Advocacy services for adults with health and social care needs
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Stakeholder	Page no.	Line no.	Comments	Developer's response Please respond to each comment
British Association of Social Workers – England	001		**Section 1.1** People may be entitled to the support of an advocate during an assessment i.e. before they become a service user. Perhaps it is better to say "People with health and social care needs".	Thank you for your comment. We have amended the population in line with your suggestion.
British Association of Social Workers – England	001		**Section 1.2** We think that key themes should include reference to the purpose of advocacy, as stated in the relevant legislation. For example, the Care Act 2014 specifies that this is "to represent and support the individual for the purpose of facilitating the individual's involvement" [section 67 (2)], where the individual has "substantial difficulty" [section 67(4)].	
British Association of Social Workers – England	001		**Section 1.2** We think that key themes should include reference to the context of the discharge of the relevant duty. For example, in discharging the duty to address "substantial difficulty", a local authority is required to determine whether there is someone "who would be an appropriate person to represent and support the individual" [section 67(5)]. It is only when the local authority is satisfied that there is nobody is suitable for this role, that there is a requirement to appoint an independent advocate.	Thank you for your comment. We will ensure that the relevant legislation is referenced in the guideline recommendations.
British Association of Social Workers – England	001		**Section 1.2** It may be useful to make the distinction between the different roles of the advocate. An independent advocate operating under the Care Act has responsibilities for providing support to facilitate involvement, assisting the individual challenge local authority decisions where the individual wishes to do this and in some circumstances making a challenge where the individual is unable to make their own decisions.	Thank you for your comment. We would expect this to be picked up during development and to be part of the decision making process for the committee when making recommendations.

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British Geriatrics Society	General	General	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? COVID-19 has highlighted the ability to use online platforms to communicate between patients (adults with health and social care needs). Provision of information in short video format or infographics etc should be considered, as well as the use of online platforms (NearMe/Teams/zoom) to allow discussions with an advocate without requiring in person meeting. Innovative technology like Create can allow one side of the conversation to be recorded, and then watched at a later date and then responded to.	Thank you for your comment. The committee will consider this when drafting review protocols for this guideline.
British Geriatrics Society	001	013	'Facilitating independent advocacy'. We want to ensure that methods to improve access and provide information are provided in a range of formats that will be appropriate for people of all ages, and people with disabilities (eg if online, then also available in print, and telephone access, options for people with hearing and visual impairment)	Thank you for your comment. We will add this information to the Equality Impact Assessment and ensure the committee consider this.

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British Geriatrics Society	001	013	'Monitoring services and collecting data for quality improvement'. We are supportive of this, and that monitoring data should be regularly fed back to the service to ensure access is equitable in different regions and for people of different ages, disabilities, and socioeconomic backgrounds	Thank you.
British Geriatrics Society	001	013	'Planning and commissioning services'. We would like to see clarity on what services could be included and that this will include scoping of existing services to avoid duplication and overlap. The pathway to referral and access for people who do not have a legal right to independent advocacy will need to be clear	Thank you for your comment. We will pass this on to the development team.
British Geriatrics Society	001	013	'Delivering independent advocacy'. Independent advocates should all receive training in dementia and delirium.	Thank you for your comment. We will pass this suggestion to the development team.
British Geriatrics Society	003	001	The majority of people who may require independent advocacy will be older (over 65 years, and many over 80 or 90) and the guideline and training should take this into account	Thank you for your comment. We will add this detail to the Equality Impact Assessment
Care Quality Commission (CQC)	General	General	A guideline that covers advocacy for people not legally entitled to independent advocacy has to be very carefully considered. If you take all health and social care services, the types of advocacy and population groups – the majority of advocacy for people not legally	Thank you for your comment. This guideline aims to identify the generic principles that should apply to advocacy provided by a third party across the board, regardless of whether it is for those legally entitled or not. We also aim to clarify in the guideline who is entitled

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			entitled is a significant proportion of people who are in receipt of health and social care. There are so many advocacy services that are funded through volunteers or by provision of paid staff from charitable fund raising that a guideline for every provision meeting the needs of diverse, and at times complex, groups of people may not land well. Is it not better to focus upon distinct population groups, as opposed to including everyone? Also, to consider that if only addressing advocacy services for people with a legal entitlement, and who therefore are the most vulnerable in society, may be enough?	to advocacy and who additionally would benefit. We recognise that advocacy services are provided by a wide range of service providers for a wide range of individuals and will aim to make this clear in the guideline.
Care Quality Commission (CQC)	General	General	Draft scope could consider including 16-17year olds, albeit it would not then be an adult guideline. The rationale for this is to future proof the guideline against the incoming Liberty Protection Safeguards (LPS) which includes 16-17yrs in scope, and reform to the Mental Health Act (MHA) which significantly strengthens advocacy for all ages.	Thank you for your comment. The guideline aims to cover all those who come into contact with adult services and as such we haven't defined an age. Where possible, the committee will consider the impact of advocacy in adult services on young people aged under 18.

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			It is noted that in one place the guideline states it is intended for people using adult services (as opposed to just adults), which can of course sometimes include children, but in another place it refers to adults only.	
Carers Federation Ltd	001	010 - 012	The area of focus needs expanding to state: People using or **transitioning** into adult health or social care services in all settings including **though not exclusively** those who have a legal right to an advocate	Thank you for your comment. We have updated the population to focus on a broader group of people with health and social care needs in adult settings.
Carers Federation Ltd	001	014	**Population** This needs to reflect the fact that there are instances where young people aged 16 -17 would fall within the population particularly regarding mental health legislation and the legal right to an independent advocate	Thank you for your comment. The population is intended to include those 16 and 17 year olds who are in an adult service or in transitional arrangements.
Carers Federation Ltd	001	017	**identification** Scope needs to consider the broadest spectrum of beneficiaries of advocacy balancing that with both the legal rights and the myriad of specialist non statutory advocacy offerings which can deliver positive outcomes. Any work should not be limited to the traditional statutory advocacy services	Thank you for your comment. This is the intention of the guideline.

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Carers Federation Ltd	001	022 - 034	**facilitating** • Consideration – improving access- the scope needs to be clear on its baseline looking at what and if any improvements are needed concentrating on the format and paths to accessibility and broadening any constraints of referrals. • Scope needs to establish what the statement means around "effective" independent advocacy means and perhaps include outcomes as well. It may be advocacy is available and delivered timeously though may not meet the expectations for an individual. • Scope should also consider how advocacy has embraced the current pandemic particularly where work has moved online, and innovative digital solutions brought into play substituting face to face advocacy with online support and the challenges it creates • Monitoring services and collecting data and planning and commissioning – the Scope needs to consider both areas broadly. The challenge of monitoring similar services who are not commissioned in the same way – look at the	Thank you for your comments. We expect that the guideline will identify the barriers and facilitators in this area but will pass this to the committee for consideration. The guideline committee will need to establish what is meant by effective advocacy and will use an outcomes-based approach to define this. We have updated the scope to consider virtual and non-in person advocacy. We will pass this information to the committee for consideration.

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			pros and cons of collaborative commissioning and possibly encourage all Advocacy provision to be delivered by Providers who adhere to the advocacy charter – have external quality marks and have a skilled and trained workforce holding the industry standard qualification. The quality of commissioning knowledge should be tested. The commissioning of advocacy services should also include consultation with the recipients of the services and what is required in the locality dependant on the complexity of the health and social care delivery models.	
Carers Federation Ltd	001	035 - 036	**delivering** Scope needs to explore what is meant by "effective" in each context of delivery across all ranges of advocacy services and ensure this is embedded in any final guidelines as the standard expectation including the minimum expected qualification levels.	Thank you for your comment. Although the guideline will seek to define effective advocacy, it is beyond the remit of NICE to define minimum qualification levels as this sits with the registering body.
Carers Federation Ltd	002	002 - 009	**Key considerations** • Variation in service provision and delivery – the Scope needs to establish a consistent view on how to encourage the commissioning of advocacy services in a holistic way which addresses the needs of individuals who may find they are accessing support outside of their	Thank you for your comments. This information will be passed to the development team who will discuss these with the committee.

