

## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

Stakeholder	Page no.	Line no.	Comments	Developer's response Please respond to each comment
Action on Hearing Loss	001	017	We are pleased that the draft scope recognises 'personalised communication' as a key aspect of social work for adults with complex needs. However, given the prevalence of communication difficulties in this population and the impact of poor communication on health and wellbeing outcomes, we feel that it would be beneficial to explicitly reference communication in the key areas and questions (see below).	<p>Thank you for your comment. We have revised the second bullet of key area 2 to 'promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and supporting the development of coping strategies'. This will capture the needs of people who have communication difficulties.</p> <p>We are aware that communication is an integral part of social work that cannot easily be separated into an individual topic since it impacts on all key areas. We anticipate that 'communication' may feature as a theme in many of the review questions that take a qualitative approach 'Based on the views and experiences of everyone involved, what works well and what could be improved...' as something that may have gone wrong or something that had a positive impact when done well. Therefore, recommendations could be made even if it is not a specific key area.</p> <p>Communication needs are also named as a specific characteristic for which there are equality considerations. This is noted in the Equality Impact Assessment (EIA) form: 'People with complex needs may have physical, mental health, cognitive, communication needs or disabilities and disorders (including behavioural and social communication disorders), learning disability and sensory and communication impairments'.</p> <p>Section 1.1 of the EIA form also highlights that this guideline covers a group with communication or engagement needs and how these needs may be covered</p>

## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				during guideline development. One option that was raised in this context is that: 'The committee may also consider consulting with specific groups, such as people with communication needs, to get their views heard'.
Action on Hearing Loss	002	018	<p>'Disabilities, including serious mental illness and intellectual disabilities' –</p> <p>There is no reference in the scope to sensory impairment or having communication support needs (e.g. living with d/Deafness or hearing loss; being a British Sign Language user) as a disability. While we recognise that the guideline will not be making recommendations specific to particular disabilities, we feel that this group should be explicitly included, particularly as communication needs are absent from the key issues and draft questions.</p>	<p>Thank you for your comment. We have revised the second bullet of key area 2 to 'promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and supporting the development of coping strategies'. This will capture the needs of people who have communication difficulties.</p> <p>We are aware that communication is an integral part of social work that cannot easily be separated into an individual topic since it impacts on all key areas. We anticipate that 'communication' may feature as a theme in many of the review questions that take a qualitative approach 'Based on the views and experiences of everyone involved, what works well and what could be improved...' as something that may have gone wrong or something that had a positive impact when done well. Therefore, recommendations could be made even if it is not a specific key area.</p> <p>Communication needs are also named as a specific characteristic for which there are equality considerations. This is noted in the Equality Impact Assessment (EIA) form: 'People with complex needs may have physical, mental health, cognitive, communication needs or disabilities and disorders (including behavioural and social</p>

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## Social work for adults with complex needs

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21/10/19 – 18/11/19

				<p>communication disorders), learning disability and sensory and communication impairments’.</p> <p>Section 1.1 of the EIA form also highlights that this guideline covers a group with communication or engagement needs and how these needs may be covered during guideline development. One option that was raised in this context is that: ‘The committee may also consider consulting with specific groups, such as people with communication needs, to get their views heard’.</p>
Action on Hearing Loss	005	001 - 031	<p>We recommend explicitly including approaches for communicating effectively with individuals with complex needs in 1 and/or 2, in addition to how social workers communicate with MDTs.</p> <p>Being able to communicate plays a vital role in problem solving, self-esteem, coping with change, independence and community interaction. People with sensory impairment and complex needs have unique communication and care needs that need to be considered when planning and delivering social care and support. There is substantial evidence, including the latest CQC State of Care review, to show that poor communication support provision or lack of awareness of Deaf culture within health and social care settings can lead to social isolation, ineffective care and deteriorating health and wellbeing (CQC (2019) <i>State of Care 2018/19: Full report</i>; Hunt et al, 2010. <i>Older people who use BSL – preference for residential care provision in Wales</i>. Manchester: University of Manchester; Parker et al, 2010. ‘My Mum’s Story’ A Deaf daughter discusses her Deaf mother’s experience of dementia. <i>Dementia</i>, 9(1), 5-20.)</p>	<p>Thank you for your comment. We have revised the second bullet of key area 2 to ‘promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and developing supporting the development of coping strategies’. This will capture the needs of people who have communication difficulties.</p> <p>We are aware that communication is an integral part of social work that cannot easily be separated into an individual topic since it impacts on all key areas. We anticipate that ‘communication’ may feature as a theme in many of the review questions that take a qualitative approach ‘Based on the views and experiences of everyone involved, what works well and what could be improved...’ as something that may have gone wrong or something that had a positive impact when done well. Therefore, recommendations could be made even if it is not a specific key area.</p>

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21/10/19 – 18/11/19

				<p>Communication needs are also named as a specific characteristic for which there are equality considerations. This is noted in the Equality Impact Assessment (EIA) form: 'People with complex needs may have physical, mental health, cognitive, communication needs or disabilities and disorders (including behavioural and social communication disorders), learning disability and sensory and communication impairments'.</p> <p>Section 1.1 of the EIA form also highlights that this guideline covers a group with communication or engagement needs and how these needs may be covered during guideline development. One option that was raised in this context is that: 'The committee may also consider consulting with specific groups, such as people with communication needs, to get their views heard'.</p>
Action on Hearing Loss	005	029	As further rationale for explicitly including communication - Strategies which seek to make it easier for people to communicate will also help people to connect to their local communities.	<p>Thank you for your comment. We have revised the second bullet of key area 2 to 'promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and developing supporting the development of coping strategies'. This will capture the needs of people who have communication difficulties.</p> <p>We agree about the central importance of communication but we feel that it permeates all aspects of social work for adults with complex needs. We anticipate that it will be a common thread, particularly from the qualitative evidence reviews, contributing as it does to all the key areas, rather than being an isolated issue in itself.</p>

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21/10/19 – 18/11/19

Action on Hearing Loss	010	026	2.1 - This seems a suitable place to explicitly include communication, which is fundamental to problem solving, promoting self-esteem etc.	<p>Thank you for your suggestion. We have revised the second bullet of key area 2 to 'promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and developing supporting the development of coping strategies'. This will capture the needs of people who have communication difficulties.</p> <p>We are aware that communication is an integral part of social work that cannot easily be separated into an individual topic since it impacts on all key areas. We anticipate that 'communication' may feature as a theme in many of the review questions that take a qualitative approach 'Based on the views and experiences of everyone involved, what works well and what could be improved...' as something that may have gone wrong or something that had a positive impact when done well. Therefore, recommendations could be made even if it is not a specific key area.</p> <p>Communication needs are also named as a specific characteristic for which there are equality considerations. This is noted in the Equality Impact Assessment (EIA) form: 'People with complex needs may have physical, mental health, cognitive, communication needs or disabilities and disorders (including behavioural and social communication disorders), learning disability and sensory and communication impairments'.</p> <p>Section 1.1 of the EIA form also highlights that this guideline covers a group with communication or</p>
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21/10/19 – 18/11/19

				engagement needs and how these needs may be covered during guideline development. One option that was raised in this context is that: 'The committee may also consider consulting with specific groups, such as people with communication needs, to get their views heard'.
Action on Hearing Loss	011	028	We support the inclusion of communication as a main outcome, but would like to see recognition that having clear approaches for meeting communication needs will itself play a more fundamental role in achieving person-centred outcomes.	Thank you for your comment and your support for this outcome. We anticipate that the importance of communication will feature throughout this guideline but at this stage it is not possible to pre-empt recommendations relating to this issue.
Autistica	General	General	<p>We understand the decision not to single out individual conditions in this scope, given the number of potential diagnoses that would be relevant for this guideline. We also appreciate that the guidance may occasionally benefit from referring to groups of relevant conditions, as the scope does on page 2 (lines 18-20).</p> <p>On those occasions though, we recommend that Neurodevelopmental Conditions (NDCs) would be a more appropriate grouping of conditions to reference alongside mental health problems. First, it is ad hoc for the scope (and the draft guidelines) to reference a single neurodevelopmental condition, like a learning disability, when people with other NDCs (such as autism, ADHD, epilepsies, Tourette's syndrome, Foetal Alcohol Spectrum Disorders etc.) are also more likely to have complex support needs. Second, it is increasingly clear that there is significant overlap between NDCs, and the combination of conditions in someone's neurodevelopmental diagnosis is likely to be an important factor in planning their support needs.[1][2][3]</p>	<p>Thank you for your comment. We have removed 'including learning disabilities and mental health' from the background section of the scope because we agree that this would single out these particular conditions.</p> <p>In the section 'Groups that will be covered' in the scope the following definition is provided which has been revised based on stakeholder feedback: 'For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a>).' This would therefore include people with neurodevelopmental conditions as long as they need a high level of support with many aspects of their daily life and relying on a range of health and social care services.</p>

