

Consultation on draft guideline - Stakeholder comments table
07/06/2022 – 19/07/2022

Stakeholder	Document	Page No	Line No	Comments	Developer's response
British Association of Social Workers	Guideline	011	004	1.4.1- This needs to be broadened out to ensure that it is made clear that the Advocate can meet in person, thinking about choice, whether the person would want someone else there with them for the initial visit. Thinking about compatibility. The person to be offered the type of contact that is convenient for them. All of protocols for meeting people are featured in the NICE guideline – Social Work with adults with complex needs and these protocols previously identified are easily transferable. It needs to be recognised that the person needs to be supported to make their own decision. Looking at communication holistically, accessible, person-centred approach.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation. The committee felt that adding in details about choice into this particular recommendation would alter the focus of the recommendation, which the committee wanted to be about advocates meeting people in person to support them to make initial contact with advocacy services, as people may be missing out on the opportunity to use advocacy services. The committee felt that decision making and choice had been highlighted in various recommendations in the guideline, especially the first two recommendations in the Effective advocacy section on making services accessible and person centred.
British Association of Social Workers	Guideline	011	007	1.4.2- Care Act requirement- a policy can't over-ride someone's right as this enshrined in law. Revision of policy makes reference to statutory guidance. Replace the word "should" with "must" or "are required to"	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it covered a wider group of people than just those who met the criteria of the Care Act. As the wider group involved non-statutory advocacy the strength of the recommendation did not need to change.



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British Association of Social Workers	Guideline	011	021	1.4.5- circumstances may not always be appropriate to have the same person acting – needs to be a choice for the person, improving self-determination.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as the wording 'aiming to support continuity by offering people the same advocate for different types of advocacy' indicates the person has a choice and is free to decline.
British Association of Social Workers	Guideline	012	001	1.4.7- some people detained impacted by mental health- times unable to make informed decision. Ensuring rights are upheld re representation- opt in/opt out. On reflection group agreed- 1.4.7 to be replaced by 1.4.8- Statutory right to advocacy – ongoing monitoring and review rather than withdrawal. MCA code of practice – offered advocacy – capacity opt in/opt out.	Thank you for your comment. The committee discussed the various points raised but decided not to replace the recommendation with the following recommendation in that section of the guideline as opt out is an important approach to advocacy and will become more so given the proposed changes to the Mental Health Act which may come into affect in the near future. The committee felt that opt out may not be widely understood so agreed to add it to the terms used section of the guideline.
British Association of Social Workers	Guideline	012	008	1.4.10- How is greatest need identified? What is the criteria? This is a threshold issue- might have to wait a bit longer. LA decision for Care Act if meet requirement. Contingency for capacity to ensure advocacy consortia	Thank you for your comment. The committee discussed the points raised but decided not to amend the recommendation as it was felt that the current wording was sufficient and would be understood by those reading it. The committee also felt that one of the biggest challenges in providing advocacy is ensuring that it goes to people who may need it but don't ask for it and that this recommendation would help to ensure that this happened.



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British Association of Social Workers	Guideline	012	011	1.4.11- How accessible is information about how to access advocacy?	Thank you for your comment. There is a recommendation in the Information about effective advocacy and signposting to services section of the guideline on ensuring that all information about advocacy is provided in a variety of ways to suit people's needs using accessible formats.
British Association of Social Workers	Guideline	012	015	1.4.12- get advocacy, if you ask the person about advocacy it more closely resembles the language of the legislation.	Thank you for your comment. This recommendation was aimed at ensuring that those who are unable to ask for an advocate but who are legally entitled to it are able to get advocacy.
British Association of Social Workers	Guideline	019	017	1.7.1 - Consideration of who is deemed appropriate – assumptions can be made- in certain circumstances may not be appropriate to the person. It should be about who the person wants/chooses and who is important to the person- this may not be a family member.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the current wording sufficiently covered the person's choice or when the person cannot express a view. Following another stakeholder's comment, friends was added to the recommendation so the advocates could liaise with family members, friends or carers.
British Association of Social Workers	Guideline	020	001	1.7.2- should have knowledge of who is important to the person not assumption re family member	Thank you for your comment. The committee discussed this and although they decided not to amend the recommendation with the suggested text, at another stakeholders suggestion they did add friends thus broadening the recommendation out from just family members.



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British Association of Social Workers	Guideline	020	005	1.7.3- strategic plan should capture ways of working. Creative about ways of working so info accessible	Thank you for your comment. The committee discussed this recommendation and decided to focus the recommendation on representation on Safeguarding Adults Boards as this was felt to be the most important thing to aim for and from this other aims could be achieved, such as the informing of strategic plans and annual reports.
British Association of Social Workers	Guideline	020	009	1.7.4- contracts- ensuing in advocacy contracts that the Equality Act is being upheld in terms of how to provide information about advocacy.	Thank you for your comment. The committee discussed this and decided to amend the example in the recommendation to "ensuring there is enough time in contracts to develop and provide the information in accessible formats". This was seen as a practical way of ensuring in advocacy contracts that the Equality Act is being upheld in terms of how to provide information about advocacy.
British Association of Social Workers	Guideline	027 - 028	General	Providers and commissioners should ensure that staff in organisations working with advocacy services (including social workers, members of Safeguarding Adult Board members and commissioners of advocacy) have training in the role and function of advocates who are appointed under the relevant legislation. This includes understanding that advocates: role is to facilitate involvement for those who have substantial difficulty and provide an	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the bullet point list used in the recommendation was non-exhaustive. The committee felt that some of the suggestions in the comment were already covered by some of the bullet points in the recommendation. The committee also felt that some of the suggestions were covered elsewhere in the guideline and did not sit best in this recommendation.



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				independent safeguard for people who lack capacity to make important decisions, where the individual has no suitable person who can support them help people by offering to attend meetings, writing letters and emails and making phone calls support the person to make decisions, for example by, making sure people understand their options and exploring the potential outcomes of the possible options, represent only the views of the person they are supporting, ensure the person's voice is heard and their rights are respected in all discussions, share information they receive with the person they are supporting, aim to empower the person to develop personal agency, self-advocacy and confidence can challenge certain decisions made by a local authority or health authority where the individual is unable to do so, and that there are processes for resolving disagreements set out in relevant guidance can be involved in assisting with safeguarding enquiries where the individual lacks capacity to make decisions that place them at risk of abuse or neglect. are independent of any provider service	



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Care Quality Commission	Guideline	005	014	Rec 1.1.1 Could also refer to government guidance – <u>Making decisions: the Independent</u> <u>Mental Capacity Advocate service (OPG606)</u>	Thank you for your comment. Recommendation 1.1.1 sets out who is entitled to advocacy and cites the legislation which underpins these requirements. As such it would not be appropriate to cite the document mentioned in your comment.
Care Quality Commission	Guideline	005	014	Rec 1.1.1- Could cross-reference NICE guideline <u>https://www.nice.org.uk/guidance/ng108</u> which mentions advocacy	Thank you for your comment. Recommendation 1.1.1 sets out who is entitled to advocacy and cites the legislation which underpins these requirements. As such it would not be appropriate to cite the document mentioned in your comment.
Care Quality Commission	Guideline	005	014	Rec 1.1.1 Could refer here to the particularly unique role of the post-DoLS-granted Relevant Person's representative (RPR) <u>https://www.scie.org.uk/mca/imca/roles/dols-granted</u>	Thank you for your comment. The committee discussed this but decided not to amend the existing recommendations as the post-DOLS-granted Relevant Person's representative is not yet current policy. Details on this have been added to the committees discussion of the evidence section of evidence review A. It will also be flagged with the surveillance team at NICE that future changes may impact on the current guideline.



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Care Quality Commission	Guideline	011	010	Rec 1.4.3. A Mental Health Service should also continue to facilitate access to an IMCA where relevant.	Thank you for your comment. The recommendation is specifically about people who are detained under the Mental Health Act and who have legal representation still having a right to an IMHA. The committee therefore changed the wording of the existing recommendation to clarify this. The suggested change, adding access to an IMCA, has not been made because the focus of the recommendation is on people detained under the MHA.
Care Quality Commission	Guideline	011	021	Rec 1.4.5 Could also give IMCAs as an example here.	Thank you for your comment. This change has been made.



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Care Quality Commission	Guideline	032	003	Rec 1.11.14 – Sharing insights and information with the Care Quality Commission. We would like to highlight that we have a statutory role to monitor the Mental Health Act in England. One way that we carry out this function is that we have Mental Health Act Reviewers who carry out Mental Health Act monitoring visits and interview detained patients in private. We consider access to advocacy. Our reviewers will usually seek to contact the IMHA for the ward for their insights. It assists us to carry out this function if part of the expected advocacy role is to be available to visiting bodies and to assist us with accessing the information on who to liaise with at the operational ward level. CQC also have an important Independent Voice role. There are some recently published reports where we have covered issues relevant to advocacy, informed by our operational work, which you may wish to reference/refer to. Mental Health Act annual report 2020/21 (most recently published) https://www.cqc.org.uk/publications/major- reports/monitoring-mental-health-act-202021 Page 24-26 We said that advocacy services should aim for systems where patients can seek help through any means of	Thank you for your comment clarifying the role of your organisation in relation to the Mental Health Act. Changes have been made based on your comment. A new recommendation has been added at the end of the partnership working section of the guideline on advocacy providers liaising with and facilitating regulators in carrying out their role, including in inspecting regulated services. Thank you for providing the information from the recently published reports.



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				communication, to ensure that their services are fully accessible. We support the government proposals in the reform of the Mental Health Act (MHA) to strengthen the advocacy role, improve training, encourage culturally appropriate advocacy and, provided that this is not at the expense of smaller providers, look at accreditation for advocates. In our response to the MHA white paper consultation, we also suggested that current commissioning arrangements for advocacy services limit their effectiveness. As part of the MHA reforms, we have suggested that centrally-funded IMHA services should be considered. As part of this, services should be coordinated across integrated care systems to ensure that funds are distributed fairly in accordance with need. Out of sight – who cares? Restraint, segregation and seclusion review Progress report March 2022 https://www.cqc.org.uk/publications/themes- care/restraint-segregation-seclusion-review- progress-report-march-2022 This report describes the progress made on the recommendations in CQC's Out of sight – who cares? report, published in October 2020, which looked at the use of restraint, seclusion and segregation in care services. Page 8-	



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				Advocacy When we spoke to leaders of advocacy organisations, they said that there is: a lack of resource for fully effective advocacy a lack of access to advocacy when a person is in seclusion or segregation a need for better collaboration with family members not enough staff skilled in advocacy, or in advocacy for people with autism and a learning disability Pg 57- Listening to people and acting on what they tell us We are improving how we gather the views of people who use services. In our closed cultures guidance we have included details on how CQC teams can review intelligence before and during inspection, gather feedback from advocates and request contact details for relatives, advocates, staff and visiting professionals.	



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Carers Federation Ltd	Guideline	General	General	Observation: The broad aspect of the recommendations is welcomed along with the inclusion of not capping hours and ensuring contracts and commissioning accurately reflects what is needed in resources to deliver an effective advocacy service. The reality is that commissioning will still be driven by lowest cost and guidance on the actual costs per hour of advocacy need embedding in these recommendations. The imposition of hourly rates and pay as you go advocacy contracts will not support demand or support the capacity of the advocacy sector to grow as it needs too with a diversity of Providers.	Thank you for your comment. It is not within NICE's remit to set wages or hourly rates so guidance on the actual costs per hour of advocates, cannot be embedded in the recommendations.



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Carers Federation Ltd	Guideline	General	General	Observation: NHS complaints advocacy has insufficient mention within the recommendations given the significant annual figures (many of which do not benefit from advocacy support) though most recommendations will apply to this type of advocacy. Given the introduction of the PHSO NHS complaints standards due to be implemented in April 2023 and the clear expectation around advocacy this will have a clear impact on an advocacy offer and of interest to Commissioners	Thank you for your comment. The committee discussed this but decided not to amend the recommendations as it was felt that complaints advocacy was prominently mentioned in the Legal right to advocacy section (1.1) of the guideline, and existing NICE guidance on helping people to make complaints was cross-referenced. There is also a recommendation in the training, skills and support for advocates section (1.9) of the guideline on training advocates in making information available to people about how to make complaints. Although the PHSO NHS complaints standard appears to be live it has not been implemented yet, this information has been added to committee's discussion of the evidence in the Legal right to advocacy evidence report.
Carers Federation Ltd	Guideline	001	007	Consider including Local Authority Health and Well Being Boards and/ or Local Authority Safeguarding Boards	Thank you for your comment. Changes have been made to the 'Who is it for?' section based on your suggestion.
Carers Federation Ltd	Guideline	004	008	Propose adding the following wording " and other appropriate health based Organisations"	Thank you for your comment. Changes have been made based on your suggestion.



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Carers Federation	Guideline	004	009	Propose adding word "best" to read persons	Thank you for your comment. The committee discussed
Ltd				best interests	this but decided not to amend the text as it was felt that 'best interests' is related to a particular process which did not apply in this instance and the role of the advocate is to help the person to express their own wishes.
Carers Federation Ltd	Guideline	005	020	Propose 'NHS' before 'complaints' to clarify this type of statutory advocacy	Thank you for your comment. The recommendation covers the legal requirement for local authorities to make arrangements for advocacy services to assist people making complaints as described in the Health and Social Care Act 2012. NHS complaints is something separate and is covered by different legislation. Therefore this change has not been made.
Carers Federation Ltd	Guideline	006	006	Consider amending wording to read after to "raise a concern or complaint"	Thank you for your comment. The suggested change to the text was not made because it would make the sentence less succinct.
Carers Federation Ltd	Guideline	008	001	Consider amending wording slightly to indicate an NHS complaint	Thank you for your comment. It is NICE process to use the wording from the legislation. As the wording is taken from the legislation it will not be amended.
Carers Federation Ltd	Guideline	011	021	Consider changing wording to reflect actual situation where it is not possible to provide the same advocate Advocacy Providers look to ensure they have partnerships in place with	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as the advocacy provider will need flexibility to deal with the situation depending on local circumstances.



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				other providers in the locality and pass on referrals	
Carers Federation Ltd	Guideline	011	027	Consider adding wording to end of sentence" including those patients in temporary isolation or segregation	Thank you for your comment. Changes have been made based on your suggestion. These two examples have been added to the recommendation, although following discussions the committee decided to broaden it to isolation rather than just temporary isolation.
Carers Federation Ltd	Guideline	013	001 - 028	Observation: This section is skewed towards mental health/care act advocacy. Currently there is no mention of preparing/ supporting a formal NHS complaint and the discussion surrounding this.	Thank you for your comment. The recommendations are based on statements that came from the call for evidence. The statements did not cover complaints advocacy so recommendations weren't made that focused exclusively on this. However, recommendations 1.9.3 and 1.1.2 do specifically reference complaints.
Carers Federation Ltd	Guideline	014	018 - 020	Consider amending the wording slightly to read "that all concerns whether complaints informal or formal that are raised" etc	Thank you for your comment. Changes have been made based on your suggestion.



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Carers Federation Ltd	Guideline	015	011	Consider adding wording including any local PREVENT arrangements	Thank you for your comment. The committee discussed this and decided not to amend the recommendation as there were several potential arrangements that could be cited and they didn't want to include an exhaustive list in the recommendation.
Carers Federation Ltd	Guideline	017	002	Consider the additional wording where practical and possible	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it was a non-exhaustive list of examples so advocacy providers could choose if they wanted to do this or not.
Carers Federation Ltd	Guideline	017	014	Consider the additional wording at end " if practically possible"	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as the committee were concerned that if this change were made it could be interpreted that advocacy providers shouldn't attempt to involve people with lived experience in their organisation if there are practical issues.
Carers Federation Ltd	Guideline	019	012	Consider wording to include "Advocacy Providers should consider the benefits of working together to develop mutual partnerships without compromising delivery	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as they felt that it would change it from being active "should work together to promote best practice" to being passive "should consider the benefits of working together".



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Carers Federation Ltd	Guideline	020	004	Consider at the end of sentence "where appropriate to the service offered"	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that this level of detail was not required and made the recommendation less clear.
Carers Federation Ltd	Guideline	020	011	Consider additional wording for example ensuring there is a balance between awareness and networking along with the provision of information	Thank you for your comment. The focus of the recommendation is on information provision. Awareness and networking are somewhat different aims and their addition would distract from the focus of the existing recommendation.
Carers Federation Ltd	Guideline	021	018	Also take into account the NHS complaints data available as an indication of patient experience	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that there was a lot of information sources that could be used to make an assessment of local need and it would not be possible to provide an exhaustive list.
Carers Federation Ltd	Guideline	022	017 - 018	Consider alternative wording; It is good practice not to cap the hours of support an advocate can give to an individual as this should be based on individual need and protected characteristics	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the alternative wording made the recommendation less clear.



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Carers Federation Ltd	Guideline	022	019 - 021	Observation:" providers allow enough time for advocates to undertake continuing professional development and training." Laudable though what would cpd look like?	Thank you for your comment. The first few recommendations In the Training skills for advocates section of the guideline provide non-exhaustive lists of skill development relevant to the Advocates role that continuing professional development and training could involve.
Carers Federation Ltd	Guideline	025	018	Consider adding an additional bullet point to list of training areas: 'Changes to policy and case law'	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the previous recommendation covered this sufficiently by mentioning training in justice processes that are relevant to their role.
Carers Federation Ltd	Guideline	026	001 - 009	Propose the inclusion of Health and safety responsibilities including risk assessments	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that advocates wouldn't necessarily do a risk assessment themselves but they would want access to them to inform their work.



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Department of Health and Social Care	Guideline	009	012	Is there any scope for specifically saying that certain groups need to be targeted (e.g. ethnic minorities, autistic people, people with a learning disability, children and young people)?	Thank you for your comment. Recommendation 1.3.2 specifically cites young people using adult services as an example because the committee were concerned that because of the adult population of the guideline, this group could be overlooked. They did not think the same concern existed for the other groups cited in your comment. The guideline is relevant to people who need advocacy regardless of their condition or life circumstance therefore the committee were keen for the recommendations to avoid citing specific groups to make them as inclusive as possible.
Department of Health and Social Care	Guideline	011	004	Is there any scope for remote meetings e.g. via phone or video call where this is the preference of the patient?	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that adding something on remote meetings in this particular recommendation would alter the focus of the recommendation, which the committee wanted to be about advocates meeting people in person to support them to make initial contact with advocacy services. There are other recommendations in the Improving access to advocacy section of the guideline that focus on communicating remotely or using digital platforms.



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Department of Health and Social Care	Guideline	011	026	This shouldn't be needed with the introduction of an opt out system for IMHA services as the IMHAs will be required to attend the ward to visit all qualifying patients once these are identified by the hospital managers	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as the update to the Mental Health Act is still forthcoming. The surveillance team at NICE will be notified that changes will occur that will impact the guideline so that any necessary changes can be made in future.
Department of Health and Social Care	Guideline	012	001	When advocacy is offered, including as part of opt out, there should be consideration for why a person may refuse (e.g. if they have a learning disability or autism and they are not understanding the offer being made) – see separate narrative attached	Thank you for your comment. Exploration of the reasons for declining advocacy has been added to recommendation 1.4.8.
Department of Health and Social Care	Guideline	012	003	We strongly agree with this – we will need to ensure that people get other opportunities to take up the offer	Thank you for your supportive comment.



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Department of Health and Social Care	Guideline	012	008	Again could we add specific reference to ethnic minorities, people with a learning disability or autism, children and young people	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as the committee had intentionally decided in the guideline not to use specific groups in the recommendations, unless they were useful examples, as this could have meant long lists of groups and the dangers of missing some groups out. As the guideline is relevant to people who need advocacy regardless of their condition or life circumstance the committee aimed to make the recommendations population generic and therefore more inclusive.
Department of Health and Social Care	Guideline	013	007	Could this be strengthened to make clearer the need for advocates to attend ward rounds (or that virtual options are provided, e.g. 'virtual' ward rounds	Thank you for your comment. The committee agreed to re-word the existing recommendation on attending ward rounds to make it clearer. The committee decided not to include something on virtual options in this particular recommendation as they felt that this could detract from the focus of the recommendation on accommodating the advocates availability when planning and scheduling meetings or ward rounds.
Department of Health and Social Care	Guideline	013	010	Could something be including for clinicians around trying their best to accommodate meetings being rearranged	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the preceding recommendation (1.5.3) already covered this.



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Department of Health and Social Care	Guideline	014	005	Suggest clarifying that this could include by remote communication where needed e.g. video call set up on the ward where this might benefit a person such as an autistic individual who prefers this option to a face-to-face meeting	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the following two recommendations on supporting remote communication and using digital platforms respectively cover this already.
Department of Health and Social Care	Guideline	014	006	This also includes privacy for video consultations	Thank you for your comment. The recommendation doesn't specify how the discussions take place so video consultations would already be encompassed and the committee therefore did not think the recommendation needed to be amended.
Department of Health and Social Care	Guideline	014	012	Should also include privacy	Thank you for your comment. The recommendation is focussed on practical support to help people to communicate with their advocate remotely, whilst the following recommendation on digital platforms covers privacy as it states they should be used only when it is safe, effective and appropriate to do so. So recommendation 1.5.9 does not need to be amended.



