People's experience in adult social care services: improving the experience of care and support for people using adult social care services

Consultation on draft guideline - Stakeholder comments table

22/08/17-03/10/17

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Arthritis Research UK	Short	16	19-120 (Involving people in service design and improvement)	We suggest that the guideline should: Reinforce the need for local authorities to communicate people's rights under the Care Act so that people are more aware of how they can be involved in coproducing care and support services.	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation and have cross-reference to the Care Act throughout. The Committee thought this was important to include specifically given its cross-cutting importance to this guideline. We include the additional text on making people aware of their rights and entitlements in line with the Care Act in recommendation 1.2.1.
Arthritis Research UK	Short	NA	General	Arthritis Research UK has set out recommendations for both local government and central government, on the provision of social care services for people with arthritis, which can be found here: http://www.arthritisresearchuk.org/policy-and-public-affairs/our-policy-positions/social-care.aspx	Thank you for your comment. The NICE guideline is aimed at a much larger population i.e. all adults receiving social care (not just those with arthritis). Hence there are no specific recommendations on this condition.
Arthritis Research UK	Short	4-5	16-30, 1-15 (Access to care)	We suggest that the guideline should ensure that local planning documents adequately capture the social care needs of the population (e.g.): Local authorities should ensure that their local planning documents, including STPs, JSNAs and JHWSs, capture the social care needs of people with arthritis, and plan for the provision of social care services for people with arthritis, stratified by level of need.	Thank you for your comment. The issue of local planning documents adequately capturing the social care needs of the population was out of scope for this guideline, which focused on the views and experiences of people who use services.
Arthritis Research UK	Short	7	5-19 (Section 1.3 Information)	We suggest that the guideline should: Encourage local authorities to use their information and advice services to communicate people's rights around needs assessments to people with care and support needs and their carers who aren't in touch with the formal care and support system.	Thank you for your comment. The Guideline Committee agree it is useful to highlight the role of information and advice services and have strengthened recommendation 1.2.2 to include the role of community spaces as well as specialist services for related populations such as homeless health centres.
British Association for Social Workers (BASW)	Short	4	1.1.6	Communication aids. No mention is made in the example of communication aids for those with hearing impairment and also suggest advice on helpful communication methods for those with a hearing impairment. (Clear speech, good lighting, facing the person directly).	Thank you for your comment. The Guideline Committee agreed on the importance of communication aids. We have amended this recommendation (now 1.1.5) to include reference to hearing loops, clear lighting, and minimal noise interference. This issue has been noted in the Equality Impact Assessment form.
British Association for Social Workers (BASW)	Short	5	1.13	Assumes that the person who is having a care and support needs assessment has capacity. If not then sharing of information with family and friend's carers may be appropriate. There are also specific guidance for situations where someone may be at risk of suicide where guidance indicates that sharing of information with carers may be appropriate see: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/271792/Consensus_statement_on_information_sharing.pdf Issues re confidentiality where people are self neglecting: https://www.scie.org.uk/publications/reports/69-self-neglect-policy-practice-building-an-evidence-base-for-adult-social-care/files/report69.pdf Suggested that advice is given on the evidence of the benefits of working consensually with carers leads to better outcomes. Achieving this is a complex area of work and requires high level skills and judgements in working with people who are being assessed for care and support needs and their family carers. Carers rights for an assessment under the Care Act should also be included, or cross referenced in this section.	Thank you for your comment and link to specific resources. The Guideline Committee agreed that the level of detail in this recommendation is sufficient. However, reference to advocates and more clarity about the timing of review of care and support decisions and this has now been included. Recommendation 1.1.16 also states: 'If a person lacks the capacity to make a decision about whether they wish their carers, family and friends involved , the provisions of the Mental Capacity Act 2005 must be followed'. We have added a footnote stating that there is a forthcoming NICE guideline in development on Carers: provision of support for adult carers to recommendation 1.1.15.

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British Association for Social Workers (BASW)	Short	8	1.4.3	1.4.3 Local authorities must ensure that care and support needs assessment under the Care Act 2014 for people ~~who use or who may need social care services~~ with care and support needs focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve. RATIONALE Prefer wording used in Care Act. Original wording has elements of being service-led.	Thank you for your comment and your support for the guideline. We have now revised recommendation 1.3.3 as follows: 1.3.3 Local authorities must ensure that care and support needs assessment under the Care Act 2014 focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day-to-day life.
British Association for Social Workers (BASW)	Short	9	1.4.8	1.4.8 An assessment cannot state what services will be provided to an individual. This process cannot take place until an assessment of needs has been completed and the local authority has agreed with the individual which of their care and support needs will be met.	Thank you for your comment. The Guideline Committee agree that what services will be provided to an individual is negotiated during the process of assessment where the local authority has agreed with the individual which of their care and support needs will be met. The amended recommendation (now 1.3.8) reads: 1.3.8 Ensure that care and support needs assessment documentation about the person is accurate, up to date and well maintained and clarifies what assessed needs will be met and how.
Care and Repair England	Short version	General	General	Having a good, decent, warm, accessible home plays an important role in supporting the delivery of good social care for people living in the community – in their own homes and in supported and specialist housing. It can enhance the experience of social care for those who use adult social care services. Indeed, housing interventions such as adaptations to the home are an important ingredient in delivering social care services to people in their own homes. We have some concern there is very little mention of housing in the NICE guidance on improving the experience of people using adult social care especially given the recognition in the Care Act of the role housing can play in supporting people's wellbeing and independence. Some reference to the role of housing in the document would encourage a greater focus on the delivery of holistic services for people using adult social care services. We make some suggestions where housing might be highlighted and propose a broader research idea.	Thank you for your comment. The Guideline Committee agree on the importance of accommodation in terms of health and wellbeing. While it was out of scope to search the housing literature – and therefore we cannot make specific recommendations on housing – the recommendations apply to people wherever they live and this is also made clear in the Scope. In addition, we have added a reference to housing in 1.2.4 to make clear that this is one of the many aspects of people's support needs that should be considered in care planning. We have also revised recommendation 1.3.10 to state that a named coordinator should liaise with housing as well as health and social care.
Care and Repair England	Short version	Page 6	Line 12	Suggest this says liaises and works with all health, social care **and housing** services	Thank you for your comment. We agree it is important to highlight the role of housing and as such have amended recommendation 1.3.10 accordingly.
Care and Repair England	Short version	Page 7	Line 7 -9	Where there is reference to the types of care and support we would suggest adding a reference to housing	Thank you for your comment. We have amended the introduction to make clear that the Care Act places a duty on local authorities to integrate health social care and related services to promote wellbeing. We have amended 1.2.4 to say that information about housing should be provided. And that care assessments should take into account a person's housing status, and where and who they want to live with. Also, see rec 1.3.4 which says 'care assessments should take into account a person's housing status, and where and who they want to live with'
Care and Repair England	Short version	Page 7	Line 13	Information about care and support **including housing** options	Thank you for your comment. We have amended the introduction to make clear that the Care Act places a duty on local authorities to integrate health social care and related services to promote wellbeing. We have amended 1.3.4 to say that information about housing should be provided. And that care assessments

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					should take into account a person’s housing status, and where and who they want to live with**.**
Care and Repair England	Short version	Page 27	Line 1	As well as the use of technology we would like to have seen research on the role of adaptations and other housing interventions and would draw your attention to the work of our Catch 22 project which also identifies work already occurring about housing interventions which can be drawn upon. http://careandrepair-england.org.uk/wp-content/uploads/2017/06/Catch-22-Brochure-Online.pdf	Thank you for your comment and for the link to resources. Research on the effectiveness of adaptations and other housing interventions was out of scope for this guideline and research evidence on people’s views and experiences of the role of housing adaptations was lacking. The Guideline Committee made a research recommendation in this area: What are the views and experiences of people who use adult social care services on assistive technologies?
Care Quality Commission	Full	General	General	The overall guideline promotes improving people’s experience of care in a person centred way. The recommendations support the fundamental standards of care and support the regulation of care providers by the Care Quality Commission.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
Care Quality Commission	full	398	General	We would recommend making reference to the following guidelines as they promote improving patient outcomes and experience for medicines. SC1 Managing medicines in care homes, NG67 managing medicines in community settings and NG5 Medicines optimisation. These could also be referenced in other parts of the guideline such as 1.14.2, 1.4.4 and 1.2.2.	Thank you for your comment. We have reviewed these guidelines for relevance to this guideline and added a cross-reference to SC1 Managing medicines in care homes to recommendation 1.4.13. Reference to managing medicines in residential settings was covered in this recommendation, reflecting the relatively greater evidence found in this area compared to other settings
Care Quality Commission	Short	4	1.1.9	This could make reference to treatment choices (e.g. medical, surgical or blood products)	Thank you for your comment. We agree it is useful to highlight the issue of treatment choices and have added this to recommendation 1.1.11.
Care Quality Commission	Short	11	14	The term Practitioners is used and it’s not defined in the document. It’s unclear if they are referring to social care practitioners. In other guidance such as NG67 they have specified social care practitioners, which was defined as including, but are not limited to, care workers, case managers, care coordinators and social workers.	Thank you for your comment. The Guideline Committee agreed that we should use the term ‘practitioner’ and have defined this in the section ‘Terms used in this guideline’.
Care Quality Commission	Short	14	1.5.13	We recommend making reference to self-medication, people should be supported to self medicate when they wish and are able to do so. Reference could be made to managing medicines in care homes SC1 and NG67 guidance for medicines in community settings.	Thank you for your comment. This guideline focuses on social care practice, so we have not made reference to medication. Social care practice now increasingly includes medicines support and this recommendation was driven by evidence based in residential settings. We have reviewed the guidelines you have suggested for relevance to this guideline and added a cross-reference to SC1 Managing medicines in care homes to recommendation 1.4.13.
Carers Trust	Full	General	General	Misuse of the term “carer”. A carer is anyone who cares, **unpaid**, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. The document quotes several studies where either the authors or the participants misuse the term “carer” when referring to paid care support workers. For consistency with the main guidelines, NICE should make clear it clear where the quotes refer to paid care support worker to avoid any possible confusion with unpaid carers.	Thank you for your comment. We agree it is useful highlight this point. By carer, we mean ‘unpaid carer.’ This has been defined in the section of the guideline ‘Terms used in this guideline’.
Carers Trust	Full	General		The guidance should make more reference to the upcoming NICE Guidance for Adult Carers. When published, this guide should link to the guideline for carers to ensure that these two documents work together to complement each other. The two documents should be mutually supportive and work together to ensure that staff are aware of the need to support carers. It is important that staff see carers as partners in care, are made aware of the links between caring for the person with care and support needs, and identifying and supporting unpaid carers. The draft already refers to several other important NICE Guidelines on transition (see page 11, line 19 - 24 for example).	Thank you for your comment. We agree it is useful to highlight the significance of staff seeing carers as partners in care, and being made aware of the links between caring for the person with care and support needs, and identifying and supporting unpaid carers. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people’s views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.