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			<p>[1] Embracing Complexity Coalition (2019). Embracing Complexity: Towards New Approaches for Supporting People with Neurodevelopmental Conditions. <a href="https://embracingcomplexity.org.uk/assets/documents/Autistica-Embracing-Complexity-Report-Final.pdf">embracingcomplexity.org.uk/assets/documents/Autistica-Embracing-Complexity-Report-Final.pdf</a></p> <p>[2] Cleaton MAM &amp; Kirby A (2018). Why Do We Find it so Hard to Calculate the Burden of Neurodevelopmental Disorders? J Child Dev Disord. 4(3):10. <a href="https://childhood-developmental-disorders.imedpub.com/why-do-we-find-it-so-hard-to-calculate-the-burden-of-neurodevelopmental-disorders.pdf">childhood-developmental-disorders.imedpub.com/why-do-we-find-it-so-hard-to-calculate-the-burden-of-neurodevelopmental-disorders.pdf</a></p> <p>[3] Embracing Complexity Coalition (2019). Embracing Complexity in Diagnosis: Multi-Diagnostic Pathways for Neurodevelopmental Conditions. Available at: <a href="https://embracingcomplexity.org.uk/">embracingcomplexity.org.uk/</a></p>	<p>For those people the recommendations about the principles of social work resulting from the guideline would apply.</p> <p>Autistic people are also named as a specific group for which there are equality considerations. This is noted in the Equality Impact Assessment form.</p>
Autistica	002	018 - 020	<p>We recommend that Neurodevelopmental Conditions (NDCs) would be a more appropriate grouping of conditions to reference alongside mental health problems. First, it is ad hoc for the scope (and the draft guidelines) to reference a single neurodevelopmental condition, like a learning disability, when people with other NDCs (such as autism, ADHD, epilepsies, Tourette’s syndrome, Foetal Alcohol Spectrum Disorders etc.) are also more likely to have complex support needs. Second, it is increasingly clear that there is significant overlap between NDCs, and the combination of conditions in someone’s neurodevelopmental diagnosis is likely to be an important factor in planning their support needs.[1][2][3]</p> <p>[1] Embracing Complexity Coalition (2019). Embracing Complexity: Towards New Approaches for Supporting People with Neurodevelopmental Conditions.</p>	<p>Thank you for your comment. We have removed ‘including learning disabilities and mental health’ from the background section of the scope because we agree that this would single out these particular conditions.</p> <p>In the section ‘Groups that will be covered’ in the scope the following definition is provided: ‘For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person’s life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act</a></p>

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			<p><a href="http://embracingcomplexity.org.uk/assets/documents/Autistica-Embracing-Complexity-Report-Final.pdf">embracingcomplexity.org.uk/assets/documents/Autistica-Embracing-Complexity-Report-Final.pdf</a></p> <p>[2] Cleaton MAM &amp; Kirby A (2018). Why Do We Find it so Hard to Calculate the Burden of Neurodevelopmental Disorders? J Child Dev Disord. 4(3):10. <a href="http://childhood-developmental-disorders.imedpub.com/why-do-we-find-it-so-hard-to-calculate-the-burden-of-neurodevelopmental-disorders.pdf">childhood-developmental-disorders.imedpub.com/why-do-we-find-it-so-hard-to-calculate-the-burden-of-neurodevelopmental-disorders.pdf</a></p> <p>[3] Embracing Complexity Coalition (2019). Embracing Complexity in Diagnosis: Multi-Diagnostic Pathways for Neurodevelopmental Conditions. Available at: <a href="http://embracingcomplexity.org.uk/">embracingcomplexity.org.uk/</a></p>	<p><b>Personal partnership).</b>' This would therefore include people with neurodevelopmental conditions as long as they need a high level of support with many aspects of their daily life and relying on a range of health and social care services. For those people the recommendations about the principles of social work resulting from the guideline would apply.</p> <p>Autistic people are also named as a specific group for which there are equality considerations. This is noted in the Equality Impact Assessment form.</p> <p>We have noted the cited references, but because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether these will feature as evidence in the guideline, although they are likely to be useful contextual information.</p>
Autistica	003	016 - 021	The Autism Act (2009) is relevant and should be included in this list.	Thank you for your comment. This list is highlighting some examples of relevant legislation and is not meant to be comprehensive.
Autistica	009	016 - 022	Needs assessments may need to take account of the fact that some people may have specific communication needs. For example, some people with neurodevelopmental conditions may use Alternative and Augmentative Communication (AAC).	Thank you for your comment. We acknowledge the importance of your point and anticipate that the proposed evidence review about social work assessment will provide supporting data.
Autistica	011	018	The guideline developers should note that the same outcome measures may not be as appropriate for different groups of people with complex needs. As an example, good Quality of Life might mean something different to an autistic and non-autistic person.[1][2][3][4]	Thank you for your comment and for the information provided. The points you make will be considered by the guideline committee during discussions and drafting of the review protocols where the outcomes measures are specified.

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21/10/19 – 18/11/19

			<p>[1] Ayres M, et al (2018). A systematic review of quality of life of adults on the autism spectrum. <i>Autism</i> 22(7):774-783. <a href="http://www.ncbi.nlm.nih.gov/pubmed/28805071">www.ncbi.nlm.nih.gov/pubmed/28805071</a></p> <p>[2] Mason D, et al. (2018). Predictors of quality of life for autistic adults. <i>Autism Res.</i> 11(8):1138-1147. <a href="http://www.ncbi.nlm.nih.gov/pubmed/29734506">www.ncbi.nlm.nih.gov/pubmed/29734506</a></p> <p>[3] de Schipper E, et al. (2016). Functioning and disability in autism spectrum disorder: A worldwide survey of experts. <i>Autism Res.</i> 9(9):959-69. <a href="http://www.ncbi.nlm.nih.gov/pubmed/26749373">www.ncbi.nlm.nih.gov/pubmed/26749373</a></p> <p>[4] de Schipper E, et al. (2015). Ability and Disability in Autism Spectrum Disorder: A Systematic Literature Review Employing the International Classification of Functioning, Disability and Health-Children and Youth Version. <i>Autism Res.</i> 8(6):782-94. <a href="http://www.ncbi.nlm.nih.gov/pubmed/25820780">www.ncbi.nlm.nih.gov/pubmed/25820780</a></p>	<p>We have noted the publications that you have cited. Because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether these reports will feature as evidence in the guideline.</p>
British Association of Social Workers	001	015	Social Workers also work with families, carers of adults and advocacy, health, voluntary and specialist organisations	<p>Thank you for your comment. We have amended this to include families, carers and advocates. However, we have not added 'health, voluntary and specialist organisations' to this sentence because the focus of this was on working with the individual person and people close to them.</p>
British Association of Social Workers	001	017	Rather than "to meet their goals" consider "to identify, agree and then support to achieve their outcomes"	<p>Thank you for your comment. We have amended this to read '...to enable people to identify, agree and meet their goals'. We decided to keep 'meet their goals' because it is plainer English than 'achieve their outcomes'.</p>
British Association of Social Workers	001	020	Rather than "services" consider taking out altogether	<p>Thank you for your comment. We have deleted 'services' as suggested.</p>
British Association of Social Workers	001	022	Rather than use "social" replace with "health and wellbeing" outcomes	<p>Thank you for your comment. We have amended this accordingly.</p>

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21/10/19 – 18/11/19

British Association of Social Workers	001	016	Consider change of sentence to “use a range of methods, models, theories and approaches including relationship-based and strengths-based approaches to support people	Thank you for your comment. We have revised this to ‘use approaches including relationship-based and strengths-based practice’ to indicate that these are only examples. There is overlap between theories, methods, models and approaches and for the sake of brevity we referred only to ‘approaches’.
British Association of Social Workers	001	012	Also include; ABI, Autism, People with substance use problems, homeless people	Thank you for your comment. We have removed ‘including learning disabilities and mental health’ from the background section of the scope because we agree that this would single out these particular conditions when there are a multitude of conditions that are relevant to this guideline.
British Association of Social Workers	002	022	Replace “social care” with “support”	Thank you for your comment. This whole paragraph has been revised and no longer includes this wording.
British Association of Social Workers	002	022 - 024	Expand to under 65 which would include specialist Outreach support, Supported Accommodation, Accommodation with support in a community setting including single tenancy and shared tenancy accommodation. Specialist residential and Nursing settings. Rehabilitation based provisions	Thank you for your comment. We recognised that it is difficult to write a comprehensive list of all possible settings that a social worker might work in. We have therefore revised the paragraph to refer to a ‘range of settings’. It is clear in another section of the scope entitled ‘settings’ that the guideline will include ‘All settings where social work is provided for adults with complex needs’.
British Association of Social Workers	002	026 - 028	Consider adding “health and social care teams have a statutory duty to care out a Care Act 2014 Assessment, determine eligibility, develop a support plan/personal budget to meet identified outcomes/needs. Monitor and review the success of the agreed support plans in achieving identified outcomes for the person	Thank you for your comment. This paragraph has been revised, but in the interest of brevity does not include all of the suggested wording. The background section in the scope is intentionally brief.

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21/10/19 – 18/11/19

British Association of Social Workers	005	009	Identifying and developing risk assessment plans which support positive risk taking, development and growth of a person. Support a full, purposeful and meaningful life equal in opportunity as others within society.	Thank you for your comment. This section of the scope is identifying 'key areas that will be covered'. The elements of the suggested wording are captured in various other bullets (for example 'positive risk taking' is captured in bullet point 5 of key area 2. The bullets are kept intentionally brief and details will be finalised when the protocols for these topics are discussed with the committee.
British Association of Social Workers	001	020/021/022	Suggest replacement with "Social workers have a key role in promoting individual wellbeing and helping adults achieve the outcomes they wish to achieve in their day-to-day life, as required by the Care Act 2014. This includes assessment of care and support needs, determination of eligibility and proposing how needs can be best met through the provision of services as well strengths-based interventions. In addition social workers often take the lead in safeguarding enquiries where adults with care and support needs who are experiencing or at risk of abuse or neglect, are unable to protect themselves."	Thank you for your comment. We have revised the paragraph preceding the one that has been referred to. This now includes a reference to enabling people to identify, agree and meet their goals. Some of the content of the suggested wording is also captured in other subsections of 'why the guideline is needed'. For example the 'current practice' section refers to the social worker's responsibilities to facilitate the local authority's duty to conduct needs assessments under the Care Act 2014. Strengths-based approaches are also referred to in the second paragraph of the first section. In the interest of brevity we have not adopted the full suggested wording because: (1) much of this is captured elsewhere and (2) this section of the scope is intentionally kept brief.
British Association of Social Workers	005	008	Add new line "- safeguarding enquiries"	Thank you for your comment. 'Safeguarding enquiries' was not added because (1) it is a part of other bullets within this section (e.g. needs assessment and risk assessment ) and (2) a separate NICE guideline on ' <a href="#">Safeguarding adults in care homes</a> ' is under development (and the overlap with the social work guideline will need to be assessed during development). You can follow the progress of the safeguarding guideline using the link provided.

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British Association of Social Workers	005	009	Suggest replacement of “risk assessment” with “managing risks”. This is more in accordance with the approach taken in the DHSC handbook.	Thank you for your comment. The bullet that is referred to is under the heading of ‘Social work assessment and care planning’ and therefore the focus is on ‘assessment’ rather than management. Risk management as a part of ‘individual or family casework’ is covered by bulled point 3 under the second key area.
British Association of Social Workers	005	013	Add new line “- sufficiency of personal budgets to meet needs”. The Ombudsman has criticised local authorities for creating circumstances where frontline staff “are sometimes at risk of having professional judgement overshadowed by the pressure to meet financially driven targets”. This is in relation to the requirement set out in the Care and Support Statutory Guidance: “The personal budget must always be an amount sufficient to meet the person’s care and support needs” (paragraph 11.10). It makes sense for the guidance to exclude the “organisation of services” as this is not a social work function, but it is important to include the determination of the personal budget. as social worker’s professional judgements have an essential role to play in this decision.	Thank you for your comment. Recommendations related to ‘sufficiency of personal budgets’ are outside the remit of NICE guidance. However, reference could be made to the general concept of personal budgets and support around planning and needs assessment when these topics are discussed by the committee during development.
British Association of Social Workers	005	014	Suggest that this section also includes outcome focused issues such as hospital discharge and continuing health care funding decisions.	Thank you for your comment. Outcomes are covered under the heading ‘Main outcomes. It is stated under the list of outcomes that the ‘exact list of outcomes to be considered for each topic are context dependent and will be discussed when detailed review questions are formulated’. It is therefore not a comprehensive list.
British Association of Social Workers	General	General	It is essential there is clear reference to processes that social workers are required to apply as set out in the Care and Support Statutory Guidance in the diagram after paragraph 6.12	Thank you for your comment. During the development of the guideline the committee will have to take the legal framework related to social work into account, and the final guideline will include specific reference to legislation and statutory guidance as appropriate

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21/10/19 – 18/11/19

Carers Trust	General	General	<p>Carers Trust broadly welcome the scope of the guidance.</p> <p>We are very pleased to see one of the key areas that will be covered will be “Individual or family casework approaches to support the person <b>and their family and carers</b> in:”</p> <p>We agree that the scope of the guidance should include approaches to support carers in (all page 5) “problem solving... promoting self-esteem... coping with changing life situations... and helping people connect with their local communities”</p>	Thank you for your comment.
Carers Trust	General	General	<p>Carers Trust are pleased to see the implicit inclusion of carers in decision making with the phrase “In the opinion of everyone involved” (Page 9 Line 20, Page 9 Line 26, Page 10 Line 4, Page 10 Line 13, Page 10 Line 21, Page 11 Line 1, and Page 11 Line 8).</p> <p>In the draft and final guidance NICE should make it clear that unpaid carers (along side the person with care needs and support workers) are who NICE are referring to when they say “In the opinion of everyone involved”.</p> <p>It is important carers are seen as and treated as partners in care. Carers should be included in care planning. Unpaid carers provide the majority of care across the country and are likely to be performing the majority of care for individuals with complex needs. Carers will have information about the person they care for that is vital in care planning. Involving carers in care planning has benefits for the person with care needs, the carer and the service provider.</p>	<p>Thank you for your comment. We intentionally used the broad phrase ‘Based on the views and experiences of everyone involved’ to be inclusive rather than providing a comprehensive list. We believe that these could include paid as well as unpaid carers.</p> <p>Topic 2 in the ‘Key areas that will be covered’ will address ‘Individual or family casework approaches to support the person and their family and carers’. Working in partnership with carers may be a theme that could be identified when we search for qualitative evidence, but we cannot pre-empt what recommendations will be made.</p>

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### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