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Department of Health and Social Care	Guideline	014	015	Does this mean for staying in touch between appointments/visits or in place of the visits themselves? It should be used as a supplementary to visits rather than a replacement for this	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it was not necessary to specify how the mode of communication should be used only that digital platforms could be used as a mode of communication.
					The recommendation could cover both staying in touch between appointments/visits or in place of the visits themselves. The committee also highlighted that other recommendations had stressed the importance of face to face or in-person meetings.
Department of Health and Social Care	Guideline	025	002	Could a specific reference to Culturally Appropriate Advocacy training be included? Can this also cover specialised training for working with people from ethnic minorities, people with a learning disability or autism, children and young people	Thank you for your comment. Changes have been made based on your suggestion. The committee agreed to add culturally appropriate advocacy as a bullet point to recommendation 1.9.3. The committee also discussed specialised training for the other areas raised in the comment. The committee felt that training in culturally appropriate advocacy and anti-oppressive practice were specific practical examples of training, rather than the more generic training for working with people from ethnic minorities. The committee had intentionally decided in the guideline not to use specific disabilities in the recommendations, unless they were useful examples, as this could have meant long lists of disabilities and the danger of missing some disabilities out. Instead the committee aimed to make the recommendations population generic and therefore more inclusive. The committee therefore decided to not



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					include training for people with a learning disability or autism but amended a bullet point in 1.9.3 so the recommendation read "Advocacy services should provide training, skills development and support including induction, to their advocacy staff. Training could include: • communication, including specialised communication skills, for example communicating with people with a learning disability on specialised communication skills." The scope of the guideline is people with health and social care needs in all adult settings so the committee felt that training for children and young people was not a relevant example to use in this recommendation.
Department of Health and Social Care	Guideline	026	010	Is there anything in place to support smaller organisations who can't afford it?	Thank you for your comment. Changes have been made based on your suggestion. The committee were not aware of any support available for smaller organisations to assist their Advocates to complete the National Qualification in Independent Advocacy. Recommendation 1.8.9 has been amended to account for the issue that you raise.



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Department of Health and Social Care	Guideline	027	003	Information should also cover how health and social care practitioners can identify the appropriate advocacy service to refer people under their care. E.g. under the changes to the Mental Health Act, mental health hospital managers will need to refer all qualifying patients to the appropriate IMHA provider	Thank you for your comment. This is covered by recommendation 1.10.1.
Department of Health and Social Care	Guideline	030	005	Could something be included to stipulate what should be done with the data, e.g., should it be recorded in Mental Health Services Dataset (MHSDS)?	Thank you for your comment. The committee did not want to be prescriptive about where the data should be recorded, but have already made recommendations about evaluating and sharing the data that is collected in section 1.11.
Mencap	Guideline	General	General	We hope the final guideline on 'Advocacy services for adults with health and social care needs' will incorporate key findings and recommendations from the DHSC and NHSE review into advocacy for people with a learning disability and autistic people.	Thank you for your comment. The DHSC and NHSE review into advocacy for people with a learning disability and autistic people has not been published yet and therefore it is not possible for this guideline to incorporate any of its findings. The surveillance team at NICE will be made aware of this review for future updates of this guideline.



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Mind in Brighton and Hove	Guideline	012	001	1.4.7 Advocacy providers should aim where possible to offer IMHA on an opt-out basis. This needs further consultation in line with MH act changes	Thank you for your comment. The reforms to the Mental Health Act that will impact on opt-out advocacy have not come into effect yet. The recommendation will not be amended at this stage. The surveillance team at NICE will be informed that changes to legislation may impact on the guideline.
Mind in Brighton and Hove	Guideline	013	007	This is good to see: 1.5.3 Service providers should take into account the availability of the advocate when planning and scheduling meetings, as is point 1.5.	Thank you for your supportive comment.
Mind in Brighton and Hove	Guideline	015	020	1.6.1. A positive step in recognising that, while face to face should be offered, it is not always the clients' preference and remote advocacy can be really effective. Agree with the following: Providing easy access to advocacy by a simple referral process which is clearly stated on website, leaflets, etc. and that this information is available in multiple formats (currently some advocacy providers have very complicated referral forms – it should be easy to see if you qualify for advocacy and, if so, to request it) Providing non-instructed advocacy – additionally specific training for this should be provided	Thank you for your supportive comment. There is a recommendation on training for advocates on when and how to use non-instructed advocacy in the Training, skills and support for advocates section of the guideline.



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Mind in Brighton and Hove	Guideline	015	025	1.8.6Concerned about some commissioners understanding of advocacy, in particular the independence principle. Some contracts now have average time spent – understand there needs to be boundaries and that averages allow for some flexibility	Thank you for your comment. This area is already covered by recommendation 1.10.3. A small number of recommendations in the guideline cover contracts and time, the committee mentioned some relevant examples in the recommendations, such as allowing enough to develop and provide information in accessible formats or avoiding caps on the number of hours supporting someone, as it was felt that these are certain areas that might be overlooked when contracts are drawn up.
Mind in Brighton and Hove	Guideline	017	011	1.6.5 States that advocacy organisations should include those with lived experience as employees, volunteers, board members, etc. Agreed – furthermore people with lived experience should be encouraged to apply	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that encouraging people with lived experience to apply was beyond the remit of the guideline.
Mind in Brighton and Hove	Guideline	018	001	1.6.8 Suggestion that a person should stay with the same advocate throughout the process – agree this should be the case for each issue/referral for that person but not necessarily if they are a returning client as this can result in dependency rather than helping them move towards self-advocacy	Thank you for your comment. The committee discussed this and acknowledged that although it might be possible for dependency to happen if the person always works with the same advocate, the benefits of continuity, consistency, time to build up understanding and trust associated with working with the same advocate would outweigh the potential risks.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
Mind in Brighton and Hove	Guideline	019	015	1.7 Partnership Working: lots of positive content to guidelines here, which I feel would agree with aiming towards, particularly around working with BAME communities, but specific to local needs/demographics e.g.:	Thank you for your supportive comment.
Mind in Brighton and Hove	Guideline	021	004	1.7.10 Co-locating different types of advocacy services, e.g. African/Caribbean advocacy Service located in same community centre as a mental health advocacy service. Might be worth including the word "aim" or "work towards"	Thank you for your comment. The service located in the same community centre is only an example in the recommendation so the wording does not need to be amended.
Mind in Brighton and Hove	Guideline	025	002	1.9 Training Increase investment in training for advocates – this could perhaps be arranged at low/no cost with local providers, who would benefit from the advocates understanding more about their services Induction – full induction including shadowing over several weeks results in very positive feedback from new starters and sets them up well to be confident in the role	Thank you for your comment. How training is delivered will be a matter for local interpretation.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
Mind in Brighton and Hove	Guideline	029	001	1.11Useful guidance on outcomes as this can be an ongoing challenge in advocacy services to effectively collect outcome data and demonstrate outcomes. Would be useful to have more input from commissioners on this Would also be useful to have more input from commissioners in promoting advocacy amongst H&S care providers including education professionals e.g. social workers on the advocacy role – small advocacy providers have limited capacity to do this. This can only be done effectively if commissioners themselves also have a good understanding of advocacy. Great to see the guidance re. commissioners sharing info with advocacy providers about trends and themes. This does not happen routinely in some areas.	Thank you for your supportive comment. Commissioners understanding advocacy is covered by recommendation 1.10.3. The need to have more input from commissioners in promoting advocacy amongst health and social care professionals is covered by recommendation 1.10.1. Recommendation 1.11.14 covers commissioners and advocacy providers sharing information on trends and themes with other stakeholders, which could lead to sharing this information with each other as well.
Mind in Croydon	Guideline	011	005	Rec 1.4.1 "in person", I think this is a vital component particularly throughout the pandemic where remote working became much more common place. I believe that advocacy is at its most effective when the advocate is physically in the same space as the detained patient to pick up on the unspoken/non verbalised issues such as ward services and safeguarding issues.	Thank you for your supportive comment. The committee discussed this and decided to amend the rationale to include the examples of picking up on the unspoken/non verbalised issues such as ward services and safeguarding issues.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
Mind in Croydon	Guideline	011	026	Rec 1.4.6 I am in support of this statement particularly that "advocates should make regular visits to inpatient settings to identify those who would benefit from advocacy". I would suggest that regular could be defined by a particular timeframe such as weekly, in Croydon we find that it can take time to build trust and rapport with the patients, my concern is monthly visits or less frequent is not enough sufficient time to establish a working relationships with patients who are very unwell, mistrustful of professionals / have been let down by the system in general. I am speaking on behalf of IMHA services with these comments.	Thank you for your supportive comment. When the committee made this recommendation they felt it would be best to not define a particular timeframe as the individuals circumstances could affect the timeframe for visits. There is a recommendation in the Enabling and supporting advocacy section of the guideline on ensuring that there is adequate time for the advocate and person to build relationships and trust.
Mind in Croydon	Guideline	012	008	Rec 1.4.10 "people with the greatest need" I am encouraged to this statement in the draft guidance and speaking in relation to IMHA services those that use advocacy can often be the ones that shout the loudest or already use their voice to be heard and particular attention should be paid by advocacy providers to identify those who would benefit most and ensure limited services are not monopolised by those who are most capable of self-advocating	Thank you for your supportive comment.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
Mind in Croydon	Guideline	013	007	Rec 1.5.3 I am in support of this statement as too often advocates can be overlooked in ward round scheduling, last minute changes to scheduling are not communicated to advocacy providers and detained patients are denied their rights to IMHA representation.	Thank you for your supportive comment.
Mind in Croydon	Guideline	014	007	Rec 1.5.8 I am in support of this as often wards are not able to facilitate private spaces on wards where private rooms are at a premium and used for family visits or OT sessions and advocates have to meet their advocacy clients in spaces where staff and patients could over hear what is being discussed.	Thank you for your supportive comment.
Mind in Croydon	Guideline	014	028	Rec 1.5.14 I think this would be a very good initiative and am in support of this idea (number of referrals shared as part of performance monitoring).	Thank you for your supportive comment.
Mind in Croydon	Guideline	015	022	Rec 1.6.1 I think face to face advocacy provision is imperative for effective advocacy and find it encouraging this is made clear in this guidance. Remote working / remote advocacy is always sub optimal.	Thank you for your supportive comment.



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Mind in Croydon	Guideline	017	011	Rec 1.6.5 I am heartened to see this in this draft guidance, that those who have used the service and have lived experience be included in the organisation in some role of delivering the service or having input into governance. At Mind in Croydon we have a service user service user steering group for the advocacy service specifically for this reason.	Thank you for your supportive comment.
Mind in Croydon	Guideline	020	009	Rec 1.7.4 I think this section is entirely appropriate and too often Commissioners are looking to cut costs in the name of efficiency savings by limiting the time advocates have to establish the service, to meet newly detained patients who can be mistrustful of all professionals, to build rapport with unwell or distressed patients (particularly in IMHA services) requires sufficient time	Thank you for your supportive comment.
Mind in Croydon	Guideline	020	019	Rec 1.7.6 With regard to IMHA there is evidence I can speak to where gaps in service provision occur due to the interpretation of statutory obligations by varying local authorities/commissioners. I am fully in support of this statement.	Thank you for your supportive comment.



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Mind in Croydon	Guideline	022	017	Rec 1.8.6 "Avoiding caps on number of hours", I agree with the and fully support its inclusion into the guidance. For advocates to be effective and maintain their independence commissioners should ensure in advocacy contracts this is protected (an advocates ability to build relationships, meet with qualifying patients and introduce the service potentially over multiple visits so that we are accessible to the patients who have a legal right to the statutory service	Thank you for your supportive comment.
				statutory service	



Stakeholder	Document	Page No	Line No	Comments	Developer's response
Multiple System Atrophy Trust	Guideline	General	General	This draft guideline looks comprehensive and covers the main areas regarding advocacy. However, we remain concerned that statutory advocacy services are not well known about or publicised and even when people do access them they are often turned down, subject to delays and receive inconsistent follow up information about other relevant support services. Effective and person led advocacy needs to have adequate funding and this is simply not available. For example, a major issue for people with advanced MSA is getting access to NHS Continuing Healthcare. Advocacy support for this is poor and voluntary organisations such as ours, who support people with the rare progressive neurological condition called Multiple System Atrophy and who receive no public funding, are often a last resort for both information and advocacy.	Thank you for your comment. There is a recommendation in the Information about effective advocacy and signposting to services section (1.3) of the guideline on Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services providing everyone legally entitled to advocacy with information about their entitlement to advocacy and what this means. NICE guidelines cannot determine the amount of funding provided to services but there are a number of recommendations, mostly in the Planning and commissioning advocacy services section (1.8) of the guideline aimed at commissioners, that state that services should be commissioned to meet local needs or address gaps in provision.



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Multiple System Atrophy Trust	Guideline	004	020 - 021	The guideline correctly notes that little information is available about how many people access independent advocacy or how many independent advocates are currently operating. Yet there are no proposals to create an information database of those that do exist which would be enormously helpful both for statutory advocacy services and potential users themselves. We feel that this is a significant omission.	Thank you for your comment. Recommending the creation of an information database would have resource implications and therefore evidence of both effectiveness and cost-effectiveness would have been needed to support making such a recommendation. Since the committee did not have this evidence there were not able to make the recommendation you suggest. The guideline does however have a recommendation (1.11.9) that aims to improve the recording and collecting of information and data at the local level. If at the local level it was decided that a database would be useful this recommendation could be used as a driver to help enable the creation of such a database.



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Multiple System Atrophy Trust	Guideline	039	013 - 014	The guideline notes that there is no legal requirement to provide information about non- statutory advocacy services. However, if there were a national database of non-statutory organisations that could provide support it would be hard to argue that statutory services should not provide information on these. The MSA Trust has the externally accredited Patient Information Forum tick mark accreditation for our information resources (formerly NHS Information Standard) and we are also signposted from NHS Conditions website which is regularly reviewed for accuracy. A database of non-statutory services could really help signposting to appropriate support agencies. A similar database of statutory advocacy services (and contact details) could really help us provide better signposting the other way.	Thank you for your comment. Recommending the creation of a national database would have resource implications and therefore evidence of both effectiveness and cost-effectiveness would have been needed to support making such a recommendation. Since the committee did not have this evidence there were not able to make the recommendation you suggest. The guideline does however have a recommendation (1.11.9) that aims to improve the recording and collecting of information and data at the local level. If at the local level it was decided that a database would be useful this recommendation could be used as a driver to help enable the creation of such a database.
Multiple System Atrophy Trust	Guideline	057	008 - 009	We agree services should be commissioned on the needs of the local population, but this will mean that the needs of anybody with rare conditions will not be addressed. We believe there needs to be a national mechanism to ensure those with rare or complex needs are given equal access again perhaps through a database of non-statutory support.	Thank you for your comment. Recommending the creation of a national database would have resource implications and therefore evidence of both effectiveness and cost-effectiveness would have been needed to support making such a recommendation. Since the committee did not have this evidence there were not able to make the recommendation you suggest. The guideline does however have a recommendation (1.11.9) that aims to improve the recording and collecting of information and data at the



Stakeholder	Document	Page No	Line No	Comments	Developer's response
					local level. If at the local level it was decided that a database would be useful this recommendation could be used as a driver to help enable the creation of such a database.
Multiple System Atrophy Trust	Guideline	059	020 - 021	We agree that people will feel comfortable with advocates they trust. Our experience is that people with Multiple System Atrophy feel confident that we, as the MSA Trust, will act in their best interests. However, we are not publicly funded and our resources are limited so we often have to make tough decisions about who we can help and how far that help can extend. We wonder if some form of funding could be provided to organisations who can prove that they are able to advocate effectively, especially for rare groups.	Thank you for your comment. It is beyond the remit of the guideline to make recommendations on the level of funding provided to services.
Multiple System Atrophy Trust	Guideline	063	005 - 006	We would make a plea for the training available regarding advocacy to be made available free of charge for organisations such as ourselves. An online version would be cheap to produce and if it were made widely available would raise both expertise and awareness.	Thank you for your comment. How the training recommended in the guideline is made available, and any costs associated with this, will be a matter for local implementation.


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NHS England	Guideline	General	General	The gap in health inequalities is getting wider and the use of advocates to act alongside patients with protected characteristics, LDA etc is the right thing to do to improve an understanding of the importance of areas such as ill health prevention, screening, immunization, chronic disease monitoring, uptake of health checks etc	Thank you for your supportive comment.
NHS England	Guideline	General	General	Please make sure the guideline is cross referenced with the upcoming Mental Health Bill	Thank you for your comment. Cross references to legislation are only included in NICE guidance when the legislation is live. Where the committee or stakeholders felt that the forthcoming change in legislation would impact recommendations this was mentioned in the relevant committee's discussion of the evidence sections of the evidence reports. The surveillance team at NICE will be notified that forthcoming changes in legislation may impact the guideline.



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NHS England	Guideline	General	General	The document should acknowledge that some family carers are also becoming Care and Welfare Deputies appointed by the Court of Protection to make decisions for and advocate on behalf of their young people, not as a family carer but in an official legal capacity governed by the Court and the Office of the Public Guardian.	Thank you for your comment. The committee discussed this but decided it was not necessary to mention this in the guideline document as they felt that it is just one route that people may end up advocating for others and the focus of the guidance was on a trained person whose sole involvement is as an advocate.
NHS England	Guideline	006	General	Box 1 This box provides an overview of the MCA 2005 and where people have a right to advocacy when there is to be a change of accommodation (either to a hospital or care home). There is likely to be a significant impact here for people with a learning disability or autistic people. Advocacy will be very necessary here to ensure people's rights are being met and the change of accommodation is genuinely in their best interests – or for there to be a challenge (have all other least restrictive options been explored etc?). Commissioners will also need to ensure that they are meeting their duties under the Equality Act (including the Public Sector Equality Duty) as well as the Human Rights Act. The information on legal entitlement to Care Act Advocacy omits to reference increased eligibility if at risk of admission to hospital for	Thank you for your comment. A change has been made based upon your suggestion. The Care Act section of Box 1 has been amended to reference the statutory instrument which adds to the Care Act and covers increased eligibility if at risk of admission to hospital for more than 28 days. The committee discussed the suggestion to add specific sub-sections which consider the increased advocacy needs of people with a learning disability and autistic people who are at risk of admission to hospital, or are already inpatient, particularly mental health and similar specialist hospitals. However, the committee decided not to make any amendments due to this suggestion as it was felt that the guideline should apply to all groups and not be condition specific. The committee felt that by creating sections that are condition specific readers of the guidance may just look at certain sections do not apply to particular groups.



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				more than 28 days. The duty to provide access to independent advocacy applies when there is no 'appropriate individual' available to support the person's involvement. When as part of the care and support assessment or planning functions it is likely that the person will be placed in NHS-funded provision in a hospital for a period of twenty eight days or more (including places like assessment and treatment units) or care home for a period of eight weeks or more. In these cases, the local authority must provide independent advocacy (even if the person has an 'appropriate individual' available to support them) if it is satisfied that receiving advocacy would be in the best interests of the individual. This is because it is recognised that the consequences of moving into NHS funded care can be so far reaching to the individual. Propose there are clear sections on advocacy rights for people at risk of prolonged admission and who are already inpatient for what may become extended periods of time. Also specific sub-sections which consider the increased advocacy needs of people with a learning disability and autistic people who are at risk of admission to hospital, or are already inpatient, particularly mental health and similar specialist hospitals. This should include	



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				describing a wider range of advocacy options for these people and families advocating for them, recognising that statutory advocacy may not sufficiently meet their needs. There is great nuance to the varying needs of advocacy for people with a learning disability or autistic people, including when the family carer may be the person's natural advocate (even unknowingly) and also need recognition and support as such. The guidelines should acknowledge and address these particular needs separately from any 'blanket' guidance that applies to all.	
NHS England	Guideline	010	008	1.3.3 Welcome the reference to organisations informing people about advocacy.	Thank you for your supportive comment.



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NHS England	Guideline	010	026	1.4.6 Suggest also that advocates are trained / knowledgeable in learning disability and autism, communication methods etc to ensure that the most at risk of not receiving advocacy are not disadvantaged further by a lack of awareness or unconscious bias in advocacy services. Similarly, commissioners, advocacy providers and inpatient settings should all understand and implement reasonable adjustments for all disabled people, including autistic people and people with a learning disability. This could include longer appointment times for example. Services should also be aware of, and implement where necessary, the principle of more favourable treatment, as set out in the Equality Act 2010.	Thank you for your comment. The recommendation has been amended to make it more proactive so that additional effort is made to reach people who are at risk of not receiving advocacy. The committee felt that training for advocates to support people with a variety of needs was sufficiently covered by the initial recommendation in the training skills and support for advocates section. The committee also felt that reasonable adjustments were sufficiently covered by Box 2 and the recommendation linked to it.
NHS England	Guideline	012	003	1.4.8 Welcome this line about repeated engagement, including with those who initially decline support. This can be particularly important for people with a learning disability and autistic people, who, for a variety of reasons, may take time to open up and trust new people.	Thank you for your supportive comment.



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NHS England	Guideline	012	017	Section 1.5 Suggest adding a line at the beginning stating that commissioners should also inform / educate themselves about what advocacy is and the different forms it can take (including non-instructed advocacy).	Thank you for your comment. This is already covered by recommendation 1.10.3.
NHS England	Guideline	016	014	1.6.2 Overall the document is very light on the needs of those with complex communication, learning and language needs. That requires special and specific training plus a lot of time to build relationships. That does not seem referenced here at all, it would also need to be reflected in the JSNA process (in terms of the specifics of identified need to be commissioned properly and appropriately). Documents relating to these needs include CORC https://www.corc.uk.net/outcome-experience- measures/feedback-and-outcome-measures- for-children-and-young-people-with-learning- disabilities/ ; https://www.challengingbehaviour.org.uk/what- we-do/projects-and-research/valuing- individuals-and-their-families/seldom-heard/	Thank you for your comment and for providing the information. Recommendation 1.9.3 has been amended to include training on specialised communication skills. The committee decided not to amend recommendation 1.6.2 as it was felt that it is not possible within a guideline on Advocacy to make recommendations on how to meet people's communication needs. Other NICE guidelines on people's experience in adult social care services, patient experience in adult NHS services and shared decision making have been cross- referenced which contain recommendations on communication.