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Carers Trust	Full	General		As expanded on below, it is vital that provider staff are aware that, even when the person with care and support needs does not give consent for information sharing, that does not mean provider staff cannot share *any* information with unpaid carers. Information sharing with carers where consent is not given: Staff can discuss anything the carer is already aware of – this can help to make sure the carer understands the situation fully but gives no new information. Staff can give general information – such as local support services, and the kind of services available. Staff can receive information from the carer – this can be particularly useful in assessing risk and capacity. Staff can speak with the carer about how to gain support for themselves – referral to the local carers service, carers assessments, financial advice and employment advice for example. It is also important that staff know they also have a duty of confidentiality to the carer and must not pass on information about what they have discussed without permission.	Thank you for your .This recommendation is specifically about information sharing. We use the term information sharing in the guideline to refer to the sharing of information about people who use services within and between organisations. The points raised in the bullets however, are not about information sharing services and carers. Therefore, the Guideline Committee agreed that the wording of the recommendation, which is specifically about information sharing, should be retained as it is. We have added a definition of information sharing to the ‘term used’ section of the guideline for clarity.
Carers Trust	Full	10	18 – 20	Local authorities and service providers should also work with carers as they often support the person with care and support needs to navigate social care services. It is also an ideal opportunity for staff to identify carers and refer or link them into a source of support and statutory assessments.	Thank you for your comment. The Guideline Committee recognises the importance of involving families and carers. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people’s views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the mental care act should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Carers Trust	Full	10	21 – 25	It is important that staff also explain the degrees of confidentiality. For example, a person may be happy for their carer to have access to some confidential information, but not all. A good practice example in mental health is Common Sense Confidentiality, developed by Northumberland, Tyne and Wear Mental Health Trust and now widely used by other Trusts.	Thank you for your comment. We have recommended that carers, families or advocates should be involved to the degree that the person wants them to be, and if the person lacks capacity to give consent to sharing information that the MCA should be followed, The Guideline Committee felt that this recommendation (1.1.14) did not need any further elaboration as confidentiality has been emphasised in other parts of the guideline.
Carers Trust	Full	11	1 – 5	As stated above in comment 5 referring to lines 21 to 25 on page 10, it is important that staff are aware that there are degrees of confidentiality with carers and that the person with care and support needs is made aware of this to allow them to make an informed choice regarding what information can (and cannot) be shared with carers.	Thank you for your comment. The Guideline Committee felt that this recommendation (1.1.14) did not need any further elaboration as confidentiality has been emphasised in other parts of the guideline.
Carers Trust	Full	23	1 – 8	Carers should also be recruited as experts by experience. Carers have a vast amount of experience of supporting individuals to navigate the social care system.	Thank you for your comment. We have revised recommendation 1.5.3 to include carers as experts by experience, as well as people who use services
Carers Trust	Full	254	15 – 18	**Carers Trust are concerned that** the wording of this paragraph implies that carers might disregard the views of the person they care for. We recognise that staff may need to display sensitive practice around balancing the needs of both the person with care and support needs, as well as carers’ needs, including (but not limited to) confidentiality (see comment 5 referring to lines 21 to 25 on page 10 above about confidentiality);however carers’ insights into the needs of the person they care for should be sought and respected as it is the carer who will usually have the most contact with the person and will have a clear idea of their needs, wishes and capacity.	Thank you for your comment .The reference is to the sentence: ‘Parents can easily dominate these situations, and the way in which the meeting is set up can be very influential. The carer may assume that they have to speak for the person, and the whole process can become focused on the carer’s views of what the individual needs’ (Williams and Robinson 2000: 299), which was the author’s interpretation. The Guideline Committee considered the research evidence and

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				Of course, the views of the person with care and support needs should be sought, heard and respected. One way of facilitating this is working with unpaid carers who should be partners in care. A balanced approach is needed to ensure that the expertise and knowledge the carer has is used to ensure the best care and support is provided whilst also ensuring the person with care and support needs has their views heard and respected. For example, carers may have knowledge of the day to day needs of the person with care and support needs or how their condition has changed over their lifetime. This information can be very valuable when planning care.	made sure that recommendations about the involvement of carers and families should be based on the wishes of the person. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people's views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Carers Trust	Short	General		The guidance should make more reference to the upcoming NICE Guidance for Adult Carers. When published, the two documents should link to each other to ensure they complement each other. The two documents should work together to ensure that staff are aware of the need to support carers. It is important that staff see carers as partners in care and are made aware of the links between caring for the person with care and support needs and identifying and supporting unpaid carers. The draft already refers to several other NICE Guidelines on transition (see page 6, lines 20 – 25 for example).	Thank you for your comment. We agree it is useful to highlight the significance of staff being aware of the need to support carers, including an understanding of the links between caring for the person with care and support needs and identifying and supporting unpaid carers. We have added a cross reference to the forthcoming NICE guideline Provision of support for adult carers to recommendation 1.1.15.
Carers Trust	Short	4	1 – 11	The guidelines set out the need to provide people with support if they need it to express their views, preference and aspiration in relation to their care and support. However, the examples given in the draft guidelines do not include unpaid carers. Carers Trust believe this is a mistake. Staff should work with unpaid carers to support people with care and support needs to express their views. As long as conversations are within the confidentiality/disclosure agreement that the person with care and support needs has asked for, carers should be included as a way of helping the person with care and support needs express their views. Carers should be partners in care, and so it is very important that they are included in these conversations. There are different ways to facilitate the inclusion of carers in enabling the person with care and support needs to express their views. It may be that staff need to have separate conversations witmah the person with care and support needs and carers. Other conversations could happen with both the person with care and support needs and the carer where this is appropriate.	Thank you for your comment. The Guideline Committee agree it is useful to highlight the significance of unpaid carers to support people if they need it to express their views, preferences and aspirations in relation to their care and support. We have amended recommendation 1.1.5 to make reference to involving unpaid carers if that is what the person wants.
Carers Trust	Short	5	10 – 12	Carers Trust recognise that this guide is focusing on people who use adult social care services. The draft guidelines currently say; "[to] ensure that people who use services and have caring responsibilities receive support to access social care services, including information about childcare where appropriate." At the moment, the guideline refers to people who use services that have caring responsibilities. It is unclear whether this is referring to unpaid caring responsibilities or to caring responsibilities to a child. This should be made clearer to avoid any possible confusion. This could relate to two distinct groups: ☐ Disabled parents, or ☐ Parent carers **Disabled parents**	Thank you for your comment. This recommendation 1.1.13 refers to people who use services and themselves have unpaid caring responsibilities, either for a child or adult. The recommendation has been amended to clarify this.

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				Under the Care Act, one of the eligibility criteria that can trigger the provision of care and support services for a person with care and support needs is supported to be able to carry out caring responsibilities they have for a child. The Care Act says an adult's needs meet the eligibility criteria if they are unable to achieve certain specified outcomes. One of these specified outcomes is "carrying out caring responsibilities the adult has for a child." Carers Trust recognise the positive impact that provision to enable people with care and support needs to carry out caring responsibilities they have for a child or children can have. As this particular guideline could apply to adults who have a caring responsibility for a child or children, it is possible that the child or children could be young carers. If this eligibility criteria for support is triggered for the adult with care and support needs, it is also important that potential young carers are identified, and referred to support. This is one of the ways in which the Care Act and the Children and Families Act are supposed to interact. If information about childcare is shared, it is vital that staff are also reminded to establish if the child needing child care has caring responsibilities. Identifying young carers is a duty under the Care Act and this scenario would be an ideal opportunity to fulfil this duty. We know that children under the age of 5 sometimes have caring responsibility and estimates suggest there are 700,000 young carers between the ages of 5 and 17 across the UK. Carers Trust recommend that staff are reminded to establish if the child has caring responsibilities, and if so refer the young person for a young carers assessment. If NICE is to publish separate guidelines for young carers, this should be referred to here. It should also be pointed out that parents who have a disability may need extra support to carry out their parenting responsibility to a child which go beyond accessing or organising childcare. **Parent carers** Parent carers of adults with care and support needs also have their own distinct needs to enable them to continue in their caring role. Services should be provided to enable parent carers to support them in their caring responsibility in line with the Care Act.	
Carers Trust	Short	5	22 – 26	It is important that staff also explain the degrees of confidentiality. For example, a person may be happy for their carer to have access to some confidential information, but not all. A good practice example in mental health is Common Sense Confidentiality, developed by Northumberland, Tyne and Wear Mental Health Trust and now widely used by other Trusts.	Thank you for your comment. The Guideline Committee felt that this recommendation did not need any further elaboration as confidentiality has been emphasised in other parts of the guideline and references the Care Act 2014 and Mental Capacity Act which provides guidance on what can be shared and how. We have also made sure that the degree to which families and carers are involved is based on the person's wishes, of the person lacks capacity then the MCA guidance should be followed.
Carers Trust	Short	6	1 – 6	As stated above in comment 12 about lines 22 to 26 on page 5, it is important that staff are aware that there are degrees of confidentiality and that the person with care and support needs is made aware of this to allow them to make an informed choice.	The Guideline Committee felt that this recommendation did not need any further elaboration as confidentiality has been emphasised in other parts of the guideline and references the Care Act 2014 and Mental Capacity Act which provides guidance on what can be shared and how. We have also made sure that the degree to which families and carers are involved is based on the person's wishes, of the person lacks capacity then the MCA guidance should be followed.