Healthwatch Lincolnshire	005	General	<p>We have recently come across a couple of people who have multiple carers all of whom have access to the key safe. When I say multiple I mean over 30 different people and in one case over 60 different individuals providing care. This does not provide any continuity of care and is a massive safety risk due to the high turn over of staff.</p> <p>Whilst I recognise this could come under organisation of services it could be included as part of the risk assessment; impact on complex risk planning and promoting independence through lack of continuity and subsequent care workers not knowing what person is capable of has been already doing.</p>	<p>Thank you for your comment. We agree that the point you raise is an area for concern that may be explored through the draft review questions related to social work assessment and care planning, particularly on risk assessment.</p>
Healthwatch Lincolnshire	009	021	<p>More specific information on personal budgets and additional support to prior to use</p>	<p>Thank you for your comment. Recommendations related to the amount of personal budgets funding are outside the remit of NICE guidance. However, reference could be made to the general concept of personal budgets and support around planning and needs assessment when these topics are discussed by the committee during development.</p>
Healthwatch Lincolnshire	010	001	<p>At present the practice seems to be assess, financial assessment, provide service, close case. Service users need an opportunity to be contacted by and to be able to contact the same person on an ongoing basis as circumstances can change and service users are often unsure who they need to contact and how</p>	<p>Thank you for your comment. If this is an area for improvement in terms of how social work supports people to plan for the future then we are confident that relevant published research will be identified by our evidence reviews and therefore presented to the committee for their deliberation.</p>
Healthwatch Lincolnshire	011	001	<p>Speed up the process especially in relation to change in circumstances. Services need to be more responsive. In particular where a person requires disabled facilities grant can take several months and even up to a year.</p>	<p>Thank you for your comment. If this is an area for improvement in terms of how social work supports individual and family casework then we would anticipate that relevant published research is likely to be identified by</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				our evidence reviews and therefore presented to the committee for their deliberation.
Healthwatch Lincolnshire	011	014 General	All of the above	Thank you for your support for the outcomes listed in the draft scope.
Mencap	General	General	<p>The draft scope makes clear that ‘adults with complex needs’ means ‘people needing a high level of support...and <b>relying on a range of health and social care services.</b>’ (pg 4). It also says ‘social workers in local authorities or in integrated health and social care services have statutory duties to <b>assess the person’s needs and plan and coordinate care.</b>’(Pg 2). In the introduction about why the guideline is needed it would be helpful to <b>spell out how serious the consequences can be</b> when people with complex needs do not get their needs met/ gaps in care, and that the importance of ‘effective care coordination’ is well-recognised.</p> <p>For example:  <b>The Learning Disability Mortality Review (LeDeR) Annual report 2019</b> (the latest report of the review into the deaths of people with a learning disability in order to identify learning and tackle health inequalities and avoidable deaths) has made a number of recommendations, including the need for better care coordination across health and care.</p> <p>The <b>Transforming Care programme</b> - to ensure people with a learning disability and/ autism and behaviour that challenges get the right support in the community and are not stuck in mental health units, where they are at increased risk of abuse and neglect - also recognises the importance of effective care coordination for these individuals who may need complex packages of support in the community involving social care, health and housing (See <b>Building the Right Support service</b></p>	<p>Thank you for your comment. The background section in the scope is meant to be a brief introduction highlighting why the guideline is needed. It is meant to be concise rather than comprehensive and provides a brief rationale for the need to develop guidance in this area.</p> <p>One of the ‘Key areas that will be covered’ is ‘needs assessment’ and ‘the role of social workers within multidisciplinary teams and how they communicate, support and work with others’ which identifies a need and would be expected to also include how teams communicate in the co-ordination of care. The objective of the second key area ‘Individual or family casework approaches to support the person and their family and carers’ is then to identify ways to address these needs.</p> <p>We have noted the reports that you have cited. Because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether these reports will feature as evidence in the guideline, although they are likely to be useful contextual information.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			<p><b>model</b> which says that everyone should be offered a named local care and support navigator or key worker to coordinate and ensure timely delivery of a wide range of services set out in the person centred care and support plan, working closely with the person and their families/ carers where appropriate and ensuring a consistent point of contact: <a href="https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf</a> (Pg 14)</p>	
Mencap	General	General	<p>It would be helpful for this guideline to reflect the <b>learning from the Named Social Worker pilot/programme</b> funded by DHSC and run by SCIE. The Evaluation says that evidence suggests that across the 6 sites the Named Social Worker model provided the framework by which 'good social work' with people with learning disabilities, autism and mental health conditions happened in practice. Elements included protected time for a named social worker caseload, where the named social worker spent time to build up trusting relationships with the individual and the people around them; protected space and peer supervision for reflecting on practice and tackling concerns and sharing good practice; opportunity to trial and practice creative methods of engagement and approaches to deliver person-centred planning with people with a learning disability and the people around them; risk-aware permissions framework, underpinned by legislation, which empowered named social workers to constructively challenge existing decisions around mental capacity and/or packages of care; elevated the status of the named social worker role which meant that named social workers worked confidently across MDTs of professionals and families to ensure the voice and wishes of the individual led</p>	<p>Thank you for your comment. The aim of the guideline is summarised as follows: 'With an increasing need for social care, variation in provision and stretched resources, it is vital to ensure commissioning and delivery is informed by the best available evidence about effective ways of working. The <a href="#">Chief Social Worker for Adults' annual report: 2018 to 2019</a> identified knowing what works and developing a better evidence base for social work practice as priorities. This guideline will support these priorities.'</p> <p>We have noted the report that is cited. Because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether this report will feature as evidence in the guideline, although it is likely to be useful contextual information.</p> <p>The identification and discussion of evidence has not yet taken place so recommendations cannot be pre-empted.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			decision-making. See: <a href="http://www.innovationunit.org/wp-content/uploads/NSW-evaluation-summary-report-1.pdf">www.innovationunit.org/wp-content/uploads/NSW-evaluation-summary-report-1.pdf</a>	
Mencap	General	General	<p>Our experience from supporting families trying to get their loved ones out of institutions, is that families often end up having to 'drive' the development of a community package of care. It is clear that in many cases the main reason the person has managed to get discharged is because the family have found the housing, found the care provider and put pressure on the LA in various ways to fund an appropriate package of care to meet the person's needs, including through campaigning and the media. They should not have to do this. We welcome the development of this guideline focusing on social work and complex needs and highlighting what good looks like/ what is expected of social workers working with people with complex needs. Of course, it will be important that social workers are given the capacity/ time and the appropriate skills and training to do it (this will include understanding what good support for people with learning disability/autism and behaviour that challenges looks like, understanding how to access appropriate housing for the person etc.). There must also be an important emphasis on fully involving the person and their family and listening to their expertise about the person's needs and what support the person needs.</p> <p><b>The Building the Right Support (Transforming Care) Evaluation</b> had numerous findings and recommendations, including '<b>Support the social care workforce</b>. The supply of this workforce threatens the viability of the community infrastructure that is needed. The social care workforce supporting people who display behaviour that challenges need</p>	<p>Thank you for your comment. The second of the 'Key areas that will be covered' is 'Individual or family casework approaches to support the person and their family and carers'. The related draft review questions are split into 2 parts with one looking for quantitative and another for qualitative information. The qualitative questions are framed in the following way 'Based on the views and experiences of everyone involved, what works well and what could be improved...' so some of these issues may be highlighted depending on the evidence that will be identified once to plans (protocols) for these reviews are finalised.</p> <p>We have noted the report that is cited, but because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether this report will feature as evidence in the guideline, although it is likely to be useful contextual information.</p> <p>Training is outside the remit of the guideline, but effective ways to address needs is. Economic analysis will be conducted to assess whether recommendations would be cost-effective or would have significant resource implications. The principles of how an economic analysis is carried out and what the impact of this is, are described in Developing <a href="#">NICE guideline: the manual</a> (which also</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			<p>qualifications, career pathways and pay progression in line with their counterparts in health and education. There could be social care apprenticeships for support workers who specialise in support for this group of people, as well as further incentives for professional development and the uptake of Positive Behaviour Support. Family carers also need to be considered an essential part of the workforce, enabling prevention and supporting independence to be greater priorities.’ See: <a href="https://www.strategyunitwm.nhs.uk/sites/default/files/2019-01/1%20Short%20Summary%20of%20Recommendations_0.pdf">https://www.strategyunitwm.nhs.uk/sites/default/files/2019-01/1%20Short%20Summary%20of%20Recommendations_0.pdf</a> (Pg 3)</p> <p>Of course, as well as social workers being given the time, skills and training to work effectively with people with complex needs, there must be a commitment to fund the end package required, including housing, specialist staff etc. to truly meet the person’s needs.</p>	<p>describes <a href="#">resources to support putting guidelines into practice</a>).</p>
Mencap	General	General	<p><b>Key areas/ issues that will be covered</b> <b>Social work assessment and care planning</b> It would be helpful for this to include a focus on the importance of a ‘comprehensive’ assessment looking at all the person’s needs, including the importance of having professionals with the right expertise inputting (including across social care, health and housing) and the assessor having the right knowledge and skills to be assessing a person with the particular needs the person has (for example, knowledge and skills around positive behaviour support if they are assessing a person with a learning disability who displays behaviour that challenges). This should happen in line with the Care Act, but we know all too often people with a</p>	<p>Thank you for your comment. In the ‘Key areas that will be covered’ section of the scope both needs and risk assessment are highlighted as topics that are included. Within these key areas we will be looking for quantitative and qualitative evidence (see the ‘Key issues and draft review questions’ section). The qualitative questions are framed in the following way ‘Based on the views and experiences of everyone involved, what works well and what could be improved...’ so some of the issues (such as skills and knowledge) may be highlighted depending on the evidence that will be identified once to plans (protocols) for</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

