: mental health; NICE: National Institute for Health and Care Excellence PMLD: people with profound or multiple learning disabilities; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews.

Appendix C Quality Assessment

Quality assessment tables for scope area: Who else would benefit from advocacy and how do we identify them?

Existing NICE guidelines

Table 4: AGREE II quality assessment of NICE guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services (Clinical Guideline 136)	2011	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	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	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	89 The recommendations are specific and unambiguous but a small number of recommendations lack identification of the intent or purpose of the recommended action. The different options for management of the condition or health issue are clearly presented, though in a few cases, the description of	67 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	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.	90

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			users of the guideline are clearly defined.	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.	options and the description of populations most appropriate to each option are not given. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	there are directions on how users can access these. There is little to no detail given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Autism spectrum disorder in adults: diagnosis and management (Clinical Guideline 142)	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.	94 The guideline development group included a range of individuals from relevant professional groups, and information about their profession	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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly	71 Descriptions of barriers and facilitators are vague. Feedback from key stakeholders were obtained. There is description of how the recommendati	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline.	94

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			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.	clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.	presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	ons 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 to assess guideline implementation and monitoring or auditing criteria.	Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Psychosis and schizophrenia in children and young people: recognition and management (Clinical Guideline 155)	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 audience were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making 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.	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.	88 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 description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	95

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
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	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	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	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	94

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			were included in guideline development. The target users of the guideline are clearly defined.	the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.	grouped together in one section. The description of recommendations are summarised as flow charts.	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 to assess guideline implementation and monitoring or auditing criteria.	and addressed explicitly.	
Home care: delivering personal care and practical support to older people living in their own homes	2015	100 The overall objective of the guideline, the health question covered by the guideline, and the population to	100 The guideline development group included a range of individuals from relevant	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly	100 The recommendations are specific and unambiguous, and the different	92 There is some description of the facilitators and barriers and how these influenced the formation of	100 The funding body has been stated and there is an explicit statement reporting the	98

		Domains						
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
(NICE Guideline 21)		whom the guideline applies are specifically described.	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.	described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by 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	options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification	funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				though the methodology for this procedure is unavailable.		criteria to assess guideline implementation and monitoring or auditing criteria.		
Transition from children's to adults' services for young people using health or social care services (NICE Guideline 43)	2016	100 The overall objective of the guideline, 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	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			clearly defined.	development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
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	94 The guideline development group included a range of individuals from relevant professional groups, and information about their	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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the	98

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
						and monitoring or auditing criteria.		
People's experience in adult social care services: improving the experience of care and support for people using adult social care services (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 recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The 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	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				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.		directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Cerebral palsy in adults (NICE Guideline 119)	2019	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in	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	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	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	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	99

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Looked after children and young people (Public Health Guideline 28)	2015	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views of the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making 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.	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.	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Domestic violence and abuse: multi-agency working (Public Health Guideline 50)	2014	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.	72 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. There is no report that the	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	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendati	92 There is some description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendati	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have	93

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			target audience (for example, people affected by domestic violence and abuse and their families and carers, or members of the public) were included in guideline development. The target users of the guideline are clearly defined.	data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.	ons are grouped together in one section. The description of recommendations are summarised as flow charts.	ons can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.	been recorded and addressed explicitly.	
Needle and syringe programmes	2014	100 The overall objective of the	72 The guideline development	96 Systematic methods were used to search for	100 The recommendati	96 There is description of	100 The funding body has been	94

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
(Public Health Guideline 52)		guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. There is no report that the target audience (for example, people affected by domestic violence and abuse and their families and carers, or members of the public) were included in guideline development. The target users of the guideline are	evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, 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	ons are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource	stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			clearly defined.	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.		implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		

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

Formal Consensus

Table 5: AGREE II quality assessment of included guidelines

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

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			were not defined.	methods for formulating recommendations provided. Some health benefits have been considered when making recommendations. No explicit links to recommendations, and no procedure for updating guidelines have been included.				

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument

Table 6: ROBIS quality assessment of included systematic reviews

Domains (Low concern/High concern/Unclear concern)						
Systematic review reference	**Year**	**Study eligibility criteria**	**Identification and selection of studies**	**Data collection and study appraisal**	**Synthesis and findings**	**Overall risk of bias**
Harflett 2015	2015	Unclear concern	Unclear concern	High concern	Unclear concern	Unclear concern
Macadam 2013	2013	Low concern	Low concern	Unclear concern	Unclear concern	Unclear concern
Ridley 2018	2018	High concern	Unclear concern	High concern	Unclear concern	High concern

ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Table 7: CASP quality assessment of included qualitative studies

Screening questions (Yes/No/Can't tell)											
Qualitative study reference	**Year**	**Clear statement of aims of research**	**Appropriate methodology**	**Research design appropriate to address aims**	**Appropriate recruitment strategy**	**Appropriate data collection methods**	**Relationship between researcher and participants adequately considered**	**Ethical issues taken into consideration**	**Data analysis sufficiently rigorous**	**Clear statement of findings**	**How valuable is the research**
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Roberts 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable
SERIO 2021	2021	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Turner 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable

CASP: Critical Appraisal Skills Programme

Appendix D Excluded studies

Excluded studies for scope area: Who else would benefit from advocacy and how do we identify them?

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

Table 8: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Bauer, B., Wistow, G., Dixon, J., Knapp, M. (2013). Investing in Advocacy Interventions for Parents with Learning Disabilities: What is the Economic Argument? Personal Social Services Research Unit. Available at: http://eprints.lse.ac.uk/51114/1/Investing%20in%20advocay.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Chatfield, D., Lee, S., Cowley, J., Kitzinger, C., Kitzinger, J., Menon, D. (2018). Is there a broader role for independent mental capacity advocates in critical care? An exploratory study. Nursing in Critical Care, 23(2), 82-87.	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
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)
Healthwatch (2015). Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. Available at: https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 44(2), 219-230.	Publication is based on case-studies,

Study	Reason for Exclusion
Lawson, J. (2017). Making Safeguarding Personal. What might ‘good’ look like for advocacy? Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf [Accessed 07/04/2021]	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
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 Who else would benefit from advocacy and how do we identify them?
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 Who else would benefit from advocacy and how do we identify them?
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]	Summary of Macadam 2013: No additional information reported
National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister’s Briefing Note. Unpublished.	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished.	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
National Development Team for Inclusion (2016b). Advocacy Outcomes Toolkit: An accompanying guide to the advocacy outcomes framework. Available at: https://www.ndti.org.uk/assets/files/Advocacy_Outcomes_Toolkit.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
National Development Team for Inclusion (2020). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021]	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?