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NHS England	Guideline	017	008	1.6.4 Could this line be re-worded to focus on 'best interests'?	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it isn't really about best interests. Advocates work with people to help them express their views regardless of whether the thing they want is in their best interests. Although it mentions people who lack the capacity to instruct their advocate, the recommendation is about ensuring the advocacy remains person led.
NHS England	Guideline	021	017	1.8.1 By their nature this group of people are seldom heard and cannot lobby to be included. People may well also be living out of area and those links can be fragile and they can be forgotten. If someone has Adult CHC they will not have a social worker (they are allocated to those with LA funded care). This document as one about standards should also define what is needed to ensure what a JSNA process needs to do to make that meaningful and effective so that advocacy can be commissioned to meet the range of needs effectively. This is also a process that requires a good local understanding of complexity and need and shared data across education, health, social care and housing.	Thank you for your comment. It is beyond the remit of NICE guidelines to stipulate what a JSNA process should do. The recommendation does say that co- production should be used when commissioning advocacy services, which should help ensure that people who are seldom heard are given the opportunity to voice their opinions and be involved in what services are commissioned.



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NHS England	Guideline	023	016	1.9.2 Line 16 – could this line be amended to read 'personal budgets, personal health budgets and integrated personal budgets'. This would help clarify that there is a broader range of personal budget support available.	Thank you for your comment. This change has been made.
NHS England	Guideline	025	018	1.9.3 Suggest adding reference to training in human rights, Human Rights Act	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as one of the existing bullet points covered training in understanding human rights and how to promote them.
NHS England	Guideline	027	003	1.10.1 Suggest adding a line about understanding what advocacy is / isn't	Thank you for your comment. Changes have been made based on your suggestion. The committee decided to add a new bullet point on 'what advocacy is' to the existing recommendation.
NHS England	Guideline	030	008	1.11.5 Recommend adding what types of advocacy were accessed	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the list of examples was non-exhaustive and this data is likely to be collected anyway.
NHS England	Guideline	035	011	Welcome recommendation for more people to access non-statutory advocacy.	Thank you for your supportive comment.



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NHS England	Guideline	038	007	Raising awareness - GP surgeries might be an opportunity to provide information on their website with links and also paper information within the surgery such as at the reception desk, notice boards etc. And accessible forms of information. Also practice staff should be aware of the training and that non statutory advocacy can be offered to those who are not legally entitled to it as this uptake is particularly low. Perhaps each primary care locality (PCN level) should have someone who takes the lead for this?. This doesn't mean primary care would have to provide the information but at least be knowledgeable to signpost a patient	Thank you for your comment. Changes have been made based on your suggestion. The committee discussed this and decided to amend recommendation 1.10.2 to include understanding what additional advocacy is available locally. The committee felt that training for staff on non-statutory advocacy was already covered by recommendation 1.10.1. Various recommendations in the Information about effective advocacy and signposting to services section (1.3) already cover who should be providing information (1.3.1 - 1.3.3), what it should cover (1.3.1 - 1.3.3) and accessible formats (1.3.4). The guideline has not been prescriptive about how the information should be provided, so use of GPs websites could be one method that is used.



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NHS England	Guideline	042	006	Agree with the recommendation. Wider issue here though is that often advocates work to single issues only (often as a result of commissioning arrangements). Some of the issues listed could be avoided by advocates working in the longer term with people and taking a holistic, whole life approach. This is the ideal but we recognise there are practical barriers to this, such as funding, time constraints etc.	Thank you for your comment. A new recommendation was added to the Planning and commissioning services for advocacy section of the guideline on commissioning bodies working together to agree and publish a long- term plan. This recommendation should help enable a longer term approach to advocacy.



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NHS England	Guideline	045	001	GP practices staff may be required to work at an early stage in a patient journey with an advocate and this may provide a challenge as demand already outstrips capacity. In the longer term having a patient advocate involved is likely to facilitate the consultation as the advocate may continue discussions with the patient outside of the consultation and come back at a later stage to resume the discussion with the patient making an informed choice. Practices will need to be aware that just as extra time is often needed where a translator is involved in a consultation, extra time would also likely to be needed where a patient is accompanied by an advocate. Awareness of this part of the consultation should therefore be shared with doctor's groups such as LMCs as this could have an impact on capacity. However, this is a theme very much supported by NHSE which is 'what matters to me'	Thank you for your comment. The guideline has a section on Training and skills for health and social care practitioners who work with advocates where there are a number of recommendations aimed at health and social care practitioners, staff who may be the first point of contact for people using health and social care services, as well as staff in organisations working with advocacy services. The suggested training covers various things including what advocacy is, when and how to request advocacy, and understanding the advocates role. The training should enable GP practice staff to understand the advocates role and how it will impact on things such as consultations. Your comments about sharing with doctors groups the need for increased consultation times will be considered by NICE where relevant support activity is being planned.
NHS England	Guideline	047	015	Whilst involving an advocate early on is best practice and means that there may be fewer decisions being challenged and is not likely to impact on advocacy hours needed it may have a workforce impact in primary care as outlined above	Thank you for your comment. Your comments about sharing with doctors groups the need for increased consultation times will be considered by NICE where relevant support activity is being planned.



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NHS England	Guideline	064	008	Training is essential for primary care clinicians to be aware of who is eligible for statutory advocacy service	Thank you for your comment. This is covered by the recommendations in the Training and skills for health and social care practitioners who work with advocates section of the guideline.
Speakup Self Advocacy	Guideline	General	General	Throughout these guidelines we agree with just about all the recommendations. BUT we know that advocacy services have been underfunded and an 'easy cut' for many years. SO the capacity is just not there anymore and it will be really hard for this to change. Throughout the entire document it refers to the word 'funding' just 3 times and those times are not referring to the need for additional investment.	Thank you for your comment. NICE guidelines can't make recommendations about what funding is given to different sectors but there are a number of recommendations where this issue has been addressed indirectly. The Training skills for advocates section of the guideline contains a recommendation on commissioners and advocacy providers working with public bodies and providers to increase investment in training for advocates. The committee understood that commissioning plays a vital role in ensuring the provision of advocacy services and there is a section of the guideline on Planning and commissioning services for advocacy. The first recommendation in that section covers commissioning based on an assessment of local need. The second recommendation looks at commissioning bodies working together to create a long term plan for advocacy. And the third recommendation looks at commissioning non-statutory advocacy. The committee felt that through these and other similar recommendations in the guideline they can ensure that there is adequate provision of advocacy services in the short and long term.



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Speakup Self Advocacy	Guideline	009	002	1.2.1 We agree that EVERYONE who finds it hard to speak up or might need an advocate to help them with a big decision about their life – they should have an advocate. BUT this might be a peer or self-advocate who can support them better because they have the same experiences. This kind of advocacy needs to be funded properly though. We know that some statutory advocacy contracts say that they must do this, but we know this does not happen.	Thank you for your comment. The committee discussed this and decided not to amend the existing recommendation as it was felt that peer or self advocacy options were already covered as it says 'offer advocacy'. There is a recommendation in the Improving access to advocacy section (1.4) of the guideline that covers promoting peer and self advocacy options. NICE guidelines cannot determine the amount of funding provided to services. However in the Planning and commissioning services for advocacy section (1.8) of the guideline the committee did add a new recommendation on commissioners working together to create a long term plan for advocacy in their locality which included peer and self advocacy. This could help enable peer and self advocacy to be available to people in the long term.
Speakup Self Advocacy	Guideline	009	007	1.3 Telling people about the advocacy services in their area in the right way is very important. But we also know that some areas don't have good advocacy services in their area – it is a post code lottery. Also some areas have very high FACS criteria which stops people from getting support.	Thank you for your comment. Implementation of the recommendations in the guideline should help address the inconsistencies in the delivery of advocacy services and access to these services.



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Speakup Self Advocacy	Guideline	010	008	1.3.4 This does not say anything about accessible information for people with visual impairments and a learning disability – like audio.	Thank you for your comment. The recommendation has been amended to mention accessible formats and include the example given.
Speakup Self Advocacy	Guideline	010	014	1.3.5 We agree with this – but it should happen in other ways, like at roadshows etc. But also it needs someone the person knows well to go through the Easyread to make sure they understand it. We know that in the past advocacy is sometimes only ever accessed when the person is in crisis.	Thank you for your comment. The aim of the recommendation was to repeat information about advocacy and how to access it at each key point in the person's interaction with health and social care, the recommendation was not about how the information should be provided so this has not been amended. There is a recommendation in the Information about effective advocacy and signposting to services of the guideline on ways that information can be provided which also has cross references to further NICE guidance on communicating and providing information.
Speakup Self Advocacy	Guideline	011	015	1.4.4 If people are going to be able to 'self- refer', the self-referral process needs to be accessible to all – this would need thinking about because a lot of council websites and phone lines are not accessible.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as determining what the process will be for self-referral will be a matter for local implementation.



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Speakup Self Advocacy	Guideline	011	015	1.4.4 If people cannot communicate using speech then there need to be ways for them to self-refer. Also, a self-referral should not take a long time, it needs to be quick, easy and someone should get a response quickly. This is where peer advocacy can help – where a friend or family can help someone.	Thank you for your comment. The exsiting recommendation covers self-referral as an option for all users, including people who cannot communicate using speech. The recommendation says that providers should make it easy for people to access advocacy via flexible ways to make contact and a simple process. Peer advocacy could help in the process of self-referral but the aim of the recommendation is to make commissioners and advocacy providers make access to advocacy easy, which if done should not require others to help with the self-referral.
Speakup Self Advocacy	Guideline	011	015	1.4.4 There should be information given to people as soon as they get a diagnosis of learning disability or neurodiverse difference. There should be information provided by doctors, schools and colleges too.	Thank you for your comment. There are recommendations in the Information about effective advocacy and signposting to services section (1.3) of the guideline on information provision which are aimed at Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services. Therefore no changes have been made based on your comment
Speakup Self Advocacy	Guideline	11	21	1.4.5 We know this NEVER happens. SO we agree this should happen.	Thank you for your supportive comment.



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Speakup Self Advocacy	Guideline	011	026	1.4.6 Advocates need better wages so that they stay in their jobs. If advocates are not paid well, then they will leave and the person will have to get to know someone new.	Thank you for your comment. It is beyond the remit of NICE guidelines to recommend changes to wages.
Speakup Self Advocacy	Guideline	012	001	1.4.7 We strongly agree with this and 1.4.8, but we are not confident it will happen unless a LOT more funding is made available	Thank you for your comment. When the committee discussed the opt-out recommendation it was felt that although there was likely to be a significant resource impact in the short term it would lead to improved access to advocacy services, and the benefits of these could offset costs in the longer term. The committee were also aware that reforms to the Mental Health Act would mean that in future opt-out will become a legal duty. When the committee discussed the recommendation on IMHA being offered at the earliest opportunity and then regularly afterwards it was felt that this wouldn't have a significant resource impact.
Speakup Self Advocacy	Guideline	012	006	1.4.9 It would be great to see some peer advocates who were trained as IMHA too! Also, finding self, peer and group advocacy groups can be hard to do – so there needs to be a way in each local area to find them. Groups are stretched and underfunded – so don't have the capacity to advertise themselves.	Thank you for your comment. The recommendation was amended to add raising awareness of self-advocacy groups. Promoting self advocacy and peer advocacy options was already mentioned in the recommendation. The committee felt that encouraging peer advocates to train as IMHA was outside the remit of the guideline.



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Speakup Self Advocacy	Guideline	012	017	1.5 Advocacy has to be a part of transition and discharge planning from hospital. If someone can keep their advocate when they leave, has a connection with a self advocacy group and is already connected with people in their local area, friends, then they have a much better chance.	Thank you for your comment. The committee discussed advocacy being a part of transition and discharge planning from hospital but they felt that it was one example of an important time point and various examples could equally be used. The committee felt that it was important to keep the existing recommendation focussed on the rapid identification of the need for advocacy and referral to advocacy services in all situations so it was not beneficial to add this example to this particular recommendation. The committee decided not to amend the recommendation in regard to keeping the same advocate as recommendation 1.6.8 already covered this. The committee also felt that making recommendations on maintaining connections with a self advocacy group, people in their local area or friends was beyond the remit of the guideline. But they felt that a recommendation in the Improving access to section (1.4) of the guideline that covered raising awareness of self advocacy groups could help enable this.
Speakup Self Advocacy	Guideline	013	020	1.5.7 Support not facilitate?	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that 'facilitate' was more of an active verb than 'support'.



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Speakup Self Advocacy	Guideline	014	018	1.5.11 Writing notes and recording actions is a skill. Advocates need teaching how to do this so that notes are respectful, accurate, understood by the person. Training and guidance is needed! There should be nothing about us, without us!	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that this was already covered by recommendation 1.9.3
Speakup Self Advocacy	Guideline	015	001	1.5.15 Advocacy groups which include self and peer advocates should learn together about safeguarding.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that this level of detail was not required and that it should be left up to advocacy services to arrange training based on local circumstances.
Speakup Self Advocacy	Guideline	016	014	1.6.2 We strongly agree with this section!	Thank you for your supportive comment.
Speakup Self Advocacy	Guideline	017	003	1.6.3 We think the 'what do you want to be' is a really important thing to ask people. We think advocates should have training on and be fully aware of the 'Good Lives Framework' and the 'Better Lives Framework'	Thank you for your comment and highlighting the frameworks. The committee decided that recommendations on training should be based on the procedures or skills relevant to the Advocates role and should be generic in nature, rather than specific. Therefore no specific frameworks have been recommended.



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Speakup Self Advocacy	Guideline	017	008	1.6.4 There are toolkits like 'Seldom Heard Voices' produced by CBF and Speakup.	Thank you for your comment. NICE didn't review the toolkits as they were not submitted during the call for evidence to stakeholders. Therefore the guideline cannot recommend the toolkits.
Speakup Self Advocacy	Guideline	018	029	1.6.12 This could be really hard for advocacy providers to do unless they have the capacity.	Thank you for your comment. When the committee discussed this recommendation they felt that this was achievable, for example through training or skills development as recommended in the Training skills for advocates section of the guideline. The committee felt that there may need to be investment in culturally appropriate advocacy. This would increase access for people who have been less likely to access advocacy or had poorer service because of communication difficulties or lack of sensitivity to cultural needs. But this will reduce inequality and unfairness in accessing advocacy services and will increase their overall uptake. If commissioning is based on an assessment of local need this can be factored into commissioning advocacy services.
Speakup Self Advocacy	Guideline	019	017	1.7.1 It is essential for families, friends and others in their circle of support should be in contact with advocates, unless the person has said they should not or if there are safeguarding issues.	Thank you for your comment. Changes have been made based on your suggestion. The committee decided to amend the recommendation on liaising with families by adding 'friends'.



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Speakup Self Advocacy	Guideline	021	016	1.8 Advocacy is not commissioned on a long term basis – especially for peer and self advocacy	Thank you for your comment. Changes have been made based on your suggestion. The committee discussed commissioning on a long term basis and decided to add a new recommendation on commissioners working on a long term plan for advocacy services to the planning and commissioning section of the guideline as they felt this was the best way to achieve this. The new recommendation included peer and self advocacy.
Speakup Self Advocacy	Guideline	021	016	1.8 We don't think that words like 'consider' and 'should' are strong enough	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. Therefore it is not possible to make the wording any stronger.



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Speakup Self Advocacy	Guideline	022	001	1.8.2 Person Centredness should be right at the top and start this section. It should also say that advocacy should be well funded.	Thank you for your comment. When discussing the recommendations in the Planning and commissioning services for advocacy section (1.8) of the guideline the committee felt that it was important that the section start with a recommendation (1.8.1) involving an assessment of need as it was felt this should be the basis of commissioning, and that a failure to do this could mean that advocacy provision would not meet local needs. The committee felt that person centredness was sufficiently covered by recommendation 1.8.11. NICE guidelines do not have a remit to specify the level of funding that services should receive, so this was not added.
Speakup Self Advocacy	Guideline	023	003	1.8.10 This is an extensive list of examples, but really should list 'Neurodiverse differences' like Autism, ADHD, Dyspraxia etc	Thank you for your comment. The examples listed in Box 2 of life circumstance and experiences that could lead to discrimination or inequalities is a non-exhaustive list of examples. As the examples suggested in the comment could fall under the protected characteristic of disability in Box 2, it was not amended.



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Speakup Self Advocacy	Guideline	025	002	1.9 A lot of the things in this section are very hard to achieve without additional capacity for advocacy organisations	Thank you for your comment. As the committee understood that training is largely reliant on investment they purposefully put a recommendation aimed at helping achieve this at the start of the Training, skills and support section of the guideline.
Speakup Self Advocacy	Guideline	025	007	1.9.2 Advocates should have training to help them be more ambitious about people. – using things like the 'Good Lives' Framework' and the 'Better lives' Frameworks	Thank you for your comment. NICE cannot recommend the frameworks as they were not submitted as part of the call for evidence so haven't been reviewed.
Speakup Self Advocacy	Guideline	027	003	1.10.1 Training about advocacy for professionals should be regular, short, snappy and fun. It should be mandatory – in the same way that First Aid Training has to be provided every 2 years?	Thank you for your comment. The recommendation says that refresher training should happen every 2 to 3 years or as needed, but NICE do not have a remit to make any mandatory recommendations unless there is a legal requirement for them to be done. The format used to deliver the training will be determined by local implementation.
Speakup Self Advocacy	Guideline	027	003	1.10.1 Trainees need to be given cue cards with notes from the training so that they can refer to these after the training and in their daily working lives.	Thank you for your comment. The format used to deliver the training will be determined by local implementation.
Speakup Self Advocacy	Guideline	028	012	1.10.4 We know that being face to face for training is not always possible, but we think it should be face to face as much as possible.	Thank you for your comment. The format used to deliver the training will be determined by local implementation.



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The Advocacy People	Guideline	General	General	An overarching comment is that we agree with most of what has been written in the document and support nearly all the recommendations (although we would like to see stronger language used when referring to organisations and individuals needing to fulfil their statutory duties). We are keen to know what actions will be taken from the outcomes of this consultation, and what results we should expect?	Thank you for your supportive comment. Following stakeholder consultation the comments received are discussed with the committee and changes agreed to the guideline. Responses are also written to the comments received. Following various quality assurance checks, the guideline and its supporting documentation will be published on the NICE website.
The Advocacy People	Guideline	General	General	There is no reference to the Department of Health & Social Care in the document, and its pivotal role in ensuring people's rights are upheld. Where issues and concerns have been identified regarding people not accessing advocacy support that they are legally entitled to receive, this may point to weaknesses in current legislation which ought to be brought to the attention of government policymakers and inform future proposed amendments to relevant legislation. We wish to ask if this document, and the research and evidence which supports it, is expected to influence government policy going forward? – and via which formal mechanisms would this happen?	Thank you for your comment. As NICE is an executive non-departmental public body of the Department of Health and Social Care in England they do not usually reference the Department of Health and Social Care in the guidance they produce. The Department of Health and Social Care has had the opportunity to see the guideline and comment on it in the current consultation, and can use the guideline to inform changes to policy in future if they wish to do so.



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The Advocacy People	Guideline	General	General	The role of Healthwatch England and Local Healthwatch services is not mentioned in this document. An advocacy provider's interaction with Local Healthwatch is fundamental, especially with regard to sharing information and reporting themes and trends in each local area, thereby influencing change and improvement in health and social care service provision (potentially including better access to advocacy). Furthermore, there is a requirement under the Health & Social Care Act 2012 for Independent NHS Health Complaints Advocacy to link directly into Local Healthwatch, which has not been acknowledged in the document.	Thank you for your comment. Changes have been made based on your suggestion. The committee agreed that the best place to reference Local Healthwatch services was in a recommendation in the evaluating and sharing data sub section of the monitoring section (1.11) of the guideline.



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The Advocacy People	Guideline	General	General	We feel the language used throughout the document ought to be firmer in places. There are several references to situations where health and/or social care professionals "should" refer to advocacy services or where commissioners "should consider" taking certain actions. We wish to comment that where it is a person's statutory right to access advocacy support, those professionals have a legal duty, and "must" refer – and that commissioners "must" take actions where they have a statutory duty to ensure appropriate professional advocacy services are provided. The important distinction between good practice guidelines and legal duties / statutory requirements is not always clear within the document.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. The wording of the recommendations has been checked to ensure that this has been done correctly.
The Advocacy People	Guideline	General	General	Where a Local Authority, or health or social care service provider, is expected to fulfil certain duties and requirements with regards to individuals' access to advocacy, there ought to be a process of evaluating compliance, and of enforcement, in place. The role of the CQC would appear to be crucial in this respect, and we would wish to see recommendations made around the CQC being given stronger powers to hold councils and health and social care providers to account if they do not comply.	Thank you for your comment. It is beyond NICE's remit to recommend that the Care Quality Commission is given stronger powers.