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Carers Trust	Short	11	7 – 11	As well as working with people with care and support needs to co-produce training for potential personal assistants, providers should also be encouraged to work with unpaid carers.	Thank you for your comment. Recommendation 1.3.26 has now been amended to acknowledge the role of the carer.
Carers Trust	Short	11	16-19	Providers should also be encouraged to work with unpaid carers to co-produce policies and protocols and to ensure that there are open channels of communications. To ensure that adult social care providers provide the best service possible, it is vital that carers are brought into conversations about how services are delivered. Unpaid carers will often provide the majority of the care provided to the person with care needs and will have good insights into what is needed to for a good service. Carers, like the people with care and support needs, are experts by experience too, and their input is valuable when designing services that work for everyone.	Thank you for your comment. Recommendation 1.4.1 (bullet 1) has now been amended to state that policies and protocols should be co-produced people who use services and their carers.
Carers Trust	Short	6 – 7	26 – 29 and 1	When coordinating care, the guideline should advise the inclusion of carers (where the person with care and support needs has given consent). In reality, carers often have to do a lot of the “joining up” on behalf of services, so their views about how services can better collaborate should be sought.	We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people’s views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Carers Trust	Short	15	1 – 9	Residential settings providing end of life care need to also provide support to carers.	Thank you for your comment. We have revised this recommendation to include carers when providing support at the end of life. 1.4.18 now includes coproducing policies on end of life care with carers, and training on how to support people and their carers at the end of life
Carers Trust	Short	17 – 18	General	It is important for commissioners and service providers also use the views and experiences of carers when trying to improve services. Although this guide is focused on improving the care of people who are directly using adult social care services, one way of doing this is to ask the views of carers who are often navigating the care system on behalf of the person with care needs.	Thank you for your comment. Recommendation 1.6.2 has been amended to refer carers as well as people who use services.
College of Mental health Pharmacy	Short	13	3	This area will have a big impact if successfully implemented because a lack of continuity is one of the main complaints that we hear personally from individuals being cared for in their own home. The lack of continuity - in not having the same paid carer particularly around personal care - leads to a loss of dignity for the person being cared for. However ensuring continuity of paid carers will be challenging because this is a poorly paid area of work. Paid carers wages needs to be increased to a living wage if we are serious about implementing this point.	Thank you for your comment and support for the guideline. Whilst we acknowledge this point, carers’ wages are outside the remit of the guideline.
College of Mental health Pharmacy	Short and Full	General	General	When it comes to residential settings disappointed that no mention of appropriate mix of residents. Appropriate mix of residents ensures appropriate communal engagement which adds to the residents’ experience. Appropriate mix of residents means residential settings having appropriate admission criteria which take account of risk and level of functioning of individuals.	Thank you for your comment. We did not find evidence on the appropriate mix of residents.
Compassion Dying	FULL	General	General	Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around their treatment and care. We do this by: • providing information and support over our free phone Information Line; • supplying free Advance Decision to Refuse Treatment (ADRT) and Advance Statement forms and publications which inform people how they can plan ahead for the end of their lives; • supplying a free resource www.mydecisions.org.uk so that people can make an Advance Decision to Refuse Treatment online;	Thank you for your comment and for the links to resources.

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				☐ running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; and ☐ conducting and reviewing research into end-of-life issues to inform policy makers and promote person-centred care. As such, our comments focus on strategies we believe are needed to ensure that people have the information and support they need to plan ahead and receive the care that is right for them.	
Compassion Dying	Full	8	General	We welcome this draft guidance, yet feel the recommendations do not provide sufficiently specific information on the mechanisms available for empowering people within adult social care services to make informed decisions about their care and thereby receive the support that is in line with their goals, preferences and values. We believe that our work perfectly complements the core purpose of adult care and support, which is to help people achieve the outcomes that matter to them in their life. We particularly appreciate the guidance highlighting the value people place on choice and control over decision-making as we have learned from our service users that planning ahead gives people peace of mind and allows them to living well now. (Compassion in Dying *Plan Well, Die Well*, 2015). In 2016, we commissioned the International Longevity Centre to undertake a literature review on the impact of advance care planning which found that the process of thinking about and recording one’s treatment and care preferences results in better person-centred care and improved relationships and communication between families and healthcare professionals. Despite these benefits, our experience has shown that there is a lack of awareness among both the general public and health care professionals around the specific ways in which adults can take control of their treatment and care in case they lost capacity – i.e. Lasting Powers of Attorney for Health and Welfare (LPA) and Advance Decisions including Advance Statements. For example, we found that while 82% of people say they have strong views about what treatment they would want to refuse and accept at the end of life, only 4% of adults have an Advance Decision or a Lasting Power of Attorney for Health and Welfare (YouGov 2014).	Thank you for your comment. Following stakeholder feedback, we have strengthened several of the recommendations on supporting people to make informed decisions, including: further detail on how to provide support for people to give their views (1.1.5), further detail about the types of information that should be provided (1.2.1) and ensuring this is widely publicised (1.2.2). We have also added reference to Lasting Power of Attorney and advance statements of wishes and care preferences to recommendation 1.4.18**. There is a related NICE guideline** NG31 Care of dying adults in the last days of life in which end of life care is covered in more detail.
Compassion Dying	Full	9	Line 1 Sec1.1.6	Consider including an additional bullet point on explaining the mechanisms available for setting out preferences for future treatment and care (ADRTs, Advance Statements and LPAs) and knowing how to signpost people to experts and support organisations such as the Office of the Public Guardian and Compassion in Dying. Note that the content of a person’s Advance Statement (which deals with care preferences rather than refusal of medical treatment) is particularly useful in a social care setting and will help ensure staff are aware of the person’s cultural and religious needs and preferences. This information could be included as part of the subsection on ‘Enabling people to make decisions about their care’ and/or ‘Access to care.’	Thank you for your comment. We have added reference to Lasting Power of Attorney and advance statements of wishes and care preferences to recommendation 1.4.18. There is a related NICE guideline NG31 Care of dying adults in the last days of life in which end of life care is covered in more detail. We have revised the recommendation 1.4.19 based on your suggestion to include signposting to someone independent, for example from an advocacy organisation. We have also revised recommendation 1.4.18 to include information about documenting people’s treatment and care preferences at the earliest opportunity.
Compassion Dying	Full	10	Line 22 1.1.13	Consider including a bullet point on the value of Lasting Powers of Attorney for Health and Welfare as a mechanism for documenting these preferences. We have learned that older LGBT people find this option particularly useful. (Compassion in Dying *Planning ahead for the LGBT community*, 2016).	Thank you for your comment. We have added reference to Lasting Power of Attorney and advance statements of wishes and care preferences to recommendation 1.4.18. There is a related NICE guideline NG31 Care of dying adults in the last days of life in which end of life care is covered in more detail.

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Compassion Dying	Full	12	Line 19 1.4	1.3.2 includes a point about Local Authorities providing information about options available for people to control their own funding. A similar point about options for controlling their care and treatment could be included within 1.4.	Thank you for your comment. We have included a bullet point in recommendation 1.3.4 Care and support needs assessment should: • Involve the person and their carers in discussions and decisions about their care and support.
Compassion Dying	Full	16	Line 11 1.5.1	In 2014, the House of Lords Inquiry into the implementation of the Mental Capacity Act found that it has "suffered from a lack of awareness and a lack of understanding. The empowering ethos has not been delivered." The importance of ensuring the availability of skilled professionals in end-of-life care was also highlighted in *Choice in end of life care: government response, Department of Health, 2016* and its subsequent review, *One Year On: The Government Response to the Review of Choice in End of Life Care*, Department of Health, 2017. For Advance Care Planning to be effective, it needs to be discussed, recorded and respected. As such, it would be helpful to include a bullet point on ensuring that practitioners have the information, tools and confidence to discuss sensitive issues such as end-of-life preferences and care goals and to sign post people to relevant national and/or local organisations as needed. This could be replicated under section 1.6 (Staff skills and experience) if required.	Thank you for your comment. There is a separate NICE guideline in development about decision making and mental capacity. This was therefore out of the scope of this guideline.
Compassion Dying	Full	19	Line 28 - 1.5.17	Consider specifically mentioning the Mental Capacity Act within the bullet on training and highlighting the importance of supporting people to document their treatment and care preferences at the earliest possible opportunity.	Thank you for your comment. We have included a separate bullet to recommendation 1.4.18 on training as follows: Managers in residential settings should co-produce with people who use services and their carers a policy on end of life care including: • documenting treatment and care preferences at the earliest opportunity
Compassion Dying	Full	21	Line 4 1.6.5	It may be useful to include local and national charities as part of the other services practitioners ought to be aware of.	Thank you for your comment. We have amended recommendation 1.5.5 to include reference to the voluntary sector.
Disability Rights UK	short	3	21	Section 1,1,6 should go before 1.1.5 to emphasise that support needs to be provided before making any decision that someone lacks capacity	Thank you for your comment. We have now revised this section accordingly.
Disability Rights UK	short	5	16	The guidance needs to include a definition of co-production, perhaps the one used by TLAP otherwise it will just be consultation. Need to get over that co-production is about all stages from design, to roll out to review of services	Thank you for your comment. We have now included the definition of co-production provided by TLAP in the 'Terms used in this guideline'.
Disability Rights UK	short	9	4	We think the default position should be always to provide a copy of the assessment in writing rather than have to request one. Time and time again we find from calls to our independent living advice line that people do not have access to what is being decided about them and have to rely on memory of conversations	Thank you for your comment. We have now amended this recommendation to read as follows: 'Offer a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want'.
Disability Rights UK	short	11	2	Not sure about the use of the term 'background checks' Technically employers are not obliged to get checks such as criminal record although it might be advisory to do so. It needs to be clear that local authorities cannot insist on such checks. Also on this list there needs to be point about local authorities meeting all the costs of being an employer when deciding on the level of the direct payment	Thank you for your comment. We have removed the term 'background checks' and substituted it with 'terms and conditions' so that the bullet in the recommendation reads: 'In line with the Care Act statutory guidance, local authorities should ensure support is available, and inform people employing personal assistants about where to get support with: • their role and responsibilities as an employer (for example, payroll, and terms and conditions, redundancy and contingency planning). We have not added the additional point about local authorities meeting all the costs of being an employer when deciding on the level of the direct payment as at present this responsibility lies with the person as the employer, however we have revised the recommendation on payment process to make sure that it is able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants.