Study	Reason for Exclusion
National Development Team for Inclusion (2020). Valuing voices in Wales: Protecting rights through the pandemic and beyond. Available at: https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report [Accessed 07/04/2021]	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
National Development Team for Inclusion. (2018). The Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). The Easy Read Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/The-Advocacy-Charter-Easy-Read.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). Advocacy QPM: Assessment Workbook. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion, Empowerment Matters (2014). Advocacy QPM: Advocacy Code of Practice, revised edition, 2014. Available at https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf [Accessed 25/11/2021]	Publication has no evidence base
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire.	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Sadd, J., Machin, K., et al. (2015). Independent Mental Health Advocacy – The Right to Be Heard: Context, Values and Good Practice. Jessica Kingsley Publishers: London, UK.	Publication is a book or book chapter.
Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. Health Expectations, 16(1), 80-104.	No key findings or recommendations relevant to Who else would benefit from advocacy and how do we identify them?
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:	Publication is based on case-studies.

Study	Reason for Exclusion
https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services, easy read version. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence and University of Central Lancashire (2015). Flowchart for Open Access IMHA. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving access to Independent Mental Health Advocacy for 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:	Publication is based on case-studies.

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

Excluded economic studies

No economic evidence was considered for this scope area.

Appendix E Research recommendations – full details

Research recommendations for scope area: Who else would benefit from advocacy and how do we identify them?

No research recommendations were made for this scope area.

Appendix F Existing NICE recommendations

Table 9: Existing NICE recommendations for scope area: Who else would benefit from advocacy and how do we identify them?

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
When making decisions about moving children or young people from existing placements: • ensure children and young people are made fully aware of their right to access advocacy services when a review decision is likely to overrule their wishes and feelings.	**Looked after children and young people [PH28] – 1.13.4** Evidence statement E5.9: Seven studies (1 [++] and 6 [+]) provide evidence that preparation and support for leaving care is an important issue for looked-after children and young people. In order to improve the process of leaving care, looked-after children and young people said they needed: • improved and more timely preparation for independent living prior to leaving care to improve this transition • a network of support to provide ongoing practical help and emotional support after leaving care • greater and more appropriate information and advice about entitlements to help to make better use of services available to them on leaving care • a higher level of financial support and more advice for managing finances to prevent serious financial problems for care leavers • access to better quality and more appropriate housing	**Recommendation not used in this guideline** This recommendation was not used in this guideline because children and young people are outside the scope of this guideline (unless they are receiving adult services)	Not applicable
Such a service [effective and responsive leaving-care service] should be readily accessible to the young person and include: • specialist counselling, advocacy, peer mentoring and mental health services to support emotional needs.	**Looked after children and young people [PH28] – 1.47.2** Evidence statement E1.1: There is moderate evidence of mixed quality from 4 retrospective US cohort studies (1 [++], 1 [+], 2 [-]) to suggest that looked-after children and young people who received transition support services (TSSs) were more likely to complete compulsory education with formal qualifications than those who had not received these TSSs; whereas 1 prospective US cohort study (+) reported a non-significant finding in favour of the comparison group. Evidence statement E1.2: There is moderate evidence of a positive effect of TSSs on current employment from 1 prospective (+) and 2 retrospective US cohort studies (1 [+], 1 [-]) although 1 retrospective US cohort study reported no difference between those who had and had not received TSSs on current employment (++).	**Recommendation not used in this guideline** This recommendation was not used in this guideline because children and young people are outside the scope of this guideline (unless they are receiving adult services)	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	Evidence statement E1.3: There is moderate evidence of a mixed effect with regard to the effect of TSSs on employment history. Two retrospective US cohort studies (1 [++],1 [-]) reported that those who had received TSSs were more likely to have a better employment history than those who had not received TSSs, whereas 1 prospective UK cohort study (-) reported that those who had received TSSs were less likely to have taken an employment/academic career path than those who had not. Evidence statement E1.4: There is moderate evidence of a mixed effect with regard to the effect of TSSs on employment at case closing. Two US cohort studies, 1 prospective (+) and one retrospective (-) reported that those who had received TSSs were more likely to be employed at case closing than those who had not received TSSs, whereas 1 retrospective US cohort study (-) reported that those who had received TSSs were less likely to be employed at case closing than those who had not. Evidence statement E1.5: There is moderate evidence of a mixed effect with regard to the effect of TSSs on crime/offending behaviour. One retrospective US cohort study (-) reported that those who had received TSSs were less likely to have a problem with the law and 1 retrospective cohort study (++) reported that those who had received TSSs were more likely to have a problem with the law than those who had not received TSSs. One retrospective US cohort study (+) found no difference between those who had and had not received TSSs on never being arrested. Those who had received TSSs were less likely to have been arrested for serious crimes but more likely to be arrested for moderate crimes than those who had not received TSSs. However those who had received TSSs were less likely to receive short jail sentences and more likely to receive long jail sentences than those who had not received TSSs. Evidence statement E1.6: There is moderate evidence for a positive effect of TSSs on parenthood from 1 prospective (+) and 2 retrospective US cohort studies (1 [++] and 1 [+]), in that those who had received TSSs were less likely to be parents than those who had not.		