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Stakeholder The Advocacy People	Guideline	Page No 011	Line No 024 - 025	We agree that the individual service user experience should be seamless, but to be accountable for their work, and to be able to report to commissioners on their activities and services provided, an advocacy provider is usually obliged to record a new referral if a different type of advocacy is required, or if a different issue needs to be addressed. Advocacy support is issue-based, and	Developer's response Thank you for your comment. Changes have been made based on your suggestion. The committee discussed this and decided to amend the text to 'systems for handover are not reliant on a new referral' so that new referrals can take place without the person necessarily being aware of this or experiencing disruption.
				advocacy providers have contractual obligations around recording and reporting on individual cases and issues. Furthermore, in certain situations, another advocacy provider may need to be instructed when a different advocacy requirement arises – which would of course require a new referral. The point here is that, although new advocacy referrals may be required, the individual client need not necessarily be aware of this and should certainly not experience any disruption to the continuity of their support.	



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The Advocacy People	Guideline	012	001 - 002	We agree that opt-out IMHA is the preferred model, but this is a resource issue, and it is not just the advocacy provider's responsibility to provide IMHA on an opt-out basis – it is the responsibility of the hospital or mental health unit to facilitate this, and for commissioners to ensure adequate funding is in place to enable it. We also wish to highlight a significant problem facing advocacy providers where Private Hospitals do not operate in the same way as NHS facilities, and they are not monitored by the Local Authority as an NHS hospital/unit would be. A much better information flow from private providers into Local Authorities is needed, so that appropriate and properly resourced advocacy services can be commissioned for all patients in all hospitals.	Thank you for your comment. Changes have been made based on your suggestion. The existing recommendation was amended so that, as well as advocacy providers, those offering IMHA on an opt out basis included hospitals, health trusts and commissioners. When the committee discussed the opt- out recommendation it was felt that although there was likely to be a significant resource impact in the short term it would lead to improved access to advocacy services, and the benefits of these could offset costs in the longer term. The committee also decided to make a new recommendation to ensure that sufficient advocacy services are commissioned to meet statutory duties for people who are detained or deprived of their liberty in independent hospitals, this is in the Planning and commissioning services for advocacy section of the guideline.
The Advocacy People	Guideline	018 019	029 - 030 001 - 002	An advocacy service can and should only take account of health inequalities where it is appropriate to explore this with the client, according to their issue, and depending on the situation. It would be unnecessarily intrusive and would not respect advocacy principles, good practice or GDPR to routinely investigate or discuss someone's health inequalities, if the situation did not warrant this.	Thank you for your comment. The purpose of the recommendation is for health inequalities to be explored when there is a reason to do so. The committee reviewed the wording but did not think it would be interpreted as meaning health inequalities should be routinely investigated.



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The Advocacy People	Guideline	020	005 - 008	We do not feel this extremely important point is addressed strongly enough in the document. Local Safeguarding Adults Boards should not just "think about" ways of working with advocacy providers but ought to be obliged to have advocacy service representation and/or input – with this monitored for compliance by Local Authorities. We have experiences where some Safeguarding Boards do not allow advocacy providers to be admitted as Board members, or even to provide input to Board discussions – and this is not acceptable.	Thank you for your comment. The committee discussed this and decided to amend the recommendation to make it stronger. The committee discussed Local Authorities monitoring compliance of advocacy service representation or input on Safeguarding Adults Boards but decided not to add this to the recommendations as it was felt that this was a niche thing to monitor when various social care related organisations are keen to be represented on Safeguarding Adults Boards.



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The Advocacy People	Guideline	21	004 - 015	It cannot be a duty of the advocacy provider alone to ensure this level of culturally appropriate advocacy is made available. This has significant resource implications and, where required, must be specifically commissioned by the Local Authority. There is a responsibility for ICSs and ICBs to enable this to happen where needed and ensure advocacy services are adequately funded to provide it. We also wish to comment that it is important to avoid creating any situation of "competition" amongst local advocacy services, where multiple advocacy providers operate within the same settings – especially where funding arrangements are complicated or not clear.	Thank you for your comment. Changes have been made based on your suggestion. The committee agreed to amend the recommendation so that it was aimed at commissioners as well as advocacy providers. The recommendation already stated that work should be done in partnership with other organisations to ensure culturally appropriate advocacy, so it would not be the duty of the advocacy provider alone. The committee felt that although there may be resource implications associated with implementing this recommendation it is important to break down barriers to accessing services and building trusting relationships, which improve the effectiveness of advocacy. The aim of the recommendation is not to create competition between local advocacy services but to get advocacy providers and commissioners working in partnership with other organisations.



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The Advocacy People	Guideline	022	015 - 018	There are examples of where Local Authorities DO put a cap on the number of hours an advocate can spend supporting someone or insist on authorising any hours beyond an arbitrary limit that they impose. We believe this is not just a 'bad-practice' matter, but that legislation should be tightened up to make sure commissioners do not have the right to control this and intervene in this way – which clearly compromises an advocacy provider's independence and ability to operate within advocacy principles.	Thank you for your comment. It not within NICE's remit to make changes to legislation. However, we hope that implementation of the recommendations made in this guideline should help prevent the 'bad-practice' that you refer to.
The Advocacy People	Guideline	022	019 - 021	There are examples of where Local Authorities do not allow time for training and CPD or provide sufficient funding to enable advocates to undertake their full professional qualifications. It is not financially viable for many advocacy providers to absorb these costs, so it is important to ensure that service procurement and commissioning arrangements accommodate this.	Thank you for your supportive comment. Changes have been made based on your comment. Recommendation 1.8.9 has been amended and now states: In contracts and specifications when commissioning advocacy, commissioners should take account of the overall resources needed, so providers have enough time and funding for advocates to undertake continuing professional development and training



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The Advocacy People	Guideline	022	022 - 023	We believe that holding the Advocacy Quality Performance Mark (QPM) is a fundamental requirement which underpins everything a quality, professional advocacy service does. This is the only formal accreditation that exists for advocacy providers and ought to be mandatory. Just "considering the benefits" and making QPM optional could open the door to less competent organisations winning contracts, who do not undergo any form of external assessment of the quality of their provision.	Thank you for your comment. The committee understood the importance of the Quality Performance Mark. However, the committee were also aware that some Advocacy organisations may not be in a position to achieve accreditation. NICE guidelines cannot recommend that accreditation is mandatory. Furthermore, NICE guidelines cannot recommend a particular performance mark unless it has fully investigated all relevant accreditation schemes and compared these schemes using all the available evidence. This was not highlighted during the scope consultation as an area to be investigated by the guideline so an evidence review on accreditation was not undertaken during development of the guideline. Therefore the committee decided to make a recommendation about accreditation, using the QPM as an example.



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The Advocacy People	Guideline	025 026	018 - 028 001 - 009	Appropriate training for advocates is fundamental and we would wish this to be more strongly worded as "Advocacy services must be funded to train their advocates in the processes that are relevant to their roles". If not properly resourced within commissioning arrangements, good advocacy organisations with the integrity to provide this training are not going to win contracts because they will not be competitive against other organisations who do not provide the same levels of training.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. Therefore it is not possible to make the change you suggest. The committee had recognised the importance of investment to enable training and had written recommendation 1.9.1 to help enable this.



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The Advocacy People	Guideline	026	010 - 011	Again, the word "should" is not appropriate, since we would strongly argue that professional advocates "must" complete their national Qualification in Independent Advocacy – and advocacy providers must be properly funded to facilitate this.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. The statutory guidance to the Care Act (7.43) states that 'Once appointed, all independent advocates should be expected to work towards the National Qualification in Independent Advocacy within a year of being appointed, and to achieve it in a reasonable amount of time.' The committee noted that the statutory guidance is vague about the timeframe for achieving this qualification and in their experience, 'a reasonable amount of time' is interpreted very differently. Some members of the committee and stakeholders voiced their concern about some individuals or organisations being able to afford to undertake the National Qualification. Therefore on balance the committee decided that the recommendation should be worded as 'should'.



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The Advocacy People	Guideline	027	003 - 006	We wish to ask that the guideline is made clearer that this does not refer to advocacy providers – but to health and social care service providers, who MUST ensure information about advocacy is included in staff induction and training. Furthermore, we would urge NICE and other influential bodies to put pressure on all Universities and Colleges delivering Social Work courses to include advocacy (and the legislation that supports it) as a mandatory part of the curriculum. By delivering and embedding this training much earlier in a person's career, at the university/college stage, this will significantly ease the problem of ensuring social workers have the necessary knowledge and understanding. We also believe the CQC, the Quality Assurance Agency for Higher Education, and Ofsted ought to be tasked with monitoring and enforcing this.	Thank you for your comment. The recommendation is aimed at all providers and commissioners not just advocacy providers. In NICE guidelines 'must' is only used when there is a legal requirement to do something and there is not a legal requirement related to this particular recommendation. NICE cannot put pressure on all Universities and Colleges delivering Social Work courses to include advocacy as a mandatory part of the curriculum since this is beyond NICE's remit. It is also beyond NICE's remit to task the CQC, the Quality Assurance Agency for Higher Education, and Ofsted with monitoring and enforcing this.
The Advocacy People	Guideline	030	012	An advocacy service must only record information about a person's health inequalities if there is a genuine and relevant need to do this. GDPR says that data must only be recorded if it is relevant to what we are doing – and in most cases, it will be unnecessarily intrusive and inappropriate to collect personal social and economic information about clients.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that as it says 'identified inequalities' then the person is not going to be asked intrusive or inappropriate questions, they would just be asked about things that have been made clear to the advocate.



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The Advocacy People	Guideline	030 031	026 - 028 001 - 002	We agree that this is an important responsibility for Local Authorities and commissioners – but we wish to ask what action can be taken if health and social care providers are NOT telling people about advocacy and its access criteria, or if poor access by certain local populations is identified? Again, we believe the CQC ought to play a role in checking that appropriate action is being taken and enforcing this.	Thank you for your comment. The recommendation has been amended to indicate that further steps should be taken if practitioners are not found to be telling people about advocacy. However it was not possible to be prescriptive about what these steps would be as this will be determined by local implementation. NICE does not have a remit to tell the CQC what they should check, although they pay regard to recommendations made in NICE guidelines.
The Advocacy People	Guideline	032	011 - 013	We DISAGREE with this statement. It cannot be a function of the advocacy service to report on other organisations' fulfilment of their statutory duties regarding safeguarding. The advocacy provider's role is only to raise safeguarding alerts and ensure the necessary authorities and agencies are aware of any concerns. What happens after that is not information that would or should be shared with the advocacy service, so there is no way of knowing if statutory duties are being fulfilled by others. An advocacy service will often not even receive an acknowledgement when raising a safeguarding alert – let alone receive an update on what action has been taken – which of course would be highly confidential information, and inappropriate to disclose to the advocacy service.	Thank you for your comment. The committee discussed this but felt that advocacy providers should have a role in reporting to Safeguarding Adults Boards on the extent to which partner organisations fulfil statutory duties for advocacy and safeguarding, as this was an important part in the safeguarding role of advocacy providers. As such no changes have been made to the recommendation based on your comment.



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The Advocacy People	Guideline	032	018	We feel that this must be worded in very much stronger terms. It is a fundamental obligation for commissioners to ensure that failures in the duty to refer to statutory advocacy are addressed. If a person's legal right to receive an advocacy service is being denied, this is an unacceptable breach of statutory duty.	Thank you for your comment. The committee discussed this at length but ultimately decided not to amend the recommendation. In NICE terminology must is only used when there is a legal duty. The committee could see that the recommendation could potentially be changed to must because it is about statutory duties and there can only be certainty these were being adhered to if they were being monitored. But the committee did not feel that all of the text in the recommendation could be classed as a legal duty and they felt that it wasn't compulsory to monitor. Therefore they decided not to amend the recommendation.
The Advocacy People	Guideline	037	009 - 026	We would wish to challenge the statement that there is no economic evidence. For example, The Advocacy People's Veterans' Advocacy Evaluation Report* (co-produced with Plymouth University) and the Healthwatch West Berkshire Homelessness Report have identified the measurable economic and social benefits that can be achieved through supporting individuals and groups to have their voices heard in ways that impact upon decisions made and services provided. We feel the point here is not that there is no evidence, it is that statutory advocacy will always be prioritised over non- statutory services and there is rarely sufficient	Thank you for your comment. Whilst economic evidence was not explicitly requested during the 'call for evidence' for this guideline, if economic evidence was identified and eligible for inclusion (as discussed in the methods supplement) it would have been appraised and included in line with methods for other NICE guidelines. Whilst the 'Our Veterans' Advocacy Evaluation Report' highlighted was submitted as part of the call for evidence, given it was for a specific group of people receiving advocacy it was considered outside of the scope for the purposes of the economic evidence and was not considered in this regard. The text in this section has been reworded to make it


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				funding in Local Authority budgets to adequately resource non-statutory advocacy – and therefore its potential to achieve and measure those economic and social benefits is drastically reduced. We believe Local Authorities ought to be obliged to commission non-statutory/community advocacy because of the pressure it takes off other services. (* Our Veterans' Advocacy Evaluation Report's social return on investment calculations indicate that, for every £1 spent on delivering the advocacy service to military veterans, £4.74 in social value was created)	clearer what was done in regards to including economic evidence. Recommendations have been made in the guideline which should increase awareness of non- statutory advocacy and uptake of it (recommendation 1.2.1). The guideline also recommends commissioning advocacy services based on an assessment of local need which the committee hope will result in more non- statutory services being commissioned.
The Advocacy People	Guideline	038	004 - 028	This section of the document highlights that that there is a significant postcode lottery with regard to how information about advocacy services is made available. There are huge inconsistencies across different Local Authority areas and again, we believe that the CQC ought to have the power to enforce consistent standards across England. Every Local Authority is also different in ranging from funding good non-statutory advocacy services to not commissioning them at all.	Thank you for your comment. One of the aims of the guideline is to address inconsistencies in how information about advocacy services are made available and the recommendations in the Information about effective advocacy and signposting to services section of the guideline seek to address this. NICE does not have the remit to ask the Care Quality Commission to enforce consistent standards across England.



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The Advocacy People	Guideline	040	024 - 029	This is another place where the language needs to be stronger than just saying healthcare providers "should" refer people for non-instructed advocacy. Where a person is eligible and entitled to IMCA support, the provider "must" refer to the IMCA service, as they have a legal duty to do so.	Thank you for your comment. This part of the guideline is discussing the rationale for the recommendations made, not actual recommendations themselves. As such the language used is appropriate. The recommendation that the text is referring to is on Advocates making regular visits to inpatient settings to identify people who would benefit from advocacy and helping them to access it as this in itself is not a legal requirement this particular recommendation contains 'should'. The guideline has a initial section on the Legal right to advocacy and the recommendations there are 'must' recommendations.



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The Advocacy People	Guideline	041	General	This page highlights many of the main issues and points that we wish to raise around training, funding, and unfulfilled statutory duties. Training and understanding of many health and social care professionals means that referrals to appropriate advocacy services are often made too late or not at all. Making people aware of advocacy provision that is available to them often does not happen – and the advocacy service itself cannot do this for everyone as it will, for example, only become aware of a person in a care home who is eligible for Care Act Advocacy if that person is referred. Health and care services do not routinely make people aware of non-statutory community/group/peer advocacy – but sadly, even if they do, there may not actually be a non-statutory service funded and commissioned in their area. This all points to the need for legislation to be tightened up, for advocacy services to be properly funded, and for mechanisms of monitoring and enforcement to be put in place.	Thank you for your comment. Implementing the recommendations from the guideline should help enable the improvement of advocacy service provision so that some of the issues with advocacy that you mention may be overcome. Implementing the recommendations in the Training and skills for health and social care practitioners who work with advocates section (1.10) should improve health and social care practitioners understanding of advocacy, and help them understand when to make a referral. It is not within the remit of NICE guidance to change legislation of affect the amount of funding given to services. However the recommendations in the Planning and commissioning services for advocacy section of the guideline highlight specific areas where commissioning could improve the provision of advocacy.
The Advocacy People	Guideline	042	006	There is reference to the responsibility of healthcare practitioners, but this also applies to Social Care professionals.	Thank you for your comment. This change has been made.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Advocacy People	Guideline	043	019 - 021	The longer-term benefits of investing more in advocacy, and in initiatives such as opt-out IMHA, ought to be analysed and promoted in a more serious way (Department of Health & Social Care role?), so that commissioners can clearly see and understand the cost benefits and value for money that can derived from funding advocacy services appropriately.	Thank you for your comment. It is beyond the remit of NICE guidelines to tell the DHSC what analysis to undertake and what initiatives to promote.
The Advocacy People	Guideline	043	030	The problem of Care Act Advocacy referrals being made too late could be easily addressed at source, through ensuring proper training on advocacy, and the legislation that underpins it, is provided for all undergraduate Social Workers at university/college – before they begin to practise.	Thank you for your comment. It is beyond NICE's remit to recommend the content of undergraduate curriculums. However recommendations have been made that should ensure health and social care professionals understand who is eligible for Care Act advocacy and how to make referrals.
The Advocacy People	Guideline	045	005 - 008	We STRONGLY agree with this statement. The long-term benefits of providing advocacy support in all discussions and meetings need to be promoted so that commissioners understand the value for money that proper investment in advocacy services can yield.	Thank you for your supportive comment.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Advocacy People	Guideline	049	020 - 022	We strongly believe in the value of helping people with lived experience to become advocates, and the first step towards this is usually to support them through volunteering. Commissioners need to understand, however, that volunteers are not a 'cheap option' for providing services. Volunteer advocates must be trained to a high standard, looked after and nurtured – and their needs must be addressed. It is important to acknowledge that 'helping them' does not come without a cost.	Thank you for your comment. There is a recommendation at the end of the Planning and commissioning services for advocacy section of the guideline itself aimed at ensuring that volunteers are trained and given adequate support and supervision, as the committee felt that this does not happen in practice. Currently there are inconsistencies in the amount of training provided for volunteer advocates so there may be additional costs associated with this. The amount of training needed will depend on the role and responsibility of individual advocates and the needs of the population in their local area. It is not anticipated that all volunteer advocates will need training in all the processes and areas. Training volunteer advocates will ensure that the required service standard is met, and there might also be improvements from reduced complaints.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Advocacy People	Guideline	051	004 - 018	This is a much wider issue and advocacy services cannot address this challenge alone – and will struggle to make any impact if not resourced adequately to meet the need. The whole of society needs to be involving minority cultural groups in a more inclusive way and, since most advocacy referrals come from health and social care professionals, they in particular need to be thinking and working in a more culturally appropriate way. Much better overall joined up thinking, working, and funding is needed to tackle this properly, and it cannot be left to under-resourced advocacy providers alone to come up with the solutions.	Thank you for your comment. Although this is a wider social issue, the guideline makes recommendations that specifically relate to advocacy services, such as the recommendation that advocacy services should support their staff to develop cultural competence to meet the needs of the populations in their local areas by training, supervision and reflective practice. There is also a recommendation in the Training, support and skills for advocates section of the guideline on Commissioners and advocacy providers working with public bodies and providers to increase investment in training for advocates so that they are trained and competent to support people from a variety of backgrounds and with a variety of needs.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Advocacy People	Guideline	053	014 - 020	The way this paragraph is worded concerns us. Who is saying that it would be in the person's best interests to involve family and carers more? Could that involvement actually serve the interests of the family or carer more, rather than the person? An independent advocacy service must not be making judgements on best interests, and it is not for the family to decide what is in the person's best interests either – this all depends on whether the person themself wants that involvement. The advocacy service should play an important role in providing clarity on where families/carers can be appropriately involved. It is very important to understand that there are often conflicts within families, and advocates cannot always collaborate with families and carers because they work in a client-led, person-centred way. Applying the basic principles of advocacy and putting the person's wishes and feelings at the centre of the process may often mean that such collaboration/involvement is not appropriate.	Thank you for your comment. A change has been made based on your suggestion. The text has been amended to make it clearer that cooperation with families and carers should only happen when the person wants them to or when the person cannot express a view about this but it is in their best interests. This text mirrors that used in the recommendation which the committee discussed at length in response to various stakeholder comments and decided was the text that was appropriate to use.



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Advocacy People	Guideline	055	025 - 030	We believe this is a much wider and more complex issue that requires further discussion and analysis – and an advocacy provider's limited size and resources must be taken into consideration. It is of course essential that advocacy services do reach into all diverse communities in a culturally appropriate way. However, advocacy providers must be seen to be independent, and co-location alongside one particular community or culturally specific service needs to be thought through very carefully, to ensure that the advocacy service is not compromising its independence by doing so. There will be many different ethnic and cultural groups within any given locality, so which of these groups should the advocacy provider choose to co-locate with? Could this put other groups at a disadvantage, or might they perceive it that way? As much as possible, an advocacy provider should certainly seek to reflect the community which it serves through who it employs and who it supports to volunteer – but local advocacy services are relatively small and cannot employ/involve everyone in service provision. It will therefore be extremely difficult to ensure that a particular ethnic group representing a very small percentage of the	Thank you for your comment. The committee discussed the points raised in the comment but felt that the text did not need to be amended as it simply covered the expert testimony that was provided to the committee and the committees response to the testimony. The committee felt that co-location if carried out in the correct manner would not compromise the independence of the advocacy service and noted that there is recommendation on how advocacy providers can maintain independence in the Effective Advocacy section of the guideline. The committee also noted that the mention of co-location in the recommendation related to this text was as an example. The committee felt that although there may be resource implications associated with implementing this recommendation it is important to break down barriers to accessing services and building trusting relationships, which improve the effectiveness of advocacy.
				who it employs and who it supports to volunteer – but local advocacy services are relatively small and cannot employ/involve everyone in service provision. It will therefore be extremely difficult to ensure that a particular ethnic group	



Stakeholder	Document	Page No	Line No	Comments	Developer's response
				culture reflected within the advocacy provider's workforce. We would argue that proactive and respectful collaboration and partnership building, nurturing community relationships and developing trust and understanding of advocacy, within the widest possible number of different ethnic and cultural groups across a locality, is the key – rather than focusing on co- location and workforce recruitment. Providing advocacy skills training for individuals from each local community – so they can then share what they have learnt and inform/support their peers and family members – may be an effective approach for advocacy services to take.	
The Advocacy People	Guideline	063	025	It is stated that there 'may' be additional costs – but any training, whether for staff or volunteers, involves people's time and comes at a price, so there 'will' be additional costs.	Thank you for your comment. When discussing this recommendation the committee highlighted that some organisations are already providing training for volunteers so for these organisations there will not be any additional costs, whilst for other organisations who aren't currently doing this there will be additional costs. The use of 'may' is therefore appropriate in the text.