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Disability Rights UK	short	13	28	We think there needs to be something here covering people in community living situations to ensure people have choice over the people they live with	Thank you for your comment. The Guideline Committee discussed this issue in the context of how to incorporate concepts of compatibility and appropriate mix and suggested that the issue of people having choice in community living situations be added to Recommendation 1.3.4 with the following bullet: • take into account the person's housing status, and where and who they want to live with.
Disability Rights UK	short	16	20	Opportunity needs to be made more explicit so local authorities need to go out and actively seek users of services otherwise they will only consult the usual suspects	Thank you for your comment. Recommendation 1.6.6 states that organisations conducting research should consider how to ensure all groups are able to participate, including people who may lack capacity and with different communication needs. We also recommend that this may involve adapting different research methods (also 1.6.4) and providing materials in a range of formats.
Disability Rights UK	short	17	7	Not sure 'collecting people's views' is the right term here. Obviously co-production is much more than just that exercise so suggest communicating the results of co-production to everyone using the service	Thank you for your comment. We make reference to co-production in recommendations 1.1.9 and 1.6.2.
Dorset Council – Adult and Community Services	General	General	General	We feel that personal budgets held by the care agencies with outcome based funding streams would resolve many issues. Cultural changes are required with the general public and our health colleagues about how **we** interpret the care act and the services **we** are able to offer at the point of contact in the hospital. There seems to be little focus on our Health colleagues' responsibilities around their role in the care act, interpretation of services available. The draft document reinforces our Health colleagues' and the general public's expectations that we will bridge the gap. We feel that this will lead to further contention and divide as we are currently unable to meet holistic needs through resources and the new guidelines strengthen the belief that we will be able to go further.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended interventions. Please note however, this guideline does not focus on health colleagues' responsibilities**.**
Dorset Council – Adult and Community Services	General	General	General	Re: collection of data feedback from customers/patients - Integrated working: Is there some work to be done collecting data about patients' experience of their hospital admission-discharge from a joint working/learning perspective? We collect feedback data from our separate organisations but in the future context of integration we should be collecting this jointly and learning and changing practice at an MDT level?	Thank you for your comment. The issue of collecting data about patients' experience of their hospital admission-discharge from a joint working/learning perspective was out of scope for this guideline, which focused on adult social care services.
Dorset County Council – Adult and Community Services	General	General	General	The Challenges in the implementation are: The rural nature of the County and the limited availability of care staff. Managing expectation of customers and their families, the ability for staff to communicate the financial restraints of the County Council and the eligibility criteria. The ability to have community resources that can be used in place of a commissioned care package, Community Services that meet the needs of that specific area and the local need. Allowing staff to have the time and thinking space to build relationships and think creatively about their interventions and ways of meeting levels of need. The ability to educate staff on the benefits of preventative measures such as housing adaptations, assistive technology, physio and OT intervention. The ability to educate our care providers and health colleagues in alternative approaches such as single handed care, effectively managing risk and assistive tech.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the Committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Dorset County Council – Adult and Community Services	General	General	General	The biggest cost impact will be borne by providers delivering the standards expressed in the document. Whilst it is great to highlight the quality issues leading to satisfaction, reality tells us that the market is stretched in terms of recruitment and attracting staff with the right aptitude / skills/ knowledge (hence proud to care agenda). Therefore in order to develop the workforce / providers to these	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the Committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.

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				standards and offer the choice would inevitably come at some additional cost (possibly passed onto the LA?) – we can see some of this already in the market.	
Dorset County Council – Adult and Community Services	General	General	General	Perhaps setting some good practice and evidence-based statements about customer responsibilities in the process would help users overcome any challenges so that it has a holistic view rather than solely from an organisational perspective.	Thank you for your comment. NICE guidelines are primarily aimed at those delivering services.
Dorset County Council – Adult and Community Services	General	General	General	On the whole we feel that the NICE guidelines are very person centred and idealistic and is the way that we would wish to be working. Our concern is that there are very limited resources for ourselves and community services and a dwindling resource of preventative services and voluntary support On a one to one basis with our Customers we do feel that we work in this way already, but perhaps struggle to access some of the more holistic services within budget constraints.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the Committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Dorset County Council – Adult and Community Services	Short	4	17	Due to the rural nature of the County we have challenges with accessing care. The Dorset Care Framework is now being introduced to try and ensure there is appropriate care provision in some of the most challenging 'hotspots' around the County. This will then benefit the DToC processes and the management of customers in their own homes.	Thank you for your comment, and the case study example.
Dorset County Council – Adult and Community Services	Short	5	23	It is always a challenge to involve family and carers in a manner that is acceptable to both customer and the family member, when the customer has capacity. Ensuring the customer is at the centre of the assessment, but allowing family to feel they have been involved can prove difficult.	Thank you for your comment. We have aimed to balance these considerations in the wording of the recommendations, emphasising that carers should be involved if that is what the person wants.
Dorset County Council – Adult and Community Services	Short	6	8	We have a limited pool of carers at best.	Thank you for your comment. Recommendation 1.3.10 now makes clearer that the named co-ordinator should be identified through the care planning process. That is, that they are an existing member of staff.
Dorset County Council – Adult and Community Services	Short	8	8	The drive from the Care Act focuses on promotion of wellbeing and the advancement of wellbeing as practitioners focus. These are not the same mandatory duties. We appreciate that it is designed to complement legislation but the fact that it does not replicate or frame good evidence practice within the context of statutory duties will inevitably make it unwieldy for practitioners to embed into practice.	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation.
Dorset County Council – Adult and Community Services	Short	8	17	Paragraph makes clear expectations around assessment and support planning. Probably the biggest thing is around timescales which practitioners may be able to be explicit about but occasionally these are confused and complicated by a variety of issues beyond their control. We endeavour to do an assessment in 28 days and therefore we can make this explicit. It is an expectation that integrated services will prevent the customer having to provide the same info to numerous professionals. This is mainly down to the IT systems and the inability to share records across health and social care. In Dorset the ICMS system will allow info to be shared between adults and children's services. The Dorset Care Record will allow for info sharing between health and Social Care.	Thank you for your comment. We are glad that the recommendations make the expectations clear. We did not find any evidence in relation to timescales for assessment.
Dorset County Council – Adult and Community Services	Short	9	4	1.4.9 states we should offer a copy of an assessment to customers and doesn't state we always have to send copies out. Should we therefore be offering and then case noting or stating in the assessment summary whether the customer wants a copy or not?	Thank you for your comment. Recommendation 1.3.9 has been amended to read: 'Offer a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want'.
Dorset County Council – Adult	Short	9	7	It is not clear how this would work unless we took a very hands-off approach. ISF's would work in this way for people who want to go down that route.	Thank you for your comment. Recommendation 1.3.11 has been reworded to incorporate the term 'priorities' as follows: 1.3.11 Build in flexibility to the care

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and Community Services					and support plan to accommodate changes to a person's priorities, needs and preferences – for example, by using direct payments (see recommendations 1.3.20 and 1.3.21) and agreeing a rolling 3-monthly budget so that people can use their money differently each week.
Dorset County Council – Adult and Community Services	Short	9	15	The limited ability to access suitable care in some areas of the County can lead to the inappropriate use of the Reablement Service, Respite care or delayed discharge from hospital. Being able to access appropriate Care and have a workforce of suitable staff is something Dorset aspires to have. Having integrated Commissioning services with the CCG may improve our ability to achieve this. The statement does not clarify who should be responsible for the matching process. Assume this is providers as LA's could not do this. Choosing carers best matched to the clients – limited carers at best	Thank you for your comment. The focus of the recommendation is on ensuring that there is a process for ensuring the best match possible, acknowledging the constraints imposed by availability of staff.
Dorset County Council – Adult and Community Services	Short	10	7	With the new points based RAS in Mosaic (integrated IT) it is not clear at this time how easy it would be to be transparent.	Thank you for your comment**.** The Committee considered the potential impact you suggested and agreed that the level of detail in this recommendation was sufficient.
Dorset County Council – Adult and Community Services	Short	10	12	Peer support re Direct Payments looks like a great idea!	Thank you for your comment and your support for the guideline.
Dorset County Council – Adult and Community Services	Short	12	13	Carers to respond flexibly to daily change in needs – how will this be managed with blocks of time allocated per visit?	Thank you for your comment. This recommendation is about setting priorities and takes into account the short amount of time available.
Dorset County Council – Adult and Community Services	Short	12	27	The increased education for providers on single handed care and Assistive Technology will allow for increased continuity of care staff and have personal care met in a more client centred, flexible way.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
Dorset County Council – Adult and Community Services	Short	13	14	Ability to offer night services to allow for clients to access the toilet and to settle down in a home environment	Thank you for your comment. Recommendation 1.4.11 says that: All practitioners providing personal care should ensure that personal care needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan – for example, making sure that people can go to the toilet when and how they want. The Guideline Committee agreed that this level of detail should be sufficient and allows some local flexibility in how this may be achieved.
Down's Syndrome Association	Full	9	1-11	We strongly support the overarching principle to provide support to people to express their views, preferences and aspirations in relation to their care and support as people with Down's syndrome frequently have specific, often misunderstood difficulties expressing their views.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
Down's Syndrome Association	Full	10	15-19	We also highlight the principle that local authorities and services providers should work with people who use adult social care services to co-produce the information they provide, organisational policies and procedures and staff training. (DSA Having a Voice groups enable people with Down's syndrome of all abilities to co-produce information and offer advice as focus groups using creative approaches)	Thank you for your comment. We are glad that the recommendations are aligned with good practice that is already occurring.
Down's Syndrome Association	Full	10	21 - 28	It is vital that the person is asked if and how they would like their carers, family and friends to be involved in discussions and decisions about their care and support, that their wishes are followed and reviewed regularly (every 6 – 12 months).	Thank you for your comment and your support for the guideline. Recommendation 1.1.14 has been strengthened by the addition of the term 'advocate' and providing more detail on the timing of review to read as follows: Ask the person at the first point of contact whether and how they would like their