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	Evidence statement E1.7: There is moderate evidence for a positive effect of TSSs on housing and independent living from 6studies: 1 prospective UK cohort study and 5 retrospective US cohort studies. Those who had received TSSs were more likely to have a place to live (1 [-] and 1 [++]) and were more likely to be living independently (2 [+] and 2[-]) than those who had not received TSSs. Evidence statement E1.8: There is moderate evidence of a mixed effect with regard to the effect of TSSs on homelessness. Two retrospective US cohort studies reported that those who had received TSSs were less likely to have had a homeless episode at discharge (1 [++]) or to have ever been without a place to sleep (1 [-]) than those who had not received TSSs. However 2 retrospective US cohort studies (1 [+] and 1 [-]) reported no difference between those who had and had not received TSSs on homelessness. Evidence statement E1.9: There is evidence of mixed quality to suggest no evidence of effect of TSSs on mental health outcomes. Three retrospective US cohort studies (1 [++], 1 [-] and 1 [+]) reported no difference on general satisfaction, life satisfaction and depression. However 1 retrospective US cohort study (-) reported that those who had received TSSs were more likely to be hopeful about the future than those who had not. Evidence statement E5.9: Seven studies (1 [++] and 6 [+]) provide evidence that preparation and support for leaving care is an important issue for looked-after children and young people. In order to improve the process of leaving care, looked-after children and young people said they needed: • improved and more timely preparation for independent living prior to leaving care to improve this transition • a network of support to provide ongoing practical help and emotional support after leaving care • greater and more appropriate information and advice about entitlements to help to make better use of services available to them on leaving care • a higher level of financial support and more advice for managing finances to prevent serious financial problems for care leavers • access to better quality and more appropriate housing.		

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Health and social care commissioners, health and wellbeing boards and practitioners in specialist domestic and sexual violence services (see Who should take action?) should: • provide all those currently (or recently) affected by domestic violence and abuse with advocacy and advice services tailored to their level of risk and specific needs. This includes providing support in different languages, as necessary.	**Domestic violence and abuse: multi-agency working [PH50] – 1.12.4** Evidence Statement 11 – Advocacy interventions for victims: There is moderate evidence from ten studies that advocacy services may improve women's access to community resources, reduce rates of IPV, improve safety, decrease depression, reduce various stressors, and improve parenting stress and children's well-being. A cluster-RCT (Taft et al., 2011 [++]) revealed a significant decrease in IPV before adjustment for propensity score for pregnant and postpartum women involved in a community-based mentorship programme. A RCT (Sullivan et al., 2002 [++]) reported improvements in mother's depression and self-esteem and children's well-being following participation in home visitation advocacy services. A before and after study (Howarth et al., 2009 [+]) evaluated the effect of Independent DV advisor services (IDVA), demonstrating improvements in women's safety and a decrease in abuse. A RCT (Bair-Merritt et al., 2010 [+]) found a decrease in IPV rates for mothers involved in a home visitation programme. A cluster RCT (Coker et al., 2012 [+]) observed a decrease in depressive symptoms and suicidal thoughts for rural women receiving advocate services, but found no difference in self-perceived mental health or accessing of hot-line services. A cross-sectional study (Kendall et al., 2009 [+]) reported improvements in: perceived safety and safety planning for participants provided with emergency department advocacy counselling services. A RCT (Allen et al., 2004 [+]) revealed improvements in women's access to community resources regardless of presenting need, following post-shelter advocacy services. A before and after study (Poole et al., 2008 [+]) found a decrease in various stressors (partner, housing, mental health, legal and physical health) for women using substances who were accessing shelter services. A before and after study (Price et al., 2008 [+]) found that women receiving support services reported improvements in their safety and quality of life and their children's safety, and caseworkers also reported improvements in women and children's safety. Finally, a qualitative study (Cath Gregory Consulting, 2008 [+]) revealed that a 24 hour helpline service facilitated abused women in understanding abuse and making changes to their lives, and provided links to available supports and services.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	Evidence Statement 27- Multi-component advocacy interventions: Four studies reviewed by Rizo et al. (2011) [+] evaluated multi-component interventions with advocacy as a primary intervention focus (Blodgett, et al., 2008; Crusto, et al., 2008; McFarlane, et al., 2005a, 2005b). One individually assessed study also evaluated a multi-component advocacy-based intervention (WhitesideMansell et al., 2009, RCT, [+]).There is moderate evidence that multi component interventions with a focus on advocacy are effective in reducing the trauma symptoms and stress in both children and families, and in improving child behaviours such as aggression. Evidence Statement 28- Multi-component therapy and advocacy interventions: Two studies reviewed by Rizo et al. (2011) [+] evaluated multi-component interventions including therapy and advocacy components (Ernst, et al., 2008; C. M. Sullivan, et al., 2002), in addition to two individually assessed studies (Finkelstein et al., 2005, before and after [+]; Noether et al., 2007, non-RCT [+]). There is moderate evidence of effectiveness of multi component interventions including both therapy and advocacy among diverse populations of women and children, some with co occurring issues of substance use and mental health issues. These interventions increased knowledge and awareness about violence and safety planning, improved self-esteem and self competence and improved interpersonal relationships.		
Consider the need for independent advocacy if a person lives alone, has difficulty expressing their views and aspirations or lacks capacity.	**Home care: delivering personal care and practical support to older people living in their own homes [NG21] – 1.4.9** Evidence statement 2.10 – Time to care: continuity of care: There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that managers recognised the importance of continuity of care and made attempts to create teams of workers who worked regularly with individual service users, arranged introductory visits to enable service users to meet their new home care worker in advance. Inadequate sick leave procedures and high staff turnover are concerns which could negatively impact on continuity of care. There is moderate evidence from one UK qualitative study (Devlin and McIlfatrick, 2010, +) that community nurses perceived continuity of home care staff as an integral feature of high quality palliative care.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a specified population may be too prescriptive and risk excluding some populations or	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
		circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	
Consider making independent advocacy available to support young people after they transfer to adults' services.	**Transition from children's to adults' services for young people using health or social care services [NG43] – 1.5.4** Evidence statement 9: Factors that prevent the implementation of effective transition strategies and practice in children's and adults' services. There is evidence from 1 moderate quality study (Sloper et al. 2011 +/++) that the lack of joint funding streams and lack of services can hinder successful implementation of transition strategies. There is evidence from 1 good quality qualitative study (Kingsnorth et al. 2010 ++) that barriers to implementation are different information-sharing protocols across different agencies and sectors, lack of staff expertise in how to support transitions, high staff turnover and difficulties in establishing new roles when there is no previous experience. There is evidence from 1 moderate quality systematic review (Kime et al. 2013 +/++) that professionals in children's services may hinder young people's transition into adults' services because they are concerned about the different culture and provision there. Evidence statement 25: Poor inter- and intra-agency communication and coordination. Poor inter- and intra-agency coordination, gaps in levels of integration between sectors, lack of communication between paediatric and adult physicians and other adult care services in the community can hinder transitions, according to moderate quality evidence from 3 systematic reviews (Binks et al. 2007 +/+; Jordan et al. 2013 +/+; Kime et al. 2013 +/++), and 4 individual studies (Allen et al. 2012 +/++; Care Quality Commission 2014 overall assessment ++; Por et al. 2004 +/++; Shaw et al. 2004 +/++).	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
		this review for more information.	
At admission, offer all people access to advocacy services that take into account their: • language and communication needs • cultural and social needs • protected characteristics (see the GOV.UK page about discrimination).	**Transition between inpatient mental health settings and community or care home settings [NG53] – 1.3.4** Evidence statement HA13**:** There is moderate quality evidence from a small cross-sectional study in Birmingham (Commander et al. 1999 +/-) that Transition between inpatient mental health settings and community or care home settings: NICE guideline full version (August 2016) 275 of 345 black and Asian patients are more likely than white counterparts to be compulsorily admitted, are viewed by service providers as more likely to display negative behaviour such as hostility, are more likely to be admitted with police involvement, and are less satisfied with the admission process (recs 1.3.4, 1.3.6). Other considerations: Advocacy services must be provided under the Care Act 2014 section 67 of part 1, BUT it only has to be done if the authority judges that the person is unlikely to be able to understand, retain, weigh up information or communicate their wishes. The GC wished to extend this offer to the whole population, and stressed the need for independence in advocacy services (rec 1.3.4).	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a specific population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Organisations or individuals conducting research or seeking feedback from people who use services should ensure that independent advocacy is available and offered when:	**People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86] – 1.6.8** Evidence statement RQ4.6 – supporting decision making for people who lack capacity: This evidence statement is based on a small amount of evidence from one mixed-methods study of medium level quality that people who lack capacity can be supported in participating in decisions. Redley et al. (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that, whilst advocacy support for people	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
- this would help someone to take part or - the person expresses a preference to use advocacy.	found that, in over half of their cases, people who lacked capacity were supported in participating in decisions made on their behalf. The study found that people who lack capacity can be supported in participating in decisions.. Other considerations: The Guideline Committee considered some of the difficulties in gaining someone's informed consent to take part in surveys, but the Guideline Committee noted that if people can be supported to make their own decisions around their healthcare, an advocate may be able to support a person in expressing their views and experiences. The Committee considered the resource implications of offering advocacy, and acknowledged that this would be likely to represent an additional resource. However, this was balanced against the potential for particular groups, particular people with learning disabilities or who may lack capacity, to be excluded from giving their views and experiences in the absence of support.	participating in research is important, this recommendation was better placed in the context of the original guidance and may detract from the core issue covered in recommendation 1.2.1.	
When working with children and young people with psychosis or schizophrenia: - offer access to a trained advocate.	**Psychosis and schizophrenia in children and young people [CG155] – 1.1.7** Adapted from the NICE guideline on Service User Experience in Adult Mental Health: improving the experience of care for people using adult NHS mental health services [CG136] – see below for underpinning evidence (CG136; 1.1.2). The GDG considered this recommendation to be relevant to the care of children and young people with psychosis or schizophrenia because it pertained to the key issue of communication (in terms of it being the bedrock of a good relationship). This recommendation was adapted because the GDG wished to stress that healthcare professionals need to take account of the child or young person's developmental level, emotional maturity and cognitive capacity, particularly when considering their autonomy and ability to make decisions about their treatment. In their expert opinion the GDG judged that children and young people would benefit from access to peer support.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference**	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
		source not found. in this review for more information.	
When working with people using mental health services: • offer access to a trained advocate.	**Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services [CG136] – 1.1.2** Evidence to recommendations: The recommendations for these aspects of the experience of care included the need for health and social care professionals to engage service users and carers in an atmosphere of optimism and hope, with empathy and without judgement; to foster autonomy in the service user; to offer an advocate to support the service user, especially at times of difficulty; to ensure continuity of care; and to provide information about treatments, services, side effects, national and local resources, including websites that may be helpful. Involving families was also a key issue to 'get right': the guidance group wanted one approach for service users who wanted the family involved and another for when they did not, a clear difference is in tactfully negotiating and balancing confidentiality and information sharing differently in each situation. All these issues were placed in care across all points on the care pathway in the NICE guidance.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a specified population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Ensure that all service users in hospital have access to advocates who can regularly feedback to ward professionals any problems experienced by current service users on that ward.	**Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services [CG136] – 1.6.13** Evidence to recommendations: The problems identified by the qualitative reviews and analyses and the surveys revealed a broad range of problems which resonated with the experience of the guidance group. For example, poor involvement in decision making, lack of time given to discuss treatment,	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Advocates may be formal Independent Mental Health Advocate (IMHAs), or former inpatients who have been trained to be advocates for other service users not detained under the Mental Health Act (1983; amended 1995 and 2007).	lack of support to keep in touch with family, not being listened to and lack of information about conditions, treatments, side-effects, ward operations and complaints procedures. Service users found it difficult to build a therapeutic relationship with some professionals and felt that they were not always given emotional support, empathy, respect and privacy. Access to mental health professionals and interaction with others was thought to be limited and insufficient activities were provided. Some service users felt they had no confidence and trust in psychiatrists and nurses. Service users often felt that staff on the ward did not know who they were or about any previous care they had received. Finally, there were problems reported of service users being placed on mixed wards and adolescents placed on adult wards. The GDG expressed a wide range of service user requirements, such as service users being involved in decisions relating to their care and treatment, including admission into a hospital ward of their choice; having copies of their assessment, treatment and discharge plans; having an effective and positive risk assessment management plan, having facilities and support for family or carer visits; having complaints handled efficiently; procedures explained clearly and an effort to have service users orientated to the hospital ward environment. The GDG felt strongly that service users who are parents with caring responsibilities should receive support to access the full range of mental health and social care services. This support should include information about childcare to enable them to attend appointments, as well as groups and therapy sessions, hospital care in local mother and baby units for women in the late stages of pregnancy and within a year of childbirth, and finally a family room or space in inpatient units where their children can visit them. The GDG discussed the following issues that apply across all points on the care pathway, but were of particular importance to hospital care. The recommendations for these aspects of the experience of care included the need for health and social care professionals to engage service users and carers in an atmosphere of optimism and hope, with empathy and without judgement; to have discussions in a confidential environment where privacy and dignity are respected; to foster autonomy in the service user and to provide information about treatments, services, side effects. Health and social care professionals should discuss if and how the service user would like to have the support and involvement of their family or carer. When working with people using mental health services and their family and carers ensure that	existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	health care professionals are easily identifiable and approachable and that they refer to service users using their preferred name and title. Also health care professionals should use clear and comprehendible language that service users can understand. Ensure that service users who are parents are provided with support to access the full range of mental health and social care services. Areas specifically of importance to improve the experience of hospital care included providing an atmosphere of hope and optimism; focusing on the emotional and psychological needs of service users; providing information to service users and their family or carers about treatment plans, activities and services available; an orientation of the hospital ward and procedures should be offered and more activities at evenings and weekends should be made available. Service users should be involved in decisions for their care and a formal assessment should occur within two hours of admission, followed by daily sessions with a healthcare professional and an option of weekly sessions with a consultant. Regular multidisciplinary meetings to discuss the management of care should take place and the trust should ensure that inpatient care includes access to all treatments recommended in NICE guidance.		
Healthcare professionals should have access to trained interpreters for women who are not English speaking, and to advocates for women with sensory impairments or learning disabilities.	**Long-acting reversible contraception [CG30] – 1.1.2.3** Good practice point (recommendation for best practice based on the experience of the Guideline Development Group): Accurate, up-to date information is essential to enable users to make an informed and voluntary choice of a contraceptive method. User satisfaction and successful use of contraception depend on adequate knowledge and accurate perceptions of the method. Counselling is a face-to-face communication in which one person helps another make decisions and act on them. The ultimate goal of contraceptive counselling is to allow women to choose a method they feel most comfortable with and will continue using, taking into account their lifestyle preferences and concerns. Contraceptive counselling helps women to learn more about contraception and combats misinformation about contraceptive methods. In addition, counselling can provide the basis for informed consent and set the stage for increased user satisfaction with the method chosen. Informed choice is facilitated by promoting understanding of the relative effectiveness of the method, how it works, insertion and removal procedures, correct use, common side effects, health risks and benefits,	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	when to seek medical advice, information on return to fertility after discontinuation, and advice on STI protection and sexual health.	See the **Error! Reference source not found.** section of **Error! Reference source not found.** for more information.	
Managers and staff working in domestic violence and abuse services and staff in all health and social care settings (see Who should take action?) should: • Think about referring someone to specialist domestic violence and abuse services if they need immediate support. This includes advocacy, floating support and outreach support and refuges. It also includes housing workers, independent domestic violence advisers or a multi-agency risk assessment conference for high-risk clients. • Think about referring someone to floating or outreach advocacy support or to a skill-building programme if they need longer-term support. Also explore whether they would like to be referred to a local support group.	**Domestic violence and abuse: multi-agency working [PH50] – 1.8.4 & 1.8.5** Evidence Statement 8 – Provider education: There is inconsistent evidence from four studies that provider education interventions are effective in improving screening practices or clinical enquiry. The strongest evidence comes from an RCT (Lo Fo Wong et al., 2006 [++]) which compared focus group with full training interventions, and found modest improvements in awareness of and identification of DV for both conditions, but were greater in the full training condition, and another RCT (Feder et al., 2011 [++]) which found improvements in referrals, and an increase in disclosures of DV following an education and advocacy intervention. One before and after study (Bonds et al. 2006 [+]) found a modest increase in women's self-reports of screening following a multimodal education programme for health care providers. One RCT (Coonrod et al., 2000 [+]) found that a training programme for medical residents increased knowledge about DV but did not significantly increase rates of diagnosis of DV. Evidence Statement 31 – Effectiveness of partnerships for increasing interagency information sharing and policy development: There is moderate evidence from nine studies that partnership approaches have been effective in improving relationships, practices and policies of partner agencies to address DV. Five quantitative and mixed methods studies provide evidence on the effectiveness of partnerships for improving relationships, policies and practices to address DV. A before and after study (Banks et al., 2008a [+]) examining collaboration between child welfare and DV agencies found that stakeholders reported: improved collaboration, staff training, introduction of written guidelines, and sharing of agency resources. A cross-sectional study and qualitative evaluation (Penhale et al., 2007) of a multi-agency approach to protect vulnerable adults from abuse based on 'No Secrets'/ 'In Safe Hands' found that stakeholders perceived partnership working as effective in	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	developing new ideas and improving policy making and implementation; yet disagreed on the effect of partnerships on: creating unrealistic expectations among partners, benefiting providers over consumers of services, and the status of partner agencies. A cross-sectional study (Robinson, 2003 [+]) evaluating the Women's Safety Unit (WSU) which offers a central point for a range of support services for DV victims and their children, reported the following successes: the development of protocols with the police and Crown Prosecution Service, the improvement of court procedures for DV, the provision of DV training, the development of relationships and provision of support to prosecutors on DV cases, and collaboration with the Police and other agencies in receiving and providing referrals. A cross-sectional and qualitative study (Robinson, 2006a [+]) evaluating a sample of MARAC case outputs found that key informants viewed the main outputs to be information sharing and the identification of key agency contacts. A cross-sectional and qualitative study (Steel et al., 2011 [+]) examining the experiences of a national sample of MARAC members reported that their MARAC was effective, particularly in improving: information sharing, agency representation; and the involvement of the IDVA in representing the victim; and the majority of survey respondents reported that their MARAC was familiar with and followed the CAADA principles for effective MARAC, while quality assurance data revealed that some principles (information sharing and administration) were more consistently followed than others (action planning). In addition, there is evidence from four qualitative studies. One qualitative study (Allen et al., 2008 [+]) found that coordinating councils were effective at improving knowledge of other partner members and relationships and facilitating institutional change (including the creating of new procedures, protocols and policies). An evaluation of a partnership between voluntary and criminal service sectors to offer support services to victims with a partner attending a domestic abuse court revealed that the partnership was regarded as having strong relationships, partner commitment, and effective advocacy for victims and the court. A study (Robinson & Rowlands, 2006 [+]) evaluating the Dyn project, an advocacy service for gay, bisexual, transgender and heterosexual men who have experienced DV reported improvements in: information-sharing, knowledge of the needs and availability of services for male victims. Finally, one study (Sharp & Jones, 2011 [+]) found that a multi-agency model of service delivery for children/ young people and mothers who		