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The Advocacy People	Guideline	063	028 - 029	Has this paragraph been written with the meaning that was intended? We do not understand the logic of the statement: "Training volunteer advocates will ensure that the required service standard is met". There are many systems, processes, and procedures that a good advocacy provider must have in place to ensure required standards are met, and volunteer advocates will generally need just as much supervision and performance monitoring as paid staff.	Thank you for your comment. The paragraph is looking at the impact recommendation 1.9.8 may have. It discusses how the recommendation may affect practice and justify why although there might be costs involved or changes to practice it is worth training, supporting and supervising volunteers. It was felt that one of the benefits of training volunteers was that it will help advocacy providers achieve the required service standard.
The Challenging Behaviour Foundation (The CBF)	Guideline	002 - 006	General	Training, skills and support for advocates We agree with Rec 1.9 that there should be increased training for advocates. However, we a concerned training is not always sufficient, and therefore this recommendation needs strengthening. The guidelines do not allow for sufficient training and implementation time for advocates for adults with severe learning disabilities. Individuals from this group too often receive inconsistent or ineffective advocacy, which fails to fulfil the role set out in the MHA Code of Practice. Additional training is necessary for professionals and advocates to recognise what advocacy is, I.e., that advocates do not speak for the patient. Advocates must authentically relay a patient's wishes, and do not speak or make decisions on their behalf.	Thank you for your comment. Recommendations in NICE guidelines can only use the word 'must' when there is a legal duty to do so. As such it is not possible to make the wording of the recommendations in section 1.9 any stronger than they currently are. It is hoped that implementation of the recommendations made in section 1.9 and 1.10 should improve the training that professionals and advocates receive. When developing the guideline the committee purposely decided not to make the recommendations condition specific so that they were inclusive, although specific examples have been used where it was felt to be beneficial. The committee felt that the guidance does cover the needs of individuals with severe learning disabilities in the context of Advocacy and will help enable this group to receive effective advocacy. In



Stakeholder	Document	Page No	Line No	Comments	Developer's response
				The guidance does not properly recognise the needs of individuals with severe learning disabilities and how to make sure they receive effective advocacy. This advocacy guideline must be linked to existing NICE guidance to ensure individuals receive the right support, in particular: <u>Overview Disabled children and</u> young people up to 25 with severe complex <u>needs: integrated service delivery and</u> organisation across health, social care and education Guidance NICE <u>Overview Learning disabilities and behaviour</u> that challenges: service design and delivery <u>Guidance NICE</u> <u>Overview Challenging behaviour and learning</u> disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges Guidance NICE	addition, recommendation 1.9.3 has been amended to specifically reference training in specialised communication skills which will be relevant to those with severe learning disabilities. Links to specific NICE guidance about conditions or circumstances where advocacy is likely to be helpful have been added to the Advocacy guideline.



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The Challenging Behaviour Foundation (The CBF)	Guideline	004	013 - 015	What is an Advocate Whilst we agree with definition of an advocate provided in the draft guideline, we know from our experience supporting families with a relative with severe learning disabilities whose behaviour challenges that families often have to act as advocates for their relatives. The guideline should recognise families' roles within advocacy to ensure that this guideline will be effective.	Thank you for your comment. The committee agreed that family members play a vital role in advocacy and amendments to the context section have been made to reflect this. However, the focus of this guideline is on a trained person whose sole involvement is as an advocate and so recommendations have not been made about family members undertaking advocacy.



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The Challenging Behaviour Foundation (The CBF)	Guideline	006 - 008	009	Legal Right to Advocacy Box 1 sets out the current legal entitlement to advocacy and the relevant acts. However, the law could be improved to offer better support for family carers who are advocates for their relative and this needs to be reflected in the guidance. The revised code of practice for the Mental Health Act 1983 provides guidance for professionals. The Mental Health Act Code of Practice (MHA CoP) recognises family carers' knowledge of their relative but does not recognise their potentially vital role in understanding a patient's communication, and nor does it statutorily require this – for instance, by requiring Independent Mental Health Advocates (IMHAs) to consult family carers when assessing a patient's needs and wishes. Therefore, whilst we agree with the guideline's summaries of each act, we feel that it should recognise the vital role of families.	Thank you for your comment. The committee discussed this but decided not to amend Box 1 in the Legal Right to Advocacy section as it was felt that this simply describes the law as it is and not how it can be improved or should be practiced. The committee did decide to add some text to the context section of the guideline highlighting the vital role that family members and friends play in the lives of people who draw on support, whilst reiterating that the focus of this guidance is on a trained person whose sole involvement is as an advocate.



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The Challenging Behaviour Foundation (The CBF)	Guideline	009	002	Who else may benefit from Advocacy We support Rec 1.2.1 that advocacy should be provided to people who are not covered by the legal entitlement but would still benefit from it. There is a systematic assumption that if patients have the capacity, they can advocate for themselves. However, this is not necessarily the case. We suggest that family carers of adults with severe learning disabilities whose behaviours challenge should be highlighted as individuals who may well benefit from advocacy even if they have no legal entitlement. We know that families often have to fight to ensure their relative receives appropriate care and support – and that often this has a serious negative impact on their wellbeing. The psychological trauma suffered by family carers of children and adults with a learning disability and/or autism when the system fails to support their relative is highlighted in our report 'Broken: The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required' Broken CBF final report (challengingbehaviour.org.uk)	Thank you for your comment and highlighting the reports. The committee decided not to add illustrations of who might benefit from non-statutory advocacy to recommendation 1.2.1. In the committee's experience the reasons that a person may benefit from advocacy are related to their circumstances or situation rather than their personal characteristics. Therefore, the committee focused on defining these circumstances in the recommendation. In addition including a list of groups in the recommendation could have been interpreted as being an exhaustive list, resulting in some people not being given access to non-statutory advocacy because they were not listed.



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				And by Peter Baker et al. in (Baker, P., Cooper, V., Tsang, W., Garnett, I., & Blackman, N. (2021). A survey of complex trauma in families who have children and adults who have a learning disability and/or autism. <i>Advances in</i> <i>Mental Health and Intellectual Disabilities</i>) This evidence of secondary trauma experienced by family carers demonstrates the importance of access to good quality experienced advocacy for family carers.	



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The Challenging Behaviour Foundation (The CBF)	Guideline	009 - 010	General	Information about effective advocacy and signposting to services We agree with the recommendations in this section that outline what information individuals are legally entitled to. We further support Rec 1.3.4 which outlines reasonable adjustments that can be made to make this information accessible to individuals with a variety of needs, such as easy read versions. However, we would suggest that within Rec 1.3.4 or as a stand-alone recommendation it must be made clear that for individuals with a severe learning disability it may also be appropriate to share all this information that they are legally entitled to with their family carer. We know that family carers are the people that know their relative best and, in many cases, act as an advocate for them. Therefore, it is important that they are given the same access to information and that this is a legal entitlement for them as well as their relative.	Thank you for your comment. The existing recommendation has been amended to include providing information to families or carers. It is beyond the remit of NICE guidelines to recommend that it is a legal requirement for family carers to be given access to information.



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Stakeholder The Challenging Behaviour Foundation (The CBF)	Guideline	Page No 011	Line No 004 - 006	Comments Improving Access to Advocacy We suggest an addition to this recommendation that health and social care providers must make reasonable adjustments when providing advocacy for adults with severe learning disabilities who may not communicate verbally. It may take longer for advocates to get to know and build relationships with individuals who do	Developer's response Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that this particular recommendation was about advocates meeting people in person to support them to make initial contact with advocacy services. The committee also felt that another recommendation in the Enabling and supporting effective advocacy section of the guideline already covered adequate time for the
				not communicate verbally. Therefore, providers must ensure advocates can meet adults' multiple times in the process to support them to begin formally accessing advocacy services.	advocate and person to build relationships and trust according to their individual needs.



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The Challenging Behaviour Foundation (The CBF)	Guideline	011	021 - 025	Improving Access to Advocacy We support Rec 1.4.5 that advocacy providers should aim to support continuity by offering people the same advocate for different types of advocacies. However, for this to be effective it means that advocates must be sufficiently knowledgeable of all different types of advocacies which will require advocates to have existing training, knowledge and experience. Additionally, there needs to be consideration about the individuals needs when they are assigned an Advocate, for example, an individual with a severe learning disability would be provided with an advocate who has knowledge/experience of learning disabilities for this to be most effective to the individual.	Thank you for your comment. There are recommendations in the Training, skills and support for advocates section of the guideline on advocacy services providing training, skills development and support to advocates which should help enable advocates to be sufficiently knowledgeable of different types of advocacy. It is beyond the remit of the guideline to cover how advocates are assigned, however understanding individual needs is a key component of advocacy, as highlighted in the person centred recommendation in the Effective advocacy section of the guideline.
The Challenging Behaviour Foundation (The CBF)	Guideline	013 - 014	001 - 005	Enabling and supporting effective Advocacy The recommendation 1.5.7 mentions supporting any communication needs. However, it should specify that for individuals with a severe learning disability, practitioners may need to introduce the advocate to the specific methods the individual uses to communicate and highlight any family members or support workers it might be helpful to consult with when advocating for the individual. The recommendations do not consider the needs of	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that as the bullet point in the recommendation already stated "supporting any communication needs" the specific needs stated were encompassed by this. Various examples with equal validity, such as the one stated in the stakeholder comment, could have been used in the recommendation but the committee felt that the example that was already used "arranging an interpreter" was a useful example to use in this particular recommendation. The committee felt that the



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				adults with severe learning disabilities who may not communicate verbally and how they may express themselves and what they want differently and in a way which is not immediately recognisable. Adults with a learning disability may find it difficult to understand the options available to them in each situation, and what they can and cannot do. For all adults with learning disabilities supported by health and social care, including adults who are admitted to mental health hospitals and whose daily lives are restricted by the Mental Health Act 1983, it is vital that they are aided in their communication of, and understanding of, what they want to do and what they can do in their current situation. Therefore, advocacy should: •aid an individual's understanding of their rights, including their rights under the Mental Health Act as appropriate) •ensure that people's rights are upheld (including rights under the Mental Health Act if appropriate) •ensure that people received appropriate support, care and treatment, including in hospital if appropriate •ensure that their needs and wishes are understood beyond their current setting. For example, an adult with learning disabilities currently living in a mental	rest of the comment is more about what the advocates role is whereas this particular recommendation is about what the health and social care practitioners should do to facilitate advocacy.



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				health hospital setting might aspire to live in the community and not in the hospital	



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The Challenging Behaviour Foundation (The CBF)	Guideline	016	General	Effective Advocacy The recommendations do not effectively consider that in order to be effective, advocacy must be long-term and not issue-based. This is particularly important when advocating for adults with severe learning disabilities where it may take longer to develop a relationship between the individual and the advocate. In addition, if individuals with severe learning disabilities have limited verbal communication, it will be extremely beneficial for their advocate to have knowledge of their previous experiences/ reasons for requiring advocacy. The result of 'issue-based advocacy' is that the advocate is unlikely to get to know the individual they are advocating with. The advocate is, therefore, less likely to understand how, and why, the patient is in crisis. Issue- based advocacy also restricts advocates, including IMHAs to only discussing the patient's care in the short term and prevents them from planning for the care and support required for the patient's preferred future lifestyle and home. Consequently, issue-based advocacy prevents advocates, including IMHAs from having a positive impact on a individual's long-term wellbeing	Thank you for your comment. The committee discussed this and felt that it was an important point that needed raising. It was felt that a lot of advocacy was issue- based, there were a number of reasons behind this and that long-term solutions were needed. However, the committee also felt that as this was a wider issue and advocacy that is issue-based can be beneficial to people it was not useful to add anything that specifically prevented issues based advocacy. There are a number of recommendations in the guideline that go some way to addressing the points made, such as a recommendation in the Enabling effective advocacy section of the guideline on ensuring that there is adequate time for the advocate and person to build relationships and trust according to their individual needs. A new recommendation has been added in the Planning and commissioning services for advocacy section of the guideline on commissioning bodies working together to agree and publish a long-term plan for advocacy based on the assessment of need. The committee felt that this recommendation could enable advocacy providers in turn to take longer term views of the advocacy they provide.



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The Challenging Behaviour Foundation (The CBF)	Guideline	016 - 017	005 (pg. 016) 014 - 031 (pg. 016) 001 - 002 (pg. 017)	Effective Advocacy It should be clear that physical accessibility includes making sure the environment is adapted to an individual's sensory needs. This might include making sure there are no loud noises or bright lights We agree with the points listed in Rec 1.6.2 on what effective advocacy should look like. Good advocacy is long-term and must be provided by an independent advocate, who understands a person's communication, needs, and preferences, who are willing and able to challenge decisions and involves those who know the individual for example, their family members.	Thank you for your comment. The committee decided to amend the first recommendation in the effective advocacy section of the guideline, with the bullet point on meeting places broadened to cover accessibility generally rather than just physically. Thank you for your supportive comments on recommendation 1.6.2.
The Challenging Behaviour Foundation (The CBF)	Guideline	018	004 - 023	Effective Advocacy We agree with Rec 1.6.9 that Advocacy providers should maintain independence from any other organisations, to avoid any conflict of interest. However, we know this is often not the experience of adults with learning disabilities and their families where hospitals have employed their own advocates. In these situations, the independence of advocates provided by hospitals is compromised (if they are employed by a patient's hospital provider). The guideline should be aware of this issue and	Thank you for your comment. The recommendation that advocacy providers should maintain independence from other organisations, as well as other recommendations in the guideline that highlight the independent role that advocates play, should help enable advocacy services to improve in this respect.



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				make it clear that this is not proper independent advocacy.	



Stakeholder	Document	Page No	Line No	Comments	Developer's response
The Challenging Behaviour Foundation (The CBF)	Guideline	019	017 - 023	Partnership working and relationships with families and carers, commissioners, and providers We agree with Rec 1.7.1 that advocates should consult with family members and carers when the person wants them to or when the person cannot express a view about this, but it is in their best interest. There are still ongoing issues with the way that advocates work with families and carers. Families have told us (from a focus group delivered by the CBF): •that their relative's voice was not heard, •that advocates were unlikely to challenge decisions made by professionals, •that advocates failed to keep family carers 'in the loop' or to deliver effective advocacy that resulted in good outcomes.	Thank you for your comment. Implementing the recommendation on advocates liaising with family members or carers, which includes the examples of seeking information from, or sharing information with, families should help overcome some of the issues that the comment raises, such as the relatives voice not being heard or advocates failing to keep family carers in the loop.



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Stakeholder The Challenging Behaviour Foundation (The CBF)	Guideline	Page No 029	Line No General	Monitoring services and collecting data for quality improvement. There are still issues with advocacy which is reflected in recent data. In December 2021 (https://www.bbc.co.uk/news/uk-england- 59733934) the BBC investigated Tony Hickmott's 20-year stay at an ATU, and his repeated attempts to express that he wanted to go home and live somewhere else, we are reminded that helping people with learning disabilities express how, and where, they want to live their lives is crucial to their wellbeing.	Developer's response Thank you for your comment and sharing this information. Implementing the recommendations from the guideline should help enable the improvement of advocacy service provision so that some of the issues with advocacy that you mention may be overcome.
				Independent Mental Health advocacy is not only designed to help inpatients understand their rights but also to promote their wishes and aspirations to prevent them from becoming "a	
				shadow of what [they] used to be". NHS Digital data shows that at the end of May 2022 there were 2,010 inpatients with learning disabilities	
				and/or autistic inpatients in mental health hospitals in the UK. <u>https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-may-2022-mhsds-march-2022-final#</u>	



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The Down's Syndrome Association	Guideline	General	General	We are generally supportive of the recommendations outlined in the guidance and we would acknowledge the importance of advocacy services for individuals who have Down's syndrome (and their family carers, who may access advocacy on their behalf).	Thank you for your supportive comment.
The Down's Syndrome Association	Guideline	General	General	We would stress the importance of advocacy services encompassing both advocacy and self- advocacy approaches. Many individuals who have Down's syndrome have developed the skills to empower them to advocate for themselves and speak-up when they need to. The development of these skills often require significant support and the funding for these services are frequently limited.	Thank you for your comment. The committee discussed this but decided not to amend the existing recommendations as it was felt that the guideline scope set out that the guideline was about advocacy conducted by a third person. Some existing recommendations did cover self-advocacy, such as one in the Improving access to advocacy section (1.4) of the guideline which says that Advocates should raise awareness of self-advocacy options. Another existing recommendation in the Effective advocacy section (1.6) of the guideline on ensuring advocacy services are person centred highlights the need to support and help the person to self-advocate. In response to a separate stakeholder comment the committee decided to add a new recommendation to the Planning and commissioning services for advocacy section (1.8) of the guideline on commissioning bodies working together on long term planning that included various advocacy approaches, including self-advocacy.



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The Down's Syndrome Association	Guideline	General	General	In terms of who could benefit from advocacy services for adults who have health and care needs, this obviously includes those individuals who are subject to a DOLS notice and we are aware (and have responded separately to the recent consultation) that these will be changing to a LPS system and scope extended to younger people aged 16 and 17 and will apply in situations where care is provided in peoples' homes. It is essential that adequate advocacy services be provided to this group, especially as all parties will need to understand the new framework of assessment and reviewing. We expressed concern in our consultation response of the timing of introduction of these changes, against a backdrop of COVID recovery work and workforce shortages.	Thank you for your comment. The committee discussed this but decided not to amend the guideline as the introduction of Liberty Protection Standards has currently been postponed. The surveillance team at NICE will be notified that changes to legislation will impact on the guideline.



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The Down's Syndrome Association	Guideline	General	General	Another key group for whom access to advocacy services is essential are people who have a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition and are accommodated in hospital settings. The Transforming Care agenda has begun to address some of the pressing issues relating to the nature and quality of this provision, but we note that cross-government action plan on Building the Right Support was delayed several times and has just been published. We would hope to see a significant focus on advocacy for these individuals who are otherwise at greatest risk of marginalised	Thank you for your comment and highlighting this information.



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The Down's Syndrome Association	Guideline	General	General	As an organisation that provides information and advocacy support to individuals who have Down's syndrome and their families, it is our experience that many families find navigating	Thank you for your comment and providing this information. The committee were aware of the vital role that family members and friends play in the lives of people who draw on support, for example ensuring that
				the system around becoming an appointee or deputy for health and care extremely daunting and confusing. Whilst there should always be a presumption that an individual who has Down's syndrome is able to make decisions for themselves, many people will need some help	the person's voice and concerns are heard. However, the focus of this guidance is on a trained person whose sole involvement is as an advocate and so no changes have been made based on your comment.
				to do this. We have produce some resources to help families support their relative who has Down's syndrome make decisions	
				https://www.downs-syndrome.org.uk/wp- content/uploads/2021/02/Quick-Guide- Supporting-me-to-make-a-decision.pdf	



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The Down's Syndrome Association	Guideline	General		We are concerned that, whilst the COVID pandemic necessitated new ways of working in a socially-distanced way, many services have been very slow in moving back to face-to-face delivery. A blended approach has been beneficial for many people, but it is our experience that the majority of individuals who have Down's syndrome do benefit from face-to- face contact with the professionals supporting them and hope that there will be a move to usual patterns of service delivery now that vaccinations and new antiviral treatments have made this far safer for people who were previously recognised as being Clinically Extremely Vulnerable (this includes adults who have Down's syndrome).	Thank you for your comment. The committee was aware of the importance of face to face meetings and had covered this in recommendations 1.6.1 and 1.4.1
The Down's Syndrome Association	Guideline	008	General	Pg 008 – onwards Where mention is made the legislation framework which outlines specific groups for whom advocacy services should be made available, we would highlight that in April 2022, the Down Syndrome Act received Royal Assent (and whilst guidance has yet to be drafted) it will be important that this Guideline includes references to public bodies statutory duties in relation to this Act, too.	Thank you for your comment. As the Down Syndrome Act has yet to be drafted it is not possible for the guideline to reference public bodies statutory duties in relation to this Act. The surveillance team at NICE will be notified that this change in legislation may impact the guideline.



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The Down's Syndrome Association	Guideline	016	007	We fully endorse the need for public agencies, especially the NHS, to make available resources in Easy Read. We note the current review of the Accessible Information Standard being carried out by NECS. We have participated in that and additionally facilitated some Focus Groups involving adults who have Down's syndrome in order to feed-into this. We know that this (yet to be published) report makes some stinging criticism of the way in which the AIS is being implemented nationally. It is imperative that the findings from that review are taken into account when strengthening guidance to public bodies about access to advocacy services. People will only be able to access these services if information about how to do so is made available to them in ways they can access.	Thank you for your comment and information about the review and unpublished report. There is a recommendation in the Information about effective advocacy and signposting to services of the guideline on ways that information can be provided which also has cross references to further NICE guidance on communicating and providing information. The recommendation contains a non-exhaustive list of examples.



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The Down's Syndrome Association	Guideline	033	0019	We highlight the widely acknowledged health inequalities experienced by people who have a learning disability evidenced by successive LeDeR (now Learning from Life and Death Reviews) programme. We would like to have seen specific mention made of the Oliver McGowan learning disability awareness training, which is beginning to be rolled out for health and care staff across England – it is important that the widest range of professionals are aware of the risks these health inequalities pose and are mindful of addressing these in their professional practice e.g. through easy access to advocacy services for the individuals who have a learning disability accessing their services.	Thank you for your comment. The terms used in the guideline section gives focussed definitions of particular terms used in the guideline. The committee decided that recommendations on training should be based on the procedures or skills relevant to the Advocates role and should be generic in nature, rather than specific. The Oliver McGowan training is about disability awareness so not specifically relevant to advocacy. The recommendations in the guideline should improve current practice so that people do get access to advocacy which will address the health inequalities.
The Older People's Advocacy Alliance	Guideline	General	General	All evidence. Overall, OPAAL welcomes the steps that NICE is taking to recognise and consider the value of independent advocacy and look forward to seeing how these ideas can be realised and delivered as real actions. OPAAL as an advocacy membership organisation stands ready to assist NICE in the delivery of these actions in a number of ways, and is grateful to the committee for their thoughtful and considered responses to some very difficult questions.	Thank you for your supportive comment.



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The Older People's Advocacy Alliance	Evidence review A	General	General	In this document, we are concerned that by attempting to strictly define those who are entitled to statutory advocacy, you are possibly allowing for a misrepresentation of the situation which applies to the whole population, i.e. that if a person has difficulty expressing their needs and wants, they should be informed of, and encouraged to access some form of independent advocacy. This can be informal advocacy. As you go on to highlight in later documents, the legal definition of "person benefitting from advocacy" is far too narrow. For example, many older people will not qualify for statutory advocacy under the legal terms as you describe, but they can become vulnerable, even if just for a period, as different life events occur. These people must have access to independent advocacy so that their needs and wants are reflected in any service that is delivered to them. We think this is a missed opportunity to embed informal advocacy as a standard practice into all care settings.	Thank you for your comment. 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 and 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. In addition and in recognition of the issues you highlight they made a further recommendation that advocacy should be offered to people who are not covered by the legal entitlement but who would otherwise not be able to express their views or sufficiently influence decisions that are likely to have a substantial impact on their wellbeing.



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The Older People's Advocacy Alliance	Evidence review A	General	General	Appendix F - Table 8 "The evidence also emphasised the value that residents place on support from family, friends or advocates in helping them achieve their desired outcomes." Very disappointed that you have rejected this recommendation, even though the evidence emphasises the value that individuals place on informal advocacy. Your decision could be construed as making these guidelines designed to support clinicians and service providers, and not those who are supposed to benefit from the services provided. This is not what we were hoping for. Informal advocacy is well documented (and we can provide training to the committee if they are unfamiliar with it) and can very easily be defined to make for clarity to service providers. Therefore, to limit the premise to those who meet certain legal definitions when patient safety, wellbeing and happiness is at stake, is very much a missed opportunity to improve matters for all beneficiaries.	Thank you for your comment. The sentence to which you refer is not a recommendation but it is part of the evidence underpinning a recommendation made in another NICE guideline, on Safeguarding adults in care homes. The recommendation from that guideline that the committee were considering actually referred to certain actions that should be undertaken by organisations involved with safeguarding adults in care homes. The committee felt those points were already covered by their recommendations, for example the concepts of understanding the role of advocacy in relation to safeguarding and knowing when to refer people and also involving an independent advocate as legally required. The important role of families and friends is addressed in many of the recommendations in this guideline but 'informal advocacy' per se was outside the scope of this guideline.



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The Older People's Advocacy Alliance	Evidence review B	011	012 - 018	"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 identified through recognising the circumstances described." We are extremely disappointed that the committee has recognised the need for advocacy to be provided onto a far wider basis, but has not backed this up with any form of clear recommendation to support this principle and embed it into the provision of all services. We do not see how an "implied" identification process will be powerful enough to bring about behavioural change, or greater understanding of the availability and benefits of independent advocacy, be it informal, statutory or paid for by the beneficiary. We would strongly urge the committee to reconsider this point, as it affects an enormous amount of people and a positive change would be hugely advantageous.	Thank you for your comment. The committee do recognise the important points you make but as you say, without any existing NICE recommendations or any statements drafted for formal consensus they were unable to specifically recommend advocacy beyond those statutory entitlements. However they did make a further recommendation that advocacy should be offered to people who are not covered by the legal entitlement but who would otherwise not be able to express their views or sufficiently influence decisions that are likely to have a substantial impact on their wellbeing or the wellbeing of someone they have caring or parental responsibility for.



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The Older People's Advocacy Alliance	Evidence review B	093	General	Appendix G - Point 8 "Advocacy services should be available especially for people who are in residential settings." Post COVID19 this matter should be addressed as a matter of great urgency and residential settings should be compelled to promote the availability of independent advocacy for all residents. OPAAL are already working towards this outcome with our "Advocacy Checklist" initiative that we are waiting to launch.	Thank you for your comment. The recommendation about providing information to people who are entitled would apply in care homes since residential settings are encompassed within health and social care settings. It is not within the remit of NICE guidelines to compel certain action, unless of course it is already a legal requirement.
The Older People's Advocacy Alliance	Evidence review B	094	General	Appendix G Point 12 "People who don't have family need access to advocacy so they can benefit from self-directed support." The numbers of people ageing without adult children to support them in their later years is staggering. This needs to be looked at as a matter of great urgency.	Thank you for your comment. The committee agree about the important role of friends and further emphasised this by, for example, making explicit reference to friends (as well as families and carers) in the context of partnership working with commissioners and providers of advocacy.
The Older People's Advocacy Alliance	Evidence review C	009	046	"Further, in the committees' experience, providing people who are not legally entitled to advocacy but who may benefit from advocacy services with information is also very important but this is not happening consistently". Whilst we agree with the principles of this comment, the fact that it is based on the "committees experience" is frustrating, as so much evidence to support the benefits of independent	Thank you for your comment and for your support for the committee's discussions. NICE committee members are selected for their knowledge and experience and they include lay members who champion the perspectives of people who use services, carers or the public. Their expertise does not constitute evidence as such but it makes an important contribution to collective decision making and recommendations agreed through informal and formal consensus. The committee's


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				advocacy has been ruled out by you, including our own OPAAL reports, as they are based on "case studies". We find it hard to understand how some people's experiences i.e that of your committee members is acceptable as evidence, but the experiences of ordinary people are somehow viewed as of lesser value, even though they have direct, first-hand experience of what you are recommending. We urge you to go back through the evidence and include all studies based on case-studies as when it comes to the human experience there needs to be inclusion of qualitative measures. To the broader point made here, as OPAAL we agree though that much more must be done to promote knowledge and understanding of advocacy and we hope to work more closely with NICE going forwards to help achieve this aim. We will await final publication of these guidelines before sharing our future plans with you.	expertise is particularly valuable in helping them to interpret the evidence presented to them and corroborate or question the findings. In the case of this guideline, the evidence presented to the committee comprised of existing NICE guidelines, statements derived from relevant national reports and a call for evidence. In keeping with a systematic methodology, the call for evidence was made using inclusion and exclusion criteria and one of the exclusion criteria was 'Publications based on non-systematic review or case- studies', which is why the reports you mention could not be included. However please be assured that the expertise of all relevant stakeholders, including people using services and their families, contributed to this guideline, represented as they were on the expert committee as well as in the wealth of statements derived from the call for evidence and additional evidence identified by the guideline committee, which provided the source material for the formal consensus process. The expertise of people using services was also reflected in the recommendations from related NICE guidelines, which also contributed to the recommendations in this guideline.



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The Relatives and Residents Association	Guideline	General	General	The guidance should include reference to the vital importance of support from relatives and carers (as identified above) and recommend that people needing support should have the same right to access a family advocate as a 'formal' advocate (in private, face-to-face etc).	Thank you for your comment. The committee made a change based on your suggestion adding some text to the context section on the vital role that family members and friends play in the lives of people who draw on support. The committee decided not to recommend that people should have the same right to access a family advocate as a formal advocate as it was felt that although family members and friends play a vital role in the lives of people who draw on support, the focus of this guidance is on a trained person whose sole involvement is as an advocate.
The Relatives and Residents Association	Guideline	General	General	We would also like to highlight the vital importance of advocacy, both 'formal' and family advocacy. The pandemic has highlighted the damaging impact on people needing care of losing access to this support, as our helpline has heard. We have long been concerned about the lack of access to advocates and would like to see measures in the guidance to tackle this strengthened.	Thank you for your comment. Implementing the recommendations in the guideline should help enable access to advocates.



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The Relatives and Residents Association	Guideline	009	001 - 006	The draft guidance on how to identify people who will benefit from advocacy, other than those with a statutory entitlement, is too restrictive. Many people could benefit from advocacy and this may not always be immediately apparent. The draft guidance relies too much on the expertise of the person making that assessment, e.g. the wording of "substantial impact" is open to a high degree of interpretation. There should be a clear pathway to accessing this type of advocacy so that people needing support and their families/carers can understand this process and how to get access to this type of advocacy if it isn't 'offered'.	Thank you for your comment. The committee deliberated at length about how to define the group of people in recommendation 1.2.1. They wanted to ensure that people who could benefit from advocacy (but who were not legally entitled to receive it) could access these services but had to balance this against the potential cost implications of increasing the groups of people who were able to access these services. In the committee's experience the reasons that a person may benefit from advocacy are related to their circumstances or situation rather than their personal characteristics. Therefore, the committee focused on defining these circumstances in the recommendation. Whilst they acknowledge this definition could be open to some degree of interpretation, they felt that it was still an improvement on the current situation and should enable more people who need it to access advocacy.



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The Relatives and Residents Association	Guideline	009 - 010		The section on "Information about effective advocacy and signposting to services" should include a recommendation to ensure that anyone supporting a person as an unpaid ('informal') or family advocate has been identified in line with the person's statutory rights to advocacy under the Care Act and the Mental Capacity Act, following the original recommendation in Appendix F of Evidence Review A and the evidence of the value people place on support from family and friends.	Thank you for your comment. The focus of this guidance is on a trained person whose sole involvement is as an advocate. As such recommendations have not been made about informal advocates.
The Relatives and Residents Association	Guideline	017	015 - 016	The guidance should be encouraging advocacy providers to promote human rights, as protected in the Human Rights Act.	Thank you for your comment. The committee discussed this but decided not to amend the existing recommendation as it focuses on equalities. A recommendation in the Training and skills for advocates section of the guideline covers training for advocacy staff in human rights and promoting them.



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The Relatives and Residents Association	Guideline	019	015 - 023	We'd like to see more emphasis on the importance of communicating with families, carers and other representatives (such as a Relevant Person's Representative or those with Power of Attorney for health and welfare). We know from our helpline the impact a lack of contact and communication with relatives and carers has on the person needing care as well as on their families. This is particularly important for people assessed as lacking capacity on a decision, to ensure their views and wishes are understood by the advocate. This should be reflected throughout the guidance, but in particular in line 19 we would like to see "this might include" replaced with "this should include" to help emphasise the importance of communication with families and carers.	Thank you for your comment. Changes have been made based on your suggestion. The committee discussed the numerous stakeholder responses to the recommendation on liaising with families, with some stakeholders wanting more emphasis on families and others raising concerns that the involvement of family members may not always be beneficial to people. The committee reviewed the recommendation and felt that they had largely got the balance right but decided to slightly amend the wording introducing the examples by removing 'might'.



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The Relatives and Residents Association	Evidence review B	093	008	What was the outcome of the committee discussion on the statement that "advocacy services should be available especially for people who are in residential settings."? We know from our helpline that many people who move into residential settings are not provided with sufficient information and guidance around important decisions that affect them and we would like the guidance to highlight that this group of people may be in particular need of statutory or non-statutory advocacy.	Thank you for your comment. The committee agreed with this statement and discussed it as a basis for making recommendations. They agreed that advocacy is rarely available beyond that which is required by legislation so they tried to address this with a recommendation about offering advocacy to people who are not covered by the legislation but who would otherwise not be able to express their views or sufficiently influence decisions that are likely to have a substantial impact on their wellbeing (1.2.1). In addition the committee made a series of strong recommendations with the specific aim of improving access to advocacy, including that health and social care providers in all settings (including care homes) should ensure there are no obstacles to people accessing advocacy (1.4.2).
The Relatives and Residents Association	Evidence review B	094	012	What was the outcome of the committee discussion on the statement that "people who don't have family need access to advocacy so they can benefit from self-directed support."? We agree that people who don't have the support of family members are likely to have a very great need for advocacy, and we think the guidance should highlight this when explaining who may benefit from advocacy.	Thank you for your comment. There was strong agreement with the statement you mention and along with other evidence considered within this area, it led the committee to conclude that it is a person's circumstances or current situation that mean they may benefit from advocacy, rather than their characteristics. They therefore recommended that people should be offered advocacy, regardless of their legal entitlement, if they would otherwise not be able to express their views or sufficiently influence decisions that are likely to have a substantial impact on their wellbeing.



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The Royal College of Nursing (RCN)	Guideline	General	General	We do not have any comments to add on this consultation. Thank you for the opportunity to contribute.	Thank you for your supportive comment.
The Royal College of Speech and Language Therapists (RCSLT)	Guideline	016	009	In section 1.6 it states that: "1.6.1 Advocacy providers should ensure that their advocacy service is accessible, for example by meeting people's communication needs". However, it gives no detail on how to do this. Frequently people underestimate communication needs and the impact of these. The RCSLT recommend that guidance is provided on how to meet people's communication needs. The RCSLT recommend it is recorded what communication support measures were used to meet people's communication needs so this can be tracked.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was intended to be a non-exhaustive list of examples to improve accessibility. It is outside the scope of a guideline on advocacy to make detailed recommendations on how to meet people's communication needs. Other NICE guidelines on people's experience in adult social care services, patient experience in adult NHS services and shared decision making have been cross-referenced which contain recommendations on communication.



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The Royal College of Speech and Language Therapists (RCSLT)	Guideline	016	014	Section 1.62.2 talks about person centred advocacy, however there is no consideration of the advocate ensuring that the person can understand and be understood. This is critical. The RCSLT recommend that this is added. Without this, there cannot be shared understanding of expectations.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was intended to be a non-exhaustive list of examples to improve accessibility. It is outside the scope of a guideline on advocacy to make detailed recommendations on how to meet people's communication needs. Other NICE guidelines on people's experience in adult social care services, patient experience in adult NHS services and shared decision making have been cross-referenced which contain recommendations on communication.
The Royal College of Speech and Language Therapists (RCSLT)	Guideline	017	019	The RCSLT welcome the references to people's communication and safeguarding, which mirrors the guidance from Social Work England and DHSC for Independent Mental Capacity Advocates.	Thank you for your supportive comment.
The Royal College of Speech and Language Therapists (RCSLT)	Guideline	025	018	There is no mention of how advocates will access specialist support, for example speech and language therapy, to work with people with limited verbal communication. Advocates need to know how to access this community service. The RCSLT recommend this is added.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the examples used were non exhaustive and that this did not need to be singled out as something on which advocates need training. The committee did note that recommendation 1.9.3 had been amended to specifically reference training in specialised communication skills.



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The Royal College of Speech and Language Therapists (RCSLT)	Guideline	025	023	The RCSLT welcome the inclusion of communication training to advocacy staff. Many people requiring advocacy will have complex communication or cognitive skills. It is essential that advocates know how to engage with people and gain their views and wishes.	Thank you for your supportive comment.
The Royal College of Speech and Language Therapists (RCSLT)	Evidence review I	056	040 to 045	The RCSLT is very concerned that access to speech and language therapy may be prevented for "cost saving" purposes. Whilst it is welcome that advocates need communication training, they cannot and should not replace the expertise and specialist skills of a speech and language therapist in enabling a person to express their wishes and preferences. Denying people with limited communication skills this expertise is preventing choice, control and taking part in decisions. The RCSLT recommend this is amended or removed.	Thank you for your comment. The text has been changed to make it clear that there may be some circumstances where this would be appropriate but that it should not impact upon the individuals ability to take a full part in the meeting and decision making.
Think Local Act Personal (TLAP)	Guideline	General	General	Question 1 It is not clear the extent to which the guideline will be viewed as 'aspirational' or 'realistically achievable'. Whilst statutory obligations must be met and much of the guideline reflects existing established good practice we think some aspects are likely to be developmental. For example access to advocacy outside usual opening hours,	Thank you for your comment. The committee decided to add a new recommendation on commissioning bodies working together on a long-term plan for advocacy that takes into account the broad range of advocacy needs and includes non-statutory advocacy, peer advocacy and self-advocacy. The recommendation mentions that local needs should to be taken into account, which could potentially include co-production and involve



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				ensuring access to interpreters at all times when required, continuity of advocates. This is in the context of where, in general, investing in advocacy services has not been a priority for councils or NHS organisations beyond meeting the statutory minimum and there is significant variation across different areas meaning that some places will have further to travel than others. We think that a productive way to approach this is for the guideline to stipulate the need for local areas to produce a long term plan for developing advocacy services that identifies and prioritises gaps which then forms the basis for spending and investment decisions. This should include non-statutory advocacy such as self and peer advocacy which are currently not well supported. Such a plan needs to be co- produced with people who draw on care and health (including those with lived experience of advocacy support) and providers. We make some comment and suggestions about this in our detailed comments to strengthen what is already there. It may be helpful to link the guideline to the establishment of Integrated Care Systems which could provide an opportunity to take a strategic look at the development of advocacy across social care and health over larger footprints than may have	those with lived experience. It is beyond the remit of NICE guidelines to recommend what Integrated Care Partnerships should include in their strategies or what the CQC should include in their assessment frameworks. How the recommendations on training for health and social care staff are implemented will be a matter for local implementation. The Implementation team at NICE will investigate if there are additional products related to the guideline that can be developed. The committee felt that an Easy Read version of the guideline would be useful.



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				been the case in the past. We would therefore recommend that Integrated Care Partnerships explicitly include the development of advocacy in their Integrated Care Strategies and these are linked across to the Integrated Care Board five year forward plans; both 'informed by engagement and co-production at place level. Similarly, the adequacy and availability of advocacy provision should be included in the single assessment framework that the Care Quality Commission is developing for their new responsibilities for assurance of local authorities in relation to the Care Act and their oversight of integrated care systems. In relation to the training so that health and care staff know about and understand advocacy, given the huge size of the workforce, we think that this aspect of the guideline should be linked to the workforce development plans contained in the social care White People, People at the Heart of Care and also integrated into NHS workforce development planning and plans. We also think there would be scope and benefit of producing some additional products based on the guidelines targeted at key audiences: people who draw on care and health, providers and commissioners, which include actual examples to help bring the guideline to life. These could	



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				be produced or commissioned by NICE. We think an existing document produced by TLAP, Making it Real, is a useful resource that could be used as well, particularly as part of a framework for reaching judgements on the contribution of advocacy services to enabling people to live the life they want. We make these points in our detailed comments that follow.	
Think Local Act Personal (TLAP)	Guideline	General	General	Question 2 In keeping with our response to question 1 above we anticipate that there are likely to be significant cost implications associated implementing the guideline in full the most obvious of which is making advocacy available over and beyond what is required under the law (at least in the short term). The guideline as a whole should be challenging but achievable (over a reasonable period of time) otherwise there is a risk that they are not taken up as they are viewed by commissioners and funders as too much of a wish list. Hence this is why we say that areas should develop co- produced plans to guide investment. It also our view that properly investing in advocacy over time is likely to repay itself in terms of preventing or reducing problems further up the line which in the end cost more for councils and	Thank you for your comment. The committee identified those recommendations where they felt there might be a significant resource implication in the How the recommendation might affect practice or services section of the guideline. A recommendation has also been added to section 1.9 about the need to develop and publish a long term plan for advocacy based on an assessment of local need. When developing the guideline the committee decided to make one research recommendation: 'What is the effectiveness and acceptability of providing advocacy through different approaches', which could potentially lead to research into the 'cost-benefit' of advocacy support, including the effect of providing more non-statutory advocacy. The details of the research recommendation are in Evidence review K.



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Think Local Act Personal (TLAP)	Guideline	General	General	NHS organisations to resolve. That there is a lack of evidence of this 'cost-benefit' of advocacy support, including the affect of providing more non-statutory advocacy, suggests that this is an area worthy of further research and evaluation which NICE is well placed to feed into the research priority setting process for care and health, including with the National Institute of Health and Care Research. We know of one area that is undertaking some 'cost-benefit' work who may be willing to share the results. We welcome this guideline on advocacy and overall think it covers the ground well including the part played by non-instructed advocacy. The summary of the different legislation under which advocacy must be provided is informative and a useful source of reference, although ideally should be updated as and when the legal framework changes. We are strongly in support of advocacy provision extending beyond the statutory minimum and the need for advocates to be well trained and supported. Our feedback and suggestions for improvement are based on the views of a number of people who have lived experience of advocacy who have looked at the guideline. It is not clear the extent to which the guideline was co-produced	Thank you for your comment and support for the guideline. As you note, the guideline committee included two lay members who had lived experience of advocacy support (in line with NICE processes) and contributed fully to the development of all recommendations. The committee discussed self-advocacy and peer advocacy and felt that they were included in recommendations where advocates, advocacy providers and commissioners could most utilise these options so did not need to be highlighted elsewhere. It is not NICE style to include references in the guideline recommendations, unless they are cross references to other NICE guidance, legislation or are from NICE approved sources. A definition of self-advocacy and



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				with people of lived experience of advocacy support (we note there were two lay members). A few areas were felt to be insufficiently covered and/or would benefit from being strengthened. They are: The role and value and promotion of self-advocacy and peer advocacy whilst mentioned at various points are not highlighted as prominently as we think they should be. Some useful references are found in the explanation of how the committee developed its recommendations. We suggest consideration is given to whether some of this material could be lifted into the main guideline and add a definition of self-advocacy (when people speak up for themselves) and peer advocacy. Whilst references are made to engaging and involving people with lived experience (e.g. 1.8.1, 1.8.5, 1.10.4) we would strongly recommend a clear statement and recommendation is made up front in the guideline which emphasises the need to co- produce all aspects of commissioning and providing advocacy services covered in the guideline. The valuable role that advocacy can play to prevent crisis and disputes. Advocacy should not just be made available at the point of crisis or when in disagreement over decisions about care and health. A more early	 peer advocacy has been added to the Terms used in this guideline section as you suggest. The committee discussed making a recommendation up front in the guideline which emphasised the need to coproduce all aspects of commissioning and providing advocacy services but decided not to do this as they felt that it was better to mention co-production and involving people with lived experience in specific recommendations where it would be likely to have the most impact. It is hoped that implementation of the recommendations made in this guideline will facilitate earlier access to advocacy and the provision of more effective advocacy, such that issues such as crises and disputes are prevented. Recommendations have also been made that should increase awareness of the issues you raise, such as who is legally entitled to receive advocacy support, how to access it and what advocacy services are available locally. Changes have been made to the recommendations in section 1.11 to ensure that detailed feedback from people accessing services is collected to assist with monitoring and evaluation. The guideline has not been prescriptive about how these data should be collected which leaves flexibility to include both qualitative and



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				intervention and preventative type approach has the potential to improve lives and save money by addressing issues before they become protracted and more costly to resolve. Advocacy if 'done well' can help people who need health and care services/support to lead meaningful lives in line with TLAP's Making it Real framework which describes what good personalised care and support looks like.https://www.thinklocalactpersonal.org.uk/_a ssets/MakingItReal/TLAP-Making-it-Real- report.pdf There are references that relate to the value of adopting a preventative approach in the explanation of how the committee developed its recommendations. We suggest consideration is given to whether some of this material could be lifted into the guideline. The vital importance of councils and NHS organisations raising awareness of the	 quantitative data. The guideline has also not been prescriptive about what data should be collected – the recommendations only include examples of what could be collected. Decisions on this will be a matter for local implementation and may include some of the suggestions made in your comment. The committee discussed hospital discharge and felt that it was just one time point when advocacy would be useful but that there were numerous other similar time points, therefore they decided to not amend the guideline to include this. The committee felt that an Easy Read version of the guideline would be useful and have passed this feedback on to the Publishing team. NICE guidelines do not include an executive summary or case studies so these changes have not been made. The implementation teams at NICE will investigate if there
				advocacy services available and the legal entitlement to receive advocacy support. People should know what to do and where to go if they feel they are being denied access to advocacy to which they believe they are entitled. We think this point should be emphasised in the guideline. The monitoring services and collecting data for quality improvement section should be strengthened to	are additional products related to the guideline that can be developed based on your suggestions.



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				make it clear that the people accessing advocacy support should be central to evaluating the effectiveness, outcomes and impact of these services. This is a crucial element of ensuring and assuring that commissioners and providers measure what matters most to people. Process and activity data and indicators have their place but should be secondary to understanding the difference advocacy makes to peoples' lives. This will require a combination of quantitative and qualitative data to understand how good a service is, to appreciate the 'hard and soft outcomes' as one of our reviewers put it. The extent to which this guideline is adopted should be one important measure of success. How well commissioners and providers co-produce with people with lived experience should also form part of any evaluation framework and be included in this guideline. TLAP's Making it Real framework can provide a useful benchmark for all these aspects. We think there is a potential gap in the guideline that covers the need for hospital discharge policy and procedures to include reference to people's rights to advocacy. The guideline is written well but we strongly recommend that an Easy Read version is published alongside the guideline, as	



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				this will make it more accessible to many more people who will want to know about and use the guidance. We suggest that an executive summary added to the guideline. Given the richness (and length) of the guideline we think there is considerable merit in producing some 'spin off' products targeted at particular audiences which could help increase its take up. These would be for people who draw on health, care and support (a lay person's guide, what you need to know about advocacy) and 'what good looks like', one for providers and another for commissioners. We also thought the guideline would benefit from some case study examples (e.g. to illustrate advocacy in action under the different legislation) which given its advanced stage of development might be easier to incorporate in these additional products.	



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Think Local Act Personal (TLAP)	Guideline	005 006 006 - 008	009 - 020 001 - 012	[1.1] It is helpful and informative to begin the guideline by clearly setting out the legal basis for statutory advocacy provision. It will be challenging to achieve this consistently in practice because there is significant variation in provision between local areas due to differing levels of investment (referred to as a 'post-code lottery' by one of our respondents) and social workers were felt too often to act as 'gatekeepers' employing their own definition of who is entitled to advocacy. The example was given of a social worker deciding that as the person could participate in a Teams meeting this meant they had capacity and did not therefore require advocacy. This sort of defensive practice was felt to be driven by the need to protect financial resources and a fear that enabling advocacy would spur people to follow an adversarial legal route by 'bringing in lawyers.' The later recommendations in the guideline on training for practitioners are particularly welcome in this context. [Box 1] Suggest make it clear that under the Care Act an independent advocate is not the same as an 'appropriate adult'.	Thank you for your supportive comment. By clarifying the legal basis of advocacy provision and the recommendations on training for practitioners the guideline aims to help reduce variations in provision.



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Think Local Act Personal (TLAP)	Guideline	007		[Box 1] Recommend adding to the wording under the MCA Act on instructing an IMCA so the bullet point reads: 'care reviews and/or care conferences if no one else is available to be consulted.'	Thank you for your comment. It is NICE process to use the wording from the legislation. As the wording is taken from the legislation it will not be amended.
Think Local Act Personal (TLAP)	Guideline	009	001 - 006	[1.2.1] We strongly support that advocacy should be made available to people beyond strict legal entitlement as it will help prevent crisis and more costly solutions. We think it will be challenging to achieve this consistently in practice in the short term for the reasons stated at point 2 above. How this will be achieved should be included in a long term plan, as stated in elsewhere in our response. We think it would help if some illustrations were given of who might benefit from non-statutory advocacy and in what circumstances e.g. an older person in the early stages of dementia trying to work out the best options for the future, a person whose first language isn't English. A fuller non exhaustive list could be provided in the form of an Annex.	Thank you for your comment. The committee decided not to add illustrations of who might benefit from non- statutory advocacy to recommendation 1.2.1. In the committee's experience the reasons that a person may benefit from advocacy are related to their circumstances or situation rather than their personal characteristics. Therefore, the committee focused on defining these circumstances in the recommendation. In addition including a list of groups in the recommendation could have been interpreted as being an exhaustive list, resulting in some people not being given access to non-statutory advocacy because they were not listed. NICE style is not to include Annexes in guidelines. A new recommendation on long term planning has been added to the Planning and commissioning services for advocacy section of the guideline.



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Think Local Act Personal (TLAP)	Guideline	009	009 - 011	[1.3.1] It is essential that LAs include information on advocacy services as part of meeting their information and advice duties under the Care Act. As one person with lived experience said, 'I had to fight hard to find out what was available.' We suggest the guideline makes explicit that the information should cover all the advocacy services available in the local area (including peer support and self-advocacy) and not just those services commissioned or funded by the LA or NHS organisations. It should be stressed that information should not be restricted to those thought to be eligible for advocacy and should be treated as public information.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it already covers all the advocacy services available in the local area - it doesn't specify that it was only information about Local Authority funded advocacy. The third recommendation in the Information about effective advocacy and signposting to services section of the guideline covers providing information to everyone who would benefit from advocacy whether or not they are legally entitled to it.
Think Local Act Personal (TLAP)	Guideline	009 010	012 - 015 001 - 007	[1.3.2 - 1.3.3] We think the guideline should make it explicitly clear that only putting information onto a council website is not sufficient and different channels should be used to reflect that not everyone can access the internet and to avoid worsening digital exclusion. There should be pro-active signposting rather than passive information giving.	Thank you for your comment. Changes have been made based on your suggestion. The recommendation has been amended to include pro-active signposting and using accessible formats.



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Think Local Act Personal (TLAP)	Guideline	010	008 - 013	[1.3.4] We agree it is essential to make information about advocacy available in a variety of ways to suit the needs and preferences of the person, as the failure to do so was described one of our reviewers 'as a big stumbling block.' There is an opportunity to be creative and highly person-centred. In addition to the examples given in the guideline there are a whole range of other resources and support that can be used such as talking maps, Makaton etc. Consideration might be given to including a fuller non exhaustive link in the form of an Annex.	Thank you for your comment. The recommendation contains a non-exhaustive list of examples and cross references to further NICE guidance on communicating and providing information. Therefore, there is no need to add further examples.
Think Local Act Personal (TLAP)	Guideline	010	018 - 021	[1.3.6] We suggest using a different term to 'placement' when talking about of 'out-of-area' as it is not person-centred and conveys an image of people as passive recipients. It might be better to say something like 'If a person is offered health, care or support out of their home area' We strongly endorse that when a person moves from their home area to receive a service the organisation responsible for this should give the person (and their family or carers, as appropriate) information about the advocacy support available to them. This may need to be more than telling people, but actually ensuring that people know how to and can access advocacy at the point decisions are	Thank you for your comment. The wording of the existing recommendation has been changed from out of area placement to services offered out of the home area. The existing recommendation has also been changed to include assisting people to access advocacy. The committee discussed whether information provision and ensuring access for people offered services out of their home area should form part of monitoring and evaluation but felt that no changes were needed as this was covered by recommendation 1.11.7. Although the Care Quality Commission and NICE have a memorandum of understanding which means that NICE guidance can inform the CQC's existing methodology and assessment of providers,



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Stakeholder	Document	Page No	Line No	Comments being made about them moving out of their local area. The extent to which local authorities support this aspect should form part of overall monitoring and evaluation of the effectiveness of advocacy provision in local areas. It could be looked at by the Care Quality Commission as part of its new duties to assure councils	Developer's response NICE cannot recommend that the CQC specifically monitor specific areas.
				adherence to the Care Act and oversight of Integrated Care Systems.vAs a contextual point, sometimes people are faced with having to move out of their home area to receive the service they have been assessed as needing because of a shortage of local provision and in other cases because it is the most appropriate and best form of provision. The provision of information about advocacy and access to it are important in either case.	



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Think Local Act Personal (TLAP)	Guideline	011	007 - 009	[1.4.2] We strongly support people living in all settings having access to advocacy. It is essential that when advocacy is being provided that it takes place in a space that affords proper privacy, which could helpfully be reinforced here. We recommend you consider whether the guideline should make specific reference to the right to advocacy being incorporated into hospital discharge policies and procedures. It was not clear to us what is meant by 'regardless of blanket restrictions or policies that might prevent this' and so we suggest this is clarified.	Thank you for your comment. The existing recommendation has been amended to clarify policies that may prevent access to advocacy. The committee felt that private areas for providing advocacy is sufficiently covered by recommendation 1.5.6. The committee discussed whether the right to advocacy being incorporated into hospital discharge policies and procedures should be incorporated into the guideline but they felt that it was just one example of an important time point when the right to advocacy could be highlighted and that various examples could equally be used. The committee felt that various recommendations in the guideline were aimed at highlighting the right to advocacy, for example via information provision or training health and social care practitioners about advocacy.
Think Local Act Personal (TLAP)	Guideline	011	021 - 025	[1.4.5] We strongly support continuity of advocates by offering people the same advocate for different types of advocacy but are not sure how this can be realised in practice as we do not expect that all providers will be able to offer this given current levels of investment and available supply of advocates.	Thank you for your comment. The committee discussed this and felt that although the comment was correct there was no need to amend the recommendation as it was already worded as 'should aim to support' so there was some leeway for local circumstances.



	's response
Think Local Act Personal (TLAP)Guideline011026 - 029[1.4.6] We support the guideline that independent mental health advocacy should make regular visits to inpatient settings to identify people who would benefit from advocacy. One of our reviewers had experience of this in the past and felt it was more accessible and responsive in contrast to the onerous less person-centred standard approaches to accessing advocacy. It was felt to be of particular benefit to people 'stuck' on wards' without family or friends where an advocate can play an important role in getting things moving so the person can leave with the support they need. You may want to consider adding a point about their needing to be a protocol or process in place to avoid creating the impression that advocates can go ontoThank you for your positive discussed adding text about processes in place to avoid advocates can go onto	comment. The committee t having protocols or creating the impression that ds and float around at will ne recommendation as it ant to be restrictive about



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Think Local Act Personal (TLAP)	Guideline	012	006 - 007	[1.4.9] The reason for the recommendation 'IMHA services should raise awareness of service users groups and promote peer and self-advocacy options' is not as clear as it might be. We certainly think the role of peer and self- advocacy should be promoted by commissioners and providers but it would be helpful to spell out here the reason why it is seen as particularly important for IMHA services. We suggest it would be better to avoid using the term 'service user groups' as many people who draw on care and support dislike the term as it implies a dependency on formal services. You could replace with reference to disabled people's organisations and user-led organisations	Thank you for your comment. Changes have been made based on your suggestion. The terminology 'service users groups' was replaced by 'disabled people's organisations and user-led organisations'. The committee discussed the role of raising awareness of the particular groups mentioned in the recommendation and felt that it sat within the remit of IMHA services, which can include supporting them to self-advocate. Therefore no changes were made to the recommendation because of this.
Think Local Act Personal (TLAP)	Guideline	012	006 - 007	[1.4.11] Please change the language in the bullet point to get rid of 'placed' for the reasons stated above in relation to 1.3.6. It could be replaced with 'are supported outside of their home area.'	Thank you for your comment. This change has been made.



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Think Local Act Personal (TLAP)	Guideline	012	017 - 020	[1.5.1] We are very supportive of stipulating that practitioners identify the need for advocacy early on and refer without delay. One of our reviewers experience was at the opposite end. In his words it 'feels like I am pulling teeth to extract information on the who, how, where and when' of accessing advocacy with the onus too much on having to ask these questions. If this experience is in any way representative it is indicative of a significant shift in practice required to consistently fulfil this guideline.	Thank you for your supportive comment.
Think Local Act Personal (TLAP)	Guideline	013	001 - 006	[1.5.2] We support that 'enough time' is allowed to appoint an advocate and to help prepare the person for meetings etc, but based on our experience there is some distance between this standard and much current practice. This applies to most of the recommendations in this section on Enabling and Supporting Effective Advocacy.	Thank you for your comment. One of the aims of the guideline is to improve current practice by making recommendations that set standards.
Think Local Act Personal (TLAP)	Guideline	013	007	[1.5.3] We recommend the wording of this guideline changes from should to must.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. Therefore it is not possible to make the change you suggest.



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Think Local Act Personal (TLAP)	Guideline	013	011	[1.5.4] We recommend the wording of this guideline changes from should to must.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. Therefore it is not possible to make the change you suggest.
Think Local Act Personal (TLAP)	Guideline	014	006 - 008	[1.5.8] We agree that it is important that people can have discussions with their advocates in a private area. Where a meeting or discussion also involves someone from the organisation subject to the advocacy, there should be an opportunity for the person and their advocate to have time together in private (to prepare) and afterwards (to debrief). This could helpfully be made explicit in the guideline.	Thank you for your comment. The committee decided not to amend the recommendation but moved the recommendation about having discussions in a private area next to recommendations on having time to prepare and to build up a relationship, in order to make the stakeholders suggestion more explicit in the guideline.
Think Local Act Personal (TLAP)	Guideline	014	009	[1.5.9] We recommend the wording of this guideline changes from should to must.	Thank you for your comment. NICE recommendations only use 'must' where there is a legal duty to do so, in order to make a clear distinction as to where there is a legal requirement or statutory duty. Therefore it is not possible to make the change you suggest.



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Think Local Act Personal (TLAP)	Guideline	015	001	[1.5.15 and 1.5.16] We thought that the presentation of the guideline might be improved by introducing a sub heading 'Advocacy and Safeguarding'. There are quite a few other subsequent references to safeguarding (e.g. 1.6.7) and it may be worth considering whether it would work better to consolidate some or all of them into a single place.	Thank you for your comment. The committee discussed this but decided not to consolidate some or all of the safeguarding recommendations further as it was felt that by doing this some readers might not pay full attention to that particular section. The committee felt that safeguarding is everybody's business and by spreading it through the guideline it reinforces that idea.
Think Local Act Personal (TLAP)	Guideline	015	011	[1.5.16] Suggest recommending there is representation from advocacy services on Adult Safeguarding Boards.	Thank you for your comment. The committee decided to amend the bullet point on Safeguarding Adult Boards to make it more active. However, the committee were aware that although advocacy services aspire to representation on Adult Safeguarding Boards in reality this is not always achievable.
Think Local Act Personal (TLAP)	Guideline	015	020 - 023	[1.6.1] We strongly support flexibility on how advocacy support is provided based on what works best for people (i.e. face to face or online, or in combination). One of our reviewers experience was of an advocacy provider who will only undertake home visits in pairs which was felt to be off putting and made the person feel that they were perceived to be a danger and pressured to access the support online.	Thank you for your supportive comment.



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Think Local Act Personal (TLAP)	Guideline	016 017	014 - 031 001 - 002	[1.6.2] All the bullet points on how to ensure effective advocacy are welcome. We would like to see more explicit recognition of the role of co-production: involving people using the services in deciding how the service operates. This could become the first bullet point under 1.6.2, followed by moving to here the existing bullet point 1.6.5 on involving people with lived experience in the running of advocacy organisations. There may be a point to add that makes it clear that whilst there should be consistency of approach (and so some standardisation) under a person-centred approach there should be room for creativity and innovation. How well the standards that have been listed are met in practice should be reflected in how advocacy services are evaluated.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation to add co-production as it was felt that the bullets largely cover the individual actions an advocate can take to help an individual person. The committee felt that co- production is important but it is more relevant to the service level, rather than the level of the individual advocate. The committee therefore also did not want to move recommendation 1.6.5 to become a bullet point in 1.6.2. The committee felt that as the list in recommendation 1.6.2 was non-exhaustive it allowed room for creativity and innovation. The committee felt that the recommendations covering agreeing outcomes in the Monitoring services and collecting data for quality improvement section of the guideline could enable the evaluation of how effective or person centred and advocacy service is.



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Think Local Act Personal (TLAP)	Guideline	18	001 - 003	[1.6.8] We strongly support the guideline that people should wherever possible have the opportunity of having the same advocate throughout the advocacy process, but recognise in practice that this will require advocacy providers to be resourced sufficiently to have enough advocates on their books.	Thank you for your comment. When they discussed this recommendation the committee felt that there would be some cost impact as having the same advocate throughout the process would need multi-skilled advocates to be available at the start of a person's contact with advocacy. This may mean moving or employing multi-skilled workers, resulting in upfront costs. However the committee also felt that there may be less need for multi-skilled advocates later in the process if duplication of meetings and the need for handovers are reduced. The recommendation has been worded to take into account that doing this might not be possible for all providers
Think Local Act Personal (TLAP)	Guideline	018	027 - 028	[1.6.11] Consider including a suggestion that advocacy providers keep a register of interpreters and translators which they or the person can readily access.	Thank you for your comment. How providers ensure they can provide access to interpreters and translators will be a matter for local implementation. Having a register is one possible method that could be used.
Think Local Act Personal (TLAP)	Guideline	019	003 - 004	[1.6.13] Consider adding explanation of 'cultural competence' to the terms used in the guideline.	Thank you for your comment. This change has been made.