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					carers, family, friends and advocates or other people of their choosing (for example as personal assistants) to be involved in discussions and decisions about their care and support, and follow their wishes. Review this regularly (at least every 6 to 12 months, or when requested.
Down's Syndrome Association	Full	11	5	It is vital that information is 'shared with carers, families and friends as agreed'. This issue is one of concern to many of our members.	Thank you for your comment and your support for the guideline. The final bullet in Recommendation 1.1.15 has been strengthened by the addition of the term 'advocate'
Down's Syndrome Association	Full	11	7-15	We wish to highlight our support for the recommendation that local authorities and providers should consider providing people with a named co-ordinator.	Thank you for your comment and your support for the guideline.
Down's Syndrome Association	Full	13	6	That the care and support needs assessment should take into account the person's personal history and life story is important for people who have Down's syndrome, so that people's support needs are not underestimated.	Thank you for your comment and your support for the guideline.
Down's Syndrome Association	Full	18	4-7	We strongly support that providers and managers in all settings should ensure that people are informed in advance if staff will be changed and that any changes in care, e.g. when visits will be made, are negotiated with the person. Not doing so is a cause of distress for many people who have Down's syndrome.	Thank you for your comment and your support for the guideline.
Down's Syndrome Association	Full	20	17-19	It is a concern that increasingly people are undertaking needs and eligibility assessments of people with Down's syndrome without the knowledge and skills to do so. Therefore we emphasise this recommendation as being of great importance for people who have Down's syndrome.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
Guide Dogs	Short	3	10 or 11	We recommend including the option for people to undertake a period of reablement or rehabilitation if this would help them to retain or regain life skills. It would be possible to infer that "support and assistance" as currently offered is concerned with remedial caring (done to) type support rather than an empowering or facilitating intervention. From our perspective we offer a range of services. This includes a volunteer-based sighted guide service in which a volunteer supports or assists a blind person by guiding them to their chosen destination through to a guide dog mobility service where we provide training and an assistance dog so that the individual is able to independently get out and about. That would be similar to a local authority provided or commissioned rehabilitation service that trains someone in independent mobility skills. You may consider that this is a type of "support", and that it is a question of semantics. But this kind of reablement intervention feels different from the provision of an assistant as through such an intervention the individual achieves a level of independence that they had lost.	Thank you for your comment. There is a separate NICE guideline NG74 on Intermediate care including reablement.
Guide Dogs	Short	8	4-10	Whilst line 10 makes reference to promoting interests and independence, we feel that the guideline does not sufficiently reflect the elements of the Care Act Statutory Guidance that deal with prevention and specifically "reablement". The Department of Health's Care Act Statutory Guidance and additional supporting guidance from the Association of Directors of Adult Social Services make it clear that if a person could benefit from reablement, that this should be provided before any assessment of long-term care needs is undertaken and which would be subjected to eligibility criteria. Certainly in relation to vision rehabilitation for people with sight loss it is made clear that this should be a core preventative service that is not something that would be charged for or funded through a personal budget. Our impression is that pretty much everything in the short guidance that follows the assessment reference is based on a model of long-term support which is subject to funding decisions and or personal budgets or direct payments. We feel that opportunities to retain or regain skills should be explicitly addressed in the guideline.	Thank you for your comments. We have revised the background section to clarify the purpose of the Care Act. The assessment of needs in line with the Care Act would not exclude needs for reablement or to prevent or delay future care needs. There is a separate NICE guideline NG74 Intermediate care including reablement.
Guide Dogs	Short	14	5-7	We welcome acknowledgement of the existence of sensory loss amongst older people in residential care and the importance of having consistency in layout is a good example. However, we are aware that more fundamental infrastructure	Thank you for your comment, and the case study example. We have amended recommendation 1 1.5 to include reference to lighting and minimal noise

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				issues such as inadequate lighting or poor colour contrast are frequently overlooked as “inclusion” is not considered at the design stage. Given the prevalence of sight loss amongst the nursing home population we would welcome inclusion of these two basic aspects of design. We are aware that the Hertfordshire Residential Home vanguard site including training in visual impairment awareness which could well have contributed to measurable reductions in falls and depression. Although we do not believe that such health economic arguments should be necessary to underline the importance or good lighting and contrast in an environment that will have a significant number of people with significant sight loss within it.	interference and also 1.4.14 to include reference to reducing challenges in designing residential environments, including poor lighting.
Guide Dogs	Short	16	8	We applaud the guidance in recognising the valuable insights that users of services can bring to the table in terms of planning and evaluating services. We have been involved in past projects where service users have been involved in service evaluation. Improving Lives: Raising Standards used the Association of Directors of Social Services (before the split between the DCS and DASS roles) ADSS national standards of social care (Progress in sight) as a benchmarking tool. Service users had a user-friendly version of the standards to use as an audit tool and were offered capacity building training. In one example (in Wigan) they interviewed key personal from the local authority involved in the planning and delivery of social care provision for people with sight loss. They were effectively a user jury. They wrote a report and the relevant council committee of elected members heard about the initiative and invited the group to present their findings to the council. We feel this was a truly democratic form of accountability. Whilst we do not propose that the guideline is so prescriptive, we offer this as a supporting example of why service users should be fully involved in evaluations and audits as long as they are properly resourced and the exercise is not simply tokenistic. . trusted.	Thank you for your comment and support for the guideline.
Guide Dogs	Short	16	20-23	We support this and not just in relation to social care. The built environment is another are where councils can end up excluding people from town centres by not involving all user groups in the design of a regeneration scheme from the outset. We believe that co-production is a principle that should cover all aspects of public life.	Thank you for your comment and support for the guideline.
Guide Dogs	Short	27	1-16	We recognise the huge potential that new technologies offer in relation to the independence of people who are blind or partially sighted. We have been working with a range of organisations from the technology world including Microsoft to envision future possibilities. Some of these concern navigation around the built environment to assist with individual orientation and mobility. But we have also worked with external organisations such as Neatebox who have (amongst other things) developed low cost circuitry that can be added to pedestrian controlled crossing boxes and which can communicate with a smart device owned by a person with restrictive mobility to either notify a blind person when the pedestrian phase is active (to save them from having to try and feel for a rotating cone) or it can be used to seek a longer crossing cycle on that particular pedestrian phase for someone who needs a little more time to get across safely. https://neatebox.com/button-user/ These new technologies have the potential to make the world more inclusive and enhance the independence of some members of our society and we recommend that NICE explores these developments in greater detail. We would be happy to share some of our material subject to any Non-Disclosure Agreements we have with partners. http://www.guidedogs.org.uk/microsites/inspiring-future-technologies-for-everyone#.WdO18xGWypo	Thank you for your comment. We searched for evidence about service user experience of assistive technology, but found no evidence in this area. For this reason the Guideline Committee considered this a gap in the evidence and suggested a research recommendation in this area.

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Healthwatch Birmingham	Short	General	General	Healthwatch Birmingham welcomes the opportunity to respond to NICE’s consultation on *‘people’s experience in adult social care services: improving the experience of care for people using adult social care services’*. We agree with NICE on the inclusion of the following as a recommendation in this proposed guideline: • involving people in service design and improvement • Using people’s views to improve services. This proposed guideline aligns with Healthwatch Birmingham’s vision of ensuring social care users have access to quality services that meet their individual needs. Adherence by commissioners and providers to this guideline will mean that the views and experiences of service users, families, the public and carers will become central to decision-making. Healthwatch Birmingham believes that these two recommendations (as above) will have the biggest impact on how services are provided and how changes to services are made. Equally, these recommendations will help providers meet other recommendations in this guideline (for instance, recommendations on ‘access to care’; ‘enable service users to make decisions about their care’; care and support needs assessment and care planning etc). This will lead to services that can better meet the individual needs of service users, high levels of dignity and respect, and improved health outcomes. However, we are concerned that the ‘involving people in service design and improvement’ (page 16, line 19, 24, 26) recommendation states only that its main purpose is to: • Involve people in decisions about the way services are commissioned, run and are governed; and • Checking that the service is delivering quality care. In addition, the ‘using people’s views’ recommendation states that this is done to improve services. Whilst we agree that these are important reasons, we believe that the guideline fails to address the issue of involving service users in order to address issues of health inequality. Healthwatch Birmingham believes that service user involvement, their views, insight and experience should also be used to identify, understand and address health inequality issues that impact service user access to services and the quality of services. We believe that patient and public involvement, in any aspect of health and social care commissioning, can only be fully effective if one of its purposes (or even its main purpose) was to identify, understand and address health inequality. It is our view that the proposed guideline would be strengthened by a clearer link between the two public sector legislative duties. Namely legislation requiring public sector organisations to: • Engage/involve the public and patients; and • Reduce health inequality and improve health outcomes. Service delivery can only be effective if people’s differences and needs are taken into consideration. Whilst the issue of inequality has been alluded to in the guideline, there is no clear link between the two public duties outlined above. Healthwatch Birmingham has developed, in partnership with NHS England West Midlands, a “Quality Standard for using patient and public insight, experience and involvement to reduce health inequality and drive improvement”. We believe that the basic approach of the Quality Standard – to use patient and public insight, experience and involvement to identify, understand and address health inequality, could be	Thank you for your comment. We have revised recommendation 1.6.2 that research into the views of people using care to state that this research should also identify gaps in service provision. We hope the section on 1.6 Involving people in service design and improvement gives examples of best practice in this area and allows for some local flexibility in how this may be achieved.

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				incorporated into the proposed guideline for improving the experience of care for people using adult social care services. More information on this can be found here and the contact person is Andy Cave (CEO)/Jackie Spencer (Head of Public and Patient Involvement).	
Healthwatch Birmingham	Short	General	General	In addition to our comments above, Healthwatch Birmingham has received feedback from service users and their families on their experience of social care services. This feedback reveals concerns with care and support needs assessments; information on types of care and how to access care; and choice of care or residential home. Some of this feedback is given below: *'the social care system is so inflexible, difficult to access and only offers specific types of support for either physical or mental health. There is no support for either physical or mental health and there is no support for people who suffer a combination of both'.* *'….eventually someone rang and said they would do an assessment at my house. She came around and didn't know what PTSD was'.* *'…I had two social care assessments approximately 6 months apart. These assessments were completely different and I don't understand why they were different'.* *'My relative is currently in hospital and we feel pressured into finding a home for our relative as we are told he is bed blocking. I have approached the Social Worker and don't know what the result of that is. Social Worker says to look for residential care homes, but needs nursing care'.* *'Following discharge from hospital individual had a delay in assessment for Social Care. Individual had Dom Care previous to entering hospital stay but due to length of stay this care package was cancelled meaning they entered into a new round of assessment resulting in a brand new Dom care provider which they are not happy with. Does not understand why they can't have choice to go back to old provider'.* *'Caller receiving care at home for washing and caring and experiencing problems with some of the carers that come to see her. Initially the care assessment from Social Services was incorrect which caused stress. Caller suffers from anxiety as well as having physical care needs - the number of different carers is exacerbating her anxiety'.* *'I have a learning disabled adult sister (57 years old); without dementia. Since she contracted a stomach virus in April 2014 which devastated her life and ours, she has not been able to return to our terrace home. Her experiences with the social services, the care homes, and the hospital have provided some deeply unpleasant experiences. Social services abruptly and cruelly dumped her into a retirement home registered for dementia patients and left her there until our MP intervened. The social worker who dumped her there without consulting us or the Mental Capacity Act, also only said that the City Council would pay the cost for care, but we later received large bills for a home that did not take good care of her'.*	Thank you for providing the feedback to Healthwatch Birmingham from service users and their families on their experience of social care services. We hope that the guideline will help to address some of the negative experiences of social care reported. Please note that care in hospital is outside the scope of this guideline.

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Healthwatch Birmingham	Short	16-18	General	Between May and June 2017, Healthwatch Birmingham conducted interviews with service users and providers during Enter and View visits. The aim was to better understand the current situation with regard to service user engagement in residential and nursing homes. We believe that some of our findings will be useful for recommendations on Page 16 to 18.	Thank you for your comment. We are only able to consider published evidence in the development of the guideline.
Healthwatch Birmingham	Short	16 17	19-26 9-16	Although the homes we visited collected feedback, this tended to be on narrower topics, such as food and activities. One reason for this was that there was no collective understanding amongst staff on why and how to collect feedback from service users on their care. Consequently, there was no culture for collecting and using feedback in the homes that we visited. The residents and their families told Healthwatch Birmingham staff that collecting feedback depended on individual staff. A key challenge will be developing a culture within care and residential homes that welcomes service user feedback and experience. This can only be possible if the homes develop a strategy for collecting feedback. This strategy represents an opportunity to ensure that there is commitment across the care or nursing home to the use of patient and public insight and experience data and to their involvement in the design of services. To be effective, the strategy needs to be understood by all staff, promoted, and arrangements for collating feedback and experience should be clearly outlined. Such a strategy would also outline how to feed back to service users and the public about how their feedback is being used and what changes to services have been informed by service user feedback. On the other hand, service users need to be educated regarding how and why they can input into a wide range of decisions.	Thank you for your comment. The recommendations in section 1.6 aim to address building a culture of collecting and using feedback from people who use services and their families, and gives some practical suggestions for how to achieve this.
Healthwatch Birmingham	Short	17	9-16	Different residential and nursing homes we visited used different methods for collecting feedback. We believe that these various methods of collecting service user feedback provide a base for adopting recommendation 1.7.4. However, we found that a key challenge for providers in collecting feedback was communicating with service users that have dementia, a severe learning disability or any other complex needs. Therefore, Local Authorities and providers will need to develop innovative ways of communicating with service users facing communication challenges. This might require financial resources.	Thank you for your comment. At various points in the guideline, we have made reference to challenges in collecting feedback from particular individuals and have suggested communication methods that are in line with the Accessible Information Standard, as well as the use of communication aids adapted for the specific needs of people with communication difficulties. In addition, the Equality Impact Assessment also makes reference to groups with protected characteristics.
Healthwatch Birmingham	Short	17	17-20	We agree that it is possible for Local Authorities to collaborate with other organisations to gather and analyse evidence on people's experience. Healthwatch Birmingham has experience of collaborating with Birmingham City Council on gathering service user feedback. The Council has built into its provider rating system the need for providers to adopt Healthwatch Birmingham's feedback widget on their websites and feedback questions. Birmingham City Council is also incorporating patient views into their provider rating dashboard. More information on the widget can be found here: https://healthwatchbirmingham.co.uk/partners/. The contact person is Claire Reynolds.	Thank you for your comment and for the link to resources.
Healthwatch Birmingham	Short	17	9-16	Using a range of methods to gather service user feedback and experience reduces bias and helps triangulate data, especially if a mix of qualitative and quantitative data is used. During our interviews we found that some providers use a range of methods including residents meetings, surveys and individual meetings with service users. There were some providers who only used one method. We believe that it will be a challenge to get all care providers to adopt the use of different methods to gather feedback and experience. This is because of differences in resources and skills to be able to use various methods. Training might be needed for staff and managers.	Thank you for your comment. Recommendation 1.6.4 also highlights the importance of using a range of data collection methods.
Healthwatch Birmingham	Short	17 18	30 1-4	During our visit to residential and nursing homes, service users told us that they were aware of the complaints process but that they had nothing to complain about. However, we received negative feedback from the same homes when service users completed Healthwatch Birmingham's feedback postcards. This, in addition to our	Thank you for your comment. With regard to financial impact of using advocates, the Guideline Committee considered resource impact as they were developing the recommendations. It was the view of the Committee that the

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				observations, might mean that service users are uncomfortable to make a complaint to the same person they are complaining about. We therefore agree with the inclusion of recommendation 1.7.7 and 1.7.8. However, using an independent advocate to gather service user views and experiences, might have financial implications. This might even be more difficult if the advocate has to have specific experience or skills that address the service user needs.	recommendations are aspirational but achievable, and should not incur significant additional cost.
Healthwatch Birmingham	Short	18	21-27	It was not clear from our research how providers fed back to service users the actions taken as a result of their feedback. The staff that we interviewed informed us that management ensured that service user feedback was communicated to all staff so that appropriate action is taken. However, the residents felt that their feedback was not acted upon. It was clear from our visits that action had been taken in response to service user feedback. Hence the differing views could be a result of the provider’s failure to inform service users of how their feedback has informed any changes to services. We, therefore welcome the inclusion of a ‘you said, we did’ recommendation as this closes the feedback loop. If service users know that their feedback is used to improve services, they are more likely to be encouraged to give feedback.	Thank you for your comment and your support for the guideline.
Healthwatch England	Short	General	General	Thank you for the opportunity to consult on this guideline, which we are pleased to see. We have listed below some suggested amendments.	Thank you for your comment and your support for the guideline.
Healthwatch England	Short	3	9	We agree that services should treat each person as an individual, and support them to keep their independence for as long as possible. Our briefing on care homes found that the best residential services are the ones that focus on enabling people to continue living as if they were still in their own home. Accommodating residents' personal, cultural and lifestyle needs forms one of the eight quality indicators for care homes developed by charity Independent Age. Working with older people, their families and care experts, Independent Age developed the set of quality indicators in partnership with Healthwatch Camden, who then used them to gather information about seven local care homes during Enter and View visits. Independent Age refined the indicators following the visits and in light of feedback from focus groups. The eight indicators are now being promoted nationally to help improve the information about quality in care homes, and what life in a particular care home is really like. NICE could recommend that Local Authorities make use of Independent Age’s indicators when commissioning social care services.	Thank you for your comment and for the links to resources.
Healthwatch England	Short	5	16	We note that the term ‘co-production’ is included in the glossary at the end of the document. However, we suggest defining it here so that the meaning is clear to everyone who might read the document, including users of social care and their families. Rethink Mental Illness’s recent report looking at co-production in CCG’s found that only 15% of CCGs who responded had undertaken any co-production in mental health commissioning. Whilst this may not read across directly to co-production in the commissioning of social care, it seems likely that Local Authorities too will need support and guidance to embed true co-production at a strategic level.	Thank you for your comment. The first use of the term co-production has a hyperlink to the definition to assist people’s understanding.

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Healthwatch England	Short	6	3	We are pleased to see that the guideline acknowledges the Accessible Information Standard. We responded to NHS England's recent review of the Standard, sharing insight from people with sensory and communication impairment about their experiences of health and care services. As NHS England's review found that there was significant variation in the adoption and implementation of the Standard, we suggest that the reference to it in this section be strengthened to encourage further take-up. For example, 'Provide people with information they can easily read and understand in line with the Accessible Information Standard. All organisations that provide publicly-funded adult social care must follow the Standard, and the CQC have committed to look at how all services are using the Standard as part of their regulatory work', with a link to the Standard itself.	Thank you for your comment. It is not NICE usual house style to provide background information within recommendations such as referring to CQC regulatory activities. However, recommendation 1.1.5 has been expanded to provide more detail about how to meet the requirements of the Accessible Information Standard.
Healthwatch England	Short	7	18	To ensure that service users and their families are aware of local Healthwatch and the support they can provide, we suggest the wording 'local authorities should consider providing comprehensive information about other support groups, including voluntary organisations. They should also provide information about local Healthwatch services.'	Thank you for your comment. We have amended the wording on this recommendation as follows: '1.2.4 Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.' Specific reference to Healthwatch has been added to recommendation 1.6.4.
Healthwatch England	Short	8	4	When we asked Local Authorities about their waiting times for social care assessments, most were unable to provide us with the information we asked for about the timeliness of those assessments. Of the local councils who did provide information, half were either unable to provide data on waiting times or could only tell us how many people were on their waiting list (but not for how long). We suggest a recommendation in the guideline that councils should monitor the timeliness of their assessments to ensure that no-one is waiting for an unacceptable amount of time. At the same time, services should be keeping track of and understanding hospital emergency readmissions data to ensure that timeliness is not being achieved to the detriment of quality, resulting in unworkable care plans. Monitoring should look separately at assessments for people awaiting discharge from hospital and those living in the community, to avoid the unintended consequence that one group starts receiving faster assessments at the expense of the other.	Thank you for your comment. In response to your suggestion, the Guideline Committee has developed a new recommendation: '1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out.'
Healthwatch England	Short	9	1	Local Healthwatch have found that the best care plans are the ones that look beyond immediate physical needs and think about other challenges such as social isolation. Our home care briefing found that it was important to set realistic expectations for care recipients. Care staff need to read and update plans regularly to ensure care is focused around what people want and need. This is particularly important in cases where a user's ability to do certain things for themselves might be changing rapidly. Healthwatch heard of home care workers who were unfamiliar with care plans, which caused practical problems with areas such as the medicines management.	Thank you for your comment and for the link to resources. In response to your suggestion, the Guideline Committee has developed a new recommendation: 1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out.

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				This could be helped by care staff working with their clients to use physical reminders of their preferences, or making more use of technology such as automatic notification systems to update staff about important changes to plans.	
Healthwatch England	Short	13	9	Our home care briefing also found that choice and consistency was very important to people, with continuity of care workers key. Care providers could give consideration to the idea of a 'key worker' system, which one local Healthwatch suggested as a solution to the problem of lack of continuity.	Thank you for your comment. Recommendation 1.4.7 gives suggestion as to how continuity and consistency can be achieved.
Healthwatch England	Short	16	10	This currently reads 'service providers should ensure that practitioners are aware, and understand the function, of other services that they may need to work with, such as other health and social care service providers.' We agree that this is crucial, and suggest strengthening the recommendation by stressing that all relevant care staff need to understand local arrangements for how services are delivered. In our briefing on care homes, seventeen reports mentioned good access to GPs, but nine found that access to GPs was poor. Eight said it was difficult to get access to a dentist, and only one home told Healthwatch visitors that a dentist came to the home regularly. We heard that provide were not necessarily aware of local service arrangements – for example, dental services for people in care homes. Managers and relevant frontline staff must therefore understand what local arrangements are in place, as well as the general functions of other services. We suggest a link here to the useful NICE guideline on oral health for adults in care homes, which could also be listed in the 'More information' box on page 2 (it does not appear to be on the adult social services web page mentioned in that box).	Thank you for your suggestion. We have updated recommendation1.5.5 as follows: 'Service providers should ensure that practitioners are aware of the local arrangements for, and understand the function, of other services that they may need to work with, such as other health and social care service providers and services provided by the voluntary sector'. The focus of this guideline is on adult social care. We have therefore not provided a specific cross-reference to the guideline on oral health.
Healthwatch England	Short	16	15	In our home care briefing, we pointed out that and focusing on professional development is vital to ensuring staff can do their jobs effectively, potentially reducing staff turnover. People told us about the need for a basic standard of 'home care common sense' with one person mentioning that their carer was unable to boil an egg. To tackle this, Local Authorities could include basis care competency standards in their contracts.	Thank you for your comment. Staff skills and competencies for home care would be out of scope for this guidelines as this is in a related NICE guideline NG21 Home care: delivering personal care and practical support to older people living in their own homes .
Healthwatch England	Short	16	19	We agree that it is crucial to involve people in service design and improvement. However, formal service change projects are just one part of improvement. Everyday feedback and complaints are also important. Feedback can be both positive and negative, and can range from an informal comment made to a member of staff to a more formal complaint. We want to see all care homes provide user-friendly ways to give feedback, including complaints. We would like to see a recommendation that providers look to make greater and more regular use of feedback from people and relatives to address problems early and prevent minor issues escalating into complaints. It is equally important that social care services respond to feedback. 51 of the care homes visited in our briefing did not respond to the Healthwatch reports despite it being a statutory requirement to do so. This is simply not good enough and raises	Thank you for your comment. In response to your suggestion about including the issue of feedback and complaints, we have added a separate bullet point to Recommendation 1.2.1 as below: 'In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including: • local safeguarding procedures and how to raise safeguarding concerns or make a complaint'.

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				concerns about how these homes are responding to feedback from residents and their families. There is an opportunity here for the NICE guideline to remind services that they have a statutory duty to respond to these reports. Moreover, failure to respond to a report may indicate a wider reluctance to respond constructively to feedback, whether it be from service users, their families/carers or organisations such as Healthwatch. We were pleased to see that 43 homes had made tangible improvements after visits from their local Healthwatch. A further 103 care homes acknowledged the feedback provided by local Healthwatch, in many cases setting out a plan of action to address any concerns raised by residents. Providers are required by CQC to have effective complaints procedures, yet eight of the 12 local Healthwatch who specifically reported on complaints found that procedures were not clearly displayed. Despite the CQC requirements, there is relatively little transparent data around social care complaints compared with the NHS. For example, our early analysis of Local Authority complaints reports suggests that few Local Authorities report on complaints by provider. In our social care complaints toolkit, we suggest ways that Local Authorities and Healthwatch can work together to ensure that complaints systems function well and receive the right scrutiny. Although the Local Government and Social Care Ombudsman publishes national data about complaints that reach the final stage of resolution, there is a lack of national oversight. We know that people face barriers to giving feedback about care. In our home care briefing, we reported that more than 1 in 4 (27%) of people Healthwatch Barnet spoke with said they were reluctant to raise a complaint for fear it might have a negative impact upon their care. Where change has been made as result of feedback, social care services need to let users and their families know about it, in order to encourage future feedback. We suggest that the final guideline references the work of Quality Matters on Acting on feedback, concerns and compliments. One commitment from this workstream is a single complaints statement to clarify the roles of complaints handling bodies and ensure that people who use services receive consistent and clear signposting. The statement will be developed into a user-friendly tool. In order that people’s experiences of the complaints process improve, it will be crucial that commissioners and providers make use of and publicise the statement and tool.	
Healthwatch England	Short	25	3	We suggest referencing the work of local Healthwatch as a potential resource in this section, as they engage in a variety of ways with users of care services to find out more about their views and experiences.	Thank you for your comment. This section is specifically regarding recommendations for research and as such we do not highlight specific organisations here.
Healthwatch Worcestershire	Short	General	General	HWW welcomes the emphasis on Co-production throughout the document	Thank you for your comment and your support for the guideline.

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Healthwatch Worcestershire	Short	6	8	Delete the word “consider” and make this a firm recommendation. We are concerned that without this change the good practice this represents may not be uniformly implemented.	Thank you for your comment. The Guideline Committee considered this feedback but decided to retain the word ‘consider’ within this recommendation to reflect the strength of evidence underpinning the recommendation.
Healthwatch Worcestershire	Short	6	26	Delete the word “consider” and make this a firm recommendation. We are concerned that without this change the good practice this represents may not be uniformly implemented.	The Guideline Committee considered this feedback but decided to retain word ‘consider’ within this recommendation to reflect the strength of evidence underpinning the recommendation.
Healthwatch Worcestershire	Short	8	16	Delete the word “consider”. Add to the sentence “unless a different method of assessment is preferred by the person.” We are concerned that without this change the good practice this represents may not be uniformly implemented.	Thank you for your comment. We have retained the word ‘consider’ within this recommendation as it is not a legal requirement. However, we have added to the recommendation “unless a different method of assessment is preferred by the person.”
Healthwatch Worcestershire	Short	8	20	Substitute the word “have” for the word “bring”. The latter may imply that the person is required to travel to the assessment rather than this happening at a place of their choice, including their home	Thank you for your comment. We have substituted the word ‘have’ for the word ‘bring’ so that the bullet point reads: ‘the person is able to have someone they choose to be present at the assessment.’
Healthwatch Worcestershire	Short	12	1 & 7	Reverse the order of these two points. We would suggest that 1.5.3. establishing the person’s preference as to how they would like to be addressed should be done before 1.5.2 – building rapport.	Thank you for your comment. We have reversed the order of these two points as you suggest.
Healthwatch Worcestershire	Short	12	22	We would suggest point 1.5.5. is expanded to include reviewing /recording people’s participation in activities so that additional choices or encouragement can be offered to those who are not taking part. We are concerned that without this addition activity may only be geared towards those who participate and can lose sight of those who do not. Whilst it is a person’s right to choose not to do so this should not happen by default. This comment is based on our experience of carrying out Enter & View visits focusing on meaningful activity to 13 residential care settings for older people in Worcestershire.	Thank you for your comment. We have revised this recommendation to now read: 1.4.5 Day care and residential care providers should offer a choice of activities that are led by the person’s needs, preferences and interests. Encourage people to take part by including activities that motivate them, support them to learn new skills and increase their level of independence. Recognise that preferences are not fixed and may change.
Healthwatch Worcestershire	Short	15	26	Delete the word “consider” and make this a firm recommendation. We are concerned that without this change the good practice this represents may not be uniformly implemented.	Thank you for your comment. The Guideline Committee have considered this feedback and have decided to retain the word ‘consider’ to reflect the strength of evidence underpinning the recommendation.
Healthwatch Worcestershire	Short	16	4	Delete the word “consider” and make this a firm “should” recommendation. We are concerned that without this change the good practice this represents may not be uniformly implemented.	Thank you for your comment. The Guideline Committee have considered this feedback and have decided to retain the word ‘consider’ to reflect the strength of evidence underpinning the recommendation.
Healthwatch Worcestershire	Short	17	9	Delete the word “consider” and make this a firm recommendation. We are concerned that without this change the good practice this represents may not be uniformly implemented.	Thank you for your comment. The Guideline Committee have considered this feedback and have decided to retain the word ‘consider’ to reflect the strength of evidence underpinning the recommendation.
Healthwatch Worcestershire	Short	17	9	Local Healthwatch reports and intelligence should be specifically referenced in 1.7.4 as a source of evidence. Healthwatch has a statutory role to find out the views of service users and make these views known.	Thank you for your comment. We have amended 1.6.4 as you suggest to include Healthwatch as a source.
Home from Home Care	Appendix E	Page 12 -13		Survey methods to determine experience must be shaped through strong guidance about which tools to use and when.	Thank you for your comment. The Guideline Committee agreed that it is important that people have the necessary sills to design and execute and analysis. The Guideline Committee made a recommendation that in the first instance, they should consider using existing validated surveys (1.6.12) and in in recommendation 1.6.14 that local authorities should ensure that people who are responsible for interpreting and implementing the survey have the necessary skills and capacity.
Home from Home Care	Full	General	General	A guideline that runs to 410 pages has lost before it has started. If it takes this density to capture the essence of peoples experience then it will not be possible or feasible to harness the efforts needed to improve experience.	Thank you for your comment. There is a short version (approximately 30 pages) of the guideline which is the version NICE would expect practitioners to refer to. The longer version provides full details of all the evidence reviewed for those wishing to know more.
Home from Home Care	Short	General	General	All that is articulated is not new.	Thank you for your comment. The Guideline Committee were aware that some of the recommendations are similar to expectations set out in other legislation and guidance. However, the research evidence reviewed and experience of the Guideline Committee suggested that the requirements of existing legislation and

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					guidance are not being implemented in practice. This guideline therefore aims to emphasise and strengthen existing guidance.
Home from Home Care	Short		-1.1.3	Co-production - you exclude providers and only include the councils and people using services;	Thank you for your comment. Recommendation 1.1.9 relating to co-production refers to service providers.
Home from Home Care	Short		1.2.2	Moving to new care settings should reference the MCA particularly relevant for those with LD/autism	Thank you for your comment. The need to refer to the Mental Capacity Act 2005 in relation to decision making is stated as an overarching point in recommendation 1.1.6.
Home from Home Care	Short		1.7.14	Surveys only include those who have accessed services. What about those excluded by councils eligibility criteria?	Thank you for your comment. This guideline relates to the experiences of people who use adult social care services. Those who have been excluded by eligibility criteria but are self-funding would be included, but people who do not use services are out of scope of the guideline.
Homeless Link	Short	5	1-15	It is important that it is not just services that work in a person-centred way, but also the assessment and referral processes people must go through to access them. Commissioners and providers should work with experts by experience and voluntary sector stakeholders to design the whole pathway, not just service delivery.	Thank you for your comment. Recommendation 1.1.9 recommends that organisational policies and procedures (which would include referral and assessment processes) should be co-produced. The recommendations in relation to care and support needs assessment are intended to reflect a person-centred approach, see for example recommendation 1.4.4.
Homeless Link	Short	7	3-4	Language support, such as interpretation and communication aids, also need to be available to support people to access information as well as expressing their preferences.	Thank you for your comment. Reference to interpretation has been added to recommendation 1.1.5 about support to express views.
Homeless Link	Short	7	13-15	Information about care and support services should also be available in specialist services for people who may face the greatest barriers accessing services and information, such as homeless health centres, day centres etc.	Thank you for your comment. The Guideline Committee have strengthened recommendation 1.2.2 to include the role of community spaces as well as specialist services for related populations such as homeless health centres.
Homeless Link	Short	7	25-27	Voices of Stoke has developed an advocacy toolkit for the 2014 Care Act that supports people with multiple needs and their support workers to work through the eligibility criteria and identify where people might need support in that area. The toolkit is available to download.	Thank you for your comment and for the link to resources.
Homeless Link	Short	8	4-7	Housing status should be included in a person's care and support needs assessment and taken account of when developing the care and support plan that follows.	Thank you for your comment. The wording used here reflects what is in the Care Act 2014.
Homeless Link	Short	9	7-10	Regular reviews of care and support plans should be built in to the process with clear expectations around timeframes and how these will be carried out.	Thank you for your comment. This is now covered in recommendation 1.3.16.
Inclusion London	Equality Impact Assessment	11	3.2	Disability – the Equality Impact Assessment cites recommendation 1.1.3 as addressing the issue that people who are severely disabled may be at risk of having less control and choice over their care. In our experience, those with the highest level of support need are increasingly subject to care and support plans that contravene the wishes and preferences of the person in order to cut support. Our suggested additional recommendation under Comment 11 (first bullet point) above would also address this issue.	Thank you for your comment. The Guideline Committee agreed that care and support plans should be based on needs and preferences rather than financial considerations. Recommendation 1.3.3 that Local authorities must ensure that care and support needs assessments focus on the person's needs, how this impacts on their wellbeing and the outcomes they want to achieve in the day to day life, is a strong recommendation based on the duties set out in the Care Act.
Inclusion London	Short	General	General	We are disappointed that there is no specific reference to the social model of disability and human rights approaches to meeting adult social care needs. We consider there to be a benefit in highlighting the importance of understanding and application of these in commissioning and service provision.	Thank you for your comment. The UN Convention on the Rights of Persons with Disabilities is referenced in the context section for the guideline. With regard to the social model of disability, the view of the Committee was that the recommendations had been developed from this perspective, and therefore provided examples of putting this in practice.
Inclusion London	Short	General	General	People who use adult social care are currently subject to extreme anxiety and distress as a result of the way assessments are being carried out in order to cut support and make budget savings irrespective of their wishes, well-being and need. We consider that these recommendations need to be stronger and more specific in certain areas as detailed in the comments below in order to discourage bad and harmful practice and encourage more positive ways of working.	Thank you for your comment. The Guideline Committee agreed that care and support plans should be based on needs and preferences rather than financial considerations. Recommendation 1.3.3 that Local authorities must ensure that care and support needs assessments focus on the person's needs, how this impacts on their wellbeing and the outcomes they want to achieve in the day to day life, is a strong recommendation based on the duties set out in the Care Act.
Inclusion London	Short	General	General	There is growing concern at the lack of support for people who employ Personal Assistants and the risk in terms of liabilities under employment law that people are being exposed to as a direct result of Local Authority policy and practice. We	Thank you for your comment. The wording of recommendation 1.3.24 has been amended to clarify that guidance should be provided to people who employ personal assistants about all aspects of their duties as an employer.

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				consider that these recommendations need to go further to address those problems as detailed in our comments below.	
Inclusion London	Short	2	4 - 8	We are concerned that the list of legislation and guidance omits the Human Rights Act 2010. In our experiences adult social work practice is frequently in breach of Article 8 and we would therefore urge that this piece of legislation is explicitly mentioned. Additionally, we would value inclusion of the European Convention on Human Rights.	Thank you for your comment. We were unable to find reference to the Human Rights Act 2010. We have added reference to the Human Rights Act 1998 to the context section.
Inclusion London	Short	3	9	We are concerned that the guidelines confuse the concept of independent living and are not consistent with the definition according to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The General Comment on Article 19 recently published by the UN disability committee clarifies the concept of independent living (attached with this form). Independent living is NOT about doing everything for yourself, it is about having choice and control over the support you receive and the chance to live in the community with the same opportunities as other people. According to this definition, the phrase "support people to maintain their independence as far as possible" does not make sense. Social care should uphold Disabled people's right to independent living without exception. This example evidences the need for co-production with Disabled People's Organisations and training at all levels because although this draft guideline references the United Nations Convention on the Rights of Persons with Disabilities (Short version page 2 line 8), this section is then at complete odds with Article 19 of the Convention which is the single most relevant Article to adult social care.	Thank you for your comment. We have removed the phrase 'as far as possible' from recommendation 1.1.2. This should now be consistent with Article 19 of the UNCRPD.
Inclusion London	Short	5	1 - 4	In addition to recommending that commissioners and service providers consider seeking advice from voluntary and community sector organisations with expertise in equality and diversity issues, we would welcome a recommendation for commissioners and service providers to consider seeking advice from Disabled People's User led Organisations with expertise in the social model of disability to ensure they can deliver services that are consistent with human rights approaches.	Thank you for your comment. Reference to seeking advice from disabled people's user-led organisations has been added to recommendation 1.1.12.
Inclusion London	Short	5	16 - 21	In our experience Local Authorities and service providers have only a tokenistic understanding and application of co-production. We would welcome a line within this recommendation outlining that good practice co-production involves working in partnership at the design and development stage of initiatives and is more than just consultation. It is also important that co-production is adequately resourced with budgets for access and inclusion.	Thank you for your comment. We have added a definition of co-production in to the 'Terms used in this guideline' section.
Inclusion London	Short	5	23 - 26	We would welcome some form of statement here to clarify that the person has the right to involve paid carers if that is their decision. We have had an experience of needing to seek advice from a solicitor where one Local Authority refused to allow a Personal Assistant to be involved in an assessment despite this being the clear and expressed wishes of the person. The reason given was that this constituted a "conflict of interest" as the Personal Assistant was paid through the Direct Payment which the social worker was seeking to cut.	Thank you for your comment. We have added the phrase 'or other people of their choosing (for example as personal assistants)' to recommendation 1.1.14 to clarify this issue.
Inclusion London	Short	7	3 - 4	We are concerned that the Accessible Information Standard is not being implemented within adult social care. For this reason, we would encourage that this recommendation is more specific about what this entails, providing examples of the different formats in which information should be made available, including easy read, British Sign Language and in electronic version. People need to be made aware that they have the right to request accessible formats and local Authorities should record and meet the information access needs of adult social care users.	Thank you for your comment. NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the Accessible Information Standard is provided for people to find more detailed information.
Inclusion London	Short	8	3	We would welcome the inclusion of recommendations concerning referrals for Continuing HealthCare (CHC) funding and how these fit into the assessment process as poor practice in this area significantly increases the stress and distress experienced by adult social care users. As evidenced in the Inclusion London	Thank you for your comment, At the moment this is out of scope, but in due course, if there are integrated assessments this could be considered in an update to the guidelines. The Guideline Committee considered that the principles of best practice for social

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				report “One Year On: Evaluating the Closure of the Independent Living Fund”, practice varies across different Local Authorities. