Social work with adults experiencing complex needs
Consultation on draft guideline - Stakeholder comments table
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ABL Health	Guideline	General	General	General comments – Overall it seems that these guidelines set a good standard when perhaps there was none previously. It seems to be all about a holistic person-centred approach. Given that in our experience, we find a high turnover of staff (social workers) in many cases that we deal with. This means that continuity of care is affected and can have a negative impact on patients. There needs to be something included in the guidelines about quality handover from one social worker to the new one about cases so that the new social worker is aware of the patient's journey, any red-flags and to maintain a high level of trust between the patient and the social worker From what we can understand, the research has been done in a quantitative way and could not see any evidence of qualitative research (not sure if it is passed the point of further research) but we would recommend having some direct information from interviews or involving complex service users to be involved in the consultation. This document is about adults but what about regarding children and young people (which is much of the work we do) – any consideration about this? We feel that it should be included.	Thank you for your comment. The committee agreed that staff turnover is high which impacts on continuity. That was also noted in the evidence that showed that people value the continuity of a named social worker but that they experienced a lot of staff changes. Reflecting on this, the committee have added a reference to handovers into the guideline (see recommendation 1.5.11) as suggested. This was seen as particularly important to provide continuity when there is a change to the named social worker. For all evidence reviews both quantitative and qualitative evidence was searched for and direct information from interviews with adults with complex needs was included as evidence with most of the qualitative studies conducted in UK settings. Including children would have made the topic too broad (which would mean different needs, risks, services as well as different legislation to be considered) so the current guideline is restricted to adults only.
ABL Health	Guideline	General	General	Multi- disciplinary section sounds good e.g., single point of access and co-location, but it feels like that is more for governmental teams such as LA's / CCG's what about the private sector	Thank you for your comment. To clarify that this is not restricted to health and social care in the public sector other relevant settings were added to recommendation 1.7.4. It is also made clear in Box 2 that 'organisations

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					'In the context of this guideline, are bodies that employ social workers in a professional capacity. This can include local authority social care departments, health services, the criminal justice system, higher and further education and voluntary and community services.'
ABL Health	Guideline	004	002	What is a complex need? This could be open to interpretation and if so, it leaves the whole document potentially redundant. What is the classification of complex and could this be added or linked?	Thank you for your comment. A definition of complex needs is difficult and varies in health and care settings. We therefore included the definition that was used in the context of the guideline at the beginning of the document. The definition was part of a consultation during the scoping phase of the guideline development and was amended based on stakeholder feedback and has then been used to inform the search terms for the evidence reviews. The committee were satisfied that it would capture a broad range of people who would need assessment or support by social workers.
ABL Health	Guideline	005	009	1.1.3. The process must not be seen/perceived as a forced change, as something that would overturn their life, nor as an easy-fix solution for their problems (as if the SW had a magic wand). The SW will do their best to help and meet their needs. Understand that there are no right or wrong answers or a positive or negative outcome to an assessment. Whatever the type of assessment, care management or support, it is just a means to understand what is the best type of support for the current situation, so as to ensure an optimal service that can be tailored to their specific needs.	Thank you for your comment. Recommendation 1.1.3 focuses on the social worker making the person familiar with the processes and activities that the person will get involved in. This is based on evidence from several evidence reviews where people described that they did not know what was going to happen or what the aims and key processes are and how they may change. This was making them anxious and stressed. The committee therefore addressed this specifically with this recommendation. Other recommendations within the same section related to active listening and supporting the person to be actively involved (see recommendations 1.1.4 and 1.1.5). So in the context of this section the committee decided that it would be readily understood that recommendation 1.1.3 would not be a forced change or an easy-fix solution.

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ABL Health	Guideline	006	004	1.1.6 Recognize that one's own beliefs or prior views could interfere with the assessment and relationship with the patient. Be ready to build a positive relationship, free of preconceived ideas and stereotypes.	Thank you for your comment. The committee decided to keep the wording as is because it focuses on the 'action' that the social worker has to take, i.e. that the avoidance of assumptions and recognition of the impact of past experiences are set in the context of discussions with the person. This makes it a more actionable and measurable recommendation whilst keeping it in line with the sentiment of the suggested wording.
ABL Health	Guideline	007	002	**(box)** Gender reassignment as a protected characteristic - is it still protected through transition?	Thank you for your comment. The term 'gender reassignment' has been quoted from the list of protected characteristics of the Equality Act 2010. It is not in the remit of the guideline committee to define this further.
ABL Health	Guideline	007	002	**(box)** The list of life circumstances/ experiences - it may be good to add that it isn't an exhaustive list. Also, included in the list of life circumstances/experience – needs to include not just being a prisoner or offender but having family members/primary care giver in custody / having a previous conviction (it says being a prisoner and being an offender but those who have had previous historic convictions still experience discrimination / inequality In this section "coercive control" is mentioned, but not "gaslighting" or "manipulation". The three terms define three different situation. Coercive control refers to controlling behaviors resulting in an act or a pattern of acts of assault, threats, humiliation and intimidation, or other abuse that is used to harm, punish, or frighten their victim. In this case, the victims are frightened by the perpetrator, experience	Thank you for your comment. The committee recognised that for each of the listed groups there may be subcategories or related groups that would also face inequalities. This list is not only restricted to suggested examples and are intentionally only given as headings rather than a detailed definition or explanation of each. They agreed that it can be the label rather than fitting a precise definition that could lead to discrimination and inequality they have therefore left the groups intentionally broad. The committee decided that it would be impossible to have an exhaustive list or clearly define all terms within the list and they agreed to add 'including' to the heading to make it explicit that there are other groups that may also face discrimination.

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				feelings of uneasiness anguish, suffering, and they are often aware that they are being abused. In gaslighting, instead, even though the victims experience feelings of uneasiness, anguish, anxiety and are led to the verge of insanity, they are NOT aware that the person they trust and rely on is the perpetrator. As for the manipulation, both the awareness of being abused and the feelings of despair are missing. The victims are at the mercy of the perpetrator without knowing it, thus not being able to defend themselves. Furthermore, as the abusive relationship is not easy to be detected from the outside, in these cases it is more difficult for the people around the victims to realize that they are being abused and to help them.	
ABL Health	Guideline	012	013	What is decision making capacity? And how is it measured - needs to be clearer on what the 10 key areas are.	Thank you for your comment. The reference to 'decision-making capacity' has been removed from this recommendation since under the Mental Capacity Act 2005 a person is presumed to have capacity unless proven otherwise.
ABL Health	Guideline	018	017	1.2.35 – give the person a draft copy of their risk assessment – could there be some detail about how to support an individual who cannot read or write and wouldn't be able to understand assessments.	Thank you for your comment. Addressing communication needs is highlighted as a principle of social work in recommendation 1.1.2 and is also covered in other guidance cross-referenced to in this recommendation. This would include the communication needs of people who cannot read or write.
ABL Health	Guideline	019		**1.2.36** We felt that the social worker should risk assess 6 monthly as circumstances can change with complex cases	Thank you for your comment. The committee agreed that current practice is having an annual risk assessment. There was no evidence about the frequency of risk assessments and without robust evidence or consensus the resource impact of changing current practice cannot be justified. However, a review

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					can take place 'sooner if needed, in response to an identified change in the person's circumstances or a change in risks' as highlighted in the second bullet (see recommendation 1.2.39).
ABL Health	Guideline	027	011	Multi-disciplinary section sounds good e.g., single point of access and co-location, but it feels like that is more for governmental teams such as LA's / CCG's. What about the private sector?	Thank you for your comment. In box 2 it is described that in the context of this guideline, organisations are bodies that employ social workers in a professional capacity. This can include local authority social care departments, health services, the criminal justice system, higher and further education and voluntary and community services. Therefore this section is not restricted to LAs and CCGs. To make this more explicit a reference to other relevant settings was added to recommendation 1.7.4 to clarify that this is not only related to health and social care teams.
BASW Cymru	Guideline	General	General	You need to reflect the legislation and policies that other countries in the UK have to follow, e.g. in Wales we have the Social Services and Well-Being Act 2014 which is similar to The Care Act. If you don't identify any other countries legislation then at least you should include something that reflects this is predominantly English legislation and the other 3 countries of the UK need to follow theirs. Each country of the UK have their own registration organisation with their codes of conduct – this needs to be reflected if you want these guidelines to be applicable and used by all countries of the UK	Thank you for your comment. NICE guidance is developed for England. Devolved administrations may choose to adopt it. This was highlighted by adding that the guideline would follow English legislation and that other UK countries need to follow their legislation to the 'How does the guideline relate to legal duties, standards and other guidance?' section.
BASW Cymru	Guideline	General	General	There should be some consideration or recognition to how assessments have changed as a result of COVID19 in that there are occasions when contact can be virtual – this is likely to remain a feature of assessments and	Thank you for your comment. The committee discussed this but did not reach consensus on a preference for recommending either remote (virtual or phone) or in-person assessment or meetings as a particular standard approach. It was agreed that this would depend on many

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				contacts following the pandemic although can never fully replace the importance of face to face meetings.	factors and ought to be guided by the preference and the safety of the person with complex needs. They have therefore revised recommendation 1.2.7 and added a bullet about preference for remote or in-person assessment. They also added a recommendation emphasising that if there were to be potential safeguarding concerns then an in-person assessment may need to be conducted regardless of preference.
BASW Cymru	Guideline	General	General	Question 1 - Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. a) The biggest challenge is likely to be the time that social workers are able to give to developing the relationships to ensure that assessments are inclusive and holistic. With caseload sizes, it is extremely difficult to be able to give this in all cases. b) There could also be delays in ensuring that other professionals contribute to the assessment in a timely manner. c) There could be resistance from family members if they perceive that they haven't received the service they feel is essential in the past.	Thank you for your comment. The evidence consistently highlighted that relationship building is a core principle of the role of the social worker and this was in line with the committee's experience. They therefore wanted to highlight that organisations should consider making time allowances to support social workers in their role (see recommendation 1.1.11). Whist this would be challenging the committee decided that it is important to highlight this as it would set a standard for holistic social work practice. The committee did not agree that this would cause delays in contributions from other professionals since such contributions could be made in parallel rather than consecutively. They also thought that families would support having more time with a social worker since this would provide more person-centred care. Implementation challenges raised by stakeholders will be considered by NICE where relevant support activity is being planned.
BASW Cymru	Guideline	General	General	Question 2 - Would implementation of any of the draft recommendations have significant cost implications? If social worker's caseloads are reduced, then there would be a cost to the Local Authority so that more social workers could be recruited. However, there is also	Thank you for your comment. The evidence consistently highlighted that relationship building is a core principle of the role of the social worker and this was in line with the committee's experience. The recommendation that organisations should consider making time allowances to build relationships may lead to longer contact times than currently, but this would be balanced against better,

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				a current issue around both recruitment and retention of staff, so is unlikely that this would happen.	individualised services and this was supported by the economic analysis (see the related rationale and impact section. Whilst this would be challenging the committee decided that it is important to highlight this as it would set a standard for holistic, person-centred social work practice. Implementation challenges raised by stakeholders will be considered by NICE where relevant support activity is being planned.
BASW Cymru	Guideline	General	General	Question 3 - What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Better publicity for social workers by celebrating all the positive impact they have rather than the media focussing on the tragic, but overall few cases where they may appear to be failings in practice – not just around social workers but other partner agencies too.	Thank you for your comment. In discussions during meetings the committee recognised the impact of the media on the role of social workers. Their intention was that the holistic, person-centred approach that is recommended in the guideline would help to promote social work positively. Comments in relation to overcoming such challenges will be considered by NICE where relevant support activity is being planned
BASW Cymru	Guideline	General	General	Question 4 - The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication. There is likely to be a change as we move out of the pandemic (whenever that will be!) to continue with some virtual assessments. However, to ensure that there is a comprehensive assessment undertaken this is more likely to be the case with a face to face assessment. There could well be parts of the assessment that could continue to be undertaken virtually, but this would need to be by an individual situation rather than a blanket	Thank you for your comment. The committee discussed this but did not reach consensus on a preference for recommending either remote (virtual or phone) or in-person assessment or meetings as a particular standard approach. It was agreed that this would depend on many factors and ought to be guided by the preference and the safety of the person with complex needs. They have therefore revised recommendation 1.2.7 and added a bullet about preference for remote or in-person assessment. They also added a recommendation emphasising that if there were to be potential safeguarding concerns then an in-person assessment may need to be conducted regardless of preference.

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				mandate to assess virtually. For many, during the pandemic, this has had to be the way contact and assessments have taken place but there needs to be a return to face to face assessments and contact in the future.	
BASW Cymru	Guideline	004	General	**Section 1.1** There is nothing included in this section which indicates what theories the social worker has used within their assessment – there are a plethora to consider, but the most obvious would be the Social Model of Disability, Attachment, Ecological. Should there also be a reference to different tools they could use, such as Thompson's PCS model, genogram, ecomaps etc.	Thank you for your comment. No evidence was identified for any particular theory so the committee felt unable to comment on this. However, they agreed that transparency and accountability was very important. They have therefore added 'and record the rationale for the decision made' to recommendation 1.1.8. This would mean that the social worker would need to reflect on how they came to a conclusion and this could have been informed by a particular theory.
BASW Cymru	Guideline	005	004	In Wales there is a legal requirement to ensure that every family is offered a service in Welsh – they don't have to depend on asking for this	Thank you for your comment. NICE guidelines are developed for England. Devolved administrations may choose to adopt it. This is why this section does not mention this legal requirement for services in Welsh but focuses on communication needs and preferences instead.
BASW Cymru	Guideline	008	010	It may also take longer to build relationships depending on the complexity of the individual's situation.	Thank you for your comment. Whilst the committee agreed that level of complexity may vary it is hard to say how one person's needs may be specifically more complex than another's. So the committee decided not to add this because it could be misinterpreted.
BASW Cymru	Guideline	015		**1.4** This is where it would be useful to reference tools that can assist in doing this, e.g. ecomaps, Thompson's PCS	Thank you for your comment. There was no evidence for specific tools and the committee therefore decided that they could not comment on this.
BASW Cymru	Guideline	025	021	You should consider what the response should be if the person lacks capacity to give informed consent	Thank you for your comment. The 'with informed consent' aspect of the recommendation you refer to (number 1.6.2) aims to ensure that the person involved

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					has provided consent for the involvement of other professionals, and not about consent if they have capacity to provide it. The committee agree that it is important to provide correct and relevant guidance related to capacity, and have made a separate recommendation (1.2.45) cross referring to the NICE guidance on decision-making and mental capacity. There are many instances across the guideline where it would be appropriate to consider whether a person lacks capacity and it is difficult to cover all sufficiently. Therefore, the committee agree that the guideline should sign-post social workers to the principles set out in the NICE guideline on decision-making and mental capacity, so that they are able to apply them to their practice and the individual situation.
BASW Cymru	Guideline	033	012 - 013	You could also refer to the British Association's Code of Ethics too	Thank you for your comment. A reference to the BASW Code of Ethics has been added to this section, as suggested.
BASW Cymru	Guideline	034	031	What about the support of a Speech and Language Therapist to assist with communication?	Thank you for your comment. This sentence was referring to the reason why the committee recommended the social worker should discuss and actively listen to the person's experiences. Communication needs are covered by a different recommendation and reasons for this are explained earlier in the same rationale and impact section. Therefore in the context of this particular part of the rationale a reference to support of a Speech and Language Therapist is not needed.
BASW Cymru	Guideline	053	022 - 023	Some LA's in Wales have community connectors who undertake this role	Thank you for your comment. The committee decided that the social worker's role should include researching, supporting and helping people to make connections in their communities so that they can tailor this to each person they work with. It was the social workers role that the guideline is focused on and whether or not other

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					roles, such as the example of community connectors, could support this process may be a matter at the implementation stage of the guideline.
BASW Cymru	Guideline	062	015	Please include registered social workers in all 4 countries which make up the UK to be inclusive.	Thank you for your comment. NICE guidelines are developed for England. Devolved administrations may choose to adopt it. This is why the context section focuses on registered social workers employed in England.
Birth Companions	Guideline	003		**Box** This list should include removal of children by social services	Thank you for your comment. The committee recognised that there are potentially other groups that face inequalities so they noted that this is not an exhaustive list. They therefore added the word 'including' to make this explicit. The committee did not agree that 'removal of children by social services' should feature in the list because it would require further explanation. There would be situations when it is in the best interest of the child to be removed so it is not as such an equalities issue but could be a safeguarding issue.
Birth Companions	Guideline	003		**Box** This list should include removal of children by social services	Thank you for your comment. The committee recognised that there are potentially other groups that face inequalities so they noted that this is not an exhaustive list. They therefore added the word 'including' to make this explicit. The committee did not agree that 'removal of children by social services' should feature in the list because it would require further explanation. There would be situations when it is in the best interest of the child to be removed so it is not as such an equalities issue but could be a safeguarding issue.
Birth Companions	Guideline	028	011	Suggest this should go beyond health and social care, and include reference to work with other key agencies/ sectors such as criminal justice and voluntary sector organisations	Thank you for your comment. A reference to other relevant settings has been added.

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British Association of Social Workers – England Team	Guideline	General	General	**Question 1 - Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** How this will get near front line social workers as it is too complex and long also actually most of the recommendations are not really saying anything. The risk Assessment section as I understand it is about risk assessment as a part of practice not necessarily safeguarding.	Thank you for your comment. NICE guidelines are evidence based and therefore focus on what the identified studies show. During the scoping phase of guideline development it was agreed that the topics covered in the scope are those where there is variation in practice where guidance is needed and this was supported in the stakeholder consultation exercise during scoping. Searches for evidence were carried out (see the evidence reviews) and the recommendations resulted from discussions about the evidence that was identified according to protocol criteria. On reflection a paragraph was added to the guideline to explain how the guideline relates to legal duties, standards and other guidance to make the evidence based approach clearer. The guideline is about an average length and level of complexity and the committee felt that it is emphasising a person-centred approach which will promote social work and social work best practice. The committee agreed that risk assessment is a part of practice but have added a recommendation related to safeguarding to this section.
British Association of Social Workers – England Team	Guideline	General	General	**Question 3 - What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** Through the document there is clear evidence of a lack of research which has been available for the committee to draw upon. Examples of research that we feel would better inform this guideline have been cited in the comments provided below.	Thank you for your comment. Whilst there was relatively little evidence there was some evidence to draw on and where there was a specific gap in the evidence base the committee made research recommendations to encourage research which could then inform an update of this guideline in future. We will look at all other stakeholder comments and see whether any of the suggested citations would have met inclusion criteria.