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			current location or transferred to a new location. There needs to be a transparency between Providers to hand over any work in an efficient way. • Trade-offs – the Scope needs to clarify and examine why there may be concerns in this area and establish by consultation remedies that can be built into both commissioning arrangements and a Providers flexibility of delivery • Consideration should be given to broadening out the membership of the Committee to look at current practice- the audience guideline does not specifically cover the expertise needed in NHS Complaints, Care Act, Non statutory Community and Self advocacy. Independent advocates can be volunteers – paid or non-paid. • There should be consideration of how the Committee will build into this scope any consideration on the delivery of non-instructed advocacy. • A key consideration not included is the relationship an advocate must build across many interested parties to support an individual – this can be the family, Health care provider/	We recognise that in order to be equitable, there may be more cost or differential recommendations may be needed. We expect our committees to work in line with NICE principles and make judgements about fair and equitable distribution of scarce resources. Once committee recruitment has been completed, we will identify whether the committee could benefit from further expertise or whether to seek expert witness testimony. We will pass these suggestions to the guideline developer. The intention is to provide generic principles that will apply across all advocacy provided by a third party. Thank you. We will pass this to the guideline developer for consideration. Thank you. We have added partnership working with family and other practitioners to the scope.

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			social care provider – other specialised advocates, interpreters, and commissioners	
Carers Federation Ltd	002	015	**who is guideline for** The guidelines should consider broadening the membership to understand that independent advocacy is delivered for NHS Complaints, Care act, non-statutory work and that **not** all independent advocates cover all areas of advocacy	Thank you for your comment. The breadth of advocacy will be considered and outlined by the guideline committee.
Carers Federation Ltd	003	001	**Equality considerations** Consideration should be given to expanding the wording to reflect the people advocacy services are working with and the degree of expertise needed. For example: dealing with deaf/deafened cohort of service users brings in specialist communication needs and this is further compounded if that person is also from a BAME background.	Thank you for your comment. We will add more detail on intersectionality to the Equality Impact Assessment.
Fair Treatment for the Women of Wales (FTWW)	001		**Section 1.2** In the section, 'Key themes to include', we would recommend that in the first instance NICE describes what is meant by 'advocacy' in this guideline (and beyond). We note that the draft scope positions, 'Delivering independent advocacy – What does effective independent advocacy look like?' towards the bottom of the section, whereas it may be more prudent to have this	Thank you for your comment. The guideline itself will outline in more detail what is meant by advocacy. The guideline pertains to advocacy on behalf of individuals rather than on behalf of a group.

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			definition nearer the top, reflective of the fact that independent advocacy can vary widely in terms of who delivers it and in what form(s). Independent advocacy can incorporate formal provision (a commissioned service with trained professionals) and informal provision (a friend / family-member / member of peer group), and can be delivered one-to-one or on behalf of a group of service-users / patients (ie civil advocacy, which would not necessarily be considered lobbying and therefore out of scope) to ensure their voices are heard by way of representation, engagement, and involvement in processes to design / deliver health or social services (co-production). Ideally, the guideline should be comprehensive enough to cover all of the above, so that those bodies responsible for delivering health and social services fully appreciate both the breadth and efficacy of independent advocacy / advocates in their dealings with service-users / service-user groups and are supportive of its aims, not least in terms of commissioning / funding arrangements.	

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Fair Treatment for the Women of Wales (FTWW)	001		**Section 1.2** In the section, 'Key themes to include', the draft scope lists 'Planning and commissioning services for independent advocacy'. We would suggest that this category be broadened to encompass the types of logistical and financial support which could be made available to organisations providing independent advocacy services who wouldn't necessarily require or be in a position to engage with such formal arrangements as commissioning. This is particularly pertinent to those smaller / grassroots organisations or charities which may well already be providing independent advocacy on behalf of groups of service-users / patients.	Thank you for your comment. NICE do not have a remit to make recommendations about funding streams. The guideline is aimed primarily at public sector organisations and recommendations as to how they might plan and commission services are intended to be made in this section, rather than expecting advocacy organisations to do this.
Fair Treatment for the Women of Wales (FTWW)	003	003	Equality Considerations – Equality Impact Assessment, section 1.2, 'Disability'. We would urge NICE to consider using social model language in the section pertaining to disabled people and refer to 'impairments' rather than 'people with disabilities'.	Thank you for your comment. We have updated the term used in our Equality Impact Assessment to "disabled people". We have retained the heading "Disability" as this matches the legislative framework.
Fair Treatment for the Women of Wales (FTWW)	003	003	Equality Impact Assessment, section 1.2, 'Gender Reassignment'. We would ask that NICE refers to the difficulties accessing gender reassignment services in the UK rather than just England. Whilst we acknowledge that NICE guidelines cover health and care in England,	Thank you for your comment. As NICE guidelines have a primary focus on England, it is important that the Equality Impact Assessment also focuses on England.

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			and decisions on how they apply in other UK countries are made by ministers in the devolved nations, we believe that the EQIA should still be as inclusive as possible, if only to make the relevance of them clear to the devolved administrations / service providers.	
Gender Identity Research and Education Society (GIRES)	General	General	It is important that financial barriers to the provision of adequate independent advocacy services are directly addressed in the guidance.	Thank you for your comment. Allocation of funding to services is outside NICE's remit.
Gender Identity Research and Education Society (GIRES)	002		**Table 1.2** The exclusion of issues already covered in existing NICE guidelines is of course entirely appropriate. However, the landscape of practice and policy around shared decision-making and capacity in the context of transgender people has undergone some changes since then, and advocacy services may be needed to enable equitable access to care, as is correctly noted in the Equality Impact Assessment document. We therefore suggest that these exclusions be defined more narrowly, to exclude matters already 'decided' in the specific guidance documents mentioned, but that the specific	Thank you for your comment. We have removed these points from the exclusion list and highlighted these as key guidelines to link to instead as the generic principles of advocacy that are covered by this guideline will likely enable better approaches in these areas. We have further highlighted this for consideration in the equality impact assessment and the guideline will aim to identify who would benefit from advocacy.

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			interactions of these guidelines be open to consideration and the current scope include matters relating to decision-making and capacity where guidance on advocacy services and their provision are likely to interact in ways not adequately covered in extant NICE guidelines.	
Healthwatch Wakefield	General	General	The guidance should look at the amount of advocacy hours a patient or service user would need/be entitled to perhaps some kind of scoring matrix to determine a service level	Thank you for your comment. The guideline will look at generic principles that should apply to advocacy. In terms of entitlement and service level, given that individual circumstances are likely to determine this, it is a level of detail beyond the remit of this guideline.
Healthwatch Wakefield	General	General	Will the service be limited to what the Local Authority can afford to provide? [Especially if it is opened up to people not currently legally entitled to an independent advocate]	Thank you for your comment. The aim of this guideline is to outline where and how advocacy can be useful. Allocation of funding and services is outside NICE's remit.
Healthwatch Wakefield	General	General	The guidance should cover response times once a referral is made for an independent advocate and there should be different levels depending on how urgent the referral is.	Thank you for your comment. Timing is included in the section on facilitating independent advocacy and we aim to make recommendations in this area.
Healthwatch Wakefield	General	General	Would there be a maximum waiting time for people to be allocated an independent advocate [especially if the urgent referrals take all the available capacity]	Thank you for your comment. Timing is included in the section on facilitating independent advocacy and we aim to make recommendations in this area.