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	experience violence, was beneficial in improving knowledge, awareness, and communication of staff and partner agencies.		
All health and social care professionals providing care and support for adults with autism should: • consider whether the person may benefit from access to a trained advocate.	**Autism spectrum disorder in adults: diagnosis and management [CG142] – 1.1.4** Summary – experience of families, partners and carers of adults with autism**:** A number of themes emerged from the literature that captured the experience of families, partners and carers of adults with autism. Although living with a person with autism could be challenging and could lead to reduced work, accommodation and leisure opportunities, and to financial strain, there was a recognition and sense of pride in their caregiving achievements. Psychological distress was common and often linked to coming to terms with the lifelong impact of autism on their son or daughter as well as their own increasing stress and anxiety. The impact of autism was keenly felt on relationships within the family including the parental relationship, other siblings and spousal relationships. Advice and help from services and from other families, partners and carers of adults with autism was valued highly. Parents also struggled to come to terms with a new identity as a carer and the sense of isolation or ostracism that this could entail. There was relatively little qualitative evidence of families, partners and carers' experience of services either for themselves or for their son or daughter. No doubt this reflected the limited availability of services for adults. There was considerable concern about the availability of day, residential, employment and support services and the need for support from specialists to access these services. There was little comment on services accessed by families and carers themselves, but there was recognition of the need for increased information about autism (coupled with better trained and informed staff). Some families, partners and carers reported gaining real benefit from involvement in advocating for services for their children and others with autism. Evidence to recommendations: The summary above identified serious limitations in the services available for families, partners and carers to facilitate and support their active involvement in the care of their child with autism. The GDG considered this, along with the evidence base for the Service User Experience in Adult Mental Health NICE guidance, and their knowledge of, and expertise about, services for families, partners and carers. This led the GDG to identify a number of issues, which in combination with	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