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British Association of Social Workers – England Team	Guideline	General	General	**Question 4 - The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.** **Hospital Discharge** References to hospital discharge in the NICE guidance are incidental to the main focus of the document which is to develop an overall common framework for assessment and care management. The current NICE guidance on Hospital Guidance is QS136(2016) "The transition between patient hospital settings and Community or care home settings for adult with social care needs" Recommend that this is referenced in the guidance. (It is based on previous good practice and is at variance with the current Discharge to Assess policy introduced during the pandemic). In summary although I agree with the points made about hospital discharge and the social work role in multi-disciplinary teams both could be strengthened particularly in the case of hospital discharge where the effectiveness of the assessment and care management process is critical to the working wider health and social care system. **Specific Points from the Guidance** 1 Transfer from hospital is one situation which should lead to a review. Agree with this 2 A person centred approach may prevent hospitalisation and improve outcomes Agree	Thank you for your comment. The topic of transfer from hospital to the community and discharge planning was outside the scope of this guideline. Therefore specific searches were not carried out and the committee were not able to comment on this. Instead they have cross references to all relevant NICE guidelines focusing on transition between services, settings and levels of care would be important: • Transitions between inpatient hospital settings and community or care home settings for adults with social care needs (in particular section 1.5 on discharge planning) • Transition between inpatient mental health settings and community or care home settings (in particular section 1.5 on discharge planning) • Transition from children's to adults' services for young people using health or social care services (in particular section 1.2 on transition planning) • Intermediate care including reablement (in particular section 1.7 on transition from intermediate care). See recommendation 1.5.12 in the section Supporting people to plan for the future.

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British Association of Social Workers – England Team	Guideline	004		**1.1.1** **Original states:** "demonstrate professional curiosity" **Proposed amendment:** ""demonstrate professional judgement and professional curiosity" **Rationale:** Using professional judgement is an essential feature of what social workers do and ought to be referenced. Social Work England refers to professional judgement in the *Guidance on the professional standards*[1] as follows: "Using an evidence-informed approach to make impartial decisions is an integral part of social work practice. Social workers will listen to people, without bias or prejudice, and use evidence from assessments, alongside social work theories, models and research to apply their professional judgement."	Thank you for your comment. We have added 'professional judgment' to this point as suggested.
British Association of Social Workers – England Team	Guideline	013		**1.2.10** **Original states:**" The social worker must conduct the needs assessment for adults with 7 complex needs in compliance with statutory guidance (Eligibility outcomes 8 section of the Care Act 2014), and taking account of the following: • whether the person's needs arise from or are related to a physical or 10 mental impairment or illness • whether the person would have difficulties in achieving 2 or more of the ten listed outcomes • whether there is a significant impact on wellbeing. **Proposed amendment:** After the last bullet point add a new line as follows:	Thank you for your comment and for the information provided about the SCIE publication and the scoping review commissioned by Lyn Romeo. The recommendations about planning for, conducting and recording assessments were not based on effectiveness evidence, they were based on the results of a qualitative review and reflected the requirements of the Care Act and statutory guidance. As you point out, the committee also used their expertise and knowledge, which includes their experience of other supporting guidance, to strengthen the basis for the recommendations. During discussions the committee did mention the availability of various guidance and advice about the conduct of assessments, including the SCIE material but they agreed to sign post to the Care Act itself and statutory

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				"Social workers should take into account the guidance provided by SCIE on eligibility determination **https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/what-does-significant-mean** **Rationale:** It is concerning that there is no reference to SCIE anywhere in the draft guidance. BASW's view is that the methodological approach to situations where there is no effectiveness evidence relies too heavily on the experiential knowledge of the committee, and consequently important guidance developed by other bodies and reference works are precluded. We suggest this inclusion in relation to eligibility, as the recommendation in the draft guidance is especially reflective of the lack of experiential knowledge of the committee. In response to the comments made in the guideline about the lack of research on the effectiveness of social work with adults particularly assessment and care management. We would like to draw attention to the following paper which contains a significant amount of research in this paper which was commissioned by DHSC Chief Social Worker for Adults Lyn Romeo: https://www.basw.co.uk/resources/effectiveness-social-work-adults-systematic-scoping-review	guidance because it is mandatory for assessors to follow these rather than those other guides/ sources of information. In light of your comment however reference to these discussions and specific mention of the SCIE guidance has now been added to the evidence report about assessments, which describes the committee's discussion of recommendations in this section of the guideline. In relation to the paper commissioned by Lyn Romeo, this would not in itself be considered for inclusion because it is a scoping review rather than a systematic review. In response to your comment we have nevertheless checked the studies included in that report and can see that they would not have been eligible for inclusion in the assessment or case management reviews of effectiveness evidence. This is because the studies pre date the review protocol publication date cut-off or because they do not fit other protocol criteria such as the study design or country in which the research took place.
British Association of Social Workers – England Team	Guideline	024		**1.5.6** **Original states:** "Social workers should ensure that care plans: • take account of the person's wishes and preferences • are delivered as agreed	Thank you for your comment. The committee has discussed and taken on board most of the suggested changes to the recommendation. However, the committee highlighted that including 'using the available resources' will not provide enough clarity to social

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				• meet the person's needs • record any unmet needs." **Proposed amendment:** "Social workers should ensure that care plans: • take account of the person's wishes and preferences • state how the person's eligible and non-eligible needs would be best met • record any perceived under-met eligible needs • identify how arrangements will be made to meet eligible needs using the available resources." **Rationale:** 1. Social workers cannot by themselves ensure that the care plan will fully meet the person's needs. It is the local authority's duty under the Care Act to ensure that a care plan meets the person's eligible needs. Social workers can articulate their professional judgement about how needs would be best met, but the final decision rests with the local authority and other factors can be taken into account. 2. There shouldn't be any intentional recording of unmet eligible needs because the local authority has a duty to meet all such needs. However, it may be concluded by the person concerned and/or the social worker, that some needs will be under-met, and social workers should ensure that this is recorded. 3. The concept of 'making arrangements to meet needs' is better understood than 'delivering care plans', and this terminology is favoured in policy statements by the DHSC. All care plans have to	workers who are organising a care plan. They agreed that identifying how arrangements will be made should sufficiently cover how resources should be used, and allows for flexibility across local authorities depending on current resource availability at the time. The committee also recognised that at the point of organising a care plan, the social worker can only record needs that may be unlikely to be met, but without consulting the local authority it would not be apparent if the needs would be 'under-met', therefore they agreed on an edit to some of your suggested wording to reflect this: 1.5.6 Social workers should ensure that, at time of writing or review, care plans: • take account of the person's wishes and preferences • state how the person's eligible and non-eligible needs would be best met • identify how arrangements have been or will be made to meet eligible needs • record any eligible needs which are unlikely to be met or only partially met, the reasons they can't be met or only partially met, and any potential actions that would allow them to be met in future. The rationale section of the guideline and the committee's discussion of the evidence section in review C has been updated accordingly to reflect the detail added to this recommendation.

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				identify the resources available to meet needs (including the requirement to specify a personal budget) and say how they will be used and what for (e.g., direct payment to purchase x hours of home care). 4. Information about Care and Support Planning would benefit from a greater focus.	
British Association of Social Workers – England Team	Guideline	024 040 042 058 061		Given the introduction of the Discharge to Assess hospital discharge policy and model, the view from frontline practitioners and people with lived experience is that the guideline falls short in terms of hospital discharge. BASW England is keen to ensure that the role and contribution of social work and social workers in hospital discharge is recognised in terms of: The application of and adherence to the Mental Capacity Act and the Human Rights Act ensuring people's human rights are upheld. A key role in assessments and planning undertaken in hospital for people needing care on discharge Advocacy: Ensuring the voice of the person and their wishes and feelings are sought, heard, and inform decision making Promotion of the social model of care and support which looks beyond a person's medical needs focussing on the barriers to independence ensuring the person gets the	Thank you for your comment. The committee discussed that specific approaches to hospital discharge planning were outside the scope of this guideline and are covered in detail in specific guidelines on transition from hospital settings. The committee agreed that cross-referencing to a number of guidelines, focusing on transition between services, settings and levels of care would therefore be important: • Transitions between inpatient hospital settings and community or care home settings for adults with social care needs (in particular section 1.5 on discharge planning) • Transition between inpatient mental health settings and community or care home settings (in particular section 1.5 on discharge planning) • Transition from children's to adults' services for young people using health or social care services (in particular section 1.2 on transition planning) • Intermediate care including reablement (in particular section 1.7 on transition from intermediate care) See recommendation 1.5.12 in the 'Supporting people to plan for the future' section.

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				right support at the right time to maintain their independence, choice, and control.	
British Association of Social Workers – England Team	Guideline	027		**1.6.7** **Recommendations on the provision of out of hours services** There is evidence that out of hours SW services may prevent some hospital admissions. There is also a view expressed that out of hours services are not clearly communicated. I suggest that the implications of this issue need to be explored and discussed further. Should the out of hours service offered by social work services be extended? (Including the resource implications of this) There may be examples in practice where Social Work Teams have changed their hours to meet the demands of hospital discharge	Thank you for your comment. The recommendation to which you refer is specifically related to decision-making over applications for detention under the Mental Health Act and ensuring this can be done at any time. The committee agree with you that extending social work provision more generally could be beneficial but they did not feel they had the evidence on which to make such a broad recommendation.
British Association of Social Workers – England Team	Guideline	027		**1.7** **Role of Social Workers in multi-disciplinary teams.** BASW has long had concerns from social workers in multi – disciplinary teams about their professional independence leading up to development of the BASW Charter for Integrated Working (2016) The NICE guidance meets many of these concerns particularly the need for social workers to have access to supervision and training where the team manager is not a social worker. I think BASW could go further and propose that integration is even more effective if co-located teams with social work and health managers work alongside each other. There is also the distinctive role that social workers play as advocates for example in CHC assessments and in a statutory safeguarding role. So, I Suggest we propose	Thank you for your comment. The committee agreed that the BASW charter for Integrated Working is relevant but the recommendations were based on the identified evidence. A reference to the charter was added into the rationale and impact section. The committee decided not to include the suggested new recommendation because they thought that the sentiments of these points were already covered elsewhere, particularly in the principles section.

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				adding the following to the NICE guidance from the BASW charter. "Support social workers in having an independent voice, in advocating for people's rights and in refusing to take actions that are unethical and unlawful" This would be supportive of the role those social workers often play under the Mental Health and Capacity Acts)	
British Association of Social Workers – England Team	Guideline	042 - 047		**1.2.15- 1.2.18** **Assessment – risk assessment** Is it useful to have safeguarding wrapped up in concept of harm? The risk Assessment section as I understand it is about risk assessment as a part of practice not necessarily safeguarding. I have read the section on harm and understanding the principle and as a frontline social worker I don't think this is particularly helpful. An idea may be to break down the different types of harm/abuse and make reference to relevant guidance or if no guidance available then the case for this to be developed could be made. There is a lot of information out there that could be cross-referenced. A comprehensive assessment framework could be developed. The principles of safeguarding need to be made clear in this guideline as well as the advocacy duty and the approach of Making Safeguarding Personal. There needs to be a section included which brings in adults with complex needs where a safeguarding	Thank you for your comment. The committee have added a recommendation outlining that social workers must follow local safeguarding policies where there is a reasonable cause to suspect a person is experiencing or is at risk of abuse or neglect. If a need for action is established, the social worker must follow statutory safeguarding processes as set out in the Care Act 2014 (see recommendation 1.2.21). The details of how safeguarding actions are then carried out are outside the scope of this guideline and are covered by legislation under the Care Act 2014. The committee therefore did not comment on this in further detail.

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				concern has been highlighted. Not encompassing this within the catch all phrase of harm.	
Compassion in Dying	Guideline	004	019	We wholeheartedly welcome the recognition that there is a power imbalance between the person and social workers and would recommend such a recognition in all NICE guidelines that cover relationships between individuals and health and care professionals.	Thank you for this comment in support of the guideline.
Compassion in Dying	Guideline	009	009	We welcome the inclusion of the Mental Capacity Act 2005 in this section as this remains a law that is insufficiently understood amongst health and care professionals	Thank you for this comment in support of the guideline.
Compassion in Dying	Guideline	015	012	The specific mention of engaging in advance care planning with reference to the guidance which explains advance decisions and powers of attorney is also appreciated as it goes beyond simply discussing future care wishes to documenting these preferences.	Thank you for your comment in support of this guidance.
Compassion in Dying	Guideline	016 and 017	006 and 010	Clarifying that unwise decisions do not automatically mean that the person lacks capacity is hugely important and well explained here.	Thank you for this comment in support of the guideline.
Compassion in Dying	Guideline	017	016	We recommend expanding the first bullet as follows in order that the process of best interest decision making is made clearer: - ascertain the person's best interests by referring to any written documents of care preferences and involving attorneys for health and welfare, if appointed, in decision-making processes.	Thank you for your comment. To address this the committee revised the first bullet of this recommendation to: 'ascertain the person's best interests (using the best interest checklist in line with section 4 of the Mental Capacity Act) including identifying whether there is a Lasting Power of Attorney or Court Appointed Deputy with appropriate decision-making powers to make best interests decisions' (see recommendation 1.2.32).
Compassion in Dying	Guideline	024	014	We suggest including a recommendation here regarding the sharing of the care plan with other relevant professionals such as the person's GP in order to ensure a more joined-up approach to care.	Thank you for your comment. The committee recognised the importance of the input from other healthcare professionals, and have already highlighted this in bullet 4 of recommendation 1.5.5. This is also supported by recommendation 1.7.2 which focuses on the sharing of

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					information within multidisciplinary teams. The recommendations do not highlight what types of information to share as the committee agreed this would be dependent on the person, their needs, and the professionals involved. Recommendation 1.1.9 also highlights the rights of the person when sharing information across teams as a general principle.
Compassion in Dying	Guideline	026	016	We welcome the recommendation that the person's advance statements must be referred to when making decisions about their care as this action is what makes person-centred care a reality.	Thank you for your support for this recommendation.
Compassion in Dying	Guideline	026	024	In the examples of people to be involved, please include " attorney for health and welfare"	Thank you for your comment. These are examples and the list is not meant to be exhaustive. An 'attorney for health and welfare' is not always required in such situations. Therefore the committee decided that adding this as an example could be confusing because it would suggest that this would be mandatory.
Mencap	Guideline	General		The introduction explains that 'Adults with complex needs' are defined as adults who need a high level of support with many aspects of their daily life and rely on a range of health and social care services and this may be because of illness, disability, broader life circumstances or a combination of these. This is a broad group of people. Whilst it does cross-reference a number of guidelines, it may be helpful to include reference to NICE guidelines focusing on the specific needs of people with a learning disability at particular points (e.g. NICE guidance on people with a learning disability and behaviour that challenges).	Thank you for your comment. The guideline is now cross-referring to a broader range of other related NICE guidelines. This includes a reference to the NICE guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' (see recommendation 1.1.10).
Mencap	Guideline	General		It could also be helpful to have as an underpinning theme that it is important to recognise where specific expertise is needed -for example where someone with a learning disability has complex communication and	Thank you for your comment. The committee reflected on this and thought that input from other specialist services would be important as suggested. They thought that this would be best placed in the 'assessment'

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				health needs, and ensure that best practice guidance and standards are followed, and that specific expertise is brought in where needed. The right expertise is important to ensure that people are properly involved in decisions and that their needs are properly identified and met e.g. through the development of suitable care packages. (Examples might be where a person with a learning disability displays behaviour that challenges and it would be important that good practice guidance is understood and followed. Another example, may be where someone has profound and multiple learning disabilities – see 'Supporting people with PMLD: core and essential service standards')	section of the guideline. To highlight a need for additional expertise, a bullet point was added to recommendation 1.2.11 highlighting that social workers should identify 'whether there are any unmet needs that may relate to a condition or difficulty that may need input from other specialist services, for example from speech and language services or mental health services'.
Mencap	Guideline	General		Throughout the guideline we would like to see a stronger focus on listening to and involving family and the legal requirements to consult and involve families and good practice guidance around this. Family are often the consistent people in an individual's life and can be crucial communication partners particularly where someone with a learning disability has complex communication needs. There are numerous examples where families have not been listened to or have been excluded. They can be seen as overprotective but so often we read in Safeguarding Adults reviews and independent reviews that the family was raising concerns and they weren't acted on. Note: A recent report from CQC, Home for Good focused on successful community support for people with a learning disability and autistic people. The report includes eight stories of people who have previously been placed in hospital settings, who are now thriving in community services. Its findings echo what we know	Thank you for your comment. The committee agreed that the family often play an important part in supporting the person with complex needs if this is what is needed and wanted by the person. There were already recommendations in the consultation version of the guideline which reflected this (see for example recommendations 1.1.2, 1.2.17 and 1.5.4). To accentuate this, the committee have added further reference to involving the family where wanted and needed to recommendation 1.1.4 and also 1.2.10 which specifically refers to the family's role in assessments. In addition and in light of this and other stakeholders' comments the committee strengthened this by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present. In line with the CQC report the committee emphasised throughout the guideline that the approach to social work should be individualised, including treating people with respect and dignity, recognising and

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				already. They found good community support featured: person-centred care; appropriate, bespoke housing and environments; involving families.	supporting their decisions and choices (see recommendation 1.1.1)
Mencap	Guideline	General		It would be helpful to have in the guideline a focus on planning ahead for children with complex needs coming into adult services. This is important at the individual, service and local population levels. For example, ensuring there are care providers with the right skills, suitable housing available in order to properly meet people's complex needs.	Thank you for your comment. The committee agreed that transition into adult services can be challenging. They noted that this was a topic of other NICE guidelines specifically focussed on planning in situations of transition. The committee agreed that cross-referencing to a number of guidelines, focusing on transition between services, settings and levels of care would be important: • Transitions between inpatient hospital settings and community or care home settings for adults with social care needs (in particular section 1.5 on discharge planning) • Transition between inpatient mental health settings and community or care home settings (in particular section 1.5 on discharge planning) • Transition from children's to adults' services for young people using health or social care services (in particular section 1.2 on transition planning) • Intermediate care including reablement (in particular section 1.7 on transition from intermediate care). See recommendation 1.5.12 in the section Supporting people to plan for the future.
Mencap	Guideline	General		We think the information on the MCA should Include the principles, and also more detail about Best interests decision-making and the requirement to consult with family and others who know the person well (and the other elements of the Best interests checklist).	Thank you for your comment. Whilst the MCA is a principle, the committee agreed that best interest decision-making would feature more intuitively in the assessment section. Recommendation 1.2.32 has been updated to provide additional detail on best interest decisions, such as the best interest checklist (which includes the requirement to consult with families) as well as a reference to Lasting Power of Attorney or Court

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					Appointed Deputy with appropriate decision-making powers.
Mencap	Guideline	004 - 010		The following elements, which we know are important when working with people with a learning disability and their families, could perhaps be reflected more strongly in the principles for social workers: -the importance of working in a person-centred way -the importance of co-producing with individuals and their families -understand what outcomes the person wants and ensure a focus on 'outcomes' not just 'process' -value the experience and expertise of individuals and their families -Recognition of the key role that families and others who know the person well can have especially where an adult may not use formal communication such as words and signs -working with individuals and families in a trauma-informed way.	Thank you for your comment. The guideline makes many person-centred recommendations emphasising the need to actively listen to the person's experiences, wishes and preferences and avoid making assumptions (see for example recommendations 1.1.1, 1.1.5, 1.1.6). The committee also recommended focussing on outcomes as listed in the Care Act 2014 (see recommendation 1.2.11). It is recommended that the social worker respects the validity of the person's lived experience and values their first-hand knowledge (see recommendation 1.1.1). Furthermore it is recommended that the social worker ascertains the person's needs and wishes for family support (recommendation 1.1.4). There was no evidence related to social workers using a trauma-informed approach so the committee were unable to comment on this but thought that an individualised approach would take any previous experiences with services into account (see recommendations 1.1.5 and 1.1.6).
Mencap	Guideline	006	018 - 022	This could be stronger as there is a duty to make reasonable adjustments under the Equality Act.	Thank you for your comment. The legal duty relates to the protected characteristics under the Equality Act and not necessarily to the whole range of circumstances in box 1. However, the committee reflected on this and decided to strengthen the recommendation in two ways: (1) 'should consider' was changed to 'must consider' and (2) it was added that the rationale for the decision should be recorded.