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Think Local Act Personal (TLAP)	Guideline	019	017 - 023	[1.7.1] Consider adding to the guideline 'Advocates should liaise with family members and carers when the person wants them to or when the person cannot express a view about this but it is in their best interests and there is a clear reason to do so.' It was noted when looking at this specific guideline that not everyone has family or friends to liaise with which can make the person even more dependent on the professionals involved in their life. Whilst not taking away from this guideline on the valuable role that family and friends can play, this should be recognised and take into account within the guideline overall. Feedback from one of our reviewers was they felt that their social situation was being judged which ran counter to advocacy support being based on understanding the needs and personal circumstances of each person.	Thank you for your comment. The committee discussed adding 'and there is a clear reason to do so' but decided not to amend the recommendation as it was felt that the current wording sufficiently balanced liaising with family members or carers, and the person's choice or when the person cannot express a view it being in their best interests. Following another stakeholder's comment, friends was added to the recommendation so the advocates could liaise with family members, friends or carers. The committee discussed dependency on professionals but decided not to amend the recommendation as if that change were made it would alter the focus of the recommendation, which the committee wanted to be about liaising with family and carers.
Think Local Act Personal (TLAP)	Guideline	020	016 - 021	[1.7.6] We agree that commissioners should work with other commissioners to identify gaps* and develop a long term view of what advocacy services are needed. It might be better to make explicit that the long term view should result in commissioners developing a long term plan for developing advocacy services. This process should be based on co-production and centrally involve people with lived experience, as well as	Thank you for your comment. The committee made a change based on your suggestion adding a new recommendation to the Planning and commissioning services for advocacy section of the guideline on commissioners working together on a long term plan based on an assessment of local need. As the focus of the new recommendation was on long term planning the committee did not want to distract from that by adding in co-production and the involvement of people



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				advocacy providers. We recommend that the guideline is redrafted to reflect both these points. It would also make sense to move 1.7.6 (as amended) to join up with what is said at 1.8.1. It might be worth adding that the need for advocacy services outside of ordinary working hours should form part of the gap analysis, perhaps as an example.	with lived experience, as the recommendation (1.8.1) immediately above the new one covered co-production already. The committee discussed moving recommendation 1.7.6 but decided not to do this as it was felt that the aim of 1.7.6 was getting commissioners to work together and by moving it from the Partnership working section of the guideline this aim could be lost. The committee discussed the example of a gap analysis but decided not to add it to the recommendations as it was felt that how an assessment of local need should be conducted should be left up to local advocacy providers.
Think Local Act Personal (TLAP)	Guideline	021	001 - 003	[1.7.9] The reference to commissioners of IMHA services working in partnership with other commissioners to understand and maximise the impact of IMHA provision on mental health service development should extend to involving people with lived experience and advocacy providers.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that adding other groups could detract from the focus of the recommendation which is about getting commissioners to work together. The first recommendation in the Planning and commissioning services for advocacy section of the guideline includes commissioning services in co-production with people who use services.



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Think Local Act Personal (TLAP)	Guideline	021	004 - 015	[1.7.10] We fully agree that advocacy providers should work in partnership with other organisations to ensure culturally appropriate advocacy that meets local needs, but think the use of the examples listed is problematic, as these relate only to mental health advocacy which seems too narrow. We also think it is essential to make it crystal clear in the guideline that advocacy should be available, accessible and culturally sensitive to all ethnicity groups and we are not sure this section achieves this. For example, it is not clear whether the term 'Black community' is intentionally meant to refer just to the Black community or used as an umbrella term for all minority ethnic groups. If the latter it might be better to use the term Black, Asian and minority ethnic communities (BAME), acknowledging that there is not a consensus on this term and others are in use (similarly without consensus). Some clarification is required here please. It should also be recognised that the need to be culturally appropriate is not confined to ethnicity, as there are other marginalised communities where this should apply. A case study approach might be more effective at illustrating the key points rather than a list approach. The point on increasing the diversity of staff within advocacy	Thank you for your comment. Changes have been made based on your suggestion. The examples used in this recommendation came from an included study that looked at mental health advocacy in African and Caribbean men and from expert witness testimony which was sought about BAME communities because the committee did not feel that they had enough expertise in this area. This is covered in more detail in evidence report G. The term 'Black community' is intentionally meant to refer just to the Black community as these were the examples used in the study. NICE editorial policy is that specific ethnic communities should be used where that is what is meant rather than umbrella terms. Having discussed the points raised by this comment the committee decided to add another example relating to a different ethnic group so that it made it clear that advocacy should be available, accessible and culturally sensitive to all ethnicity groups. NICE do not use case studies in their guidelines. The committee discussed amending the bullet point on increasing the diversity of staff but felt that it did not need changing as it was felt that how diversity should be increased would be up to local advocacy providers.



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				services is well made but it might be better to rephrase it along the lines that the staff group (including volunteers) should reflect the local population and where this is not the case positive action undertaken to achieve a workforce that is representative of the population/communities served.	
Think Local Act Personal (TLAP)	Guideline	021	017 - 021	[1.8.1] We think the opening paragraph would be much improved if it started by saying that a long term plan about what is needed should be developed based on an assessment of local need etc. This should link back to what is said at 1.7.6 which might usefully be combined with what is said here. We strongly support the need to do this in co-production with people who draw on health and care support, but see our general point about the importance of co- production being made clearer and more explicit early on in the guidance.	Thank you for your comment. Changes have been made based on your suggestion. The committee discussed long term planning and decided to add a new recommendation on this to the planning and commissioning section of the guideline. The committee decided that this addition would sit better on its own as the second recommendation in this section. The committee also felt that recommendation 1.7.6 should remain a separate recommendation as its focus is on commissioners working with other commissioners. The committee discussed co-production and felt that co- production and the involvement of people with lived experience was sufficiently covered in the guideline.



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Think Local Act Personal (TLAP)	Guideline	022	001 - 004	[1.8.2] We agree that it is important and necessary to consider commissioning services that can also be used by people who do not meet the criteria for statutory advocacy but could benefit from access to advocacy. This should be part of the assessment of need and production of a long term plan for advocacy support, as we have previously stated.	Thank you for your supportive comment. The committee decided to make changes based on your suggestion. A new recommendation was added to the Planning and commissioning advocacy services section of the guideline on commissioning bodies working together on a long term plan.
Think Local Act Personal (TLAP)	Guideline	022	011 - 014	[1.8.5] We strongly support people who use advocacy services being involved in planning and designing advocacy services, but see our general point about the importance of co- production being made clearer and more explicit early on in the guidance.	Thank you for your comment. The committee discussed this but decided not to make any changes based on your comment. This was because they felt that co- production and lived experience were mentioned at specific places in the guideline already where they felt it was most relevant and would have the most impact.
Think Local Act Personal (TLAP)	Guideline	022	015 - 018	[1.8.6] We strongly support that commissioners should avoid placing caps on the number of hours an advocate can spend supporting someone as the amount of support a person gets should depend on their need and personal circumstances. It is about going at the pace of the person.	Thank you for your supportive comment.
Think Local Act Personal (TLAP)	Guideline	022	022 - 023	[1.8.8] We support advocacy providers having external accreditation providing the accreditation process is undertaken properly and is not a tick box exercise.	Thank you for your supportive comment. The committee also felt that it was important that accreditation is undertaken properly, so used the example of the Quality Performance Mark.



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Think Local Act Personal (TLAP)	Guideline	023 - 024	009 - 010	Box 2 - Consider adding into the box explanation that some people fall into multiple groups e.g. a disabled person who is also a refugee. Also add a sentence on intersectionality with a cross reference to the explanation given of this in the terms used section.	Thank you for your comment. Changes have been made based on your suggestion. Similar text to that suggested has been added to Box 2 and intersectionality has been added to the terms used in this guideline section with a hyperlink from Box 2.
Think Local Act Personal (TLAP)	Guideline	024	002 - 006	[1.8.11] We agree the point but wonder whether it should be brought together with the points made at 1.7.10.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it sat better on its own and in its current place after Box 2 on the Characteristics, life circumstances or life experiences relating to inequalities.
Think Local Act Personal (TLAP)	Guideline	024	011 - 013	[1.8.12] Second bullet point might be improved by some re-ordering and by inclusion of self- advocacy. It could say: 'services tailored to the local population are made available - including statutory and non-statutory advocacy, the latter including self-advocacy, peer advocacy and family advocacy.'	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that re-ordering the words as suggested would not improve the recommendation. The divide between statutory and non-statutory advocacy is not always a neat divide and self-advocacy, peer advocacy and family advocacy could potentially be involved in certain instances of statutory advocacy.


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Think Local Act Personal (TLAP)	Guideline	025	003 - 004	[1.9.1] We agree that training of advocates will need investment, but wonder whether the guideline here should first recommend that commissioners with providers (involving people with lived experience) first undertake an assessment of the effectiveness and adequacy of the current level of investment and build the need for any further investment into their long term plan.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that it was about investment in training and that there was already a widely held view that this was needed. The committee also felt that an assessment of the effectiveness and adequacy of the current level of investment was a broader question and one that might be answered by the research recommendation in the guideline on What is the effectiveness and acceptability of providing advocacy through different approaches? The committee also pointed out that a new recommendation on commissioning bodies working together on a long term plan based on an asessment of need had been added to the Planning and commissioning services for advocacy section of the guideline.
Think Local Act Personal (TLAP)	Guideline	025	013	[1.9.2] Suggest add personal health budgets alongside personal budgets to the list of bullet points.	Thank you for your comment. This change has been made.



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Think Local Act Personal (TLAP)	Guideline	026	010 - 011	[1.9.4] Consider adding a link or explanation of the National Qualification in Independent Advocacy	Thank you for your comment. There is some further information on the National Qualification in the relevant Why the committee made the recommendation section of the guideline and the committees discussions of the Evidence section of evidence review I. As there is only one National qualification and information about it is readily available it was not felt necessary to give further explanation about it.
Think Local Act Personal (TLAP)	Guideline	027	003 - 006	[1.10.1] We support health and social care practitioners receiving training on advocacy at induction with refresher training. This will be a very big undertaking, given the combined size of the social care and health workforce and staff turnover. It would be most effective and efficient if there was a recommended common curriculum (this could vary according to type of staff) rather than it being left purely to local areas to decide. The chances of this recommendation being taken forward are likely to be increased if it is linked to the government's plans for workforce which for social care are laid out in the White Paper, People at the Heart of Care, particularly the Knowledge and Skills Framework and the equivalent plan(s) for the NHS.	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that recommending a common curriculum was beyond the remit of the guideline. The committee also felt that recommending a common curriculum would contradict one of the recommendations that highlighted tailoring training to practitioners' roles and responsibilities.



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Think Local Act Personal (TLAP)	Guideline	027 028	024 - 030 001 - 011	[1.10.3] We support this recommendation, but wonder whether the list of what advocates do might come much earlier in the guideline so as to convey understanding of the role at the outset.	Thank you for your comment. The committee discussed this but decided not to move the list of what advocates do earlier in the guideline. This was because it was felt that the list is in this recommendation specifically because these are the things that should be included in training for other practitioners. The committee also felt that readers are unlikely to read the whole guideline through from the beginning so even if the list was moved earlier in the guideline this wouldn't guarantee that it would be read or read first.
Think Local Act Personal (TLAP)	Guideline	028	014 - 015	[1.10.4] We strongly endorse that providers of advocacy training should include people with lived experience in the designing and delivering training, but in line with our earlier point, we would like a stronger point made early on in the guidance on the need for co-production throughout all aspects of design and delivery of advocacy services. During our discussion it was noted that some advocates will have experienced advocacy support themselves which is positive.	Thank you for your comment. The committee discussed this but decided not to amend the guidance so that the importance of co-production was made clearer and more explicit early on. This was because they felt that co-production and lived experience were mentioned at specific places in the guideline already where they felt it was most relevant and would have the most impact.



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Think Local Act Personal (TLAP)	Guideline	029	016 - 030	[1.11.3] We agree that it is essential to measure outcomes that show the impact on people using an advocate. The guideline here might be improved by making it more explicit that the views of people accessing advocacy should be sought on how effective/good the advocacy support has been in assisting them to achieve the agreed goals/outcomes of receiving advocacy support. See also next point below.Where a person is unable to speak up for themselves other creative ways should be used to establish this.	Thank you for your comment. Changes have been made based on your suggestion. The committee discussed this and felt that recommendation 1.11.3 didn't need amending but recommendation 1.11.6 was amended to include capturing detailed feedback from people using advocacy services. It was felt that this change would enable the capture of information on the views of people accessing advocacy on how effective/good the advocacy support has been in assisting them to achieve the agreed goals/outcomes of receiving advocacy support. Recommendation 1.11.10 also recommends tailoring the formats and methods of seeking feedback about advocacy support to the person's communication needs and preferences.
Think Local Act Personal (TLAP)	Guideline	030	018 - 019	[1.11.6] We agree that advocacy providers should collect information on the impact of their services, but think referencing this to the 'their impact on society' maybe a bit too vague and general. The most important impact to understand is on the people accessing advocacy and the extent to which advocacy support is effective in achieving their outcomes.	Thank you for your comment. A change has been made based on your suggestion. The committee agreed to amend the recommendation so that it read 'impact of their services'.



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Think Local Act Personal (TLAP)	Guideline	031 032	028 - 029 001 - 004	[1.11.14] It is important to share insights and key information with relevant stakeholders. This will be easier to achieve with the agreement of some standardised reporting formats and metrics covering both quantitative and qualitative data (including people's stories). Whilst there is a risk of structures changing, consideration to be given to whether to add Integrated Care Boards and/or Integrated Care Partnerships to the list at 1.11.4. Consideration might be given to recommending that the format for standardised approaches to reporting on advocacy should be agreed at this level. As an additional point, whilst advocacy services are not regulated by the Care Quality Commission, we would expect that the availability and quality of advocacy services should be considered as part of the their new responsibilities from April 2023 for local authority assurance under the Care Act and oversight of integrated care systems. We suggesting adding to the list of relevant stakeholder disabled peoples' and user-led organisations and Race Equality Councils.	Thank you for your comment. Changes have been made based on your suggestion. Integrated care partnerships and boards were added to recommendation 1.11.14. The committee discussed adding disabled peoples' and user-led organisations and Race Equality Councils to the list of relevant stakeholders in the recommendation but decided not to as this was a non-exhaustive list of examples which already mentioned voluntary and community sector organisations. It is beyond the remit of NICE guidance to recommend that the Care Quality Commission investigate the availability and quality of advocacy services as part of their new responsibilities. There is a recommendation in the Monitoring services and collecting data for quality improvement section of the guideline on advocacy providers and commissioners working in partnership to develop shared, consistent, practical and robust methods to record and collect information and data. This recommendation gives ICBs or ICPs the possibility of agreeing formats for standardised approaches at that level.



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Think Local Act Personal (TLAP)	Rationale and Impact	037	025 - 026	Whilst in the long term investing in non- statutory advocacy services may reduce or remove the need for long term investment in advocacy services especially in employing new advocates, this is not proven and it is therefore important to regularly review advocacy providers have adequate staffing levels.	Thank you for your comment. It is beyond the remit of NICE guidelines to recommend the reviewing of staffing levels.
Think Local Act Personal (TLAP)	Rationale and Impact	038	004 - 006	We agree with the Committee's assessment that local authorities have a legal duty to make information available about the care and support services in their area, but that this does not always happen, which suggests this should be monitored, perhaps through the Care Quality Commission's forthcoming responsibilities to assess how well councils are implementing the Care Act.	Thank you for your comment. NICE does not have a remit to tell the CQC what they should monitor. There are a number of recommendations in the Monitoring services and collecting data for quality improvement section (1.11) aimed at Commissioners or Local authorities as these are the actors most likely to monitor services and implement changes. An example of this is recommendation 1.11.8: Commissioners should check that advocacy providers have a robust method of quality assurance that monitors and reports on their quality of service.



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VoiceAbility	Guideline	General	General	The direction relating to ensuring that enough 'advocacy hours' are commissioned to ensure an effective service is very welcome. Some consideration could be given to guidance on the hourly cost per 'advocacy hour' as there is huge variation nationally. There are figures quoted in the DHSC impact assessment for Liberty Protection Safeguards of £37 per hour, and also comparable cost (in terms of qualification/training expectations) in the PSSRU for social work assistants at £35 per hour (2021).	Thank you for your comment. It is beyond NICE's remit to set wages or hourly rates and guidance on hourly costs of advocacy are outside of the scope of this guideline. All recommendations are made with consideration of the economic impact they will have. This includes consideration of the cost of advocates time and how this may vary depending on the type of advocacy and the geographical area. For example, the cost of advocates' time is explicitly considered in the economic evaluation of training which is reported in Evidence report I of the guideline ranging from £33 per hour to £53 per hour based on the differing assumptions used.
VoiceAbility	Guideline	General	General	Overall, we strongly support the content of the draft guideline which will be an extremely valuable resource for those commissioning, providing and using advocacy services.	Thank you for your supportive comment.
VoiceAbility	Guideline	001	007	Expand list of 'Who is it for?' to include Safeguarding Adults Boards – particularly as they are referenced later from p.32 as having an important relationship with advocacy providers and advocates	Thank you for your comment. This change has been made.



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VoiceAbility	Guideline	004	002 - 012	Propose adding words or a sentence to the context section that refers to advocates role in protecting human rights and also in safeguarding – which features positively in the guideline as a whole	Thank you for your comment. Changes have been made to the context section based on your suggestion.
VoiceAbility	Guideline	004	008	Propose adding 'health services' after councils as worth identifying as a significant area of work	Thank you for your comment. This change has been made.
VoiceAbility	Guideline	005	020	Consider adding 'NHS' before 'complaints' to aid understanding	Thank you for your comment. The recommendation covers the legal requirement for local authorities to make arrangements for advocacy services to assist people making complaints as described in the Health and Social Care Act 2012. NHS complaints is something separate and is covered by different legislation. Therefore this change has not been made.
VoiceAbility	Guideline	006 - 007	012	Consider adding further information about Liberty Protection Standards in the section on MCA as this will be a significant area of work for advocacy providers and advocates – the government is currently consulting on a new Code of Practice for the MCA including Liberty Protection Standards	Thank you for your comment. The committee discussed this but decided not to amend the existing recommendations as the post-DOLS-granted Relevant Person's representative is not yet current policy. Details on this have been added to the committees discussion of the evidence section of evidence review A. It will also be flagged with the surveillance team at NICE that future changes may impact on the current guideline.



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VoiceAbility	Guideline	011	007 - 009	Strongly support the text the recommendation that health and social care providers in all settings should help people to access an advocate regardless of blanket restrictions or policies that might prevent this. The Valuing Voices report provides evidence of how access to advocacy was restricted during the Covid pandemic and the implications and problems that arose.	Thank you for your supportive comment and for providing the information on the report.
VoiceAbility	Guideline	011	021	Propose additional clarity added to recognise that depending on commissioning arrangements, there may be different providers for different types of advocacy	Thank you for your comment. The committee discussed this and felt that although the comment was correct there was no need to amend the recommendation as it was already worded as 'should aim to support' so there was some leeway for local circumstances.
VoiceAbility	Guideline	011	026	Propose adding a sentence at the end of this paragraph – 'Particular efforts should also be made to facilitate access to advocacy for those in seclusion or segregation' as they will not come into contact with advocates when they are visiting the wards	Thank you for your comment. This change has been made.
VoiceAbility	Guideline	012	001	This should also be included under the section for health and social care providers - advocacy providers cannot operate an opt-out system for IMHA without the co-operation of relevant hospitals/health trusts	Thank you for your comment. The recommendation was amended so that, as well as advocacy providers, those offering IMHA on an opt out basis included hospitals and health trusts.



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VoiceAbility	Guideline	013	010	Consider adding 'This request should be met wherever possible' to place onus on the health/social care practitioner to explore the request in addition to the advocate supporting the person make the request	Thank you for your comment. The committee decided that this change would fit better in the preceding recommendation about accommodating the advocates availability when planning and scheduling meetings or ward rounds as this was aimed at service providers.
VoiceAbility	Guideline	013 & 014	020 - 028 & 001 - 005	Strongly support these recommendations on health and social care practitioners facilitating advocacy as their role is absolutely vital in facilitating access to advocacy services. This comment also applies to p.14 lines 9-14 on the practical requirements of facilitating access.	Thank you for your supportive comment.
VoiceAbility	Guideline	014	005	This comment also applies to page 13 line 3. The advantage of the advocacy provider arranging interpreting is that helps to protect confidentiality (between the advocate and the person being supported). There could be some clarity added in terms of who should bear the cost of interpreting (for example, recharged to commissioner/health and social care providers).	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as they did not feel that it was important for the advocacy provider, rather than health and social care professionals, to arrange interpreters, or that this would necessarily help protect confidentiality. The committee felt that the key issue is that the person gets an interpreter if they need one. The committee also felt that recommending who should bear the cost of interpreting was not within the remit of the guideline.



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VoiceAbility	Guideline	014	015	Propose re-ordering of 2nd half of sentence and slight change of wording so that after 'communicate with the person' it then reads 'when necessary or the person prefers it and only when it is safe, effective and appropriate to do so' – this is to help emphasise that advocates will need to make a judgement – particularly in relation to the use of social media platforms where confidentiality of communications may not be secure	Thank you for your comment. This change has been made.
VoiceAbility	Guideline	015	013	Perhaps include 'if this is what the person wants, or it is in their best interests where they lack capacity to make that decision for themselves'	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the extra text was implicit in the recommendation.
VoiceAbility	Guideline	020	010 - 012	Consider some additional clarification here. For example, adding 'ensuring there is enough time in the contract to develop the information' or 'ensuring there is enough time in the contract for networking and awareness raising about the advocacy service'	Thank you for your comment. A change has been made based on your suggestion. The text was amended so that it covered "enough time in the contract to develop the information". The committee felt that as the recommendation was focussed on developing information they did not want to distract from this by adding an example on networking or awareness raising.
VoiceAbility	Guideline	021	017 - 021	Strongly support the recommendation that commissioning of advocacy services should be based on an assessment of local need and the need to recognise structural health inequalities and work in co-production.	Thank you for your supportive comment.



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VoiceAbility	Guideline	022	001 - 004	Strongly support the recommendation that advocacy services that advocacy services should be commissioned for people who do not meet the criteria for statutory advocacy but could benefit from using them.	Thank you for your supportive comment.
VoiceAbility	Guideline	022	019 - 021	Strongly support the recommendation that commissioners should include time allowances in contracts and specifications so providers allow enough time for advocates to undertake continuing professional development and training.	Thank you for your supportive comment.
VoiceAbility	Guideline	025	018	Consider adding an additional bullet point to list of training areas: 'Changes to policy and case law'	Thank you for your comment. The committee discussed this but decided not to amend the recommendation as it was felt that the previous recommendation covered this sufficiently by mentioning training in justice processes that are relevant to their role.