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	the themes identified above, suggested some key areas for the development of recommendations. These included: the involvement of families, partners and carers in the care of their family member or friend (and how this can be approached if the person with autism does not wish for them to be involved); the assessment of the needs of families, partners and carers; information about and help in accessing care and support for their family member; and a range of family and carer support groups. The GDG carefully considered these issues and the implications of the themes identified in Section 4.3.8 in the drafting of recommendations in the following areas: a) The involvement of families, partners and carers in the care and treatment of their family member or friend and the information, assessment, care and interventions that families, partners and carers might themselves need: the aim was to ensure that all recommendations in these areas (concerned with the families, partners and carers directly or the care of their family member or friend) were drafted in such a way as to reflect the issues and concerns that emerged from the thematic analysis and the GDG's knowledge and expertise. b) Principles of care: the GDG's decision was informed by Section 4.3.9 and the evidence base from the Service User Experience in Adult Mental Health NICE guidance (NCCMH, 2012) to identify important areas where a new recommendation needed to be developed for this guideline.		
Offer (or help people to access): • welfare and advocacy services (for example, advice on housing and legal issues).	**Needle and syringe programmes [PH52] – 1.9.7** Evidence statement Q3.4b: There is evidence from 3 good quality (++)[1–3] and 1 moderate quality (+) study[4] to suggest that a range of harm reduction interventions (referrals to drug treatment and other services, HIV testing, medical care) in addition to needle and syringe programmes were accessed and valued by people who inject drugs. [1] Long 2004, [2] Power 1996, [3] Porter 2002, [4] Phillips 2007 Evidence statement U7 – Additional harm reduction services: Five studies[1–5] (all [+]) reported views and perspectives on, and experiences of, additional harm reduction services offered by specialist needle and syringe programmes and pharmacies. Two studies[1,2] identified that trusting relationships between people who inject drugs and needle and syringe programme staff were felt to be key to facilitating engagement in additional harm reduction services in specialist needle and syringe programme settings. Two studies[3,4] explored the potential for additional harm reduction services to be delivered by	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that	Not applicable

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	pharmacies. Expansion of services was desired by both people who inject drugs and pharmacy staff. However, barriers to expansion were identified including the need to tackle negative attitudes towards people who inject drugs by some pharmacy staff, and the need to identify private spaces for the delivery of such services. One study[5] acknowledged that opportunities for disseminating information to users of NSVMs were limited but participants in this study did not feel that this was a major concern. This evidence is directly applicable to the UK. [1] Parker et al. 2012, [2] MacNeil and Pauly 2011, [3] Mackridge at al. 2010, [4] Lutnick et al. 2012, [5] Dodding and Gaughwin 1995	would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	
When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members or carers: • offer independent advocacy to the person and to their family members or carers.	**Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11] – 1.1.2** Trade-off between clinical benefits and harms: The GDG agreed that lack of involvement in care planning and inadequate information were a serious impediment to the provision of effective care. Harms were likely very limited but attention should be paid to the right to confidentiality of both service users and carers. Trade-off between net health benefits and resource use: The GDG took into account that providing information and support to service users and carers, as well as promoting their involvement in care planning, might entail modest resource implications, which would, however, be offset by provision of more effective care and of improved outcomes resulting from service users' and carers' involvement in decision making. Improved outcomes for people with a learning disability and behaviour that challenges are also expected to lead to a reduction in costs associated with behaviour that challenges, which can be substantial (for example, costs incurred by inpatient placements). Other considerations: The experience of care for service users, families and carers demonstrated that are significant shortfalls in access to services and the quality of care provided. It was striking that many service users, families and carers had clear views about what might help them, but felt that often their voices were not heard. Families felt that the support that they provided was not recognised and lack of support from services often undermined them in their attempts to care for their relative. A number of specific concerns were also identified including the overuse of medication, limited access to psychological interventions, avoidable and costly out-of-home placements	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	and assessments often not being followed through. Considering all this information, the GDG judged that it was important to set out some general principles underpinning good care. These focused on the proactive involvement of service users, families and carers in the planning and delivery of their care and the setting in which it is delivered.		
Identify and support people at risk of less favourable treatment or with less access to services for example, people with communication difficulties or who misuse drugs or alcohol. Support may include help to access advocacy.	**Transition between inpatient hospital settings and community or care home settings for adults with social care needs [NG27] – 1.1.2** Evidence statement HD6: There is a good amount of mixed quality evidence that including people and families in decision-making and preparation for discharge affects the quality of transitions from hospital. A study (Benton 2008 +) of patients' experiences of intermediate care found they lacked understanding about the purpose of the unit and their potential for rehabilitation. Two studies Pethybridge (2004 -) and Huby et al (2004 and 2007 ++) found that individual needs are ignored and patients are excluded from decision making about treatment and discharge. A systematic review (Laugaland et al 2012 +) showed that successful interventions involved caregivers and included patient participation and/or education. Similarly, another systematic review (Preyde 2011 +) found that a lack of family or patient education during discharge was significantly related to readmission. Finally, 1 RCT (Li Hong et al 2012 ++) reported mixed results. When patient-carer dyads received empowerment educational sessions on admission and discharge there was no significant difference in caregivers' emotional coping for depression, anxiety and worry and no reduction in the amount of caregiving; the only differences were less role strain and caregiver preparedness to participate in post-hospital care. Evidence statement HD7: There is a small amount of moderate quality evidence that certain groups of stroke patients are excluded from specialist care and support, including hospital discharge services. A qualitative study from the UK (Mold et al 2006) found that hospital- and community-based professionals ration stroke services in a way that excludes younger stroke patients, people with communication difficulties and people with addictions.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
For disabled young people in education, the named worker	**Transition from children's to adults' services for young people using health or social care services [NG43] – 1.2.10**	**Recommendation not used in this guideline**	Not applicable

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should liaise with education practitioners to ensure comprehensive student-focused transition planning is provided. This should involve peer advocacy, and friends and mentors as active participants.	Other considerations: Expert witness Peter Winocour stated that a fully resourced multidisciplinary team appears critical to implementation, including a named worker to support transition care and the actual transfer of care. Expert witness Robert Carr explained how their service users are often uncertain of who to contact in services. They have found it effective to have a named worker (lead nurse) who is accessible via text and who provides information and advice. Expert witness Janet McDonagh stated that: 'The potential of a transitional care coordinator is obvious from the complex nature of health transition ... However it continues to be underrecognised in many who already undertake this role [Shaw 2014]. It is important to state that this does not necessarily have to be a nurse or other health professional and may be a youth worker or indeed a more basic health navigator role [van Walleghem 2008]."	This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	
Consider providing access to independent advocacy whenever it is wanted or needed by a person with a learning disability and behaviour that challenges. As a minimum, it must be offered by local authorities as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.	**Learning disabilities and behaviour that challenges: service design and delivery [NG93] – 1.2.8** Other considerations: Recommendations 1.2.8 and 1.2.9 were consensus recommendations following on from discussions about the importance of the availability of advocacy to enable involvement in one's own care and decision-making, but also that to be effective, advocates had to have specialist knowledge of navigating services for learning disabilities and behaviour that challenges. The view of the committee was that this could only happen if the commissioner made sure that independent advocates could demonstrate they had this specialist knowledge and skills in this area.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too	Not applicable

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		prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	
When there is a possibility that someone will be admitted to hospital, including as an informal admission, local authorities and clinical commissioning groups should give them and their family and carers accessible, independent information and advice about their rights, access to independent advocacy and other possible options for treatment, and care and support.	**Learning disabilities and behaviour that challenges: service design and delivery [NG93] – 1.8.3** Evidence statement DS08 – Making the right use of inpatient services: This evidence statement is based on expert witness testimony from a case study of services in Devon (comprising testimony from a commissioner, a provider from a charity that supports people with learning disabilities, and the mother of a young women with learning disabilities who had previously displayed behaviour that challenged services). The expert witnesses stated that in their experience it is difficult for inpatient services to be effective unless they are provided for a short period of time and are treatment focused. Treatment would include medication and also therapeutic activities based on real skills learning and good social and leisure activities. The expert witnesses thought that inpatient services were usually more effective when they focused rehabilitation and were very clear about the route to discharge, and when they work in partnership with the person and their family and any community supports that person may have.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
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Offer independent advocacy whenever it is wanted or needed by a person with a learning disability. As a minimum, it must be offered as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007.	**Care and support of people growing older with learning disabilities [NG96] – 1.1.11** Adapted from the NICE guideline on Learning disabilities and behaviour that challenges: service design and delivery [NG93] – see above for underpinning evidence (NG93; 1.2.8).This was agreed by the committee as a means of emphasising the important role of advocacy in supporting the guideline population, especially given that some people will not have friends and family available for the planning and provision of support. By the same token, even people with families should have access to advocacy as a means to mediate differences in opinion or simply because the person does not wish to involve family members in certain discussions of decisions.	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	Not applicable
Care home providers should ensure that all residents can use advocacy and independent complaints services when they have concerns about medicines.	**Managing medicines in care homes [SC1] – 1.6.11** Assessing and improving resident participation in safeguarding: The UK government policy a Statement of government policy on adult safeguarding recommends 6 principles to use 'to measure existing adult safeguarding arrangements and to measure future improvement'. The 6 principles are empowerment, prevention, proportionality, protections, partnership and	**Recommendation not used in this guideline** This recommendation was not used in this guideline because the committee agreed that	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	accountability. These principles can be translated into outcomes in relation to resident's medicines, such as 'I had the information I needed [and] in the way that I needed it' and 'the people I wanted were involved'. The GDG discussed the principles and agreed that one of the key interventions that could help ensure that the principles are achieved is advocacy. Advocacy has been defined in A Scoping Study of Advocacy with Older People in Wales (2010) for the Older Peoples Commissioner for Wales as a principled activity encompassing 3 broad principles of independence, empowerment and inclusion. The CQC's Essential standards of quality and safety (outcome 1A) states that care home providers should ensure the 'people who use services are involved in and receive care, treatment and support that respects their right to make or influence decisions' and that the service should make 'people who use services aware of independent advocacy services wherever they are available'. Advocacy and support systems in the Children's Homes: National Minimum Standards (standard 1[1.5]) require that 'Children have access to independent advice and support from adults who they can contact directly and in private about problems or concerns, which is appropriate to their age and understanding.' Advocacy has been found to be effective with diverse populations of older people in a range of settings. The Health Foundation and the SCIE have stated that all care home residents should have access to an independent advocate. The GDG found evidence of a range of proposed models of advocacy, ranging from independent advocates for each care home provider, including local or national schemes, through to professional standards for advocacy (such as the NMC). The GDG was aware however, that not all local advocacy schemes are available in all areas. Additional evidence suggests that advocates should be trained to recognise abuse and, in the context of inappropriate prescribing of medicines, should act as an advocate for the resident during medication review (see section 3.8). The GDG concluded that all residents living in care homes should have access to advocacy and independent complaints services to address concerns relating to medicines.	adopting or adapting existing recommendations from NICE guidelines that had a much narrower population may be too prescriptive and risk excluding some populations or circumstances that would benefit from advocacy. See the **Error! Reference source not found.** section of **Error! Reference source not found.** in this review for more information.	

CB: cognitive behavioural; CBT: cognitive behavioural therapy; CQC: Clinical Commissioning Group; DV: domestic violence; DMPA: depot-medroxyprogesterone acetate; GC: guideline committee; GDG: guideline development group; GP: General Practitioner; HMSO: Her Majesty's Stationery Office; IDVA: independent domestic violence advisor; HIV: human immunodeficiency virus; IMCA: Independent Mental Capacity Advocate; IPV: intimate partner violence; LNG-IUS: levonorgestrel-releasing intrauterine system; MARAC: Multi-Agency Risk Assessment Conferences; NCCMH: National Collaborating Centre for Mental Health; NICE: National Institute for Health and Care Excellence; NMC: Nursing *and Midwifery Council; NSVM: needle and syringe vending machines; OB:GYN: obstetrician-gynaecologist; OR: odds ratio; PID: pelvic inflammatory disease; RCT: randomised controlled trial; STI: sexually transmitted infection; TSS: transition support services; WSU: Women's Safety Unit*

Appendix G Formal consensus

Additional information related to scope area: Who else would benefit from advocacy and how do we identify them?

Table 10: Formal consensus round 1 statements and results for scope area: Who else would benefit from advocacy and how do we identify them?

Statement no.	Statement	References	Percentage agreement	Action taken
1	Advocacy services should ensure that gaps in advocacy provision are covered for parents with learning disabilities.	Roberts 2012, Turner 2012	100.00%	Carried forward to committee discussion
2	Young people in transition can struggle to access advocacy.	Turner 2012	70.00%	Redrafted for round 2
3	Advocacy services should ensure that advocacy services are provided to everyone who needs it (including people of all backgrounds).	Roberts 2012, NDTi 2012	83.33%	Carried forward to committee discussion
4	Advocacy services should ensure that gaps in advocacy provision are covered for people with caring responsibilities.	Roberts 2012	91.67%	Carried forward to committee discussion
5	Further research on family advocacy is needed (including the role of agencies in advocating for families).	Roberts 2012	60.00%	Redrafted for round 2
6	Further research on family advocacy is needed (including links statutory advocacy).	Roberts 2012	77.78%	Redrafted for round 2
7	Advocates should involve family carers in the provision of advocacy.	Roberts 2012	66.67%	Redrafted for round 2
8	Advocacy services should be available especially for people who are in residential settings.	NDTi 2012	91.67%	Carried forward to committee discussion
9	Advocacy services should be available especially for those who have few choices.	NDTi 2012	75.00%	Redrafted for round 2
10	Advocacy services should be available especially for those subject to legal restrictions.	NDTi 2012	83.33%	Carried forward to committee discussion
11	Access to advocacy is recommended for adults with profound and multiple learning disabilities.	Harflett 2015	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
12	People who don't have family need access to advocacy so they can benefit from self-directed support.	Harflett 2015	90.91%	Carried forward to committee discussion
13	Veterans may benefit from advocacy.	SERIO 2021	80.00%	Carried forward to committee discussion
14	Advocacy can be provided to those who are unable to personally instruct their advocate.	NDTi2014a	91.67%	Carried forward to committee discussion

Table 11: Formal consensus round 2 statements and results for scope area: Who else would benefit from advocacy and how do we identify them?

Statement no.	Statement	References	Percentage agreement	Action taken
2	Young people in transition can struggle to access advocacy due to age-based differences in legislation and a shortage of advocates leading to long waiting times.	Turner 2012	66.67%	Discarded
5 & 6	Further research on advocacy is needed, including, for example, research on family advocacy and advocacy undertaken by agencies.	Roberts 2012	70.00%	Discarded
7a	Where appropriate and where the person involved has capacity and provides consent, advocates should engage with family carers in the provision of advocacy.	Roberts 2012	72.73%	Discarded
7b	Where the person involved does not have capacity, advocates should engage with family carers on the provision of advocacy only if it is deemed by the advocate to be in the person’s best interest.	Roberts 2012	63.64%	Discarded
9	Advocacy services should be available to everyone who needs it, including those who have few choices because of their complex needs, to ensure that they are adequately represented.	NDTi 2012	80.00%	Carried forward to committee discussion