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Mencap	Guideline	009		As mentioned above, in addition to ensuring social workers have up to date relevant legal literacy, it is important that they have the right expertise/ bring in the right expertise to understand the needs and what good support looks like for people with specific needs, for example people with a learning disability. It is important professionals have had appropriate training around the needs of people with a learning disability and autism, including those with profound and multiple learning disabilities and those who display behaviour that challenges. There has been a particular focus around the importance of commissioners understanding what good support looks like and ensuring the right support and services in the community are commissioned for people with a learning disability and/or autism who display behaviour that challenges – as unsuitable support, which doesn't meet the person's needs can lead to crisis situations and inappropriate admissions to inpatient units (See CQC's Out of Sight report and Baroness Hollins review into long-term segregation).	Thank you for your comment. Training requirements for social workers are outside the scope of the guideline because they are the responsibility of other bodies, such as Social Work England. The committee agreed that learning disability training forms part of any social work training curriculum so social workers should have some knowledge about this. However, the committee agreed that the identification of needs that may require input from other specialists is important and have therefore added this into the needs assessment section with examples of speech and language services and mental health services (see recommendation 1.2.11). The committee decided that the details of work with people who have challenging behaviour and learning disabilities is outside the scope of the guideline because this is the focus of another NICE guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities' and a cross reference to this has now been added.
Mencap	Guideline	010 - 014		At the start of the Needs assessment section and throughout the guideline it would be helpful to say that this should be read in conjunction with the Care Act statutory guidance. It would be helpful if, as well as saying about the right to a Carer's assessment, it is explained that needs assessments are 'carer blind' and that eligible needs may be met by a carer but only if the carer is 'willing and able'.	Thank you for your comment. The committee agreed that any needs assessment has to be in line with the legislation of the Care Act 2014. This is also the case with the Mental Capacity Act in the risk assessment section. The committee therefore decided to include a preamble to the guideline to explain how the guideline relates to legal duties, standards and other guidance. This includes a statement clarifying that actions already required by law, or recommended in guidance, are not replicated here unless specific evidence is identified in

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				In planning and conducting the assessment it may be helpful - as the focus is on adults with complex needs – to reference the requirements in the Care Act around 'having assessors appropriately trained and with the experience and knowledge necessary to carry out the assessment'. For a needs assessment for someone with complex needs it is likely that skills around communication and a good understanding of the Mental Capacity Act are going to be very important. It would be helpful to have more about the MCA in the section on the needs assessment, not just in the Risk assessment section. In relation to supported self-assessment – it may be helpful to include this from the Care Act statutory guidance: 'Whilst it is the person filling in the assessment form, the duty to assess the person's needs, and in doing so ensure that they are accurate and complete, remains with the local authority'. By realising people have complex needs it is perhaps likely that a supported self-assessment is not going to elicit the detail needed to ensure the assessment takes into account everything it should. A social worker carrying out the assessment and asking the right questions may be an important element in ensuring it is done properly. Pg 13, pare 1.2.10 - We think it would be helpful to include more about what 'wellbeing' means and also how bullet points 2 and 3 link together (whether there is a significant impact on wellbeing must also be specifically considered in relation to bullet point 2).	our searches that show that other guidance may not always have been followed. Continuous professional development in relation to legal literacy has also been highlighted in section 1.1 as a general principle of social work. Issues around carers' needs and what should be expected of them are covered in the NICE guideline on supporting adult carers to which the guideline cross-refers. The details of training are outside the scope of the guideline because they are the remit of other bodies such as Social Work England, but identifying communication needs are one of the principles highlighted in section 1.1 (see recommendation 1.1.2). The committee were conscious of the challenges of supported self-assessment and they therefore included a recommendation about discussing the advantages and disadvantages of this option with the person taking into account the complexities of their needs (see recommendation 1.2.8). The committee agreed that wellbeing is often interpreted in a narrow way relating to health so they have included the definition from the Care Act 2014 in the 'Terms used in the guideline' section. Evidence was not identified about joint health and care assessment but the committee recognised that seeking other specialist's advice and input is important if there are needs that are outside the expertise of the social worker. They have therefore added this into the needs assessment section (see recommendation 1.2.11).

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				It may be helpful to include this from the statutory guidance: 'Where a person has both health and care and support needs, local authorities and the NHS should work together effectively to deliver a high quality, coordinated assessment'. This is likely to be very important for adults with complex needs – as to meet the person's needs effectively joint-working between social care, health, housing etc is likely to be crucial.	
Mencap	Guideline	014		On page 14 there is information about making a 'complaint' but we think there should be information about the steps that can be taken if there is a disagreement about what is in the person's best interests including ultimately a referral to the Court of Protection if necessary (see MCA Code of Practice pg 90 'If someone wants to challenge a decision-maker's conclusions, there are several options..').	Thank you for your comment. Details of legal complaints under the Mental Capacity Act Code of Practice are outside the scope of this guideline. This is a complex issue and the guideline therefore includes a cross reference to the NICE guideline on decision-making and mental capacity which covers this in detail.
Mencap	Guideline	014		We think it would be helpful for it to be clearer how the Risk Assessment section relates to a Needs assessment under the Care Act. A needs assessment should cover all of a person's needs and the care and support plan should detail how the person's needs will be met. It would be helpful to explain what the Risk assessment is adding to the process. We want a robust needs assessment and care package which fully meets the person's needs, so it would be helpful to be clear about the purpose of the risk assessment. Also on page 15 it should perhaps make clear that this is about conducting a risk assessment (rather than a needs assessment). It should be clear where a needs assessment under the Care Act or and MCA assessment are being referred to and where it is another	Thank you for your comment. The differences between needs and risk assessment sections are outlined in the sub-sections on conducting the assessment. Recommendation 1.2.11 refers to the purpose of the needs assessment according to the Care Act's eligibility criteria. Recommendation 1.2.22 highlights that the aim of the risk assessment is to identify (1) risks to the person from their own behaviour (including accidents, self-neglect and suicide or self-harm) (2) risks from others (including physical or sexual violence, psychological harm, neglect or exploitation) (3) risks of harm to others (4) risks of loss of independence or breakdown of caring arrangements. There may be an overlap that some risks could also signify a need but not all needs are risks so the committee agreed that these sections complement each other. They are also based

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				sort of assessment. Similarly in the section on support to plan for the future it would be helpful to make reference to care and support planning and reviews under the Care Act to ensure the requirements of the Care Act are met.	on different evidence reviews. We have added 'risk' to the subheadings within the risk assessment section to avoid confusion. The section on supporting people to plan for the future is based on evidence rather than repeating the requirements of the Care Act. However, the committee agreed that it would help the reader of the guideline to know how the guideline relates to legal duties (such as the Care Act or the Mental Capacity Act), standards and other guidance so they have added a paragraph to the guideline to explain this.
Mencap	Guideline	016		On page 16 there is some information about assessing mental capacity. We think this should include that it may sometimes be appropriate to involve medically trained professionals eg. learning disability psychiatrists or psychologists and it may also be appropriate to refer to the Court of Protection. There are some big personal decisions where assessing capacity will be complex and where the MCA Code of Practice isn't up to date e.g. around the complexities of on-line activity and relationships.	Thank you for your comment. A reference to input from other specialist services such as speech and language or mental health services has been added to the needs assessment section (see recommendation 1.2.11). There are only some recommendations related to the assessment of mental capacity included because the details of this are covered by legislation and are also a focus of a separate NICE guideline on decision-making and mental capacity (including a specific section on assessment which outlines some of the complexities to which the committee cross referred).
Mencap	Guideline	020		Individual or family casework – this could be a good place to mention signposting to independent support for individuals and families about knowing their rights e.g. around the Care Act and Mental Capacity Act. It can be opaque how the local authority has arrived at decisions and this is not helpful in building trust. Empowering families to understand their rights, including understanding the parameters in which decision making takes place e.g. being clear what it is the LA will assess, is likely to be helpful and lead to a better experience for everyone.	Thank you for your comment. The committee already recommends that the social worker should inform the person being assessed about where and how they can access information about their rights under relevant legislation, such as for example the Care Act 2014, the Human Rights Act 1998 or the Mental Capacity Act 2005 (for example, providing written or oral information or signposting to relevant online resources or agencies) - see recommendation 1.2.3. The committee thought that this was most relevant in the assessment section but once the person knows where and how to access this

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					information they would be able to revisit this in relation to individual or family casework.
Mencap	Guideline	021		Helping people to connect with local communities and reduce isolation. It might be helpful to link this to the needs assessment under the Care Act – where all needs should be identified and there should be discussion for how these will be met. There could be a message about importance of a focus on 'prevention' in line with the Care Act.	Thank you for your comment. The recommendations under 'helping people to connect with local communities and reduce isolation' aim to connect people with services to reduce isolation, and are not aimed at identifying all of a person's needs. This is better covered in other sections of the guideline. The guideline covers needs assessment in section 1.2 and reference is made to the Care Act in a number of recommendations. Recommendation 1.5.6 has been edited and now sets out that a person's care plan should state how their needs will be met, and should identify how arrangements will be made to meet need. This recommendation covers your suggestion for including reference for a discussion on how needs will be identified and met. With regard to a message about 'prevention', this issue is largely covered under the section 'Supporting people to plan for the future', where the recommendations aim to support people with a care plan so that an unplanned escalation of need is prevented or avoided.
Mencap	Guideline	025		In the 'Responding to an escalation of need, including urgent support' section it would be good to highlight the importance of social workers having a focus on early intervention and prevention in order to help avoid needs escalating. It would also be helpful to include a need to plan ahead and have emergency/contingency plans in place to help avoid unplanned crisis situations. If people with LD/autism are at risk of admission to an inpatient unit then in line with NHSE policy they should have a Care and Treatment Review in the community -	Thank you for your comment. The section 'Responding to an escalation of need, including urgent support' is specifically about the approaches to take once there has been an escalation of need, and therefore prevention and early intervention would be more appropriate for section 1.5 which covers supporting a person to plan for the future. The intention of all the recommendations in section 1.5 is to support social workers to work together with the person to create a care plan that would address and meet the needs of the person, so that as much as possible, needs do not remain unmet (which could lead

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				which involves the right professionals, the person and their family coming together to help ensure the right support is put in place and to help avoid inappropriate admission to an inpatient unit. This part of the guidance could include that if people with a learning disability and/or autism are at risk of being sectioned under the MHA, social workers should contact the local Transforming Care lead and ensure the person has a Care and Treatment Review. In relation to needs escalating and risk of sectioning it would be helpful to also include a link to the NICE guideline on learning disability and behaviour that challenges, here.	to an unplanned escalation of need or emergency situation). With regard to a Care and Treatment review, this is not something that is organised by the social worker, rather an expert who is qualified in healthcare, and therefore cannot be included as a recommendation for this guideline. However, the committee agree that social workers are often involved in Care and Treatment reviews, and have added this as an example of the possible things to consider when assessing jointly with other colleagues (see recommendation 1.6.2). A cross reference to the NICE guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities' has been added to the guideline in section 1.1. This provides detailed recommendations on the issues raised and also tailors the recommendations to people with learning difficulties and challenging behaviour, who are one of many groups of adults with complex needs.
Mental Health Matters	Guideline	048	026	**Recording and reviewing the assessment** There is not a mention of when a risk assessment needs to be updated after an incident or changes in risk, whether this should be completed over several sessions.	Thank you for your comment. This has now been added to recommendation 1.2.39 related to a review of the risk assessment.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	General	General	The introduction states this document applies for age 18 and over but may have relevance for ages 16-18. This age group and early adulthood may involve educational placements for young people with complex needs and include more than one place of residence that must be considered in social needs assessment and planning	Thank you for your comment. The guideline was developed for adults and evidence was searched for on people over the age of 18 (as would be expected from the title of the guideline). Educational placements and places of residence of 16 to 18 year olds did not feature in the guideline because this was not part of the scope. However, there are many recommendations that could have relevance for the 16 to 18 year age group including preferences for where meetings take place, individualised assessment of needs and risks and others topics. A cross-reference was added to the NICE

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					guideline on Transition from children's to adults' services for young people using health or social care services which covers many relevant topics for this age group.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	General	General	For those aged 16 and over the age of consent to medical treatments is relevant to all social care plans	Thank you for your comment. The guideline focuses on 'adults with complex needs' but as stated at the beginning it may also be relevant for people aged 16 to 18 with complex needs who have completed the transition from children to adult services. Competence of 16 to 18 year olds falls under the jurisdiction of the Mental Capacity Act and once a person reaches the age of 16, they are presumed in law to be competent. Therefore the recommendations related to capacity in the guideline also apply to this age group including consent to medical treatments. Throughout the guideline an individualised supportive approach is recommended based on the wishes, preferences and needs of the person (which may differ according age and many other factors). The details of assessment of factors related to decision-making and mental capacity are outside the scope of this guideline and that is why the committee cross-referred to the NICE guideline on decision-making and mental capacity which covers people aged 16 and over.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	General	General	A definition of 'complex' will be important in relation to both the individuals, their carers and the social work resources	Thank you for your comment. A definition of complex needs is difficult and varies in health and care settings and the committee agreed that this is important to the person, families and carers as well as practitioners. We therefore included the definition that was used in the context of the guideline at the beginning of the document. The definition was part of a consultation during the scoping phase of the guideline development and was amended based on stakeholder feedback. It has then been used to inform the search terms for the

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					evidence reviews. We are therefore unable to make changes to this definition. The committee were satisfied that it would capture a broad range of people who would need assessment or support by social workers.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	General	General	The changes in the brain of adolescents continues until at least 25 and should be considered in relation to any decision making, goals and aims	Thank you for your comment. The guideline focuses on 'adults with complex needs' but as stated at the beginning it may also be relevant for people aged 16 to 18 with complex needs who have completed the transition from children to adult services. Competence of 16 to 18 year olds falls under the jurisdiction of the Mental Capacity Act and once a person reaches the age of 16, they are presumed in law to be competent. Therefore the recommendations related to capacity in the guideline also apply to this age group. Throughout the guideline an individualised supportive approach is recommended based on the wishes, preferences and needs of the person (which may differ according age and many other factors). The details of assessment of factors related to decision-making and mental capacity are outside the scope of this guideline and that is why the committee cross-referred to the NICE guideline on decision-making and mental capacity which covers people aged 16 and over.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	010	General	Specify the potential need for Communication Aids including advanced enhanced Aids for all person centred meetings and if applicable for carers too.	Thank you for your comment. The identification of any communication needs is covered in the 'Principles of social work for adults with complex needs' section (see recommendation 1.1.2). This section is overarching and applies to all other parts throughput the guideline. However, the committee also recognised that social workers should in their assessments take into account 'whether there are any unmet needs that may relate to a condition or difficulty that may need input from other specialist services' and added as an example 'speech

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					and language therapy services' (see recommendation 1.2.11). This may then include input on the need for communication aids.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	023	General	Include advice on the need for carers to accompany an individual when in hospital to provide necessary social care if that is preferred by the individual	Thank you for your comment. Recommendation 1.5.4 covers the inclusion of key support networks, including carers, in a person's care plan, if preferred by the person and with their consent. The care plan should set out the individual's preferences for when they are in hospital and therefore this recommendation sufficiently covers the suggestion you made.
Network for Children with Exceptional Healthcare Needs - NSS CEN	Guideline	023	General	Recognise the possible role of young carers/siblings in assessment and planning meetings	Thank you for your comment. The guideline already covers carers and family input in recommendations 1.2.6 and 1.5.4. The wording of the recommendation in 1.2.6 has been amended to be more inclusive of anyone the person would like to be present, which could include siblings and young carers. It is therefore not necessary to specify these separately as they would not be excluded using the current wording. In addition and in light of this and other stakeholders' comments the committee strengthened the role of families by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present (see recommendation 1.2.36).
Royal College of Nursing	Guideline	General		We do not have any comments to add to this consultation. Many thanks for the opportunity to contribute.	Thank you for your comment.
Sheffield Clinical Commissioning Group	Guideline	General		Reference should be made to other pieces of legislation and statutory guidance rather than just NICE guidance	Thank you for your comment. The guideline makes frequent reference to the: • the Care Act 2014 • the Mental Capacity Act 2005 and also mentions:

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					• the Mental Health Act 2007 • the Human Rights Act 1998 • the Equality Act 2010 Furthermore throughout the also refer to the Social Work England professional standards, the Professional Capabilities Framework from the British Association for Social Workers and the Code of Ethics from the British Association for Social Workers. A paragraph was added to explain that the guideline aims to complement legislation and guidance by providing evidence-based recommendations about how social work interventions including assessment, care management and support for adults with complex needs could be improved.
Sheffield Clinical Commissioning Group	Guideline	General		If talking about abuse there should also be refence to how professionals respond to non recent allegations of abuse and neglect and how they should respond to these, not just for the person with complex needs but taking in to account on going risks to others	Thank you for your comment. To address such potential safeguarding issues the committee have added a recommendation to highlight that safeguarding issues can be noticed in the risk assessment process and that it is therefore a legal duty in line with the Care Act 2014 that the social worker adheres to local policies to keep the person safe. The details of allegation management processes are outside the scope of this guideline.
Sheffield Clinical Commissioning Group	Guideline	General		There should also be reference to People in a Position of Trust and LADO concerns where the person with complex needs maybe abused and neglected by the professional caring for them	Thank you for your comment. The guideline promotes person-centred social work approaches that would treat people with dignity and respect (see recommendation 1.1.1). The committee already highlighted that social workers should discuss and actively listen to the person's 'experience of disadvantage, discrimination or abuse' and 'past experiences of services' (see recommendation 1.1.5). It is also recommended that the social worker should discuss with the person how their

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					experiences may impact on their care needs and preferences and in these discussions 'recognise that some people's prior positive or negative views and experiences of social work (which could relate to abused and neglected by the professional caring for them) may impact on the relationship with the social worker and services' (see recommendation 1.1.6). The details of processes related to Local Authority Designated Officer's allegation management processes are outside the scope of this guideline.
Social Care and Leadership Team	Guideline	General	General	It's really helpful that recommendation 1.1.14 includes a link to Social Work England professional standards. It would also be helpful if there was a contextual section to demonstrate how the guidance links with other social work standards and to explain what is distinct about NICE guidance. From conversations I have had with numerous social workers and social work organisations there is often confusion between SWE's standards, the BASW PCF and other knowledge and skills statements. Also, many social workers aren't familiar with NICE's social care guidance, believing that NICE is primarily about medication and health, so may be surprised that this guidance is being developed and may question how appropriate it is to be developed by NICE. However, if there was clear alignment with SWE and BASW within the guidance, this may help to contextualise the guidance. Similarly, if SWE and BASW referred to NICE guidance this could also help to reduce confusion and give credibility and trust to social workers about using NICE guidance.	Thank you for your comment. A section was added to the beginning of the document to outline how a NICE guideline complements legal duties, standards and other guidance. This also explains that NICE guidelines provide evidence-based recommendations which are different to professional standards or legislation. This will provide contextual information as suggested.
The Challenging	Guideline	General	General	NICE guidance must address the needs of adults with severe learning disabilities whose behaviour challenges. Currently this guidance often presumes the individual	Thank you for your comment. We have now cross-referred to a broader range of guidelines. This includes a reference to the NICE guideline on 'Challenging

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Behaviour Foundation				receiving social care will have verbal communication. It would be helpful if definitions of learning difficulty and learning disability, including severe learning disability and profound and multiple learning disability were included to avoid the terms being used interchangeably as they describe very different needs. Adults with severe learning disabilities may have limited verbal communication and may use other methods of communication such as Makaton signing, picture exchange systems, talking mats. Social workers must be aware of the communication needs of the individual they are supporting and have relevant training/ skills in using these alternative communication methods. For further information about communication see: Communication and Challenging Behaviour. Effort should always be made to consider what is in the best interest of the individual and involve them in decision making as much as possible. For further information please see Seldom Heard - Challenging Behaviour Foundation. This guidance must make specific reference to individuals with complex needs who do not communicate verbally - and how their views and experiences are collected and heard It is important that the guidance also acknowledges the 'digital divide' and 'Digital literacy' and how this may present barriers at an individual level.	behaviour and learning disabilities: prevention and interventions for people with learning disabilities'. Providing definitions about individual specific conditions (such as learning disabilities) within the broad spectrum of adults with complex needs would be difficult since there are so many conditions that could be considered as a complex need. Therefore the committee decided that this is better covered by a cross-reference to guidelines that cover this particular topic. In relation to communication difficulties, we have added that a needs assessment should also include the identification of needs that may have to be addressed by other specialist services such as speech and language or mental health services (see recommendation 1.2.11). The social worker may not have the relevant expertise related to alternative or augmentative communication so the committee agreed that it is important to ascertain where other specialist input is needed to fully address such needs. The committee commented on remote and in-person meetings and recognised that there are pros and cons of these approaches and did not reach consensus in recommending one over another. A recommendation was amended to include a reference to 'remote or in-person' assessment' in relation to preferences for practical arrangements with the caveat that where there are safeguarding concerns in-person assessments are likely to be needed.
				Adults with severe learning disabilities may display behaviour that challenges. Challenging behaviour must be recognised as communication of an unmet need and	The committee made a recommendation that social workers must explore the least restrictive alternatives to address the need when an unplanned escalation of need

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				the social care workforce must be aware of appropriate interventions, such as positive behaviour support, to identify the cause of behaviour and reduce incidents. There must be clear links made to the existing challenging behaviour NICE guidance throughout this guidance. (See Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE and Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE.) Individuals with severe learning disabilities whose behaviour challenges are also at increased risk of inappropriate restraint and seclusion and inappropriate medication (See latest data on restrictive interventions in inpatient settings here: Learning disability services monthly statistics from MHSDS: Data tables - NHS Digital). According to Public Health England every day 30,00 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for. Family carers often provide lifelong support to their relative and know the individual best and therefore social workers must actively consult and listen to family carers when providing support to the individual. This must be emphasised throughout the guidance.	occurs (see recommendation 1.6.3). The aim of this was to help prevent inappropriate restraint and seclusion.
The Challenging Behaviour Foundation	Guideline	General	General	When publishing the guidance, NICE should also consider how they will ensure it is implemented to make sure it translates to good practice on the ground and improved outcomes for individuals with learning	Thank you for your comment. This comment will be considered by NICE where relevant implementation support activity is being planned.

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				disabilities. One family carer noted the following in relation to their relative's care 'knowledge of any existing guidelines around the management of behaviour described as challenging was not only woeful but highly alarming.'	
The Challenging Behaviour Foundation	Guideline	General	General	In order for social workers to have the most effective and positive relationships with adults with learning disabilities and their families, they need to be aware of trauma the individual and their family may have experienced. We support the reference in the guidance to distrust of services and past trauma that the individual may have experienced, but the guidance must also highlight the trauma experienced by the family carers of individuals with learning disabilities. Our survey of family carers demonstrates the impact on families of the system repeatedly failing to provide the necessary support for their relative. For more information see: Baker, P., Cooper, V., Tsang, W., Garnett, I. and Blackman, N. (2021), "A survey of complex trauma in families who have children and adults who have a learning disability and/or autism". (A survey of complex trauma in families who have children and adults who have a learning disability and/or autism | Emerald Insight) For more information see: Broken CBF final report (challengingbehaviour.org.uk). In addition, many people with learning disabilities may have suffered poor treatment, abuse or restrictive interventions either as an inpatient or within the community. We support the guidance that social workers	Thank you for your comment and for the suggested citations. In a number of recommendations the committee already highlighted that social workers should discuss and actively listen to the person's 'experience of disadvantage, discrimination or abuse' and 'past experiences of services' (see recommendation 1.1.5). The trauma as experienced by families can be explored within these discussions and also could be explored in holistic assessments of needs and risks. It is also recommended that the social worker should discuss with the person how their experiences may impact on their care needs and preferences and in these discussions 'recognise that some people's prior positive or negative views and experiences of social work (which could relate to the trauma of not receiving the right support) may impact on the relationship with the social worker and services' (see recommendation 1.1.6). Therefore previous traumatic experiences with services should be identified and discussed. The suggested article by Baker (2021) was not included as evidence since it did not match the inclusion criteria of the guideline protocols with regard to the role of the social worker or social work approaches to learning disability and/or autism. There was no specific evidence that was identified about 'trauma awareness training'. However, the committee agreed that a person-centred approach that is individualised to each person's circumstances and

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				should be aware and sensitive to these issues. However, the guidance must go further and recommend trauma awareness training for all social workers especially those supporting people with learning disabilities to ensure that social workers are fully equipped to deal with trauma related behaviours that might arise and can do their best to not trigger past traumatic experiences, for example, if the individual they are supporting suffers from PTSD. This trauma awareness training should also help them to understand that family carers might also have PTSD or struggle with trauma from their previous experiences. For more information we suggest looking at: Changing poor practice - Challenging Behaviour Foundation Trauma support - Challenging Behaviour Foundation	needs would address concerns about previous negative experiences and traumas related to services. With regard to the cited reference, Baker 2021 is not included as evidence because it does not meet inclusion criteria because it does not focus on the role of the social worker or social work approaches for people with learning disability and/or autism. The other two sources of information (changing poor practice and trauma support) do not meet inclusion criteria because of the types of article / study design (they are not research articles that compare different approaches quantitatively or describe the perspectives of everyone involved qualitatively).
The Challenging Behaviour Foundation	Guideline	General	General	As family carers and other relatives are frequently so involved in the care of relatives with learning disabilities it is important that social workers understand how to build and maintain positive relationships with family carers in order to have a positive relationship with the individual and ultimately, provider the best wholistic support. We would suggest that one way to provide extra support for families would be creating and encouraging family support networks and peer support (Wellbeing of family - Challenging Behaviour Foundation) This is particularly important when individuals are unable	Thank you for your comment. The committee agreed that the family often play an important part in supporting the person with complex needs if this is what is needed and wanted by the person. There were already recommendations in the consultation version of the guideline which reflected this (see for example recommendations 1.1.2, 1.2.16 and 1.5.4). To accentuate this, the committee have added further reference to involving the family where wanted and needed to recommendation 1.1.4 and also 1.2.10 which specifically refers to the family's role in assessments. In addition and in light of this and other stakeholders' comments the committee strengthened family input and

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				to communicate verbally – the guidance needs to ensure this group of individuals are specifically identified and included in this guidance We know from our work with family carers that families sometimes feel victimised or ignored by the system, sometimes leaving them tramatised. Understandably, this can make it harder for families to trust social workers. It is important social workers are aware of this when building new relationships with individuals and their families and make particular efforts to listen carefully to the individual and their family and actively build trust. Social work professionals have a role in ensuring individuals with complex needs and their families have access to independent high-quality advocacy. 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. 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	support by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present. There was no evidence identified related to family support networks or family peer support. However, the committee recognised the importance of family support and recommended that organisations should consider providing training to social workers to gain specialised and advanced skills in family interventions (for example, behavioural family interventions, family group conferences and restorative approaches). Local carer support services and peer support for carers is also recommended in the NICE guideline on supporting adults carers to which the guideline cross-refers. A person-centred approach to social work is emphasised throughout and active listening and building trusting relationships has been highlighted as general principles, this includes also taking account of prior experiences of services or systems (see recommendations 1.1.5 and 1.1.6). Identification of a need for advocacy services had already been raised as one of the principles of social work for adults with complex needs (see recommendation 1.1.2) which is an overarching section of the guideline. Advocacy has now also been flagged up in recommendation 1.2.5 in the needs assessment section. The committee did not add further detail related to advocacy services because this is the topic of a separate NICE guideline that is currently in development. Therefore they have cross-referenced to this guideline in section 1.1 to signpost to guidance on the topic. They have also cross-referred to the NICE guideline on 'Challenging behaviour and learning

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				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" – Family carer involved in the Medway Advocacy Project (Advocacy. CBF Projects. The Challenging Behaviour Foundation, UK) This guidance must also link to NICE guidance currently in development on Advocacy services for adults with health and social care needs.	disabilities: prevention and interventions for people with learning disabilities'.
The Challenging Behaviour Foundation	Guideline	General	General	The NICE guidance must also consider that adults with learning disabilities may have specific sensory needs and their environment can have a significant impact on their wellbeing and/ or behaviour. Social workers must be aware of this when considering an individual's living environment or carrying out visits/ appointments outside an individual's familiar environment. Reasonable adjustments must be made as required. The NICE guidance must include: Making sure that social workers consult with family	Thank you for your comment. We have added 'sensory or communication need or impairments' as potential needs to be established by the social worker when first contacting someone, and throughout provision of support. This is in the 'general principles section' and all recommendations in this section are overarching and are relevant in all other parts of the guideline. The details of such sensory needs would depend on each person and would have to be individualised so the committee decided that they could not go into specific details in recommendations as is suggested. We have added the example of adults with learning disabilities to

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				carers/carers or the individual where possible prior to a visit in regard of specific sensory needs. This may include the social worker not wearing perfume, aftershave or other products with a distinctive smell and this may be distressing to someone who is highly sensitive. In terms of out of home environments social workers should consider things such as: Noise level, are they loud noises or lots of overlapping sounds? A quiet environment without intrusive sounds and/or constant music being played or tv sound. Overuse of media on the ward reduced, echo reduced, tv not on as a constant etc. Bright lights Is the environment autism friendly and safe? For example, if the individual displays challenging behaviour such as headbanging or PICA is the environment safe for them. Disabled access, for example, disabled toilets, ramps for wheelchairs etc Architecture changed so that reflections are not a source of over stimulation, glass, mirrors and lights well considered and non-obtrusive. Journey length when planning external meetings, will the	the rationale section and used noise level or brightness of light as examples as suggested.. Assessments of needs such as wheelchair access would be covered in the needs assessment section. Provision of home adjustments or other equipment are outside the scope of this guideline but it is recommended that the social worker ensures that it is stated how the person's eligible and non-eligible needs would be best met and that it should be identified how arrangements will be made to meet eligible needs (see recommendation 1.5.6). To give greater emphasis on the involvement of families we have added to section 1.1 (Principles for social work with adults with complex needs) that the social worker should take into account 'the person's wishes and needs for family support'. In addition and in light of this and other stakeholders' comments the committee strengthened family input and support by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present.

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				individual have to travel a long way in the car? We recommend that social workers must discuss these needs with others involved in the individual's care (including family carers).	
The Challenging Behaviour Foundation	Guideline	General	General	The NICE guidance on adults with complex care needs must make clear reference to the following relevant NICE guidance on: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (nice.org.uk) Learning disabilities and behaviour that challenges: service design and delivery (nice.org.uk)	Thank you for your comment. We have added a cross reference to the NICE guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities". We have not cross referenced to the service design and delivery guideline since that is very specifically related to the service configuration related to learning disabilities rather than related to organisational matters related to the role of the social worker and the role of social work interventions.
The Challenging Behaviour Foundation	Guideline	General	General	During the Coronavirus pandemic, existing social care inequalities have been emphasised. This must be recognised in the guidance. Families have shared experiences where they have felt professionals have not respected their rights and the privacy of their own homes during this period. One family carer told us: "People involved with caring for a relative with a severe learning difficulty should not have their Human Rights removed because it is a pandemic, and a care manager has decided what risks should be taken in their own home. When the owner of a home pays council tax should they not have the right to live and protect themselves at home as they see fit?" (family carer) The NICE guidelines should ensure that family carers are properly consulted and included in decision making,	Thank you for your comment. The guideline recommends a holistic, person-centred approach to social work which emphasises that people are treated with respect and dignity, recognising and supporting their decisions and choices. They have also recommended that social workers have up-to-date relevant legal literacy including of the Human Rights Act 1988. Therefore, the committee agreed that the guideline aims to address inequalities including related to privacy in people's homes.

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				and the rights of individuals and their families upheld, even during lockdown restrictions.	
The Challenging Behaviour Foundation	Guideline	General	General	Social workers must be aware of the consequences of prioritising cost over high-quality care. The priority should always be to ensure the care package fully meets the needs of the individual. They are uniquely placed to advocate for individuals. There are competency standards for social workers supporting individuals with learning disabilities for example and these standards should be referenced. Layout 1 (basw.co.uk) There are systemic issues where cost saving and cutting corners are prioritised over care. Frequently, we hear from family carers and the relatives of individuals with learning disabilities that social workers have tried to encourage them to agree to reduced cost care packages that are less expensive for the Local Authority (LA) despite not meeting the complex care needs of the individual. When care packages are reduced it can often result in an individual reaching crisis, increased pressure of family carers to provide unpaid support and unnecessary and inappropriate inpatient admissions which can have an extreme negative impact on the individual and often occur because of inadequate care plans or because of funding disagreements.	Thank you for your comment. The committee took into account the BASW professional capabilities framework and the Social Work England Professional Standards which sets standards for social workers and this is documented in several of the rationale and impact sections (see for example the rationale and impact section on 'Principles of social work for adults with complex needs' and 'Responding to an escalation of need including urgent support'). It is recommended that the social worker ensures that it is stated how the person's eligible and non-eligible needs would be best met and that it should be identified how arrangements will be made to meet eligible needs taking into account the person's wishes and preferences (see recommendation 1.5.6). How this is implemented is outside the scope of this guideline. The committee discussed issues around cost savings leading to sub-optimal care. Therefore the guideline promotes a person-centred approach to social work which would tailor assessment, planning and support to the person's needs. They emphasise that a care plan should state how the person's eligible and non-eligible needs would be best met, identify how arrangements will be made to meet eligible needs and record any eligible needs which are unlikely to be met or only partially met, the reasons they can't be met or only partially met, and any potential actions that would allow them to be met in future (see recommendation 1.5.6). This should lead to care packages that would address the person's needs

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					and that plans are made to address unmet needs and ultimately to better outcomes.
The Challenging Behaviour Foundation	Guideline	General	General	Adequate support systems should be in place for social work professionals to support mental health and wellbeing. This might include implementing peer support programmes between social workers to share knowledge, best practice and expertise. For example, the CBF has a professionals' email network (Professionals' Email Network - Challenging Behaviour Foundation) where professionals can share information, advise and expertise, the NICE guidelines should suggest a similar network to organisations that employ social workers.	Thank you for your comment. The guideline already covers support for social workers, for example recommendations 1.1.15 and 1.2.41 highlight a need for social workers to share best practice and learn from each other as well as providing peer support or counselling following serious incidents. Whether or not this would be implemented with an email network would depend on the systems and processes of each organisations and making recommendations about how to do this is outside the scope of the guideline.
The Challenging Behaviour Foundation	Guideline	General	General	It is very important that the NICE guidelines consider how it can best achieve a resilient and appropriately skilled social care workforce. The Core Capabilities Framework for Supporting People with a Learning Disability must be referenced where appropriate. The recently published Building The Right Support (BTRS) evaluation report identifies the need to better support the social care workforce (Evaluation of Building the Right Support: Final Reports | The Strategy Unit (strategyunitwm.nhs.uk)). The recently published CQC State of Care report warned of a crisis in the workforce which must be tackled to prevent a "tsunami" of people without the care they need over the coming months. The report is clear that if promised government funding for social care is to have any effect, a focus on developing a clearly defined career pathway, with training and consistent investment, and higher overall levels of pay for social care staff is	Thank you for your comment. The details of social work training are outside the scope of the guideline because these are the remit of other professional bodies, such as Social Work England. Funding and the general state of Social Care is something that the committee was conscious of but the guideline needs to highlight best evidence based practice in support of the person with complex needs as well as the social worker. The guideline includes a number of recommendations that highlight the support that organisations should provide for social workers, such as considering giving them time allowances so that they can build relationships (recommendation 1.1.11), continuous professional development related to equality and diversity and legal literacy (recommendation 1.1.12 and 1.1.13), debriefing, peer support and counselling to support staff safety (recommendations 1.2.40 and 1.2.41).

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				essential. (CBF response to CQC State of Care Report 2021 - Challenging Behaviour Foundation:) Recent reports and recommendations have highlighted the need for improved support and training for the social care workforce. For example, Baroness Hollins' Review into seclusion and segregation (Thematic Review of the Independent Care (Education) and Treatment Reviews - GOV.UK (www.gov.uk)) recommended improvements to the learning disability and autism training for health and social care workers and assessors. The Department for Health and Social Care responded that it is 'in a position to support all immediate recommendations and then Minister for Care, MP Helen Whately expressed strong support. The NICE guidance must address the identified need for improved training for this workforce. Evidence based Positive Behavioural Support is a person-centred approach to supporting children and adults with a learning disability. PBS is a framework for developing an understanding of behaviour that challenges rather than a single therapeutic approach, treatment or philosophy. It is based on an assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop interventions (pbsfamilycarerresource2019.pdf (challengingbehaviour.org.uk)). For more information see: Positive Behaviour Support - Challenging Behaviour Foundation Social workers and other relevant professionals should also complete the Oliver McGowan training in learning disability and autism. (The Oliver McGowan Mandatory	

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				Training in Learning Disability and Autism. | Health Education England (hee.nhs.uk)). For more information see: 20211021_stateofcare2021_print.pdf (cqc.org.uk)	
The Challenging Behaviour Foundation	Guideline	General	General	The NICE guidelines must consider how data is collected and published around assessment decisions. Availability of accurate data is important for ensuring accountability and monitoring implementation of best practice guidance.	Thank you for your comment. The committee made a number of recommendations related to recording and reviewing assessments and plans. A recommendation was also amended to include recording of decisions related to reasonable adjustments. Having such records would allow collection and monitoring of data and would ensure accountability.
The Challenging Behaviour Foundation	Guideline	General	General	Furthermore, adults with severe learning disabilities are unlikely to be able to participate in discussions around their own social work interventions, for example, risk management plans. The guidelines do not consider or refer to the fact that not all adults with complex care needs will be able to have an active role in discussing their own care. Whilst this should always be offered or attempted it may not always be realistic and in situations where the individual is unable to participate, for example, because of a severe learning disability their families must be consulted to speak on their behalf. The guidelines further fail to mention issues relevant to individuals with severe learning disabilities, for example, there is also no mention of challenging behaviour and how this might impact on social work interventions. This could create numerous problems, such as, social workers being unaware and lacking understanding about what challenging behaviour is or how to support individuals with challenging behaviour and their families.	Thank you for your comment. The committee agreed that the family often play an important part in supporting the person with complex needs if this is what is needed and wanted by the person. There were already recommendations in the consultation version of the guideline which reflected this (see for example recommendations 1.1.2, 1.2.17 and 1.5.4). To accentuate this, the committee have added further reference to involving the family where wanted and needed to recommendation 1.1.4 and also 1.2.10 which specifically refers to the family's role in assessments. In addition and in light of this and other stakeholders' comments the committee strengthened family input and support by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present. This guideline covers a broad range of people with complex needs and therefore talks about the principles of social work intervention that would generally apply and for which

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				If social workers are not aware of the impacts of serious learning disabilities, then they will not have the skills or knowledge to be able to effectively support this group or their families. Overall, there seems to be little accounting for the specific needs or people with severe learning disabilities within this guideline. The NICE guidelines must consider the needs of all adults with complex needs. We would recommend that the NICE guidelines include reference to challenging behaviour including an accurate definition of challenging behaviour, further information on this can be found at What is challenging behaviour? - Challenging Behaviour Foundation. In addition, social workers must be aware that individuals with learning disabilities whose behaviour challenges are at increased risk of restrictive interventions. Furthermore, social workers must understand the consequences of inappropriate use of restraint and must encourage other carers or support staff involved in the individuals care to have the correct restraint training, for example in de-escalation techniques and proper recording of restraint incidents. The NICE guidance must include this so that social workers have the knowledge to help prevent incidents of restraint when supporting individuals who have learning disabilities and challenging behaviour. Further information on this can be found here: Restraint seclusion medication - Challenging Behaviour Foundation	evidence was identified, specific to social work approaches. Detailed recommendations related to challenging behaviour and learning disabilities are outside the scope of this guideline since this is already covered in another dedicated guideline. The committee added a cross-reference to the NICE guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities' which covers support and interventions for family members or carers as well as assessment of challenging behaviour and support planning.

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The Challenging Behaviour Foundation	Guideline	010	013	As it currently stands, the assessment template employed is not fit for purpose. In response to this consultation one family shared their experience of an assessment carried out by a professional who had no background knowledge of their son or his traumatic experience in services, and who also failed to consult other relevant professionals and support staff involved in his care. The result was that there was an initial recommendation that the individual be moved from individual supported living to a care home setting which, had the family not insisted on the review being repeated, would have been extremely detrimental to his health and wellbeing, possibly leading to readmission to inpatient services. The guidance must be strengthened to ensure all relevant individuals (professionals and family members) are consulted and the adult's prior experience of care and support is taken into account.	Thank you for your comment. No evidence was identified about any particular templates and the committee was therefore unable to comment on this. The committee agreed that prior experiences impact on the perception of services in future and recommended that social workers recognise that some people's prior positive or negative views and experiences of social work may impact on the relationship with the social worker and services (see recommendation 1.1.6). The role of other professionals is given further emphasis by (1) the social worker identifying whether there are needs that would require input from other services such as speech and language or mental health services (see recommendation 1.2.11) and (2) adding perspectives of professionals to the needs assessment section related to self-assessment (recommendation 1.2.10) and in risk assessments when there is a significant risk of harm (see recommendation 1.2.25). The committee also agreed that family often play an important part in supporting the person with complex needs if this is what is needed and wanted by the person. There were already recommendations in the consultation version of the guideline which reflected this (see for example recommendations 1.1.2, 1.2.17 and 1.5.4). The committee have added further reference to involving the family where wanted and needed to recommendation 1.1.4 and also 1.2.10 which specifically refers to the family's role in assessments. In addition and in light of this and other stakeholders' comments the committee strengthened this by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk

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					management, should the person wish them to be present (see recommendation 1.2.36).
The Challenging Behaviour Foundation	Guideline	013	002 - 006	Guideline 1.2.9 states that 'social workers must ensure that the information provided by supported self-assessment is an accurate reflection of the person's circumstances by cross referencing it with information from other sources.' More clarity is needed around the 'other sources' required. It should not be left up to the individual social workers discretion regarding who they speak to. Families must be consulted and a failure to include this in the guidelines means they may be overlooked. In addition, not all adults with complex care need will be able to complete a self-assessment, for example, it is unlikely that a non-verbal adult with severe learning disabilities would participate in a self-assessment for social services. Alternative methods must be used to gather the views and experiences of the individual with severe learning disabilities. This might include talking mats, Makaton signing etc. See Seldom Heard - Challenging Behaviour Foundation	Thank you for your comment. That this would typically involve the perspectives of family or carers or the multidisciplinary team has been added to this recommendation. With regards to self-assessment for people who may find this difficult, a potential need for an advocate was added to a recommendation about preparatory initial contact. This highlights that social workers should take into account whether the person would have substantial difficulty in being involved in the assessment and if so, whether an independent advocate should be provided (see recommendation 1.2.5). In respect to potential difficulties for the person to conduct a self-assessment a recommendation states that the social worker should discuss with them the advantages and disadvantages of this option, taking into account the complexities of their needs (see recommendation 1.2.8). The potential need for input from other services, for example speech and language services, has been added to recommendation 1.2.11.
The Challenging Behaviour Foundation	Guideline	018	006 - 016	We agree with draft guidelines 1.2.33 and 1.2.34 that social workers should consult all relevant agencies when reviewing a risk assessment. However, the guidelines must be clear that if appropriate, the family carer or closest relative of the individual receiving the risk assessment should also be consulted. Families often know and understand the individual best. From the families we support, we know that families are	Thank you for your comment. The committee agreed that family input is important and based on this and other stakeholders' comments have accentuated their role by adding that the person and their family, advocate or carer should be involved in case conferences (see recommendation 1.2.36). However, the committee discussed that their involvement could sometimes present a risk to themselves or others so they added this

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				often 'kept in the dark' and left out of the decision-making processes, even though they are typically the person that best understands their relative. We would suggest that the guidelines make it clear that family carers should be given the option to attend and contribute to the case conference and should be properly supported to do this. This would enable families to be active partners in the decision making.	as a caveat so that the social worker can take this into account.
The Challenging Behaviour Foundation	Guideline	020 - 021	022 - 023 (pg 20) 001 - 008 (pg 21)	We agree with guideline 1.3.3. that social workers must understand the options available through legal frameworks so they can effectively support the rights of the person and the rights (and limits of the rights) of family members, including in situations of conflict and challenge. It is encouraging to see the NICE guidelines emphasises human rights and relevant human rights acts. However, in the case of the Liberty Protection Safeguards we raise concern that the code of practice has not been released yet. The Safeguards are scheduled to be implemented by April 2022; how can the NICE guidelines help to assure that social workers will have proper training in these safeguards before they are implemented?	Thank you for your comment. One of the principles in section 1.1 calls for organisations to provide continuous professional development to ensure that social workers have up-to-date relevant legal literacy. This could be the case with the Liberty Protection Safeguards when the code of practice is released.
The Challenging Behaviour Foundation	Guideline	025	009 - 010	We agree that it should be considered for all people who receive social work support that they have a named social worker. All adults with learning disabilities (and their families) must be offered a named social worker. The NICE	Thank you for your comment and for raising the various lived experiences of families and carers. The committee agree on the importance of a named social worker, however, a strong recommendation would have a large resource impact and logistical implications, which is not currently supported by the evidence. Nevertheless, edits have been made to the wording of the recommendation to make it as strong as possible. There was no evidence

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				guidelines should place a stronger emphasis on this, it should not be considered optional. The guidelines should be clearer about what a named social worker means and how this can improve the quality of care for adults with complex care needs. A named social worker who knows the individual and their family well, including the history of their interactions with social care support is important for maintaining good quality of care. The consistency of a named social worker can help build constructive positive relationships between an individual, their family carers and the social worker. Family carers in touch with the CBF tell us that their relative's social worker changes often and this means they must constantly update new professionals rather than having someone that already knows the history of their relative's care. Constantly having to repeat the individuals' care history can often be traumatic to parents particularly if their relative has suffered abuse or poor treatment in the past, these can be triggering memories to have to explain repeatedly. Other families report that they have access to a social work that is "issue based"- I.e. when there is a problem such as hospital admission. This crisis management approach is unhelpful and costly (in human and financial terms). Another family carer reported that her sons LA "moves round" all social workers every 6 months to different geographical "hubs"- which she feels has no	located which met our protocol criteria, for a named social worker for specific groups of adults with complex needs and therefore recommendations have not been made to specify who would benefit the most from a named social worker. The committee agree that the details of a named social worker could range from an assigned social worker, or an assigned team and that this would depend on the resources available. Therefore, together with a lack of evidence on the specific detail of a named social worker, they were unable to provide further clarity in the recommendation. It is described in the 'committee's discussion of the evidence' section in evidence review C that the aim of this recommendation is to ensure continuity of care and highlights the benefits of a named social worker in working towards this. The committee recognised the importance of allowing for enough time for social workers to build relationships with people, and this has already been addressed in the guideline in recommendation 1.1.11. The committee also recognised that differences in opinion can arise between social workers and people. They have recognised that named social workers may change, although possible reasons for this are many and therefore are not highlighted in the recommendation. The committee agreed on recommendation 1.5.11 to facilitate continuity of care in cases of handover, whilst at the same time allowing for flexibility. There is also a recommendation in the guideline (recommendation 1.2.14) on how to approach the complaints procedure, and it is hoped that this recommendation will encourage ongoing review of complaints and lead to improved practice and care for all.

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				benefits, and is detrimental to her son. For individuals with severe learning disabilities, it can be particularly difficult to regularly build new relationships with social workers. It would also be beneficial to social work professionals to have sufficient time to build relationship with individuals and their families as they will be able to provide more effective input. However, there must also be flexibility and room for named social workers to be changed should the family request this, for example, if a family carer issued a complaint about their named social worker, they should still be entitled to having a single named social worker, but that does not mean they have to remain with the same social worker. " I naively thought that the social worker would have in depth learning disability knowledge and experience given that my son has a severe learning disability and complex needs. I had to explain everything to him- eventually I had to make a formal complaint. I hoped his social worker would be someone my son could rely on for knowledge and expertise- that was far from the case. He was eventually removed- I am still waiting for a new social worker...."	
The Challenging Behaviour Foundation	Guideline	040	001 - 012	We support the reference in the guidelines to how following recommendations and providing high quality social care support can prevent individuals reaching crisis and potential admission to hospital. We agree that this is a key outcome of improving the guidelines. For adults with severe learning disabilities whose	Thank you for your comment. Throughout the guideline the committee have recommended a person-centred approach by developing trusting relationships between the social worker and the person (see the principles outlined in section 1.1). Having such an approach that identified needs and risks and how to meet or prevent them from escalating is likely to impact on downstream

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				behaviour challenges there is a risk that lack of appropriate support in the community leads to admission to inpatient mental health settings (Transforming Care data - Challenging Behaviour Foundation). It is essential that social workers are fully aware of this. Furthermore, adults with learning disabilities might have already experienced time in an inpatient setting and still be recovering from the trauma of that or readjusting to life in the community. These are also factors social workers must consider when working with these individuals and their families. The guidelines have highlighted the financial incentive of preventing admission to inpatient settings. The guidelines must also emphasise the profoundly negative impact that hospitalisation can have on adults with severe learning disabilities whose behaviour challenges. It is important that social workers are aware of the abuse and neglect that may occur within learning disability and autism inpatient wards. If the NICE guideline does not include this, social workers may not be fully aware of why it is so important that people with learning disabilities are as much as possible allowed to live in the community and not in hospitals. For further information on these issues see: Tea-smiles-and-empty-promises-family-stories.pdf (challengingbehaviour.org.uk) clearly shows the negative impact of inpatient admissions and Cawston Park Serious Case Review - Challenging Behaviour Foundation. Social workers must understand that many of the challenges faced by adults with severe learning disabilities are likely to become worse after time in an inpatient unit and that they will ultimately require more	costs such as hospital admissions. The committee added a number of cross-references to other relevant NICE guidelines, such as the guideline on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities' and also a number of transition guidelines such as the NICE guidelines on transitions between inpatient hospital settings and community or care home settings for adults with social care needs and the NICE guideline on transition between inpatient mental health settings and community or care home settings. The committee also considered the point about abuse and neglect and added a recommendation highlighting that social workers must follow local safeguarding policies when they have reasonable cause to suspect a person is experiencing or is at risk of abuse or neglect whatever setting they are in. If a need for action is established, the social worker must follow statutory safeguarding processes as set out in the Care Act 2014 (see recommendation 1.2.21).

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				support to resettle back into the community after having spent time in an inpatient unit. Individuals with lived experience of inpatient settings and their families should be actively involved in the development of delivery of training for social workers to ensure professionals understand the potential negative consequences if social care support is not effectively delivered in the community.	
The Disabilities Trust	Guideline	General	General	We recommend that the impact that cognitive impairment may have on the practices of prioritising person centred care and decision making by the person with complex needs, is considered throughout the guidance, as cognitive impairment may affect an individual's ability to seek and accept support, take part in decision-making and carry out day-to-day tasks related to their care. Possible areas of cognitive impairment, for inclusion within the guidelines include: Poor memory Lack of concentration Difficulties with decision making Problems multi-tasking Irritability Impulsivity Fatigue or difficulties sleeping	Thank you for your comment. We have added 'cognitive impairment' to the list in box 1 to emphasise the importance of this in the context of reasonable adjustments. The details of making mental capacity assessments are outside the scope of this guideline because they are the focus of the NICE guideline on decision-making and mental capacity and the Mental Capacity Act to which the guideline cross-refers (which applies whether the impairment or disturbance is permanent or temporary). Recommendation 1.2.23 now includes a cross-reference to recommendation 1.4.19 of the NICE guideline on decision-making and mental capacity which describes the challenges of assessing capacity for people with cognitive impairments.

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				Poor insight	
The Disabilities Trust	Guideline	General	General	The guidelines infer an individual either does or does not have capacity, but it does not take into account possible 'grey areas', wherein an individual may perform well under interviews, formal testing or during structured assessments, while also exhibiting marked limitations in day-to-day function, such as dressing, personal care, preparing meals and attending appointments. This dissociation between performance in formal interview settings and daily functional ability is known as 'frontal lobe paradox', with acknowledgment that it may have devastating consequences for individuals. Whilst individuals may have capacity to make decisions about their own care, they may require support to implement those (e. g. someone may express a wish to engage in substance misuse rehabilitation but fail to engage or comply with the process). Involving someone from the individual's trusted support network may support them to achieve their expressed intentions regarding their own care. At-risk groups who may be particularly susceptible to frontal lobe paradox/cognitive impairment due to a potentially heightened risk of brain injury, include: Survivors of domestic abuse – for instance, The Disabilities Trust found that amongst 100 women at HMP/YOI Drake Hall, 62% reported their brain injury was caused by domestic abuse, which was also the leading cause of injuries (The Disabilities Trust, 2019).	Thank you for your comment. The committee agree that this is important and have added 'cognitive impairment' to the list in box 1 highlight this in relation to reasonable adjustments. The details of mental capacity assessments is outside the scope of this guideline because it is the topic of the NICE guideline on decision-making and mental capacity and the Mental Capacity Act to which the guideline cross-refers (which applies whether the impairment or disturbance is permanent or temporary). Recommendation 1.2.23 now includes a cross-reference to recommendation 1.4.19 of the NICE guideline on decision-making and mental capacity which describes the challenges of assessing capacity for people with cognitive impairments. With regards to the cited studies and reports: The studies by The Disabilities Trust, 2014 and 2019, did not meet inclusion criteria because of the study type/design. Norman (2016) was not included as evidence because it did not focus on the role of the social worker in the context of cognitive impairments. Whilst the committee was conscious of such impairments, the assessment of mental capacity is legislated by the Mental Capacity Act and also the focus of the NICE guideline on decision-making and mental capacity rather than the social work guideline.

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				Homeless – in 2014 study amongst homeless participants in Leeds, The Disabilities Trust found 48% reported a history of traumatic brain injury (TBI) (The Disabilities Trust, 2014) Prison leavers – research by The Disabilities Trust found nearly half of men (47%) at HMP Leeds and nearly two-thirds of women (64%) at HMP/YOU Drake Hall reported a history indicative of brain injury. Those with complex needs, but without a next of kin may also be at increased risk, as it may be more difficult for social workers to identify possible discrepancies in their account. By acknowledging the possible role of cognitive impairment amongst these at-risk groups, the guidelines will highlight to social workers areas of complexity with regards to capacity assessments. The guidelines should provide a few brief scenarios to assist readers in identifying how such difficulties may display in practice, and what might be done to support individuals. We refer the panel to the paper by Norman (2016) which illustrates the impact of cognitive factors on the presumption of capacity and on safeguarding.	
The Disabilities Trust	Guideline	General	General	Throughout the guidelines there are a great many roles and responsibilities assigned to social workers. We are concerned that this level of expectation may put additional strain on social workers. We suggest that the guidelines make explicit recommendations for seeking support from other professionals, such as neuropsychologists to ensure that both the individual and the social worker understand the person's needs	Thank you for your comment. There are many recommendations in the guideline that highlight organisational support for social workers (see for example recommendations 1.1.11 to 1.1.15). These are meant to alleviate the strain on social workers. With regard to input from other professionals, we have added bullet point 3 into the assessment section that social workers should identify whether there are any unmet

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				and how these can be supported during the assessment processes and once care is put into place. For example, the guidelines recommend social workers' involvement in family therapy, but it later acknowledges (page 51, line 1) the lack of evidence supporting the efficacy of family therapies carried out by social workers. As such, it is recommended that the guidelines encourage consultation and reliance on professionals from other fields (i. e. psychologists specialising in family therapy) to alleviate the workload for social workers and utilise professional expertise available in the wider health and social care systems.	needs that may relate to a condition or difficulty that may need input from specialist services, for example from speech and language therapists or psychiatrists (see recommendation 1.2.11).
The Disabilities Trust	Guideline	General	General	Throughout the guidelines, 'wellbeing' is referenced, however, a definition is not offered as to what this entails. "Wellbeing" can encompass a multitude of factors, from physical health, financial stability, emotional health to healthy relationships (and many more) and as there is no consensus for a single definition of wellbeing, we recommend that the panel agrees on an operational definition of wellbeing, which provides clear indication of how it can be measured, to be used throughout.	Thank you for your comment. We have referred to regulation 1(2) of the Care Act 2014 for the definition of wellbeing and have added this to the 'terms used in the guideline'. This is then hyperlinked in the recommendation to clarify what is meant by this term in the context of this guideline.
The Disabilities Trust	Guideline	005	004	When identifying and supporting communication needs, the further recommended guidance on line 4 (1.1.15 of the 'NICE guideline on people's experience in adult social care services: improving the experience of care and support for people using adult social care') does not mention how social workers might implement this. It is therefore recommended that the guidance explicitly suggests that Social Workers seek professional support, including from Speech and Language Therapists (SaLTs) as an option for identifying and supporting	Thank you for your comment. The committee agreed that it is important that social workers recognise when input from other specialist services are needed. However, they decided that this was not restricted to communication alone. They have revised the assessment section to include a reference to a need for input from other specialist services which specifically gives as examples speech and language services or mental health services (see bullet point 4 of recommendation 1.2.11).

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				adults with complex needs to communicate.	
The Disabilities Trust	Guideline	005	026	Whilst 1.1.4 acknowledges a number of factors which may impact an individual's involvement in discussions and decision-making, it does not take into account cognitive impairment. Possible types of cognitive impairment which could influence the support people need to engage in discussion and decision-making fully and actively, include (but are not limited to): Poor memory Lack of concentration Impulsivity Emotional dysregulation Difficulties with initiation Problems multi-tasking Lack of self-awareness or insight, also known as the frontal lobe paradox (George & Gilbert, 2018), wherein an individual may not be aware of their symptoms and the extent to which these affect them Social workers' awareness of the possibility of cognitive impairment will enable them to better identify the support individuals may need to take part in these conversations, including a potential referral to a clinical neuropsychologist for complex capacity assessments, or	Thank you for your comment. Recommendation 1.1.4 was made to address various matters that were identified in the evidence, for example that cultural differences can create challenges for practitioners, and that differences in cultural perspectives can lead to care needs not being met. The evidence also highlighted the importance of family support, as well as the impact of past experiences and expectations (see the rationale and impact section related to this section). Addressing inequalities for groups that may face discrimination by making reasonable adjustments is covered in recommendation 1.1.8 and we have now added 'cognitive impairment' to box 1 outlining characteristics, life circumstances or life experiences relating to inequalities to ensure that cognitive impairment is considered by social workers.

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				cross-referencing individual's self-report with family members' or carers' perspective to account for lack of insight.	
The Disabilities Trust	Guideline	007		**Box 1** We suggest that the term "cognitive impairment" is added to the list in Box 1 to ensure social workers are aware of, and make adjustments, for the possible impact of memory loss, language difficulties, problems regulating attention, impulsivity and lack of insight / frontal lobe paradox.	Thank you for your comment. We have added 'cognitive impairment' to the list in Box 1 as suggested.
The Disabilities Trust	Guideline	012	013	Section 1.2.6 introduces options for individuals who have 'decision-making capacity', however, the guidance does not provide an explanation as to what decision-making capacity should look like and how this can be assessed. This is a concern, as some individuals with frontal lobe damage may appear able and even perform well in interviews, formal neuropsychological testing and during one-to-one assessments, despite experiencing marked difficulties in their day-to-day life (George & Gilbert, 2018). Individuals with this condition, known as 'frontal lobe paradox', may request a self-assessment and appear competent during the assessment process, but struggle to complete day-to-day tasks. This does not necessarily mean the individual lacks decision-making capacity, but they may require additional support to carry out their preferred care on a day-to-day basis. Whilst the guidelines imply there either is or is not decision-making capacity, neuropsychological evidence on how people with frontal lobe damage function reveals that there may be uncertainty (e. g. fluctuating capacity,	Thank you for your comment. The focus of this section is on approaches to needs assessment' of which assessment of decision-making capacity features only partly because the details of this are the focus of the NICE guideline on decision-making and mental capacity as well as in the Mental Capacity Act to which the guideline cross-refers (which applies whether the impairment or disturbance is permanent or temporary). The NICE decision-making and mental capacity guideline also includes a recommendation related to executive dysfunction and the challenges associated with this so a cross reference was added to this specific recommendation. Furthermore, acquired brain injury was added to box 1 as a life circumstance and experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered. The committee agreed that not all complex needs can be addressed by the social worker and have therefore added to a recommendation that the social worker should identify unmet needs that may relate to a condition or difficulty that may need input from other specialist services, for example from speech and language services or mental health services (see

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				capacity dependent on support and when day-to-day decisions are made). We therefore recommend that the potential for 'grey areas' associated with the frontal lobe paradox, is specifically mentioned in the guideline to ensure social workers are aware and seek professional support as and when appropriate. It is important to note that while frontal lobe damage, and the frontal lobe paradox, have been primarily described for people with acquired brain injury, or certain forms of neurodegenerative condition (e. g. frontotemporal dementia), these difficulties can be present whenever there is damage to the frontal lobes, and associated neural networks. Therefore, assessors should look out for the functional symptoms and signs of these difficulties rather than solely rely on medical diagnosis or functional imaging. With consent, it is important to gather collateral information from family or people that know the individual well. Furthermore, if there is still concern, professional advice should be sought from a neuropsychologist	recommendation 1.2.11 in the needs assessment section). Brain damage to the frontal lobe is likely to be one of these conditions where other specialist input is needed not only related to decision-making capacity but also to other needs that may result from having such a condition.
The Disabilities Trust	Guideline	012	013	The guidelines do not provide information on how individuals can be supported to have decision-making capacity. The guidance should reiterate the four steps to establish capacity: The person must be able to understand the information Retain this information long enough to be able to make the decision	Thank you for your comment. The focus of this section is on approaches to needs assessment' of which assessment of decision-making capacity features only partly because the details of this are the focus of the NICE guideline on decision-making and mental capacity as well as in the Mental Capacity Act to which the guideline cross-refers (which applies whether the impairment or disturbance is permanent or temporary). This includes details on all steps associated with the assessment of decision-making and mental capacity.

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				Weigh-up the information available to make the decision Communicate the decisions Whilst going through these steps, social workers should consider how these could be affected by cognitive impairment / frontal paradox, how people could be supported, while also recommending that social workers seek professional support in more complex cases (i.e. where there is uncertainty as to whether the person has capacity).	The NICE guideline on decision-making and mental capacity guideline also includes a recommendation related to executive dysfunction and the challenges associated with this so a cross reference was added to this specific recommendation. Furthermore, cognitive impairment was added to box 1 as a life circumstance and experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered. The committee agreed that not all complex needs can be addressed by the social worker and have therefore added to a recommendation that the social worker should identify unmet needs that may relate to a condition or difficulty that may need input from other specialist services, for example from speech and language services or mental health services (see recommendation 1.2.11 in the needs assessment section). Brain damage to the frontal lobe is likely to be one of these conditions where other specialist input is needed not only related to decision-making capacity but also to other needs that may result from having such a condition.
The Disabilities Trust	Guideline	016	General	On the sections 1.2.21 through to 1.2.32 the guidance mentions "mental capacity", however, has not provided further information as to what a lack of capacity would look like. Whilst capacity is discussed in greater detail on page 44, under the section 'why the committee made the recommendations' (line 17), this should also be mentioned earlier on the guidance, including: how capacity can be assessed, what some of the difficulties may be in assessing capacity, including frontal lobe paradox	Thank you for your comment. Cross references to the NICE guideline on decision-making and mental capacity and the Mental Capacity Act (which applies whether the impairment or disturbance is permanent or temporary) were already included in the consultation version of the guideline. This covers the assessment of mental capacity in detail. It is therefore not the focus of the current guideline. The committee agreed that there were particular challenges in the assessment of mental capacity for people with cognitive impairment and have therefore directly highlighted a specific recommendation

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				illustrative scenarios to assist social workers in supporting individuals who may have capacity to make decisions, but due to cognitive impairments may struggle to carry these out on a day-to-day basis.	in the NICE guideline on decision-making and mental capacity that refers to this matter.
The Disabilities Trust	Guideline	017		**1.2.28** We acknowledge the relevance of the statement "social workers should respect people's rights to make decisions that the practitioner perceives as risky or unwise…". However, the guidance does not provide examples of what this could include. Including some examples of these situations would enable social workers to identify what decisions could be perceived as risky or unwise, otherwise this remains subjective and could differ depending on the reader's views and experiences.	Thank you for your comment. The committee discussed this but were unable to provide examples because 'unwise decisions' are not generalisable. They depend on the person's individual circumstances.
The Disabilities Trust	Guideline	040	006	On this section ('How the recommendations might affect practice'), the recommendation "for a preparatory initial contact" provides contradictory information by stating there may be "an increase in the number of contacts, with both a potential resource impact" and yet, within the same section, also acknowledging this "would not be routinely done". This may be confusing for the reader, as on page 44 (line 1) the guidelines go on to reinforce the need for "several contacts so that the person's context and environment is fully understood" and a rapport can be built. We recommend that the wording on this section is revised to provide clear and consistent guidance for social workers by changing the original recommendation to offering a preparatory initial contact to the individual and at least one other party as a routine, even though this may not always occur, as the parties may decline this contact.	Thank you for your comment. This section was confusing and contradictory as stated and has been revised for clarity. However, the recommendation relating to a preparatory initial contact was based on little evidence and having a preparatory initial contact with everyone would be a change to current practice. This could have a resource impact if implemented as a mandatory requirement so the committee could not recommend this strongly because the evidence was not robust enough to justify this.

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The Disabilities Trust	Guideline	059	001	While the guidelines refer to working within multidisciplinary teams (MDT), there is no specific definition of what the composition of the MDT should be. Does an MDT include education specialists, neuropsychologists, occupational therapists or Speech and Language Therapists (SaLTs)? The composition of the MDT team will have an impact on the scope and extent of professional support and supervision accessible to social workers. In the absence of representation of specific areas within the MDT, the guidelines could encourage social workers to seek "ad hoc" support from relevant professionals.	Thank you for your comment. Configuration of services including the constituency of multidisciplinary teams were topics that were outside the scope of this guideline. The committee could therefore not comment on this. However, the committee added to the needs assessment section that the social worker should identify when input from other specialist services may be needed and speech and language and mental health services were given as examples (see recommendation 1.2.11).
The Down's Syndrome Association	Guideline	004	010	We would generally agree with all of the 'Principles of social for adults with complex needs', however, it is our experience that the workforce within adult social work is often transient and staff move on (either through internal reorganisation, career progression or by leaving the profession). This results in the experience of many of the adults who access support being different from these well-intentioned guiding principles. In many instances, individuals and their families do not have the opportunity to develop a relationship with their social worker and build trust. These relationships take time to nurture and frequent allocation of a new social care professional does not allow for this. The current difficulties in recruiting and retaining staff across the social care sector has made these difficulties even more pressing.	Thank you for your comment. The committee discussed that there are workforce challenges but thought that the 'Principles of social work for adults with complex needs' would apply whether or not there is continuity of the same named social worker supporting the adult with complex needs (for example treating people with dignity and respect 1.1.1, helping the person to be actively involved 1.1.4 and active listening 1.1.5). It was recognised that this would take time and therefore the committee recommended that there is organisational support by making time allowances for social workers in caseloads (see recommendation 1.1.11). They recognised that the continuity of a named social worker is preferable and recommended this in 1.5.10. They also recommended that organisations have processes for 'a clear handover if the social worker has to change' to make sure that there is continuity which would aid building a relationship with a new social worker (see recommendation 1.5.11). It is hoped that these principles would improve the work of the social worker

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					as well as the outcomes for the person with complex needs.
The Down's Syndrome Association	Guideline	005	001	The extended periods of lockdown and news ways of working have not always helped individuals' experience of social work. Virtual working may be seen as more efficient and a necessary step to keep people safe during the early part of the pandemic, before vaccinations were possible, but virtual or telephone contact does not easily suit the majority of people who have complex needs and it is our experience that many services have been very slow in returning to face to face meetings. Many areas seem only able to offer online meetings. It should be noted that there is a significant digital exclusion issue, with many individuals through either age, disability or poverty being unable to get on line.	Thank you for your comment. The committee discussed this but did not reach consensus on a preference for recommending either remote (virtual or phone) or in-person assessment or meetings as a particular standard approach. It was agreed that this would depend on many factors and ought to be guided by the preference and the safety of the person with complex needs. They have therefore revised recommendation 1.2.6 and added a bullet about preference for remote or in-person assessment. They also added a recommendation emphasising that if there were to be potential safeguarding concerns then an in-person assessment may need to be conducted regardless of preference.
The Down's Syndrome Association	Guideline	005	017	This information needs to be localised, as there seems to be significant regional variances in the way in which services are organised (and in many cases) eligibility criteria. Individuals need to have a clear picture of their local offer.	Thank you for your comment. Recommendation 1.1.3 focuses on the social worker making the person familiar with the processes and activities that the person will get involved in. This is based on evidence from several evidence reviews where people described that they did not know what was going to happen or what the aims and key processes are and how they may change. This was making them anxious and stressed. The committee therefore addressed this specifically with this recommendation. The committee agreed that this information may be different depending on where the service is based. However, they decided that the principles of making sure that the person is sufficiently informed about what they are involved in would remain the same. They have therefore not changed the wording.

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The Down's Syndrome Association	Guideline	005	027	We would fully endorse the protocols of "Tell Us Once", where relevant information told to one professional or local authority officer is recorded and shared amongst others who have a need to know this information. Telling personal stories, giving an account of past experiences and outlining support needs, medical histories etc. can be distressing and exhausting for many people. It is often a cause of frustration that individuals need to retell their story multiple times in the course of an assessment in the progression for a request for support.	Thank you for this comment in support of the guideline.
The Down's Syndrome Association	Guideline	006	018	We would particularly draw attention to the issue of health inequalities experienced by people who have a learning disability. The LeDeR programme https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/ highlights that men and women who have a learning disability die between 20 and 25 years younger than those without a learning disability. It is hoped that these inequalities will be addressed, in part, by the upcoming Oliver McGowan mandatory learning disability awareness training for health and care staff. https://www.bild.org.uk/oliver-mcgowan-mandatory-training-trial/ We would record that this training does not cover the specific health profiles of adults who have Down's syndrome and there would still be a need for more specialised training for relevant staff.	Thank you for your comment. The committee recognised that people with learning disabilities face inequalities and therefore mentioned them specifically in Box 1 and in the Equality Impact Assessment form. Recommendation 1.1.8 emphasises this point stating that social workers must consider whether reasonable adjustments can be made to protect against or help the person deal with discrimination arising from being in any of the groups in Box 1. To make this recommendation stronger the committee have added that social workers should 'record the rationale for the decision made'. This will mean that they have to actively consider and reflect on their decision-making so that they are aimed to reduce inequalities. It was decided not to refer directly to the Oliver McGowan learning disability awareness training since it is 'upcoming' and not yet been fully rolled out. However, the committee discussed that any social work training / education would include some aspect of approaches to working with people with learning disabilities.
The Down's Syndrome Association	Guideline	008	008	We would cite widespread and longstanding issues of recruitment within the social care sector (exasperated by the COVID pandemic). Many services are operating with	Thank you for your comment. The committee agreed that there are recruitment and workforce shortages in the social care sector. There was evidence that social

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				longstanding staff shortages and are many are heavily reliant on agency staff to fulfil essential staffing roles. This aim is laudable, but in many cases impractical.	workers commonly reported not having sufficient time to build relationships and that this had negative impact on them as well as the person with complex needs. The resulting recommendation highlights that organisations should consider making time allowances with the aim to support social workers in their role. The wording is intentionally focusing on organisation to 'consider' this because the committee recognised that giving additional time to everyone would not be possible due to resource constraints.
The Down's Syndrome Association	Guideline	009	001	We would hope that relevant staff would have an early opportunity to access the Oliver McGowan Learning Disability Awareness Training https://www.bild.org.uk/oliver-mcgowan-mandatory-training-trial/	Thank you for your comment. The committee were unable to add a reference to this since it is not yet implemented.
The Down's Syndrome Association	Guideline	009	009	It is our experience, through calls to our helpline, that many social care professionals need greater levels of training the Mental Capacity Act. Frequently families have been given misinformation from professionals who seem confused about the implications of this Act.	Thank you for your comment. The committee captured this in recommendation 1.1.13 which notes that organisations should provide continuous professional development to ensure that social workers have up-to-date relevant legal literacy and sufficient knowledge of the Mental Capacity Act as well as of other relevant legislation. This ensures that it is not only covered once during training but is regularly refreshed.
The Down's Syndrome Association	Guideline	011	002	We would include here information about Carers Annual Health Checks – awareness of these is variable and generally very low.	Thank you for your comment. The committee were unable to comment on a Carers' Annual Health Check since this is not a mandatory or legal requirement in NHS services. It was also outside the scope of this guideline since it is not a social work approach but rather a health service approach to working with adults with complex needs and their families. Recommending this without robust evidence was not possible due to resource implications associated with this.

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The Down's Syndrome Association	Guideline	011	017	Location of an assessment interview and time of day could all be subject to a "reasonable adjustment" and make this process much more meaningful for an individual who has a learning disability. We would again cite the difficulties many people have experienced over the last 18 months of the majority of interactions and meetings being online – this does not suit many people.	Thank you for your comment. Preferences for practical arrangements for the assessment including time and place are covered in recommendation 1.2.6. The bullet list is not exhaustive and other preferences than those listed as examples can be considered where appropriate. Preferences for 'remote or in-person' assessment is now highlighted as a separate bullet point so that either a virtual, phone or in-person meeting could be planned. Whilst online meetings do not suit all people the committee discussed advantages for some people and there was no consensus about recommending one over the other. It was decided to base these decisions on preference where possible unless there is a safeguarding concern where an in-person assessment is likely to be needed (which has been added to the guideline - see recommendation 1.2.7).
The Down's Syndrome Association	Guideline	013	006	Individuals should have an opportunity to challenge or correct information, which is held about them which they feel is inaccurate. At the very least, a note should be recorded in relation to any information, which is contested by the individual.	Thank you for your comment. The opportunity for people to be able to challenge or correct information is already recommended (see recommendation 1.2.12).
The Down's Syndrome Association	Guideline	014	013	Where an adult remains living in the family-home (with parents or siblings), due regard should be given to risks perceived by family-carers, especially in relation to their resilience to cope with any unpaid caring roles.	Thank you for your comment. Recommendation 1.2.22 covers all aspects of risks including risks to the person, risks from others, risks of harm to others as well as risk of loss of independence. One of the principles in section 1.1 is to find out the person's wishes or needs for family support and therefore the family or carers may be involved in the risk assessment where appropriate.
The Down's Syndrome Association	Guideline	015	005	This aspect of risk assessment is crucial. It is often our experience that, sadly, individuals often need to reach a point of crisis before interventions or support are provided. The urgency of a situation often becomes a key to getting support provided. The principles of	Thank you for your comment. The committee agreed that the principle of prevention is important. This also relates to supporting people to plan for the future with the aim to discuss and implement a care plan that would prevent an escalation of need (see section 1.5). Taking

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				prevention and promotion of of individual's wellbeing should have a higher prominence.	a person-centred approach to planning would not only help prevent crises but would also promote wellbeing.
The Down's Syndrome Association	Guideline	020	019	We would highlight here the difference between “important to” and “important for” involved in person centred planning approaches (see http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/sorting-important-tofor/ for more information).	Thank you for your comment. This recommendation was based on evidence for interventions related to individual or family casework (which could be broadly classified as task-focused) as well as qualitative evidence that highlighted the benefits of goal setting. The committee therefore focused on the person's goals and desired outcomes. These could be important to or important for the person. There was no evidence that was identified for the particular approach highlighted in the hyperlinked resource therefore the committee decided that they were unable to comment on this.
The Down's Syndrome Association	Guideline	019	021	In addition, access to advice should be extended to other organisations supporting individuals, including the third sector, who often provide advocacy to individuals and their families and during the course of this work, identify a safeguarding concern.	Thank you for your comment. This recommendation was focused on the social worker's need for advice from organisations whenever they are working in relation to immediate concerns about risks. This was based on evidence showing that this was particularly valued by social workers. The term organisations refer to bodies that employ social workers in a professional capacity. This can include local authority social care departments, health services, the criminal justice system, higher and further education and voluntary and community services (see box 2). A new recommendation has been added highlighting what to do when there are safeguarding concerns (recommendation 1.2.21) to draw attention to the requirement that processes laid out in the Care Act 2014 would need to be followed.
The Down's Syndrome Association	Guideline	021	015	The principles of Circles of Support could be a useful and sustainable complimentary approach here https://www.mentalhealth.org.uk/sites/default/files/a-guide-to-circles-of-support.pdf	Thank you for your comment. The committee agreed that this particular intervention was an interesting one and highlighted it as an example of an intervention in the protocol, unfortunately evidence specific to this intervention and relevant to the protocol was not located

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					and therefore the committee decided not to comment on this. There are many approaches that were highlighted when the protocol was drafted which are relevant for different needs and preferences, but it would be difficult to pick out any specific one to mention in the recommendation since little evidence was identified for this topic. The committee agree that the recommendations to talk to people about social networks and preferences for social contact would cover similar sentiments to those in approaches such as Circle of Support. This did feature in the discussion when recommendations were drawn up so Circle of Support has now been included as an example of a useful support system for some groups of people in the committee's discussion of the evidence section in evidence review G.
The Down's Syndrome Association	Guideline	023	008	This should include information about Carers Annual Health and access to welfare benefits advice.	Thank you for your comment. The committee discussed that the Carers Annual Health check is not a mandatory requirement for NHS services and introducing it would therefore have significant resource implications. This recommendation therefore signposts carers to the most relevant and up to date NICE guidance for them.
The Down's Syndrome Association	Guideline	024	003	This is often a major flaw in the system, where there is no reasonable regard given to anticipatory needs – the fact that support needs are likely to increase e.g. following a diagnosis of dementia, where the condition is progressive. Individuals tend to always be "catching up". By the time, an increased level of support has been agreed the person has progressed to requiring a still higher level of support.	Thank you for your comment. The committee agree that it is important to address ongoing changes in need, and that changes happen even between the time of assessing and then agreeing the appropriate support. This has already been addressed with recommendation 1.5.5, specifically the second bullet. The committee agree that the way to address ongoing changes of need is to ensure that the care plan is revised and reviewed in response to rapid changes and that such plans should be flexible and responsive. They agreed that this recommendation would capture various situations,

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					including the issue raised in the comment, which involve evolving needs and changes to the level of support required. To address this, further detail has been added to the 'Committee's discussion of the evidence' section of evidence review C.
The Down's Syndrome Association	Guideline	024	027	Sometimes the review period seems set and services are reluctant or unwilling to review provision.	Thank you for your comment. This recommendation was made with the intention to address such concerns by aiming for a more personalised approach to care planning and review, with a more flexible review period that is dependent on an individual's fluctuating and changing needs. The committee agreed that this recommendation would standardise practice in line with the statutory guidance 13.13 of the Care Act so that all people would get a review at least one a year.
The Down's Syndrome Association	Guideline	025	009	We fully endorse this proposal and feel this should be given a high level of priority. This would aid communication and accountability and go some way to developing better working relationships between key professionals and service users.	Thank you for this comment in support of the guideline.
The Down's Syndrome Association	Guideline	025	014	We note that it is our experience that continuity is a rarity.	Thank you for this comment. The committee's aim was to improve this.
The Down's Syndrome Association	Guideline	026	005	This should include possibility of referral from another organisation e.g. a third sector organisation supporting the individual.	Thank you for your comment. The recommendation has been amended to include 'community organisations' of which the voluntary sector is included under the definitions of organisation in box 2.
The Down's Syndrome Association	Guideline	027	016	It is our experience that often professionals working within health who have NHS email address have difficulty sharing reports with colleagues who do not have an NHS email. In some cases this reverts to officers having to print our and post the report, due to their inability of sharing this electronically.	Thank you for your comment. The committee agreed that systems are not always compatible but they wanted to emphasise that in principle sharing of information can be helpful. It is outside the scope of the guideline to make recommendations on the details of the electronic systems that may facilitate this.

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The Down's Syndrome Association	Guideline	028	011	We would cite the soon to be launched Oliver McGowan Mandatory Learning Disability awareness Training, which is built upon the model of coproduction.	Thank you for your comment. The content of the training of social workers is outside the scope of the guideline because it is the remit of other organisations such as Social Work England. A reference to the Oliver McGowan Mandatory Learning Disability awareness Training could not be added because this material has not been launched yet.
The Down's Syndrome Association	Guideline	029	001	We would endorse this. There have been various model of key working (as pilots) trialled around the country and within various populations e.g. The Early Support key working model for disabled children. These are always highly rated by families, but usually end when the pilot finishes.	Thank you for this comment in support of this guideline.
The Down's Syndrome Association	Guideline	029	004	The current arrangements around home working, which seem likely to continue well beyond lockdown, seem to stand in the way of this aim.	Thank you for your comment. Whilst co-locating can be a challenge it was discussed that some services have experienced that home working has improved multidisciplinary working by using virtual means of meeting team members in different roles (which is a form of 'virtual' co-location).
The Down's Syndrome Association	Guideline	029	007	We would particularly support the development of shared budgets.	Thank you for this comment in support of this guideline.
The UK Multiple Sclerosis Specialist Nurses Association (UKMSSNA)	Guideline	General	General	The UKMSSNA feels that the guidance has considered all key areas that factor in social work interventions with adults with complex case needs. We are in agreeance with the suggested courses of action in all parts of the guidance. Our only comment is 1.7.4 we agree with this section but feel that there is not enough emphasis on the social workers knowledge of how a condition/illness can affect an individual and can cause the complexity of an individual's needs. It is agreed that working as a Multiple Disciplinary Team (MDT) to work through the complexities of an individual case can be extremely	Thank you for your comment. One of the principles in section 1.1 highlights that organisations, commissioners, and social workers should recognise that people with complex needs may experience the impact of intersectionality, resulting in increased inequalities in access to and outcomes of health and social care (see recommendation 1.1.14). The committee decided that this should be in the context of every social work interaction with the person not only restricted to multidisciplinary team working and that is why it is in the general principles section. The committee agreed that

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				useful and this integration can promote shared vision and improve outcomes. We also agree that it is the actions of individual members of the MDT, the communication between this group and the knowledge of each other's role within the individuals care that ultimately leads to the effectiveness of the care outcome measures. Consistent feedback from each member of the group post assessment or intervention and the shared plans of care that lead to its success. The easier access of MDT meetings has improved greatly since the Covid pandemic due to virtual meetings being accessible to all members of the care team and has allowed colleagues to 'drop in' where their diary commitments would have previously prohibited attendance. We would like to propose that the success of the MDT and social worker to assess manage and support an adult with complex needs could be taken one step further if the social worker is given training and support from their employer or specialise in an area in which a disease could increase the complexity of the case. For example, specialising in Neurological conditions, mental health or learning disabilities. There are case studies (can be provided if required) of how a social worker with expert knowledge of how Multiple Sclerosis affected the adult in terms of cognitively, executive functioning level, emotionally and physically can have a positive impact and address the persons needs more effectively and lead to improved patient outcomes. The UKMSSNA wants to stress that having knowledge of a disease or diseases is different to having knowledge of the profound effect it can have on a person and how it can	the awareness of this could be helpful in a multidisciplinary setting. That some of the recommendations could be implemented using virtual meetings such as case discussions to get input from other members of the team is highlighted in the related impact section. Interdisciplinary training to promote shared understanding of each role in the team is something that was recommended based on evidence that the roles were sometimes not readily understood by everyone (see recommendation 1.7.4). However, issues around the training of social workers was outside the scope of the guideline since this is the responsibility of other bodies such as Social Work England. Therefore a search for evidence was not conducted and the committee were unable to comment on whether social workers should receive specialist training on health or neurological conditions. The committee agreed that health training would be a change in practice and would have cost implications and without a search for evidence they would not be able to justify this. In their discussion related to this the committee decided that there is a need to mention in the guideline that in assessments social workers need to identify needs that may require input from other specialist services, for example speech and language or mental health services. They have therefore added this to the needs assessment section (see recommendation 1.2.11).

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				make the nature of the case more complex from a Biopsychosocial point of view. If a social worker was to be given training in their area of specialist interest or was to part of a team (for example a neurology team) it is thought that this would have a positive effect on the management of the adult with complex needs. We acknowledge that this would have initial cost implications, but this method of care has been shown to have a positive impact on the individual and the team.	
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	001	008	Transition processes for people aged 16 to 18 with complex needs is variable. How would competence be ensured for them to partake in adult processes?	Thank you for your comment. The guideline focuses on 'adults with complex needs' but as stated at the beginning it may also be relevant for people aged 16 to 18 with complex needs who have completed the transition from children to adult services. The committee agreed that the details of the transition from children's to adults' services for young people using health or social care services is covered in depth in the related NICE guideline and have now included a cross reference to this. Competence of 16 to 18 year olds falls under the jurisdiction of the Mental Capacity Act and once a person reaches the age of 16, they are presumed in law to be competent. Therefore the recommendations related to capacity in the guideline also apply to this age group. Throughout the guideline an individualised supportive approach is recommended based on the wishes, preferences and needs of the person. This would also apply to the age group of 16 to 18 year olds.
UK Psychosocial Professionals in Cystic	Guideline	007	003	Life circumstance and experiences are different from intrinsic needs such as long term conditions, autism, learning disability, sensory impairments etc. Would you consider a 3rd category of additional needs/differently abled.	Thank you for your comment. The committee discussed a suggested third category but it was very difficult to create a new category without creating overlaps. So they decided to keep the original wording to capture the

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Fibrosis (UKPPCF)					broad range of equality groups that a social worker may come across.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	008	009	Time allowance is well known but how have teams implemented this? Is there guidance either from social work or psychology or IAPT services to show recommendation for extended time in social workers caseloads? For eg …. Consecutive sessions over ….months for relationship building and detailed assessment.	Thank you for your comment. There was evidence that social workers commonly reported not having sufficient time to build relationships and that this had negative impact on them as well as the person with complex needs. The resulting recommendation highlights that organisations should consider making time allowances with the aim of supporting social workers in their role. There was no evidence identified in relation to IAPT services or for frequencies of sessions. Therefore the committee decided that they could not comment on this.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	017	011	For unwise decisions SW should take additional support of multidisciplinary colleagues assessment.	Thank you for your comment. It was added that the perspectives of family members and multidisciplinary team members should be taken into account if a person makes a decision that is likely to put them at significant risk (see recommendation 1.2.25). The committee decided that this would be a better place to add this than in relation to unwise decisions which may not always need input from the whole multidisciplinary team.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	025	021	Could there be a list of unplanned escalation of needs? How is escalation understood?	Thank you for your comment. Escalations of needs can only be observed in the context of each individual person's circumstances and experiences. The committee was therefore unable to summarise these in a list. They agreed that a general list would potentially be detrimental to person-centred approaches. There was also no evidence related to lists or the benefits of them in this context.
UK Psychosocial Professionals in Cystic	Guideline	026	016	'advance statement' of their wishes or crisis planning could be confused to advanced directive in case of end of life. Can another term be used?	Thank you for highlighting this. The committee accepted your point but they wanted to keep this wording intentionally broad (a statement can be written or verbal rather than an advance directive which is a formal document) so they ensured there is a clear description in

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Fibrosis (UKPPCF)					the rationale section, which explains that these terms are not to be confused.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	027	026	SW work in various types of organisations. Often specislist social workers could be as lone workers in multidisciplinary teams. To Debrief shortly after a crises is difficult for lone workers. What are the recommendations where immediate debrief is not possible?	Thank you for your comment. Regardless of whether or not the social worker is the only one with this role in the multidisciplinary team, there would always be a reporting / supervision structure in place in all work places. The committee wanted to ensure that the social worker is supported. The committee used the words 'prompt' to emphasise that it is important to do this as soon as possible and it is aimed to remedy situations where lone workers may not get the opportunity to currently be debriefed or to be debriefed after long delays. The committee did not want to make another recommendation about situations where it may not be possible to have this because this would weaken what they were trying to achieve.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	042	015 - 016	Variability across the country due to resource variability impacts outcomes. Can there be a link between resource and recommendation and a progressive recommendation in places where there is lack of resources.	Thank you for your comment. This section describes how recommendations may change practice. It was highlighted that a preparatory initial contact is not current practice everywhere. Whilst the committee agreed that this may be due to resource variability, recommendations are made to reduce such variability and improve inequalities in access to services. It would be difficult to make progressive recommendations every time there is a lack of resources because the evidence in many cases was not robust enough to justify this.
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	061	008	There are specialist NHS commissioned services for people with long term specialist conditions such as cystic fibrosis. The recommendation is for so integrated teams, with social workers embedded within the multidisciplinary team. There are several hospitals that have successfully operated this model. The ones who are not able to look at colocation are often because the	Thank you for your comment. There are many logistic or financial reasons why co-location my not always be possible. The committee have therefore not made a strong recommendation to routinely do this but have asked organisations to think about this as an option. The reason for this is described in this section of the guideline.

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				role of the social worker is not clarified or the supervisory structure is not clarified.	
UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF)	Guideline	061	027	The context clarifies the remit well, could be at the beginning of the document.	Thank you for this comment. We have moved the context section to the beginning of the document, as suggested.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	General	General	The interface with Continuing Care Criteria could be made more explicit. The framing of this guidance is at a very prescriptive, micro level – this is very helpful for newly qualified workers but should perhaps have a more discretionary tone for experienced practitioners. There is a risk with such detailed guidance that it will be followed mechanistically, hit the target, but missing the point. Crucial in this process is the ability to build a relationship, so that the person who uses services and their carer feel confident to share their views and concerns. It would be beneficial in the introduction to say about the purpose of the assessment, for example, following the WHO's International Classification of Functioning's approach of identifying and exploring how contextual personal and environmental factors interface with impairment and illness to shape outcomes for the individual.	Thank you for your comment. The guideline focuses on social work interventions and provides recommendations based on evidence reviews that cover areas where practice varies and legal requirements are not always being met. The continuing care criteria relates to the need for a full assessment of eligibility for NHS Continuing Healthcare. This is not the same as a social work needs assessment in relation to the Care Act 2014 and falls outside the scope of the guideline. Matters such as relationship building with the person and their family are covered in section 1.1 which also highlights matters such as active listening and treating people with dignity and respect. This promotes a person-centred approach that takes into account the person in a holistic way that identifies their needs, which could include environmental factors where relevant. The introduction now includes a section on how the guideline relates to legal duties, standards and other guidance. However, the committee have not referred to the WHO International Classification of Functioning approach since this was not identified in the evidence related to assessment of needs.
United Kingdom Acquired Brain	Guideline	005	018	1.1.4 could be expanded to explicitly include the person's expectations and emotional state.	Thank you for your comment. We have added 'the person's expectations and emotional state' to the recommendation as suggested.

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Injury Forum/UKABIF Brain Injury Social Work Group /BISWG					
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	007	002	Box 1 Marriage and civil partnership missed of the list of protected characteristics? The list of life circumstances and experiences should be qualified to say it includes (currently reads as definitive). It is currently a curious mix of factors that are life circumstances and significant life events. Perhaps separate into two lists? Either add Acquired Brain Injury to this list or use the term Neuro-diversity.	Thank you for your comment. The protected characteristic 'marriage and civil partnership' was missed out in error and has been added. We have also added 'including' to the heading as suggested to emphasise that this is not an exhaustive list. The committee intentionally made this a mix of life circumstances and experiences to highlight the range of groups that a social worker may come across. The term 'acquired brain injury' was added to box 1 as suggested so that social workers consider how to make reasonable adjustments.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	008	001	isn't it now the UK GDPR?	Thank you for your comment. We have amended all reference to this accordingly in the guideline.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	010	020	Comes across quite legalistic – it is important that the social worker also informs the carer of what the benefits of having an assessment could be.	Thank you for your comment. This recommendation is based on the legal requirement to inform families about a carer's assessment and it is therefore intentionally worded in this way. The included cross-reference to the NICE guideline on supporting adult carers then signposts to the general topic of carer support including discussions about the benefits of such assessments.

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United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	011	009	Very good point – one of the few times this document considers emotions.	Thank you for this comment in support of the guideline.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	011 - 012	018	Cross reference third bullet point with the possible need for those who have substantial difficulty to have an independent advocate under the Care Act 2014.	Thank you for your comment. We have added the potential need for an independent advocate to the third bullet point as suggested.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	021	017	Highlight the need to be mindful that the support network may not be acting in the person's best interest, for example cuckooing or mate crime.	Thank you for your comment. The committee discussed this suggestion and agreed that this was an important risk to consider. They discussed that there is a range of different risks for different people. They also discussed that where a situation may be a risk for one person, it will not necessarily be a risk to another, and agreed that it would be difficult to choose specific situations of risk to highlight in the recommendation. The committee agreed that social workers ought to have safety in mind when thinking through new networks and connections with people. The committee agreed that it would be helpful, based on their discussion around this comment, to edit the wording of the recommendation 1.4.4 to include 'beneficial to wellbeing' so that the social worker is prompted to think about whether any new networks would meet this requirement and would not put the person at risk. The related rationale section of the

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					guideline as well as the 'committee discussion of the evidence' section of the evidence review have been updated accordingly.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Guideline	025	009	Would strengthen this point from 'should consider' to 'should – otherwise there is unlikely to be continuity of the named social worker.	Thank you for your comment. The committee agreed that the wording 'should consider' could be taken too literally and have changed it to 'should provide' to emphasise the importance of a named social worker. However, a strong recommendation such as this would have a large resource impact and other service implications, for which the evidence is not robust enough. They therefore had to add the caveat 'whenever possible'.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review A	General	General	**Appendix D - Table 7** It is reassuring to see the Committee recognised that self-assessment is not appropriate for many people. In Complex Cases, the person's ability to complete a self-assessment is often hampered. In general, most complex cases come to the assessment stage for allocation to a practitioner (social worker) via professional referrals.	Thank you for your comment. Table 7 in appendix D presents the findings as extracted from the included studies. The points about self-assessment in that section of the evidence review have been made by study authors rather than the committee although this is something that is consistent with the committee's experience, as explained in other sections of the evidence review. This is also reflected in the recommendations, for example, that social workers should offer individualised support if people with complex needs choose to complete a self-assessment and that this support should take into account the complexity of the person's needs. Furthermore, acquired brain injury was added to box 1 in the guideline as a life circumstance and experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered.
United Kingdom Acquired Brain Injury	Evidence Review A	016	General	The quantitative "assumptions" around the length of time needed to complete a Needs Assessment could be construed to be a target or benchmark to calculate costs when setting budgets. In reality, social workers often	Thank you for your comment. To address this the following text was added immediately after where the assumptions are described. "It should be noted that assumptions around the length of time for a preparatory

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Forum/UKABIF Brain Injury Social Work Group /BISWG				spend well more than an hour getting to know the person and their situation. This is especially true with Complex Cases where other factors such as Carers' and/or Family Members' views need to be taken into account. Senior Managers and Assistant Directors of Social Services need to calculate costs to set budgets and appoint practitioners and work within the financial constraints on their Local Authority. However, to suggest that in meeting those constraints, a social worker must time-limit their work to such a degree, smacks of Managerialism. I would point to Humanising Managerialism: Reclaiming Emotional Reasoning, Intuition, the Relationship, and Knowledge and Skills in Social Work by Pamela Trevithick, Published 3 July 2014 in the Journal of Social Work Practice.	meeting are intended to be illustrative and there will be large variation in the complexity of cases and the time needed to effectively undertake them. These assumptions should not be seen as a target or an upper limit and longer meetings may often be necessary."
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	008	021	and 'general' General Comments on PICO. In context of acquired brain injury (ABI). The intervention (risk assessment by social workers) 'thoroughly considering someone's preferences, strengths, resilience, mental capacity and mitigating factors.' ABI is often a fluctuating condition, particularly affected by fatigue and mood. Because of these factors, all of someone's preferences, resilience etc may fluctuate from hour to hour, day to day. This poses a problem with one-off visits and assessments, especially when the social worker has not had previous contact with the person with ABI.	Thank you for your comment. The section of the evidence review to which you are referring is the description of the intervention which was the focus of that particular evidence review. No studies were identified which matched the protocol criteria. However, on the basis of the qualitative review about risk assessment and supported by their own experiential knowledge, the committee were able to write recommendations about the importance of tailoring risk assessments to the person's strengths and needs. Acquired brain injury was added to box 1 in the guideline as a life circumstance and experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered. They also specifically recommended that the social worker should consider conducting the risk assessments over several contacts

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					which would potentially identify some fluctuations in people's condition. This would, for example, provide the opportunity to develop rapport between the person and the assessor and also ensure the person's perspectives on risks, needs, strengths can be fully understood even if they change or fluctuate. The committee agreed that this addresses your point so they did not make further changes.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	008	General	A further, related issue, is around that of self-awareness, and acceptance of deficit by the person with brain injury. The person may know how to do a task (knowledge that has been retained since prior to the ABI), yet they will not have the abilities post-injury to do the task. Due to preservation of language skills, the person with ABI may be A further, related issue, is around that of self-awareness, and acceptance of deficit by the person with brain injury. The person may know how to do a task (knowledge that has been retained since prior to the ABI), yet they will not have the abilities post-injury to do the task. Due to preservation of language skills, the person with ABI may be completely convincing, and convinced, of their capacity to carry out specific tasks ranging from self-care to financial management. This places risk on the person with ABI. A social worker without any understanding of this issue could easily believe the person to be capable of these tasks. Due to issues around personal acceptance of ABI, combined with perceived and real social stigma (reflecting a lack of condition specific understanding around), in our experience the person with ABI is quite likely to mask the true extent of their symptoms and the effect of these symptoms on their daily living.	Thank you for your comments about the challenges of social work risk assessments with people with ABI. Although the qualitative evidence review only located one study which reported findings from a person with ABI, the overall findings from this review generated themes relevant to your description. These include the importance of facilitating open discussions in risk assessments and understanding risk from different perspectives as well as helping to balance risk assessment with autonomy (as well as other related themes). On the basis of these (and all other themes in this review) the committee were able to make recommendations for social workers to conduct risk assessments as part of a holistic process taking account of people's strengths, needs and wishes, which would capture the ways in which these things change over time. Furthermore, acquired brain injury was added to box 1 in the guideline as a life circumstance and experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered. The committee also agreed that there are limits to the expertise of social workers and have added that a needs assessment should also identify potentially unmet needs that may need input from other specialist services, such as speech and language or mental health

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				The point around social stigma and understanding of ABI, has a direct relationship to the social model of disability (which is seemingly being used for definition of complex needs. This is compounded by the fact that ABI is often (but not always), a hidden condition. (– relevant to Population and phenomenon of interest and how complex needs are deined.) Masking by the person with ABI is likely to be exacerbated by their own understanding of disability, especially when it is a hidden condition. This is because most people injured hold, to varying degrees, an intrinsically ableist viewpoint, (as does much of society). All these factors can mean the person with ABI may appear to have capacity, where in fact this may not be the case. Especially the case with frontal lobe damage, see Frontal Lobe Paradox). "considering the role of involved family and the person's wider social support network and environment in contributing to or mitigating risks" – this needs to be framed within the lack of condition specific knowledge around ABI. All families are different, although in our experience, very few families are prepared and readily able to manage with the heterogeneity of ABI's symptoms. This is due to a range of practical and attitudinal issues, as well as more basic issues relating to social determinants of health, especially for those people who are lower down the social gradient of health who have access to less resources.	services (which would address some of the specific needs around ABI that may not best be met by a social worker). The committee acknowledge your point about people potentially misrepresenting their own risks or capabilities and they agree this is mitigated by the recommendations, for example through involving others such as families, carers and multidisciplinary teams, albeit with the person's agreement. In addition and in light of yours and other stakeholder's comments the committee strengthened this by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present. The committee also addressed the scenario of the person being assessed as lacking capacity to make decisions related to risks. Overall the committee think that the recommendations made about risk assessment do address the issues you highlight about masking capabilities and adopting a social model of disability. Without more specific evidence pertaining to people with ABI the committee were unable to make condition specific recommendations but it is made clear in the guideline that the recommendations apply to social work support for all adults with complex needs, including needs which fluctuate.

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				This again is reflected in social support. Similar to families, no two communities are the same, especially in relation to the spread of resources and access to these. This also applies to access to third sector support in a persons community.	
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	009		Outcome/Critical/service focused outcomes – "adverse events resulting in emergency medical treatment or admission to hospital – events might include suicide, attempted suicide, adverse reaction to psychological therapy, self-harm, falls (or others) and these will be treated as a composite measure of outcome." – some people with ABI are at risk of not attending hospital due to PTSD from time spent in acute care. This is particularly the case with people who have had traumatic brain injuries, but not exclusively. Post-ABI problems with initiation and fatigue can also be a barrier to accessing treatment. Normalisation of pain as a daily experience can also prevent people from recognising the extent of injury/need for medical attention.	Thank you for your comment. This section of the evidence review is referring to the summary of the review protocol. The outcomes listed were discussed and agreed with the committee to reflect what a risk assessment should be aiming to achieve or contribute towards both from the point of view of services but most crucially, from the perspective of people using services and their families or carers. No studies were located which matched the review protocol for this effectiveness question.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	011	009	Stevenson, 2019 (dementia) and O'Hare, 2013 (physical disabilities) - these included studies are at risk of not reflecting the complexity of life with ABI – a condition which often encompasses elements of both these conditions plus more. These studies will be limited in their applicability to people with ABI and their experience of Social Work assessments. (noted that the studies are not considered to offer rich data [p17].	Thank you for your comment. The population for the evidence review was adults with complex needs as defined in the protocol (a definition that is intentionally broad). If studies fitting the protocol had included people with ABI then these would have been included. The studies that were included in the review generated themes related to many of the points raised in this and other related comments. These themes provided the committee with the basis to make recommendations for the conduct of individualised, flexible and person centred assessments, including risk assessments in a way that acknowledges and is responsive to the complexity and fluctuating nature of the needs and experiences of the

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					guideline population. Finally, on the point about the section describing the quality of the evidence, this describes that there were concerns about the adequacy of some of the themes or findings when judged according to the GRADE CERQual methodology. This generally means that a limited amount of evidence was underpinning that theme or that the evidence didn't adequately explain or explore a potentially complex finding. The committee took such judgements into account when discussing whether and to what extent to use each finding or theme as the basis for a recommendation.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	011	034 - 036	The conditions experienced by the study populations each have some common elements of ABI, but ABI is itself a very complex condition for each individual, which has led to long-term issues for people fallings into the gaps between services. It is a concern that findings here may replicate this lack of accommodation for people with ABI.	Thank you for your comment. The population for the evidence review was adults with complex needs as defined in the protocol (a definition which was intentionally broad) and if studies fitting the protocol had included people with ABI then these would have been included. The studies that were included in the review generated themes related to many of the points you have made in this and other comments. These themes provided the committee with the basis to make recommendations for the conduct of individualised, flexible and person centred assessments, including risk assessments in a way that acknowledges and is responsive to the complexity and fluctuating nature of the needs and experiences of the guideline population. They also provided the committee with the basis to make recommendations about the fundamental importance of a multidisciplinary approach to supporting the complex and changing needs of this population, including but not exclusively focussed on people with ABI. Furthermore, acquired brain injury was added to box 1 in the guideline as a life circumstance and

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					experience that could lead to discrimination or inequalities for which reasonable adjustments must be considered. The committee also agreed that there are limits on the expertise of social workers and have added that a needs assessment should also identify potentially unmet needs that may need input from other specialist services, such as speech and language or mental health services (which would address some of the specific needs around ABI that may not best be met by a social worker). The committee agree that if these and the other guideline recommendations are implemented that practice as it relates to people with complex needs will improve, be more joined up and ultimately improve people's experiences and outcomes.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	013	008	We support the idea of organisational support for the individual social worker when making risk assessments for people with ABI to minimise risk to the client and optimise practitioner confidence in their decisions.	Thank you for your comment. The committee also agreed that this review finding - that organisational support for the conduct of social work risk assessments - contributed to good practice in this area. On the basis of this and other relevant identified evidence the committee were able to dedicate a whole section of the guideline to recommendations about the support that organisations should have in place for social workers supporting adults with complex needs.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	013	023	The use of strategies is essential for most people with ABI – this is due to deficits in executive skills (which, as already noted, may fluctuate throughout the day and from one assessment to the next, yet not be indicative of either an overall decline or improvement). People with ABI are at an increased risk of developing 'maladaptive strategies' – a way to manage their own impairment. This can both enable them and place them at risk	Thank you for your comment. The committee acknowledge your point about people potentially developing maladaptive strategies and they agree this is mitigated by the recommendations, for example through cross-referencing information gathered during assessments with others such as families, carers and multidisciplinary teams, albeit with the person's agreement. The committee also recommended that risk assessments could be conducted over several visits which would help identify needs that may fluctuate and

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					that needs are reviewed whenever a person's circumstances or risks change. Furthermore, the committee recommended that in complex risk management situations involving potential risks of serious harm, the social worker should initiate and participate in a case conference involving all relevant agencies. Taken together the committee think that the recommendations made about risk assessment do address the issues that are highlighted in relation to risks associated with complex situations and the potential development of maladaptive strategies.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	016	008-010	Has independent research been commissioned to find out what Cares and family members feel about the qualitative questions?	Thank you for your question. Independent research is not commissioned as part of the NICE guideline development process. However, the draft review questions were subject to the stakeholder consultation on the draft scope and the review questions were then finalised by the guideline committee, which included carers and family members.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	016	012 - 014	In our experience, lines of communication between people with ABI and ASC teams/individual social workers have been problematic. This has often been because of a lack of effective strategies to promote information retention by the service user. Strategies that work for the person with ABI need to be implemented by the social worker, and the person will need to prompted to use them each time, as well as referring to things like diaries/photos/whiteboards etc in future, so that a narrative history is maintained. Clearly, current pressures on the ASC system is very likely to exacerbate these stresses.	Thank you for this information. This section of the evidence review refers to the summary of the qualitative review findings. The committee used the review findings about the importance of communication between the social worker and person being supported to make recommendations. These included the recommendation in the opening section of the guideline which stated that when first contacting someone, and throughout provision of support, the social worker should establish with the person or with their family, carers or people important to them whether there are any advocacy, sensory or communication needs. The committee agree that this should illicit information about the kinds of needs and strategies, such as photos, whiteboards and others.

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United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	017	004 - 006	Outcome/Critical/service focused outcomes – "adverse events resulting in emergency medical treatment or admission to hospital – events might include suicide, attempted suicide, adverse reaction to psychological therapy, self-harm, falls (or others) and these will be treated as a composite measure of outcome." – some people with ABI are at risk of not attending hospital due to PTSD from time spent in acute care. This is particularly the case with people who have had traumatic brain injuries, but not exclusively. Post-ABI problems with initiation and fatigue can also be a barrier to accessing treatment. Normalisation of pain as a daily experience can also prevent people from recognising the extent of injury/need for medical attention.	Thank you for this information. This section of the evidence review refers to the description of the outcomes for the effectiveness question that the committee felt mattered the most. Had studies been included then data on these outcomes would have been extracted and used by the committee to make recommendations. No studies were identified which matched the review protocol for this effectiveness question but the committee made recommendations about risk assessment based on the qualitative review and supported by their own experiential knowledge.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	018	003 - 013	See opening general comments on lack of insight and self-awareness of *some* people with ABI. This can be a barrier to engaging in an accurate conversation about needs and abilities.	Thank you for your comment. The committee agree you raise an important point and one that is addressed by many of the guideline recommendations, starting with the general principles which describe how social workers should provide people with the support they need to be fully and actively involved in discussions and decision-making and in doing so they should take into account a number of factors such as whether the person might be reluctant to ask for help or raise issues because of personal, societal or other factors, such as stigma or mistrust of services and also that these discussions might be affected by the person's expectations and emotional state. The committee also address the point you raise through the recommendations on needs assessment and risk assessment. Recommendations in these sections emphasise the importance of taking an individualised approach to assessment, planning preparatory conversations or visits to enable the person's full involvement in the subsequent assessment

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					and also sharing the write up of assessments before they are finalised as well as reviewing these when needs change over time. The committee also recommended triangulating information with input from multidisciplinary teams and families and carers and overall they believe that any lack of awareness or insight will be mitigated if the guideline is implemented. In addition the committee recognised that there are limits to the expertise of social workers and have added that a needs assessment should also identify potentially unmet needs that may need input from other specialist services, such as speech and language or mental health services (which would address some of the specific needs around ABI that may not best be met by a social worker).
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	018	015 - 023	We fully support the promotion of legal literacy training. We believe this needs to be contextualised to the nuances of ABI to minimise potential risks that may come about from laws such as the Mental Capacity Act being incorrectly applied.	Thank you for your comment. The committee did not have the basis on which to make a specific recommendation about the nuances of legal frameworks and how they might relate to people with specific conditions. However, they agree that the training they recommend for all social workers in this context will ensure they have a good grasp of the legal frameworks as they apply to all adults with complex needs. The committee agreed this would benefit people using services as social workers would be able to support them with appropriate and specific care and knowledge and this will apply regardless of the person's condition.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury	Evidence Review B	019	009 - 012	Agreed that it is important to take into account the opinions of family, carers, or other relevant persons in establishing a person-centred approach (PCA) towards the individual. This is a way of triangulating around the problems that arising out of poor insight and awareness, post-ABI. (see comment 3).	Thank you for your comment in support of these recommendations.

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Social Work Group /BISWG					
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	019	017 - 021	We support the building of a relationship between professional and client and believe assessment over several visits is a good way to establish a more accurate picture of the person with ABIs everyday life. Agreed that this will not be possible in every case, such as where there has been a dramatic escalation of need – in which case we would recommend the engagement of a family member, carer, other adult to support with a PCA (see comment 21).	Thank you for your comment. The committee agree that this is important and they believe this issue is well covered in the guideline, for example in the recommendation for the social worker to ask the person their preferences about the practical arrangements for an assessment, including whether they would like any carers, family members or other people important to them to be present. In addition and in light of yours and other stakeholder's comments the committee strengthened this by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review B	023	017 - 021	Where relevant research into risk assessments by social workers of people with ABI has not been identified (in other comments here), we would support the panel's recommendation for further research. This is important for people with ABI, due to the pan-impairment nature of the condition. Often conflated by the broad range of possible symptoms, especially they're potential invisibility and fluctuation, the broad range of complexity requires any research gaps to be filled with robust evidence to maintain the welfare of people with ABI who are supported by social workers assessing risk.	Thank you for your comment. The committee agree that there is a need for research on risk assessment to cover the full range and variation of strengths, needs and circumstances among adults with complex needs. In particular, the committee recognised that checklists supporting risk assessments may need to be tailored for different groups of people with complex needs and may have more value in some contexts than others. Therefore future research is needed to provide evidence about what sorts of risk checklists might be most valuable for whom and in what contexts, and how social workers can best be guided and supported to use them effectively in a person-centred and collaborative way. Although this research recommendation relates specifically to risk assessments and the use of checklists in these assessments, the committee agreed all the research they recommended as part of this guideline

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					needed to address the full range of adults with complex needs and recognise the variation and fluctuation in needs and circumstances.
United Kingdom Acquired Brain Injury Forum/UKABIF Brain Injury Social Work Group /BISWG	Evidence Review F 4.1	017 - 018 20 and General	013 - 014 and General	Individual and Family Casework We agree that "the need for the relationship with the Social Worker demands a flexible approach" and "that there is a need to recognise the time needed for in depth interactions" However in the context of Acquired Brain Injury [ABI] the need for practitioners to have a sound knowledge of ABI is crucial to understanding the interaction needed by the individual and family[significant others] before any casework can begin.	Thank you for your comment. The committee agree that social workers need to have expertise in dealing with a wide range of people including those with acquired brain injury and they decided that many of the recommendations do already focus on the importance of social workers taking an individualised and person centred approach to supporting adults with complex needs. They also agree that the recommendations aimed at organisations help to address the importance of understanding the range of potentially complex conditions through gaining specialised and advanced skills and ensuring social workers know the options available to this population through the relevant legal frameworks. The committee also highlighted that social workers must keep their practice up to date, recording how research, theories and frameworks inform their professional judgements and this would necessarily include the knowledge needed to support the complexity of needs among this population. In addition the committee recognised that there are limits to the expertise of social workers and have added that a needs assessment should also identify potentially unmet needs that may need input from other specialist services, such as speech and language or mental health services (which would address some of the specific needs around ABI that may not best be met by a social worker).
United Kingdom Acquired Brain Injury	Evidence Review F 41.1	025		We wholeheartedly agree that " training to gain specialist knowledge and skills is not routinely covered in university "	Thank you for your comment. The committee agree that training is important to understand the full complexity of the needs of the population covered by this guideline. Although they did not review evidence to enable them to

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					teams, albeit with the person's agreement. In addition and in light of this and other stakeholders' comments the committee strengthened this by adding a recommendation that people's families, advocates and carers should be involved in case conferences for complex risk management, should the person wish them to be present. The committee also agree that the issues raised about the unique nature of family relationships is addressed by the recommendations to explore family and individual casework in a way that shows an understanding of the person and their family circumstances, and in a way that's non-judgemental and respects the validity of the person's lived experience. The committee acknowledge that these issues apply to people with ABI and their families but that they also apply to the wider population of adults with complex and often fluctuating needs. The committee recognised that there are limits to the expertise of social workers and have added that a needs assessment should also identify potentially unmet needs that may need input from other specialist services, such as speech and language or mental health services (which would address some of the specific needs around ABI that may not best be met by a social worker).

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*