		<p>learning disability and behaviour that challenges are not getting comprehensive assessments and care plans which properly meet their needs. The expertise of the social worker/assessor is key as if they don't know what 'good support' looks like then the person may end up with inappropriate care/ in an inappropriate setting.</p> <p>A person may need a creative, person-centred and bespoke option to meet their needs, but the social worker has to have the skills and confidence to explore creative options and take them forward. Fully involving/ listening to the person and their families is crucial. For decisions around placements, as well as assessing risk it is very important that social workers understand the relevant legislation, which can be complex and involve the Mental Health Act, Mental Capacity Act/ DoLS etc and the criminal justice system, to enable the person to get a package of support that maximises their wellbeing and independence.</p> <p>It would be helpful in this section to specifically refer to 'care coordination' to ensure this important area is covered in the guideline (an area we know is very important for people with a learning disability who have complex needs). Currently, the draft scope says that one of the areas that will be looked at is 'the role of social workers within multidisciplinary teams and how they communicate, support and work with others.' We would like it to be clear that someone needs to be doing the 'care coordination'. (See NICE guideline on Learning disabilities and behaviour that challenges: service design and delivery: 'LAs working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to</p>	<p>these reviews are finalised. However, we cannot pre-empt what the committee will recommend.</p> <p>We agree that an understanding of the relevant legislation is important and that is why they are listed in the 'Policy, legislation, regulation and commissioning' of the scope. However, legal training is outside the scope of the guideline.</p> <p>Another topic that will be covered is 'the role of social workers within multidisciplinary teams and how they communicate, support and work with others.'</p> <p>There are 2 NICE guidelines that address the needs of people with learning disabilities whose behaviour challenges (<a href="#">Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11]</a> and <a href="#">Learning disabilities and behaviour that challenges: service design and delivery [NG93]</a>). These are highlighted in the 'Related NICE guidance' section of the scope and can be signposted to (for example in relation to the role of care coordination for people with learning difficulties) if the committee wishes to do this during development.</p>
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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			<p>meet their needs over the long term.’ – <a href="http://www.nice.org.uk/guidance/ng93/chapter/Recommendations#enabling-person-centred-care-and-support">www.nice.org.uk/guidance/ng93/chapter/Recommendations#enabling-person-centred-care-and-support</a></p> <p>It would be helpful to include in the guideline the importance of the person and their families knowing how to, and being able to, access independent information, advice and advocacy.</p>	
Mencap	General	General	<p>In our experience, and it is reflected in recent research from New Forest Mencap, too often families are having to take on the role of ‘care co-ordinator’, which can be hugely stressful. Improved social work for people with complex needs should have a positive impact on the experience of family carers, so some outcomes in relation to family carers could be considered as well when searching for and assessing the evidence around effective social work for people with complex needs.</p>	<p>Thank you for your comment. Within these key areas we will be looking for quantitative and qualitative evidence (see the ‘Key issues and draft review questions’ section). The qualitative questions are framed in the following way: ‘Based on the views and experiences of everyone involved, what works well and what could be improved...’ This means that we will be looking not only for opinions from the adult with complex needs but also all other people involved, such as families and carers. We have noted the research that is cited, but because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether this report, although it is likely to be useful contextual information.</p>
MS Society	002	025 - 027	<p>MS is one of the most common disabling neurological conditions in the UK, affecting more than 100,000 people. Symptoms often become apparent in the 20s and 30s and can vary greatly between individuals, including; loss of balance, fatigue, pain, bladder and bowel problems, visual and memory impairment, and issues with speech. It is a progressive condition and many symptoms are</p>	<p>Thank you for your comment. We have revised the definition in the section ‘Groups that will be covered’ to specifically cover complex needs that may fluctuate: ‘For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of</p>

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## Social work for adults with complex needs

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21/10/19 – 18/11/19

		<p>'hidden'. The fluctuating nature of MS means people require differing levels of care and support at different times in their lives, or even from one day to the next. This guideline should clearly state the importance of social workers having an understanding of the nature of fluctuating conditions, like MS.</p> <p>In accordance with the Care Act (2014), the draft scope acknowledges the importance of care planning and the social worker's statutory duty to complete assessments.<sup>1</sup> An MS Society survey of people with MS found that of those respondents receiving full- or part-funded local authority support, 43% told us that they have a plan for their care.<sup>2</sup> This suggests that people are not being fully involved in the development of their care plan. This guideline should clearly state the importance of ensuring the care plan is co-produced and communicated in a way the individual will understand.</p> <p>Many people with MS will need care and support to live their daily lives, at some point. An MS Society survey of people with MS found 85% of respondents relied on their family and friends to provide some level of support.<sup>2</sup> They are not alone – Carers UK (2019) estimate that there are 8.8 million unpaid carers in the UK.<sup>3</sup> In a separate as-yet unpublished survey, we found that only 24% of unpaid carers had had a carer's assessment or joint</p>	<p>illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a>).' This would therefore include people with Multiple Sclerosis when they need a high level of support with many aspects of their daily life and relying on a range of health and social care services as well as when they need support during remission.</p> <p>The second of the 'Key areas that will be covered' is 'Individual or family casework approaches to support the person and their family and carers'. The related draft review questions are split into 2 parts with one looking for quantitative and another for qualitative information. The qualitative questions are framed in the following way 'Based on the views and experiences of everyone involved, what works well and what could be improved...' which includes the views of family members and carers.</p> <p>We have noted the cited references, but because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether these will feature as evidence in the guideline or what the</p>
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<sup>1</sup> Care Act (2014) <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>2</sup> MS Society (2019), My MS My Needs survey 2019, results to be published in 2020.

<sup>3</sup> Carers UK (2019) State of Caring Report [http://www.carersuk.org/images/News\\_campaigns/CUK\\_State\\_of\\_Caring\\_2019\\_Report.pdf](http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf)

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## Social work for adults with complex needs

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21/10/19 – 18/11/19

			<p>assessment, meaning half of respondents had unmet needs (48% of 549 respondents).<sup>4</sup></p> <p>The guidelines need to acknowledge the role of unpaid and informal carers and ensure they are involved in social care assessments and care planning, as far as the individual would like them to be, and recommend that individuals and carers are offered a joint assessment.</p>	<p>conclusions or recommendations will be, although they are likely to be useful contextual information.</p>
MS Society	004	015 - 017	<p>While the draft scope outlines the meaning of ‘complex needs’, based on the definition by the Think Local Act Personal partnership, there is no definition provided for ‘high level of support’. Neurological conditions are still misunderstood and can be complex, prone to fluctuation, crisis or relapse.<sup>5</sup> They can impact quality of life and the ability to complete day to day activities.</p> <p>Charlotte was diagnosed with MS at the age of 17, she explains that “every day is different – some days I have a lot of strength and can text my friend and go out and the next day I won’t have any energy or strength in me”. Charlotte, now 19, relies on her mum to drive to her to college and prepare meals and, on some days, help her out of bed and get dressed. Though, at the moment, her MS is well controlled and she can be more independent.</p>	<p>Thank you for your comment. We have revised the definition in the section ‘Groups that will be covered’ to specifically cover complex needs that may fluctuate:: ‘For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a>).’ This would therefore include people with Multiple Sclerosis when they need a high level of support with many aspects of their daily life and relying on a range of health and social care services as well as people in remission.</p>

<sup>4</sup> MS Society (2019) MS Family and Friends survey unpublished.

<sup>5</sup> Neurological Alliance (2019) Neuro Patience: still waiting for improvements in treatment and care <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf>

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21/10/19 – 18/11/19

			The lack of definition provided for what constitutes as a 'high level of need' leaves an element of ambiguity in this guidance. To ensure the needs of people with MS are met, the final guideline needs to detail what this criteria means and allow for fluctuation within complex conditions like MS.	
MS Society	005	020 - 021	The guidelines should recommend the sharing of information about an individual's condition and signposting to services and support. As Christine, 42 from Birmingham who lives with relapsing-remitting MS, says, "information is so valuable . . . you have to have as much information as possible". Yet, a 2018 MS Society survey of people with MS in the UK found 19% of respondents felt they had not received sufficient information in relation to their MS in the past 12 months. <sup>6</sup> For Christine, and other people living with MS, information makes her feel empowered and gives her more control of her condition.	Thank you for your comment. We recognise the importance of information sharing in this context. Although it is not demarcated as a key area in itself, we anticipate that the need for clear, accessible information will feature in the results of evidence reviews, especially those designed to locate qualitative data about what works well and what could be improved.
MS Society	009	024 - 025	In England, 1 in 6 people live with one or more neurological condition, and this is rising. <sup>7</sup> Though the draft scope includes the consideration of changing needs, we would want to see it recommend that assessing social workers have an understanding of complex conditions including neurological conditions.  Understanding neurological conditions and their symptoms is important if the planning and delivery of person-centred care to	Thank you for your comment. The population for this guideline is adults with complex needs. Although it will not focus on adults with any specific conditions, it is likely that evidence about the issues you identify will be identified by the reviews underpinning this guideline. However, please note that there is currently a NICE guideline in development about the management of multiple sclerosis in adults, which is currently in its scoping phase. Please follow this link to the NICE website for further details

<sup>6</sup> MS Society (2019), My MS My Needs survey 2019, results to be published in 2020.

<sup>7</sup> Neurological Alliance (2019) <https://www.neural.org.uk/assets/pdfs/neuro-numbers-2019.pdf>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			<p>people with these conditions.<sup>8</sup> There is an evidence gap as to the current level of understanding of neurological conditions amongst social work teams and it would be helpful if this guideline could recommend further research is carried out to address that.</p> <p>We believe given the complexity of neurological conditions like MS, there is a need for separate guidance to be developed on how people with these conditions should best be supported by social care.</p>	<p><a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10153">https://www.nice.org.uk/guidance/indevelopment/gid-ng10153</a></p>
National Autistic Society	001	012	<p>Add 'autism' to the description of who the guideline will cover, to make it clear that autistic people are not excluded even if they do not have a learning disability or a mental health need. Autism is not synonymous with learning disability or mental health. While many adults on the autism spectrum do have an accompanying learning disability or poor mental health, others do not. But the absence of a learning disability or poor mental health does not mean that an autistic person doesn't also have other complex needs associated with their autism. We know from a recent study carried out by the All Party Parliamentary Group on Autism into the Autism Act that there is a high level of unmet need amongst autistic people. More than two-thirds of autistic adults are not getting the day-to-day support they need. [Reference: APPGA/National Autistic Society, 2019, 'The Autism Act, 10 Years On']</p> <p>We recommend that the guideline scope states clearly that autistic adults should be covered in the guideline.</p>	<p>Thank you for your comment. In the section 'Groups that will be covered' in the scope the following definition is provided: 'For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a>).' This would therefore include people with neurodevelopmental conditions as long as they need a high level of support with many aspects of their daily life and relying on a range of health and social care services. For those people the recommendations about the principles of social work resulting from the guideline would apply.</p>

<sup>8</sup> NHS (2019) Interim NHS People Plan [https://www.longtermplan.nhs.uk/wp-content/uploads/2019/05/Interim-NHS-People-Plan\\_June2019.pdf](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/05/Interim-NHS-People-Plan_June2019.pdf)

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### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			We suggest the following wording: “People with complex needs, including learning disabilities, mental health needs, <u>and autism</u> , often experience difficulties in their daily lives and in their relationships with other people and social institutions.”	Autistic people are also named as a specific group for which there are equality considerations. This is noted in the Equality Impact Assessment form.
National Autistic Society	004	001	<p>As above: Add ‘autism’ to the description of who the guideline will cover.</p> <p>We suggest the following wording: “Adults with complex needs (including learning disabilities, mental health difficulties, <u>and autism</u>), their families or carers, and the public.”</p>	<p>Thank you for your comment. We have removed ‘including learning disabilities and mental health’ from the background section of the scope because we agree that this would single out these particular conditions.</p> <p>In the section ‘Groups that will be covered’ in the scope the following definition is provided: ‘For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a>).’ This would therefore include people with neurodevelopmental conditions as long as they need a high level of support with many aspects of their daily life and relying on a range of health and social care services. For those people the recommendations about the principles of social work resulting from the guideline would apply.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				<p>Autistic people are also named as a specific group for which there are equality considerations. This is noted in the Equality Impact Assessment form.</p> <p>We have noted the cited references, but because the plans (protocols) for the individual review topics have not been finalised with the committee, we are unable to say whether these will feature as evidence in the guideline.</p>
National Autistic Society	005	020	<p>Add 'reducing loneliness and/or social isolation'.</p> <p>We suggest the following wording:</p> <p><u>"Promoting self-esteem and confidence, and reducing loneliness and/or social isolation, by building on strengths and developing coping strategies."</u></p>	<p>Thank you for your comment. We recognise the importance of reducing social isolation and loneliness and although this exact wording has not been used, it is reflected in another key area in the scope about helping people to connect with their local communities by using neighbourhood networks and local area coordination, including peer support. It is also reflected in the key outcomes for which we will be searching for evidence, for example 'social capital (referring to the range of social contact that provides access to social, emotional and practical support)'.</p>
National Autistic Society	005	031	<p>Add social groups and befriending services.</p> <p>We suggest the following wording:</p> <p><u>"...including peer support, social groups and befriending services."</u></p>	<p>Thank you for your comment. We recognise the importance of social groups and befriending services and although these exact terms have not been used, they are intended to be covered by the broader terms of 'neighbourhood networks and local area coordination, including peer support'. Social work support through these particular services would be explored in the draft review question about the effectiveness and acceptability of support to help people connect with local communities. Specific approaches will be included in the review protocols, subject to discussion with the guideline committee.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

National Autistic Society	009	016	<p>Add two further questions under 'Needs assessment':</p> <p>"What training do social workers need in relation to specific types of complex needs (such as the needs of autistic adults), and how is this most effectively provided?"</p> <p>"How can social workers ensure that assessment processes work effectively for adults with a wide range of complex needs, recognising the communication challenges that many adults in this group experience?"</p>	<p>Thank you for your suggestion. We anticipate that data about specific knowledge and skills for a particular aspect of care will be identified by the proposed evidence review on what works well and what could be improved about social work assessments for adults with complex needs. This question is also likely to locate evidence relevant to the question about ensuring assessment processes address the needs of adults with complex needs and communication challenges. The key is that the guideline will cover all adults with complex needs, including but not specifically focussed on people with communication challenges.</p>
National Autistic Society	010	008	<p>Add a further question under 'Preventing an escalation of need...':</p> <p>"What is the evidence (including economic evidence) on how to avoid situations where individuals and families are unable to access help and support until they reach crisis point?"</p>	<p>Thank you for your suggestion. We recognise the importance of the point you make but we think that data relevant to this is likely to be identified by the proposed evidence review about the effectiveness of assessing and reviewing complex care and support needs and what works well or could be improved in this context. If care and support needs are effectively assessed and reviewed, then this would contribute towards avoiding the situations you describe.</p>
National Autistic Society	011	006	<p>Add social groups and befriending services.</p> <p>We suggest the following wording:</p> <p>"...including peer support, <u>social groups and befriending services</u>."</p>	<p>Thank you for your suggestion. We recognise the importance of social groups and befriending services and although these exact terms have not been used, they are intended to be covered by the questions using the broader terms of 'social and community support to promote social inclusion'. Social work support using the specific services you suggest – and any others that are relevant - would be explored in this draft review question. Specific approaches</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				will be included in the review protocols, subject to discussion with the guideline committee.
National Autistic Society	011	010	<p>Add social groups and befriending services.</p> <p>We suggest the following wording:</p> <p>“...including peer support, <u>social groups and befriending services</u>.”</p>	Thank you for your suggestion. We recognise the importance of social groups and befriending services and although these exact terms have not been used, they are intended to be covered by the questions using the broader terms of ‘social and community support to promote social inclusion’. Social work support using the specific services you suggest – and any others that are relevant - would be explored in this draft review question. Specific approaches will be included in the review protocols, subject to discussion with the guideline committee.
National Autistic Society	011	017	Add “ <u>reduction in loneliness and/or social isolation</u> ” as a further outcome under ‘Person-focused’.	Thank you for your suggestion. During drafting of the scope it was agreed that this was covered by the wider outcomes of ‘participation and inclusion’ and ‘social capital’. When the review protocols are developed by these will be considered by the committee.
NHS England/NHS Improvement	General	General	<p><b>Stakeholder list</b></p> <p>It would be useful to include the British Dietetic Association and Chartered Society of Physiotherapy as stakeholders to this scope and guideline (SC)</p>	Thank you for your comment. We will invite these organisations to register.
NHS England/NHS Improvement	010	016	With an increasing number of integrated team including Social care and health colleagues. We welcome the opportunity to review how multi professional teams can work together to effectively meet the needs of adults with complex needs and minimise delays in people accessing that support. (SC)	Thank you for your comment.

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

NHS England/NHS Improvement	010	016 - 023	Hopefully PCNs will help facilitate this. Despite best intentions of most, traditionally very little integration or real team work/understanding of roles. (DS)	Thank you for your comment. We anticipate that this proposed evidence review may identify data supporting the point you have highlighted (although we cannot pre-empt the content of recommendations at this stage).
Royal College of Nursing	General	General	Many thanks for the opportunity to contribute to this, the RCN do not have any comments to add on this occasion.	Thank you for your comment.
Royal College of Occupational Therapists	General	General	Given comment 2 above, there is a need for social workers in local authorities to collaborate with occupational therapists when undertaking assessment and interventions, particularly with people with complex needs. In terms of the scope, some consideration should be given to this specific interface, rather than just the more general reference to multidisciplinary teams.	Thank you for your comment. In the 'Key areas that will be covered' one of the topics is 'the role of social workers within multidisciplinary teams and how they communicate, support and work with others'. There would be a range of 'others' and we did not want to be too prescriptive about comprehensively listing them. However, we expect that the interface with occupational therapist may form part of this.
Royal College of Occupational Therapists	001	004	There are currently occupational therapists who work as social care practitioners. Where social work is used within the title and the content of the document, the term social care practitioner could be used instead. The content of the document is relevant for someone undertaking this role, irrespective of their professional background.	Thank you for your comment. We recognise that occupational therapists are also involved in activities that are known as social work. We also recognise a range of different professionals undertake social work activities. However, this is a guideline specifically related to social work and we have stated that we will look at social work which is 'led or delivered by a registered social worker'. This may include other practitioners as long as that work is led by a social worker. Using 'social care practitioner' instead of this approach would significantly widen the remit of the scope and would no longer specifically focus on the work that social workers carry out.
Royal College of Occupational Therapists	002	025 - 027	The statutory duties to assess are placed on the local authority and not on social workers specifically. It should be made clear that both occupational therapists and social workers are	Thank you for your comment. This has been revised to reflect the focus of the scope on social work and the fact that assessment, which can also be carried out by an occupational therapist, is a duty delegated by the local

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			employed by Local Authorities to undertake statutory assessments, or at least reference made to this fact.	authority. We have also added occupational therapists to the scope's 'who the guideline is for' subsection.
Royal College of Occupational Therapists	004	014	Consideration should be given to the guideline applying from 16, specifically given the link with the Mental Capacity Act, which applies from 16.	<p>Thank you for your comment. We have added to the 'Who the guideline is for' section that 'it may also be relevant for people aged 16-18 with complex needs who have completed transition from children to adult services'.</p> <p>However, we will not specifically search for evidence for the 16-18 year old group because this would mean to widen every search to children as well as adults. Please also note that there is another guideline '<a href="#">Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education</a>' currently in development (expected to publish May 2021) which focuses on service delivery in this age group and the transition to adult services.</p> <p>The specific topic of transition is the exclusive focus of another NICE guideline [NG43], <a href="#">Transition from children's to adult's services for young people using health and social care services (2016)</a> which covers this age group.</p>
Tees Esk and Wear Valleys NHS Foundation Trust	General	General	This guidance is welcomed. It will support social workers within our Trust, including those in generic roles, and will support our recovery pathway for service users.	Thank you for your comment.

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

Tees Esk and Wear Valleys NHS Foundation Trust	General	General	The guidance does not include anything around poverty. Given the impact this has on service users' physical and mental health, it is suggested that this should be explored in more detail.	Thank you for your comment. The Equality Impact Assessment (EIA) form lists 'Socioeconomic factors' as a specific characteristic with an impact on this guideline. The EIA form states: 'People with complex needs from lower socioeconomic background may need help to navigate the social care system to help them get the support that they are entitled to (both financial and personal). Some socioeconomic factors and social deprivation would also directly link to a higher need for social work support.' This means that specific consideration will be given to this group and recommendations covering this could be made where appropriate.
The Challenging Behaviour Foundation	General	General	<p>The Challenging Behaviour Foundation is a national charity which supports children, young people and adults with severe learning disabilities whose behaviour challenges and their families.</p> <p>We believe that with the right support, at the right time, in the right place that this group can be supported to live full lives in their communities and that they have the same right to this as everybody else.</p> <p>Family carers in contact with the CBF are concerned that improved guidance will not impact social work practice on the ground. Therefore, the guidance must make clear how its recommendations will translate into practice.</p> <p>For more information on the work of the Challenging Behaviour Foundation please see our website:</p>	<p>Thank you for your comment. NICE has already produced guidelines that address the needs of people with learning disabilities whose behaviour challenges (<a href="#">Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11]</a> and <a href="#">Learning disabilities and behaviour that challenges: service design and delivery [NG93]</a>). These are highlighted in the in the 'Related NICE guidance' section of the scope. However, since these are people with complex needs the principles of social work resulting from this guideline will also apply to this group.</p> <p>NICE guidelines make recommendations for practice rather than for implementation but during development the guideline committee will be mindful of implementation challenges. Broad principles about the types of <a href="#">resources to support putting guidelines into practice</a> can be found in <a href="#">Developing NICE guideline: the manual</a>.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			<a href="https://www.challengingbehaviour.org.uk/about-us/about-the-cbf.html">https://www.challengingbehaviour.org.uk/about-us/about-the-cbf.html</a>	
The Challenging Behaviour Foundation	002	028	The Care Quality Commission State of Care Report 2018-2019 <sup>9</sup> highlights how care for children, young people, and adults with a learning disability is 'unacceptable'. Therefore, there needs to be a focus on this group in the guidance to reduce existing inequalities in care and support.	Thank you for your comment. Social work in relation to adults with a learning disability is included in the guideline as long as they have complex needs. Including children with complex needs into the guideline would substantially widen the scope and would delay the production of this guideline. There is another guideline ' <a href="#">Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education</a> ' currently in development (expected to publish May 2021) which focuses on service delivery in this age group. Follow the link to find details about the progress of this guideline.
The Challenging Behaviour Foundation	004	015	It needs to be clear in the guidance that 'adults with complex needs' includes adults with severe learning disabilities whose behaviour challenges.	Thank you for your comment. NICE has already produced guidelines that address the needs of people with learning disabilities whose behaviour challenges ( <a href="#">Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11]</a> and <a href="#">Learning disabilities and behaviour that challenges: service design and delivery [NG93]</a> ). These are highlighted in the in the 'Related NICE guidance' section of the scope. However, since these are people with complex needs the principles of social work resulting from this guideline will also apply to this group.

<sup>9</sup> CQC State of Health Care and Adult Social Care in England 2018/19

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

The Challenging Behaviour Foundation	005	002	There needs to be focus on preventative and not just reactive approaches. Adequate support should be provided at all stages and not only when the adult is in or at risk of crisis.	Thank you for your comment. In the 'Main outcomes' section it lists timeliness (this could relate to timing to prevent an escalation of need, timing to address current need, or timing to provide urgent support). It is 'prevention of an escalation of need' rather than 'prevention of complex needs' which would be covered because everyone could have a complex need at one or another point in their lives and preventing everyone from having complex needs would not be the remit of social work.
The Challenging Behaviour Foundation	005	010	When considering the wishes of the individual and how these might change, adjustments need to be made to ensure that those adults with complex needs who are non-verbal or lack capacity have their views heard. This will involve working with the individual, family carers and others who know the individual well. Methods including PECS, Talking Mats, and individual forms of communication such as gestures, sounds and movements can be used to gain the views of adults with severe learning disabilities who are non-verbal. Social workers will also need to consider how they communicate and ensure that what they are saying is accessible for the individual. Where the individual lacks capacity, family carers and others who support this individual should be involved in decisions around best interests.	<p>Thank you for your comment. We have revised the second bullet of key area 2 to 'promoting self-esteem, and confidence and self-advocacy by building on strengths, enabling communication and developing supporting the development of coping strategies'. This will capture the needs of people who have communication difficulties.</p> <p>We are aware that communication is an integral part of social work that cannot easily be separated into an individual topic since it impacts on all key areas. We anticipate that 'communication' may feature as a theme in many of the review questions that take a qualitative approach 'Based on the views and experiences of everyone involved, what works well and what could be improved...' as something that may have gone wrong or something that had a positive impact when done well. Therefore, recommendations could be made even if it is not a specific key area.</p> <p>Communication needs are also named as a specific characteristic for which there are equality considerations.</p>

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				<p>This is noted in the Equality Impact Assessment (EIA) form: 'People with complex needs may have physical, mental health, cognitive, communication needs or disabilities and disorders (including behavioural and social communication disorders), learning disability and sensory and communication impairments'.</p> <p>Finally, in terms of mental capacity, the draft scope acknowledges the importance of this within the context of social work for adults with complex needs, citing as relevant legislation the Mental Capacity 2005 and Mental Capacity (Amendment) Act 2009. Links between this guideline and the NICE guideline on Decision Making and Mental Capacity are also anticipated and this is link is made in the draft scope.</p>
The Challenging Behaviour Foundation	005	012	<p>Transition from children to adult services needs to be considered. Early intervention is key and should be available before the individual reaches adulthood. This will reduce the likelihood of escalation of support and need as young people transition into adult services. Please see the CBF and CDC's Paving the Way (2014) resource for more information on how to develop services to provide early intervention.<sup>10</sup></p> <p>Transition is often a time when support breaks down. Adult social workers need to work closely with children and young people's services who have been supporting the individual previously.</p>	<p>Thank you for your suggestion. The population of this guideline is adults aged 18 years and over and as such transition from children to adult services is not defined as one of the key areas for investigation. Nevertheless, the guideline will focus on social work assessment and care planning, including supporting people to plan for the future, considering changing needs, wishes and capabilities. It is possible that evidence around this issue will relate to young people (18 years and over) and in this sense be relevant to planning as needs and available support change.</p> <p>The specific topic of transition is the exclusive focus of another NICE guideline [NG43], <a href="#">Transition from children's</a></p>

<sup>10</sup> *Paving the Way: how to develop effective local services for children with learning disabilities whose behaviours challenge*, CBF, CDC (2014)

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

				<a href="#">to adult's services for young people using health and social care services (2016)</a>
The Challenging Behaviour Foundation	005	016	Social workers need to work closely with the families of individuals with complex needs. Families often have in depth knowledge of the individual across their whole lifetime and understanding of how they can best be supported. Equally, reports indicate that ethnic minorities are less likely to be aware of or receive support <sup>11</sup> ; the cultural and/or religious identity of the family setting must be taken into consideration when providing support and advice as not all options may be appropriate.	Thank you for your comment. We are reassured to hear that the issues you describe are captured in the guideline scope and will be the focus of our evidence reviews.
The Challenging Behaviour Foundation	005	025	If an individual or their family refuses support, the appropriateness of the support should be considered. If the family carer and/or the individual does not feel that the support being offered is appropriate, support that meets the needs of the individual should be found/supplied. All support should be person-centred and tailored to meet good care outcomes and ensure a good quality of life for the individual and their family.	Thank you for your comment. We agree that support should be person centred and tailored to address people's needs and preferences. We anticipate the importance of this could emerge from the evidence identified in the individual reviews.
The Challenging Behaviour Foundation	006	002	The guidelines for social work for adults with complex needs should take into consideration the organisation and structure of other services. For individuals with a learning disability and/or autism and behaviour that challenges, coordinated and joined-up support across services is crucial and this should be recognized and highlighted as needed.	Thank you for your comment. It is likely that evidence about joint working and coordination of support for adults with complex needs will be identified through the evidence reviews, particularly the draft questions about integrated working among registered social workers and other practitioners. The draft scope specifically excludes the 'organisation of services' because this is an area that is dealt with in NICE service delivery guidelines.

<sup>11</sup> *Insights: Improving support for black and minority ethnic (BME) carers*, Institute for Research and Innovation in Social Services (2010)

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

The Challenging Behaviour Foundation	006	003	Adults with learning disabilities and/ or autism whose behaviour challenges are at high risk of experiencing inadequate care <sup>12</sup> and restrictive interventions. This needs to be recognized within this guidance.	Thank you for your comment. The draft scope for this guideline covers all adults with complex needs, which is often likely to include adults with learning disabilities and/ or autism. The issues you raise are therefore likely to be identified during the development of the guideline.
The Challenging Behaviour Foundation	009	002	All care plans should be built around good outcomes for the individual. Good outcomes for the individual should be the priority. Individual needs must be met appropriately and effectively and this includes the provision of early intervention to prevent people reaching crisis. This approach is not only cost effective both financially but essential to the well-being of the individual and families.	Thank you for your comment. We agree with you about the primary importance of achieving good outcomes for individuals in this context and are confident this will emerge through the evidence reviews and expertise of the guideline committee members.
The Challenging Behaviour Foundation	009	020	'everyone involved' should be defined clearly as including individuals with complex needs and their family carers. The necessary support should be provided to ensure the views of both individuals and their families are heard in discussions about what works well and what could be improved about social work assessments of complex care and support needs.	Thank you for your comment. The phrase 'everyone involved' was deliberately used to make it clear that we will be searching for published evidence about the views of everyone involved, including adults with complex needs, their families and supporters and relevant practitioners. This will be specified in the review protocols.
The Challenging Behaviour Foundation	010	010	Social work support should be consistent, take into consideration the family's views and knowledge of the individual's needs and not only be provided during or leading up to crisis. Social care should aim to have a single point of contact for all other social	Thank you for your comment. We recognise these as important issues and anticipate that the proposed evidence reviews may locate relevant data, therefore potentially providing the basis on which the committee could draft

<sup>12</sup> CQC State of Health Care and Adult Social Care in England 2018/19

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			care services and support that the individual needs/is in contact with.	recommendations (although we cannot pre-empt the content of recommendations at this stage).
The Challenging Behaviour Foundation	010	016	It is vital that services across health, social care, education and housing work together and with the individual and their family to provide care and support to the individual in their community. This co-ordinated approach should include clear lines of accountability for the individual's care.	Thank you for your comment. We recognise these as important issues and anticipate that the proposed evidence reviews may locate relevant data, therefore potentially providing the basis on which the committee could draft recommendations (although we cannot pre-empt the content of recommendations at this stage).
The Challenging Behaviour Foundation	011	006	The necessary adaptations and adjustments should be made to enable individuals with complex needs, including those with learning disabilities whose behaviour challenges and who are non-verbal, to be included in their local community.	Thank you for your comment. If this is an area for improvement in terms of how social work supports people to connect with their local community then we anticipate that relevant published research is likely to be identified by our evidence reviews and therefore presented to the committee for their deliberation.
The Challenging Behaviour Foundation	011	023	Social care should be concerned with ensuring that there is provision in the community, employment and training to prepare for and support individuals with a learning disability and/or autism and behaviour that challenges. If it is the social worker's priority to ensure individuals have equal opportunity to these as per their human rights, social care needs to ensure that the individual and the places they are headed are supported to make this transition and placement successful.	Thank you for your comment. It is anticipated that the issues you raise will be explored by a number of the proposed evidence reviews, including needs assessment, supporting people to plan for the future and helping people to connect with communities (which could include connecting with employment, education and training opportunities).
The Challenging Behaviour Foundation	012	002	Intervention and support should be early, ongoing and adapt to meet the needs of the individual. Although timeliness is important to prevent escalation of a crisis, it is also relevant to the support provided throughout an adult's life. The provision of support should be reviewed regularly and adapted according to the individual's needs. Transition from child to adult services is likely	Thank you for your comment. It is anticipated that the evidence is likely to be identified by the proposed reviews that is related to the issues you highlight (although we cannot pre-empt the content of recommendations at this stage). Please note that the guideline population is adults 18 years and above so the extent to which issues arising from the transition from children's to adult's services may be limited. However, please note that there is a NICE

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## Social work for adults with complex needs

### Consultation on draft scope Stakeholder comments table

21/10/19 – 18/11/19

			to be a time when the timely provision of appropriate support is particularly important <sup>13</sup> .	guideline [NG43] specifically addressing this important topic, <a href="#">Transition from children's to adult's services for young people using health and social care services (2016)</a>
The King's Fund	002	021	People who sleep rough have high levels of multiple and complex needs that are often unmet. The draft scope states that 'adults with complex needs may receive social care at home, in residential or nursing homes, or through short-term reablement support'. This should be extended to include social care delivered to people sleeping on the street or in hostels/supported accommodation. There is a danger that this group will be overlooked.	Thank you for your comment. We recognised that it is difficult to write a comprehensive list of all possible settings that a social worker might work in. We have therefore revised the paragraph to refer to a 'range of settings'. It is clear in another section of the scope entitled 'settings' that the guideline will include 'All settings where social work is provided for adults with complex needs'.
The King's Fund	004	013	The draft scope states that complex needs may be present from birth or may develop after illness or injury or as people get older. <a href="#">Our ongoing work in this area</a> suggests that substance use and broader life circumstances, including childhood trauma, can also create the conditions that result in people having complex needs.	Thank you for your comment. We have revised the definition as follows and it no longer includes the wording 'develop after illness or injury': 'For the purpose of this guideline adults with complex needs are defined as people needing a high level of support with many aspects of their daily life and relying on a range of health and social care services. This may be because of illness, disability, broader life circumstances or a combination of these. Complex needs may be present from birth, or may develop over the course of a person's life and may fluctuate. (Based on <a href="#">a definition of complex needs by the Think Local Act Personal partnership</a> ).'

<sup>13</sup> Mencap <https://www.mencap.org.uk/advice-and-support/children-and-young-people/education-support/transition-adult-services>