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Learning Disability England	General	General	The draft does not refer to peer advocacy or self-advocacy. For many people with learning disabilities, advocacy is accessed through these modes. We think the role of peer advocacy and self-advocacy within independent advocacy should be acknowledged and included within this scope.	Thank you for your comment. The guideline will focus on advocacy that is provided by a third party and therefore self-advocacy is out of scope. We have clarified this by adding a definition of advocacy to the scope. We recognise the importance of self-advocacy and will ensure this is referred to in the guideline introduction.
Local Government Association	General	General	The request from the Department of Health and Social Care that NICE develop a guideline on advocacy services for adults with health and social care needs is welcomed.	Thank you for your comment.
Local Government Association	General	General	In recent discussions within the Local Government Association about advocacy, we also recognised the important role that family and friends can play in providing advocacy support for adults with health and social care needs and we feel that it would be important to recognise this in the NICE guidance and include reference to this in the scope.	Thank you for your comment. We have added family and carers to the scope under partnership working. We recognise that some advocacy support will come from family and friends and this will be brought out further in the guideline.
Local Government Association	General	General	The draft scope does not mention making reasonable adjustments within services that could assist the person to be able to make their own decisions or to better understand the situation alongside the support of an advocate. We feel that this would be an important addition to the scope to reinforce the importance of reasonable adjustments to give the person as much	Thank you for your comment. We recognise that people may benefit from reasonable adjustments and as this is part of a legal framework will not be covered specifically in the guideline. This has also been covered to some degree in the NICE guideline on patient experience in adult NHS services, the NICE guideline on service user experience in adult mental health and the NICE

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			autonomy as possible whilst also having the support of an advocate.	guideline on people's experience in adult social care services, we will cross refer to these guidelines where appropriate.
Local Government Association	General	General	Clarification that people using social care services who are self-funders are included in the scope would be helpful to ensure that these people are not forgotten in respect of a right to advocacy.	Thank you for your comment. We have added this to the population for clarity.
Local Government Association	General	General	Clarification that informal/family carers are included in the scope would be helpful because advocacy services for informal/family carers are often commissioned separately to other types of advocacy.	Thank you for your comment. There is a NICE guideline on Supporting adult carers which covers this population.
Local Government Association	002	038	It would be helpful to clarify what is meant by practitioners in the key consideration *Status, knowledge and influence of practitioners*. Is this health and social care practitioners or independent advocates, or both? Status, knowledge and influence of independent advocates is important, and commissioners would benefit from understanding the training requirements for different types of advocacy.	Thank you for your comment. This is intended to cover both health and social care practitioners and independent advocates.
Local Government Association	002	041	Although there is a NICE guideline on shared decision making in development, it would be helpful for commissioners in particular to have information about all aspects of independent advocacy in one place, so inclusion of some information about the role of advocacy	Thank you for your comment. We will consider how to bring all the information together for ease of use.

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			in shared decision making in this guideline would be helpful.	
Local Government Association	002	043	Although there is a NICE guideline on decision making and mental capacity it would be helpful for commissioners in particular to have information about all aspects of independent advocacy in one place, so inclusion of some information about the role of advocacy in decision making and mental capacity in this guideline would be helpful.	Thank you for your comment. We will consider how to bring all the information together for ease of use.
Mencap	General	General	It seems quite a broad guideline. It would be helpful for it to clarify who it means by 'adults with health and social care needs'. Will it include, for example, NHS complaints advocacy? We think it would be helpful to have a specific section on advocacy for people with a learning disability.	The guideline will focus on generic principles of advocacy services and therefore will be relevant to NHS Complaints Advocacy but not specific. We've noted this in the Equality Impact Assessment and will consider this during development.
Mencap	General	General	We think it would be helpful to have a section which explains what Independent Advocacy is (and the purpose of independent advocacy) as well as explaining the different types of advocacy, for example: Statutory and non-statutory Instructed and non-instructed Formal and informal, including self-advocacy and peer advocacy.	Thank you for your comment. We've added a plain English definition of advocacy to the scope. Further detail about the different types of advocacy will be included in the guideline.

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Mencap	General	General	We think it is very important the guideline is co-produced with people who use advocacy services. This will be crucial when looking at what effective and high quality independent advocacy is. Considerations like how many times the person meets with the advocate, for how long advocacy for the person is funded, will be important when thinking about effectiveness not just training and skills of the advocate.	Thank you for your comment. The guideline committee will include members with lived experience of using advocacy services.
Mencap	General	General	Mental capacity and decision making will be very relevant to this guideline – so rather than saying this is an exclusion as there is another guideline on this –we think it would be helpful to say that is a crucial guideline that needs to be linked to, as well as including important information about MCA in this guideline as well.	Thank you for your comment. We have moved this into a separate section to explain that this key guideline will be linked to.
Mencap	General	General	Raising our sights: services for adults with profound intellectual and multiple learning disabilities (PMLD) – 2010, by Professor Jim Mansell, included a recommendation: 'Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of people with PMLD. They should include funding for continued advocacy in the package of self-directed services for adults with PMLD.' We would like to see this reflected in this guideline.	Thank you for your comment. It is beyond NICE's remit to make recommendations about funding streams. Thank you for the reference, we will pass this on to the developer team.

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			Please also see the Raising our sights Advocacy how-to guide (please note this was written before the Care Act came in, but much of it will be relevant, including explaining what good advocacy looks like for adults with profound and multiple learning disabilities): https://www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20advocacy_FINAL.pdf	
Mencap	General	General	It will be important that this guideline links in with DHSC and NHS England's forthcoming review of current advocacy provision for people with a learning disability and autistic people to identify areas for improvement.	Thank you for highlighting this work. We will keep an eye on this during development.
Multiple System Atrophy Trust	001		Facilitating independent advocacy. Does the definition of 'Independent Advocacy' include charitable organisations such as the MSA Trust and if so what criteria would be used to promote us and refer to us?	Thank you for your comment. The intention with the question on delivering independent advocacy is to outline what effective independent advocacy looks like. The guideline would not recommend specific organisations, but would instead recommend approaches that are shown to be effective.
Multiple System Atrophy Trust	002		Is advocacy for services such as assisting people to put in place Lasting Powers of Attorney covered?	Thank you for your comment. As this is beyond the scope of what health and social care services provide, this would not be covered.

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NHS England & Improvement	General	General	The draft scope is for adults. Consideration to be also given to those in the age group 16-18 years. (SK)	Thank you for your comment. The scope will include people under 18 who are using adult services and this will likely include many 16 to 18 year olds.
NHS England & Improvement	General	General	In the P1 Key themes, we think it should be made explicit the aims of advocacy and the underlying principles on which it is delivered e.g. enablement, empowerment, equality, protection from harm? (RB)	Thank you for your comment. We have included a definition of advocacy in the final version of this scope. It is intended that the guideline will identify how advocacy is best delivered and will likely consider the principles you have outlined.
NHS England & Improvement	General	General	We recommend that training requirements for advocates should be included as well as the Core Capability Frameworks for supporting autistic people and people with a learning disability. As part of the Equality and Impact Assessment, the role of advocacy for people who do not communicate with words needs to be included and how to train people in communicating to people with non-verbal communication. (RB)	Thank you for your comment. We have included training under "Delivering independent advocacy". We will include the specific information you have added about people with non-verbal communication to the Equality Impact Assessment.
NHS England & Improvement	General	General	The guideline as it stands is not explicit enough about quality of advocacy. (RB)	Thank you for your comment. Quality is intended to be covered under "what does effective independent advocacy look like?".

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NHS England & Improvement	General	General	Self-advocacy and peer advocacy and citizen advocacy and family advocacy should **not** be excluded from this guideline. We recommend that self-advocacy and peer advocacy and citizen advocacy and family advocacy should be included in the guidance. (RB)	Thank you. The guideline does not explicitly exclude these forms of advocacy but intends to focus on advocacy services that are provided by a third party (including family, peer and citizen advocacy). Self-advocacy will not be covered by this guideline,
NHS England & Improvement	General	General	The guidance needs to consider and be clearer on who is responsible for paying for advocacy. (RB)	Thank you for your comment. It is beyond NICE's remit to discuss funding streams for services. We intend to identify where advocacy would be of benefit to people using services.
NHS England & Improvement	General	General	For all people in specialist mental health and learning disability and autism inpatient settings (not just people detained under the mental health act), we recommend that advocacy is not commissioned by the providers because of issues such as; lack of independence when funded by the hospital and the quality of advocacy when delivered by one provider across a large number of services/people and the lack of oversight and scrutiny by the body which is commissioning the provider. Commissioning advocacy should include looking at the benefits to people of local advocacy and self-advocacy/peer advocacy and citizen advocacy. This needs to be done as part of the NICE Equality and Impact Assessment. (RB)	Thank you for your comment. We will include this information in the equality impact assessment and will consider this when drafting review protocols.

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NHS England & Improvement	General	General	Advocacy needs to focus on the person and representing the individual rather than crisis advocacy. The disadvantage of issue-based advocacy is that it dips in and out of peoples life's rather than supporting people with their life. Advocacy Working to support the individual while being aware of views and wishes of family members and any associated conflict (RB)	Thank you for your comment. We will highlight this to the committee when drafting review protocols.
NHS England & Improvement	General	General	When people are admitted to specialist mental health, learning disability and autism services, their previous, existing and future community advocacy should be respected and supported to continue. Long standing advocacy arrangements are important relationships in the way that family and friends are. (RB)	Thank you for your comment. We will highlight this to the committee when drafting review protocols.
NHS England & Improvement	General	General	In P2 Key considerations: rather than just health inequalities – should be concerned with inequalities generally and their impact on health and wellbeing / social determinants of health (RB)	Thank you for your comment. Equalities issues will be considered across the board for this guideline. We used the team health inequalities to mean the social determinants of health. We have noted the importance of equalities issues and intersectionality in the Equality Impact Assessment
NHS England & Improvement	General	General	Advocating for parity of esteem in meeting the mental and physical health needs of individuals (RB)	Thank you for your comment. In line with our definition of advocacy, we understand this to be about helping an individual with mental or physical health and social care needs to express their needs and wishes.

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NHS England & Improvement	001		**Key Themes** Does this include advocacy for asylum seekers access to healthcare provision eg fertility treatment? (SK)	Thank you for your comment. We would expect that the guideline includes access to advocacy for disadvantaged groups such as asylum seekers and refugees in line with legislation. It is likely that the guideline will focus on generic principles of good advocacy which will be useful across health and social care.
NHS England & Improvement	001		**Section 1.1** It would be worth stating if the guidance applies to all forms of independent advocacy. In recent years it seems some commissioners have confused / conflated 'independent' advocacy to be the same as 'statutory' advocacy, leading to reduced commissioning of broader independent advocacy. Similarly, it would be helpful to include access to peer and self advocacy services – which also form part of the independent sector. (TR)	Thank you for your comment. We have added a definition of independent advocacy to the table.
NHS England & Improvement	001		**Section 1.1** Legal rights to advocacy - this has been explored by the Personalised Care Group in NHS England. We would be happy to discuss our findings with you.	Thank you.
NHS England & Improvement	001		**1.2 'Key themes'** Monitoring of advocacy is essential. It seems that Department of Health & Social Care no longer records	Thank you.

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			uptake of Independent Mental Capacity Advocates or Independent Mental Health Advocacy – this lack of data will make the facilitation and effective commissioning of advocacy much harder. Further, it results in a lack of oversight and accountability of advocacy services. (TR)	
NHS England & Improvement	001		Suggest the guidance should relate to those in need of services not those using adult health or social care services to ensure groups aren't marginalised. (NP)	Thank you for your comment. We have amended the population accordingly.
NHS England & Improvement	001		Facilitating independent advocacy – consider inclusion of how services are communicated with communities to ensure gatekeeping isn't a challenge. (NP)	Thank you for your comment. Under the key theme of facilitating independent advocacy, we have added "addressing barriers" under the bullet on improving access.
NHS England & Improvement	001		Training and skills for practitioners must include education for those working with service users also and should not rely simply on 'training' as this undermines the understanding behind the approach. (NP)	Thank you for your comment. We will consider the breadth of what training means when developing review protocols.
NHS England & Improvement	001	001	1.1 The focus of 1.1 suggests that the focus of the guideline is only for those who are already using the service. Should there not also be a focus on advocacy for those who have been refused? (RB)	Thank you for your comment. We have amended the population to those with health and social care needs. The guideline also covers non-statutory advocacy and barriers to accessing advocacy.
NHS England & Improvement	001	024	Regarding the section on delivering independent advocacy, we recommend there being inclusion of Quality Assurance process and minimum standards and	Thank you for your comment. We will pass this to the committee for consideration.

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			measurements. This should include checking peoples consent regarding who they want to involve in their advocacy. (RB)	
NHS England & Improvement	002	General	We recommend more clarity on who this guidance is for. In the Equality Impact Assessment, it mentions prisoners and young offenders, are the guidelines not also relevant to those in the Criminal Justice System, e.g. Probation etc? Or is this covered elsewhere? (RB)	Thank you for your comment. The guideline population is intended to be inclusive, and now covers all those with health and social care needs within adult services, which would cover the health and social care of people in the criminal justice system.
NHS England & Improvement	002		**Key consideration** Also consider the diversity and ethnic distribution of practitioners. (SK)	Thank you for your comment. We have updated one of our key considerations to state "appropriateness of practice to address equalities".
NHS England & Improvement	002		**1.2 'Key themes'** The Personalised Care Group in NHS England is currently developing training for advocates on personalised care. This work is being carried out with the National Development Team for Inclusion.	Thank you for this information.
NHS England & Improvement	002		**1.2 'Key considerations'** Health inequalities is key and we welcome its' inclusion. Advocacy can play a critical role in addressing health inequalities – and wider systemic inequalities in the health and care system. For example, National Development Team for Inclusion published research in December 2020 highlighting stark issues facing particular groups during the pandemic – inappropriate	Thank you for this information.

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			use of DNACPR being a key finding. The report can be found here. (TR)	
NHS England & Improvement	002		**1.2 'Key considerations'** "Culturally appropriate and culturally sensitive practice" - This was flagged in the interim review of the Mental Health Act in 2018. It would be helpful for the advocacy sector to reflect on how appropriate its services are for different cultures / faiths / ethnicities etc. This should be widened out to include other groups e.g., how inclusive are advocacy services for LGBT people? Or D/deaf people? How inclusive are advocacy services when it comes to intersectionality? E.g. how effective and responsive are advocacy services to someone with a learning disability who is also LGBT? What support can be offered to the advocacy sector to review impact / assess its' own services? (TR)	Thank you for your comment.
NHS England & Improvement	002		**1.2 'Key considerations'** Delivering independent advocacy – could also include consideration of the inclusion of independent advocates within multi-disciplinary team discussions (TR)	Thank you for your comment. We will pass this to the development team.
NHS England & Improvement	002		**1.2 'Key exclusions'** Whilst we acknowledge that there is a separate guideline on decision making and mental capacity, it would be helpful to know that capacity will be included in	Thank you for your comment. We will explore how we make effective links between our guidance in this area.

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			the document, both in reference to statutory Independent Mental Capacity Advocates as well as non-instructed advocacy. Plus wider issues around the Mental Capacity Act / Deprivation of Liberty Safeguards and avoiding assumptions about capacity (e.g. "people with a learning disability always lack capacity"). These issues remain poorly understood across all sectors – so referencing again would be valuable. (TR)	
NHS England & Improvement	002		**Who the guideline is for** We welcome the focus on commissioners of health and social care services. Working with the National Development Team for Inclusion, the Personalised Care Group at NHS England have gathered research relating to the commissioning of advocacy. Some of the findings were worrying and indicate a pronounced post code lottery, poor commissioning practices in some area and a worrying lack of understanding / knowledge amongst some commissioners about the nature, purpose and value of advocacy.	Thank you for this information. We will pass it to the development team.
NHS England & Improvement	002		Key considerations should include review of evidence bases and suggestions for research. (NP)	Thank you.

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NHS England & Improvement	002	035	In the section regarding Status, Knowledge and influence of Practitioners, we think there should be inclusion of the status, knowledge and influence of family carers/friends, if the person has consented to them being involved (who may not have gone down a formal Power of Attorney route)? (RB)	Thank you for your comment. We have added family/carers to this section.
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcome the proposal to develop NICE guidance for Advocacy services for adults with health and social care needs. The RCN invited members who work with people in these setting to review and comment on the draft scope. The comments below, reflect the views of our reviewers.	Thank you.
Royal College of Nursing	General	General	The draft scope seems comprehensive.	Thank you for your comment.
Royal College of Nursing	002		**Section 1.2 *“Under Key considerations”*** We would suggest NICE also explicitly consider issues related to mental capacity and advocacy.	Thank you for your comment. Issues relating to mental capacity and advocacy have been covered by the NICE guideline on Decision making and mental capacity.
Royal College of Nursing	003		**Section 5** We suggest that NG97 – Dementia, assessment, management and support of people living with dementia	Thank you. We have added this to related NICE guidance as suggested.

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			and their carers should be included in the list of *"related NICE guidelines".*	
Royal College of Physicians	General	General	Just to note the RCP would like to endorse the BGS response please.	Thank you.
Royal College of Speech and Language Therapists	001		**Section 1.2 Activities, services or aspects of care** In Key themes to include, under '**identifying those who would benefit from independent advocacy**' we would like to see the following added: How to improve access and accommodation of individual needs (e.g. communication differences or disabilities) for an inclusive identification approach for who would benefit from independent advocacy This is because people with communication disabilities can be mistaken for lacking mental capacity if their communication needs are not accommodated for. These individuals may not require advocacy but would require the input of specialists (speech and language therapists) to support this decision-making.	Thank you for your comment. This would be beyond the remit of this guideline. However, other NICE guidelines including the NICE guideline on patient experience in adult NHS services, the NICE guideline on service user experience in adult mental health and the NICE guideline on people's experience in adult social care services, cover these issues and we will cross refer to these guidelines where appropriate. We will add some detail to the Equality Impact Assessment about people with communication disabilities in line with your comment.
Royal College of Speech and	002		**Section 1.2 Activities, services or aspects of care** Under **key considerations** we would like to see:	Thank you for your comments. We will add this detail to the Equality Impact Assessment.

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Language Therapists			Availability and accessibility for different population groups, including people who are under served by services **and those with disabilities including speech, language and communication needs** This is because these groups of individuals are likely to be a particular group in which considerations around independent advocacy would be discussed, however they will likely require bespoke and specialist support (from speech and language therapists) to engage with and fully understand the implications of such services and so need to be explicitly required.	
Royal College of Speech and Language Therapists	Equality Impact Assessment 001		**EIA** We are delighted to see the explicit reference to communication needs throughout the EIA. We would however encourage NICE to include explicit reference to the requirement of involving appropriate expertise (speech and language therapists) in liaising with stakeholders and developing communications for populations with communication difficulties. This can be	Thank you for your comment and suggestion. As the groups likely to have specific needs goes beyond those with communication difficulties it would not be appropriate to be this specific in this section of the Equality Impact Assessment. The guideline committee will need to consider a variety of ways to ensure the broad needs of the population of interest is met.

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			mentioned in 1.1. (in response to 'What action might be taken by NICE or the developer to meet this need?)	
Royal College of Speech and Language Therapists	Equality Impact Assessment 002		**EIA** Involving speech and language therapists can also be referred to in 1.2. 'People with communication difficulties and/or sensory impairment' section. Furthermore in 1.2 'People with learning disability and other co-morbidities' section, we would like to see explicit reference to communication difficulties experienced by people with learning disabilities. This is because speech, language and communication needs are highly prevalent in this specific population. We would recommend an addition to the following sentence: '… and services to address these conditions may not provide appropriate support to people who also have learning disabilities to take decisions, specifically those with speech, language and communication needs.'	Thank you for your comment. We haven't added this to the Equality Impact Assessment as it goes beyond the challenges faced, and focuses on potential solutions which would better be addressed by the guideline. We have added this detail in section 2 of the Equality Impact Assessment.

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Tees Valley Durham and North Yorkshire Neurological Alliance	General	General	Independent advocates should demonstrate comprehensive and detailed knowledge of the psychosocial, spiritual, cultural and environmental factors that impact on the well-being of individuals, families and communities and apply such knowledge to advocacy interventions. It is vital to include caregivers as cooperating partners in the care pathway but current service specifications exclude the carer. Advocates should demonstrate comprehensive and detailed knowledge of the decision-making process and how a variety of sources of evidence can be used to support decision-making. Collaborative working should enable critical evaluation of values and attitudes and the psychological influences that can impact on the reality of inclusion on decision-making. Understand the concepts of equality of access to effective advocacy regardless of race, ethnicity, creed, gender or social class and equity signifying fairness and impartiality. As the gap between the bureaucracy of commissioning specifications and lived experience grows ever wider, it is	Thank you for your comment. This information will be useful when developing the approach to the guideline with the committee. NICE guidelines make recommendations about interventions and are not intended to set out the roles and responsibilities of specific professionals which should be covered by professional registration.

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			crucial we reaffirm some minimum standards within public services. This is not just about consent and capacity but about managing expectation and co-production. There should be a framework for advancing advocacy interventions which are evidence-based, non-aversive, enabling and promote social inclusion. Professionals should demonstrate the ability to plan, coordinate and implement advocacy interventions based on sound research evidence. Here to, there should be a critical understanding of the ways social, cultural and political conditions impact on advocacy governance to ensure safe practice and accountable, interpersonal behaviour.	
Tees Valley Durham and North Yorkshire Neurological Alliance	General	General	*Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?* The growing body of research evidence such as, Kılınç, van Wersch, Campbell & Guy, (2017)13 and Kulnik, Hollinshead & Jones (2018)14 all highlight how living with a long-term neurological condition can affect all	Thank you for your comment and the references.

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			spheres of life, physical, psychological and social. This depletes coping skills and needs skilled advocacy to synthesise evidence from lived experience that can negotiate care pathways and improve confidence to nurture self-management skills. (Finding Meaning and Purpose: A Framework for the Self-Management of Neurological Conditions, Kilnç, Cole et al - Disability and Rehabilitation Journal,May 2020)	
Tees Valley Durham and North Yorkshire Neurological Alliance	General	General	*World Health Organisation (2012)* *- NEUROLOGICAL DISORDERS public health challenges* *Public Health England (2018)* *- Deaths associated with neurological conditions in England 2001 to 2014 - Data Analysis report* *Kulnik, S. T., Hollinshead, L., & Jones, F. (2018) "I'm still me – I'm still here!"* *- Understanding the person's sense of self in the provision of self-management for people with progressive neurological long-term conditions. Disability and Rehabilitation*	Thank you for your comment and the references.

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			The Neurological Alliance (2016) *- Parity of Esteem for People affected by Neurological Conditions Meeting the Emotional, Cognitive and Mental Health Needs of Neurology Patients, www.neural.org.uk*	
Tees Valley Durham and North Yorkshire Neurological Alliance	001		Key themes; *Who else would benefit from independent advocacy and how do we identify them?* **Clarity of purpose, Safeguard, Confidentiality, Equality and diversity, Empowerment and putting people first are the principles of advocacy.** Neurological disorders are the leading cause of disability in the UK (WHO 2012) with life expectancy for the neurological disabled consistently reducing since 2001 (PHE 2018). In a survey by the national Neurological Alliance (2020), 40% of respondents cited that their mental health needs were not being met and 30% of respondents were not referred or signposted to mental health support. Depression is common in people living with a neurological condition (Bulloch, et al., 2015). The	Thank you for this detail. We will pass this detail on to the guideline developers for consideration. We have highlighted neurological disorders in our Equality Impact Assessment.

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			need for advocacy is generated by a failure of expectation. People living with Parkinson's disease, Multiple Sclerosis (MS), life-limiting genetic conditions such as Huntingdon's disease or Friedreich's Ataxia, neuro-developmental disorders such as ADHD, ASD, Down's syndrome, Foetal Alcohol Spectrum Disorder (FASD) or those with associated cognitive impairments due to Acquired Brain Injury (ABI) or survivors of brain haemorrhage are all likely to require social care and/or mental health services in the course of managing their debilitating condition and/or co-morbidities. There must not be an age-limit applied to accessing advocacy. Currently, parents are being blamed for poor parenting of children with neuro-developmental conditions such as FASD due to lack of the basic skills of advocacy. Parent Carers of children with disabilities or life-limiting conditions such as Friedreich's Ataxia need skilled advocacy to support the care needs of their children with life-limiting illness.	The guideline will cover advocacy services for those accessing adult services, therefore the services you specify here will not be covered. It may that the principles from this guideline will be useful for advocacy services provided to these groups. There is also a NICE guideline in development on Babies, children and young people's experience of healthcare which may be of interest:

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			Friedreichs_Ataxia booklet.pdf	https://www.nice.org.uk/guidance/indevelopment/gid-ng10119
Tees Valley Durham and North Yorkshire Neurological Alliance	001		Older age adults with a learning disability and a mental age of a child are constantly being scrutinized by DWP because valid medical evidence supplied by a GP is ignored. This situation is causing elderly parents of a disabled adult considerable harm. Parents with responsibility for their son or daughter's financial affairs are often 70years plus and do not have the wherewithal to fill out lengthy forms or respond digitally. Parents live in fear of failing to secure what their son or daughter needs to live independently and receive suitable care. This entire client group have need of a skilled advocate. The changing strategic environment, loss of networks and the national Neurology Clinical Director in 2016 left policy-makers, commissioners, health-care providers and educators notably unprepared to manage the predicted rise in the prevalence of neurological and other chronic disorders and disability with ageing populations. Particularly, the impact of Covid-19 and the	Thank you for your comment. We will provide this information to the committee for consideration.

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			emergence of Long-Covid on advocacy needs have yet to be explored.	
Tees Valley Durham and North Yorkshire Neurological Alliance	001		*Facilitating independent advocacy;* Accessibility is hampered by GP's in Primary Care who lack knowledge about neurological symptoms or case management and some solutions are more social than medical. Couple this with a historical lack of in-service training and severe reductions in NHS capacity and the neuro client group can no longer guarantee skilled healthcare at the first point of contact. People with rare conditions or long-term unexplained symptoms who cannot refer to a genetic service or national 3rd Sector organization fare very badly when trying to secure a clinical diagnosis or knowledgeable support from an advocate to negotiate a care pathway. Neuro-psychology services rarely see a new patient within a year, more likely, two to three years waiting for an appointment. This removes the recognition and right of need for timely clinical care and subsequent care pathways to access community services such as rehabilitation and other therapeutic interventions,	Thank you for your comment. We will provide this information to the committee for consideration. We have also added addressing barriers to accessing advocacy to the scope.

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			psychological or crisis management or social care services. According to Professor Alston, (United Nations Special Rapporteur on Extreme Poverty and Human rights - Nov 2018)[8], 3.45 million people are from families in which someone has a disability. People with disabilities are more likely to be economically inactive and live close to the poverty line and thus, marginalised from sources of information or the tools to negotiate through services appropriate to their needs without the help of an advocate.	
Tees Valley Durham and North Yorkshire Neurological Alliance	001		*Training and skills for practitioners who work with independent advocates;* Understand there is a knowledge base to advocacy and counselling skills are desirable. They will need to evaluate their own advocacy behaviours (see principles) to identify and realise appropriate practice with emphasis on reflection, strategic planning and collaboration.	Thank you for your comment. This point was intended to highlight the training and skills that non-advocates needed to work with advocates and service users. The guideline will also look at training for advocates.

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Tees Valley Durham and North Yorkshire Neurological Alliance	001		Lack of national strategic infrastructure is failing to protect the guiding principles and rights of people who need skilled, informed services. As the UN Convention on Rights of Persons with Disabilities (2009) cites in Article 4, 'States must take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes'.	Thank you for your comment. We will highlight this information to the committee for consideration.
Tees Valley Durham and North Yorkshire Neurological Alliance	002		*Key Considerations;* We developed an education programme to mitigate the fragmentation of services, loss of strategic impetus and improve the knowledge base about neurological conditions that could initiate a more positive impact on students who would be the Health and Social Care service professionals of the future. By enabling our lived experience seminars, people living with neurological conditions deliver the sessions to medical, cognitive neuroscience, psychology, counselling psychology, occupational therapy and nursing students, not only to consider more psychosocial	Thank you for this information. Timeliness of access to advocacy is in scope.

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			issues when dealing with their patients or clients but foster a better understanding of the need for advocacy skills. We have proved that timely, advocacy support for a spectrum of neurological conditions can, regardless of the diagnosis, prevent a slide into a crisis through lack of information, poor problem-solving and lack of knowledge about services. In delivering our advocacy service, we have witnessed first-hand the psychological burden on people with a neuro-disability; the ex-offender stigmatised and unable to afford high protein drinks to stem the weight loss caused by muscle spasms of Huntington's disease; the older adult with Tourette's, socially isolated due to tics and anxiety; the ex-addict with Multiple Sclerosis where judgements were based on past addiction not neurological need; the person who lives in such chronic pain, suicide seemed the best option; a semi-paralysed person who's primary carer was hospitalised two days before Christmas and social care failed to instigate the 72hour emergency care package . All of these circumstances have caused chronic depression needing	

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			long term psychological support/interventions and front-line advocacy to resolve issues of poor knowledge throughout the public sector. We have validated the belief that lived experience can make a major contribution to a much-needed body of knowledge. Our beneficiaries become participants in a network for peer support, research, education, design information or learning resources, all as a by-product of receiving support from an advocate. Adverse or unintended consequences must be included in comprehensive risk assessments. This is an essential mechanism for governance and accountability.	
The Challenging Behaviour Foundation	001		**Section 1.2 Population** Young people and adults with severe learning disabilities who display behaviours that challenge are likely to need advocacy services and therefore should definitely be covered in the scope of this guidance.	Thank you for your comment. This group is included in the guideline and will be further highlighted in the Equality Impact Assessment.
The Challenging Behaviour Foundation	001		**Section 1.2** **Key themes to include** Identifying those who would benefit from independent advocacy:	Thank you for your comment. We will provide this information to the committee for consideration.

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			• Young people and adults with severe learning disabilities whose behaviour challenges may have specific or complex requirements and require specifically trained advocates. Advocates supporting individuals with severe learning disabilities will need understanding and expertise in non-instructed advocacy, capacity and consent, and augmentative communication. In addition, if the person displays behaviour that is challenging, they will need expertise in areas such as understanding the function of behaviours that challenge, and likely responses such as restrictive practices. For the specialist skills they need see A Guide For Advocates available here: A Guide for Advocates (England and Wales). Information Packs. The Challenging Behaviour Foundation, UK. • Adults with learning disabilities at risk of hospital admission would benefit from independent advocacy. People with severe learning disabilities may display challenging behaviour (such as self-injury and aggression),	

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			which can place them at risk of out of area placement and/or restrictive practices and of human rights violations. Independent advocates can be vital in ensuring care providers take a more proactive approach to understanding and preventing challenging behaviour through capable environments.	
The Challenging Behaviour Foundation	001		**Section 1.2 / General** Facilitating independent advocacy • Advocates for young people and adults with severe learning disabilities must be independent and separate from service providers. Case study evidence from families supported by the CBF highlights the importance of advocates being fully independent of both service providers and health and social care to ensure the individual's best interests are at the centre of decisions: *"In the past my daughter had two advocates who were very much into siding with the care provider! Now she is getting another one whom Social Care has recruited. I*	Thank you for your comment. We will provide this information to the committee for consideration. However, issues relating to funding streams are outside of NICE's remit and we will be unable to make recommendations on this.

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			am extremely wary of them. The advocate is supposed to do an assessment of my daughter soon as her funds are now partially funded by the Local Authority. I am very wary as I think the advocate is going to write very positive findings whereby my daughter is having a fantastic life and is progressing etc and that the current provider is doing a marvellous job etc. As my daughter's parents we are very frustrated and concerned with her quality of life. We keep on fighting that my daughter needs an autism specific care package which unfortunately falls onto deaf ears." • There is general consensus, particularly from a safeguarding standpoint, that the more voices, the more perspectives and more people involved in a vulnerable individual's life and committed to them, the better. • Advocates should be sufficiently funded to engage with people over a sustained period of time. We know from the families we support that often advocacy is "issue based" (only provided when there is a problem). Advocates	

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			for people with severe learning disabilities need time to develop a sustained relationship with the person they support e, so that they know the person well and can therefore effectively advocate for them. - Advocates should be employed and paid by an independent agency. This should not be the local authority in which the adult is living or due to be living (if the person is due to move}. Advocates should not be employed by the hospital that the person is staying in or by any current or future care giving agency. Agencies offering effective independent advocacy should: - have sufficient flexibility and availability to offer timely support for the individual. This should include offering enough hours of support needed by the client. A contact system with the advocacy agency offering advocacy support in 'out of office' hours if required.	

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The Challenging Behaviour Foundation	001		**Section 1.2** **Key themes to include** Information about effective advocacy and signposting to services: • Specialist vs generic advocacy: information about effective advocacy needs to be specific for the group of people it is aimed at, including individuals with severe learning disabilities who may have complex communication needs. This was a finding and recommendation from the Medway Advocacy Project (Further details can be found here: Advocacy. CBF Projects. The Challenging Behaviour Foundation, UK) • The CBF has produced A Guide For Advocates available here: A Guide for Advocates (England and Wales). Information Packs. The Challenging Behaviour Foundation, UK	Thank you for your comment. We will provide this suggestion to the committee for consideration.
The Challenging	001		**Section 1.2** **Key themes to include**	Thank you for your comment. We will provide this suggestion to the committee for consideration.

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Behaviour Foundation			Delivering independent advocacy • Advocacy should be collaborative- providers, support staff, advocates, family carers and anyone else supporting the individual should work together. It is very important that independent advocates work closely with family carers. Family carers often know the individual with severe learning disabilities best and have acted as advocates for them throughout their life. The following example from a family carer involved in the Medway Advocacy Project demonstrates the importance of independent advocates working closely with families: *"There can be difficult relationships between families and independent advocates, particularly if families feel advocates have been brought in to counter their input. But the combination of the two, working together in the best interest of the person with their own perspectives and experience can be very powerful. I will always advocate for my son – but I welcome a well-informed independent advocate who has got to know my son well and who understands him, as an additional "voice". We work together to ensure he has a good life"*	

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			– Family carer involved in the Medway Advocacy Project (Advocacy. CBF Projects. The Challenging Behaviour Foundation, UK) - Independent advocacy should be person-centred to enable the best outcome for the individual being supported. One family carer in touch with the CBF shared the following experience which demonstrates the long-term positive impact that person centred support can have: *"My son received an effective independent advocacy service when he was being discharged from an assessment & treatment centre in 2012. One of the most effective aspects was a person-centred plan that an independent advocacy service helped him and his family to develop. In all its rich, pictorial and anecdotal detail, it gave him a 'voice.' The person-centred plan informed decisions to be made in his best interests that, due to the inter-related complexities of his mental and physical health, he needed to live on his own. Nine years on, he still lives in his own home with 24-hour 2:1 support and I recognise that it played a key role in empowering our*	

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			son to lead as settled and independent a life as possible." • Advocacy should take a rights-based approach, should be long-term and consistent. • Advocacy works best when the advocate and the person they support develop a good relationship, and the advocate helps the person develop their other relationships.	
The Challenging Behaviour Foundation	002		**Section 1.2** **Key themes to include** Training, skills and support for independent advocates • Ensuring advocates for people with severe learning disabilities are sufficiently trained and have the skills and ability to do this is essential. This includes an understanding of a persons' needs and their behaviour as well as specific issues that might affect people in this group such as over-medication and restrictive practices.	Thank you for your comments. We will pass this information to the development team.

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			"It's vital the person advocating for someone with severe learning disabilities whose behaviour is described as challenging knows enough about the issues affecting quality of care to identify and challenge poor practice" – Professor Peter McGill, Tizard Centre, University of Kent. ('Commissioning Advocacy Services for individuals with severe learning disabilities')	
The Challenging Behaviour Foundation	002		**Section 1.2** **Key considerations** • Health inequalities is an important consideration. Adults with severe learning disabilities whose behaviour challenges often experience unequal access to healthcare, and advocates can have an important role in ensuring diagnostic overshadowing is avoided and appropriate reasonable adjustments are made. • Findings from our Medway Advocacy project (Advocacy. CBF Projects. The Challenging Behaviour Foundation, UK) indicated that it was beneficial to match the advocate and the person in terms of age or background where	Thank you.

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			appropriate. Advocacy should be culturally appropriate.	
VoiceAbility	General	General	**Membership of the committee** The committee's work would be strengthened by inclusion of people with experience of: 1) Care Act advocacy; 2) NHS complaints advocacy 3) Community/non-statutory advocacy 4) Self-advocacy/user-led organisation	Thank you for your comment. Once committee recruitment has been completed, we will identify whether the committee could benefit from further expertise or whether to seek expert witness testimony. We will pass these suggestions to the guideline developer. We recognise the importance of self-advocacy but for the purposes of this guideline, we are focusing on advocacy services provided by a third party.
VoiceAbility	General	General	**Definition of an adult** It needs to be made clear what is the age cut off for the guidelines. The Equality Impact Assessment makes reference to looked after children transitioning into adult services. Also, some duties related to advocacy provision, e.g. under the Mental Capacity Act and Deprivation of Liberty Safeguards (DoLS) as well as the incoming Liberty Protection Safeguards (LPS) apply to 16 and 17 year olds. In some circumstances, the Care Act applies to young people accessing transition assessments as well as young carers. Similarly, Independent Mental Health Advocacy services are	Thank you for your comment. The guideline aims to cover all those who come into contact with adult services and as such we haven't defined an age. Where possible, the committee will consider the impact of advocacy in adult services on young people aged under 18. We have added to the equality impact assessment to ensure this has been captured.

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			available to everyone detained under the Mental Health Act including children and young people. The scope will need to recognise and address the potential impact of the guidelines on young people aged under 18.	
VoiceAbility	001		**Section 1.1** **Who is the focus** **We propose a clarification through an addition (in underline) so that the sentence in 1.1 reads:** **"People using or who might be eligible to use adult health or social care services in all settings […]"** **This would better recognise that advocacy is also a crucial part of a process to enable people to establish their eligibility for support or to challenge eligibility decisions.**	Thank you for your comment. We have updated the wording of the population to People with health and social care needs.
VoiceAbility	001		**Section 1.2 Key theme: Monitoring services and collection data for quality improvement** We suggest that this should also explicitly consider appropriate quality standards, including those already existing (e.g. Quality Performance Mark, Code of Practice, etc.), and how monitoring and data collection can support mechanisms for quality improvement and for quality assurance. We also propose that the	Thank you for your comment. We will pass this information to the guideline developer to consider when developing review protocols and recommendations on monitoring.

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			committee consider how open data and consistency of data might support quality assurance and quality improvement.	
VoiceAbility	001		**Section 1.2 Key theme: Planning and commissioning services for independent advocacy (including services for those who do not have a legal right to independent advocacy)** In order to enhance advocacy provision and standards, we suggest that the committee consider how planning and commissioning of services can meaningfully engage with people who use or might use advocacy services. We also propose that the committee consider the scope and breadth of issues advocacy may cover under non-statutory advocacy which may impact on people's health and social care needs.	Thank you for your comment. We have added "coproduction of services" under key considerations for the guideline committee to consider.
VoiceAbility	001		**Section 1.2 Key theme: Relationships with families, commissioners, and providers** We propose that a key theme to include is independent advocates' relationships and work with families of people who use advocacy services and separately with commissioners and health and social care providers. We also propose consideration of the relationships between	Thank you for your comment. We have added "Partnership working and relationships with families, commissioners and providers" under Delivering independent advocacy.

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			different health and social care providers and commissioners in relation to the delivery of advocacy services.	
VoiceAbility	001		**Section 1.2 Key theme: Digital tools and digital services** We propose that the effectiveness, safety, and limitations of advocacy services delivered through remote or digital channels is recognised and considered. During the coronavirus pandemic, the use of these channels has rapidly increased and there are moves to increase the use of digital-first services. Evidence based recommendations in this area would be of substantial practical benefit. We propose the following addition to the scope (in underline) to the following key theme: "enabling and supporting effective independent advocacy (time, approach, environment, including digital-first or digital only services)"	Thank you for your comment. We have added some text to this point to include virtual and non-face-to-face services.
VoiceAbility	002		**Section 1.2 Key consideration: Trade-offs between equity and efficiency**	Thank you for your comment. We recognise that in order to be equitable, there may be more cost or differential recommendations may be needed. We expect our committees to work in line with NICE principles and

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			This assumes that such a trade-off must exist. We suggest a more open approach and that the key consideration be reworded (as underlined) to: "Achieving equity and efficiency"	make judgements about fair and equitable distribution of scarce resources. Therefore we have kept this text as it is.
VoiceAbility	002		**Section 1.2 Key consideration: Availability, access, and appropriateness of digital services** We propose that the effectiveness, safety, and limitations of advocacy services delivered through remote or digital channels is recognised and considered. During the coronavirus pandemic, the use of these channels has rapidly increased and there are moves to increase the use of digital-first services. Evidence based recommendations in this area would be of substantial practical benefit. We propose the following additional key consideration (in underline): "Availability, access, and appropriateness of digital services"	Thank you for your comment. We have added "mode of delivery" to the key considerations to address this suggestion.
VoiceAbility	002		**Section 1.2 Key consideration: consistency and geography** We propose that an additional consideration should be consistency of advocacy support and the location of	Thank you for your comment. NICE guidelines are intended to reduce unwarranted variation in practice and access to services.

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			support, e.g. as related to support away from home or individuals in health or care settings far away from their home. Ensuring equitable and quality advocacy provision for people who are 'placed out of area' is a significant issue affecting many people who use advocacy services.	
VoiceAbility	002		**Section 1.2 Key consideration: multiple decision-making processes** We propose that consideration is given to advocacy in the context of multiple decision-making processes and when a person is entitled to advocacy under several pieces of legislation for multiple reasons (e.g. people who have an Independent Mental Capacity Advocate and a Care Act advocate or who have an Independent Mental Health Advocate and Care Act advocate)	Thank you for your comment. We will pass this suggestion to the guideline developers.
VoiceAbility	002		**Section 1.2 Key consideration: Non-instructed advocacy** We would propose the committee consider how the guidelines will relate to non-instructed advocacy and whether they might offer a standardised approach to supporting people who are unable to instruct an advocate.	Thank you for your comment. We will pass this suggestion to the committee.

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VoiceAbility	002		**Section 1.2 Key exclusions** We suggest that this is more explicit about age-related exclusions. This relates to our query regarding the definition of adults and the age-range NICE expect to be affected by these guidelines. The Equality Impact Assessment refers to looked after children transitioning into adult services. Also, some duties related to advocacy provision, e.g. under the Mental Capacity Act and Deprivation of Liberty Safeguards (DoLS) as well as the incoming Liberty Protection Safeguards (LPS) apply to 16 and 17 year olds. In some circumstances, the Care Act applies to young people accessing transition assessments as well as young carers. Similarly, Independent Mental Health Advocacy services are available to everyone detained under the Mental Health Act including children and young people. The scope will need to recognise and address the potential impact of the guidelines on young people aged under 18.	Thank you for your comment. It was intended that the guideline include 16 and 17 year olds when they are transitioning to adult services or using (or in need of) an adult-based service, although decision making and mental capacity will not be covered in this guideline.
VoiceAbility	Equality Impact		**EIA Section 1.2**	Thank you for your comment. We have made the suggested change.

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	Assessment 002		**People with learning disability and other co-morbidities** Learning disability is not a morbidity factor in and of itself, therefore reference to "other co-morbidities" here is inaccurate and misleading. We propose that it is changed to (in underline): "People with learning disability and with morbidity factors or co-morbidities"	
VoiceAbility	Equality Impact Assessment 002		**EIA Section 1.2** **Looked-after children: Young people in transition to adult services are likely to benefit from independent advocacy** It is not only looked-after children who might transition to adult services. Children may be carers or receive health and care support themselves. This should be clarified and children transitioning to adult services who are not 'looked-after children' should also be considered in the Equality Impact Assessment and scope of the guidelines.	Thank you for your comment. We have highlighted this in the equality impact assessment.
VoiceAbility	Equality Impact		**EIA Section 1.2**	Thank you for your comment. We have added this detail to the Equality Impact Assessment.

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	Assessment 002		**People with communication difficulties and/or sensory impairment** We would propose adding reference to people who communicate non-verbally to reflect the range of additional communication support people may need when using advocacy services. We would also suggest a specific reference to people with cognitive impairment e.g. those with dementia who may need specialist communication support or non-instructed models of advocacy. Additionally, we propose explicitly recognising the additional and specialist communication support that Deaf people may need and how to best fully meet the advocacy needs of Deaf people.	
Wandsworth LGBTQ+ Forum	General	General	**Identifying those who would benefit** The Equality Impact Assessment is comprehensive in its scope and importantly recognises the significance of intersectionality which will have a major impact on the approach to design and implementation of appropriate advocacy services together with the efficacy of their delivery.	Thank you for highlighting the importance of socio-economic status, we will ensure this is captured in the next version of the equality impact assessment and considered during committee discussions.

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			However the fact that the impact of underlying income inequalities and relative socio economic status on the different groups identified is not specifically referenced is a significant omission which must be addressed in the Guideline *For example Wandsworth LGBTQ+ Forum is active in the area of advocacy and support for LGBTQ+ people and is witness to the heavily differential and intersectional impact of inequalities on this group compounded in many cases by serious income inequalities in particular.*	
Wandsworth LGBTQ+ Forum	General	General	**Facilitating Independent Advocacy** Facilitation of independent advocacy no matter what the target group or area of need requires protecting, sustaining and increasing appropriate investment in advocacy services without which aspiring to facilitation is simply the triumph of hope over experience. **This is in the broader context in which funding for groups which either provide or have the potential to**	Thank you for your comment. We acknowledge the challenges around availability of resources which can have an impact on who provides advocacy for whom. However, allocation of funding to services is outside NICE's remit. We've added this to the exclusions in the scope to make this clear.

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			provide independent advocacy has been sharply reduced in recent years thereby seriously compounding the effect of inequalities Independent advocacy means exactly what it says and this requires investment in an infrastructure to provide it in terms of support for existing organisations which provide advocacy for their respective client groups and support for the emergence of new community based approaches to delivering advocacy services especially in those areas and for those target groups where such services are thin on the ground or do not exist. This also implies investment in appropriate training and support for advocates whether they be paid staff or volunteers, especially so in the case of the latter. *The experience of Wandsworth LGBTQ+ Forum exemplifies the requirement. Our ability to provide independent advocacy and support for our specific target group in respect for example, of responses to hate crime and emerging problems linked to access to mainstream health and care services ,are severely constrained (especially in the face of significant*	

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			intersectional demands) by lack of appropriate investment. As noted above our efforts to establish effective and sustained advocacy services are simply "the triumph of hope over experience" and will remain so without such investment much as we seek to make the best of the situation.	
Wandsworth LGBTQ+ Forum	General	General	**Delivering Independent Advocacy** In addition to the necessary investment referred to above, in itself a precondition, delivery also requires first, acknowledgement of the role of independent advocacy by statutory actors and second effective partnership to deliver it based on mutual recognition of the specific strengths and expertise brought to the table by existing and potential independent providers. **Independent advocacy is rooted in its ability to engage effectively with groups and individuals in order to ensure that their experience and reflections on the efficacy and experience of service delivery are taken into account in its design and delivery by providers. It should therefore be recognised as**	Thank you for your comment. We have added partnership working to the section on delivering independent advocacy and will highlight this to the committee when developing review protocols.

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			such as an integral component of a partnership approach to service delivery not as a discretionary addendum to it and which in order to be effective requires statutory underpinning A good example of this approach is the way in which the obligation under Section 13 of the Health and Social Care Act makes it incumbent upon NHS England to engage with patients and carers, (people with lived experience) as advocates in design and delivery of secondary and tertiary care services. (There is a similar requirement in relation to Primary care services in Section 14 of the Act) It recognises the importance of independent advocacy as both an individual and a collective endeavour and carries this through in practice. *“In its local work Wandsworth LGBTQ+ Forum has endeavoured to deliver independent advocacy in relation to delivery and experience of services principally on a collective basis by working in partnership with local statutory organisation, (the police, the Council, the NHS) on approaches to hate crime, support for older*	

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			LGBT people, sexual and reproductive health for LGBTQ+ people , delivery of primary care and access to cancer services in including prostate cancer services for GBT people. These advocacy initiatives have principally been delivered by voluntary effort which in the final analysis places significant limitations on their development and efficacy. They demonstrate both very clearly the limited and somewhat ephemeral nature of independent advocacy which largely relies on goodwill in the face of quite significant problems of inequality and access while at the same time clearly showing what might be achieved with more sustainable funding"	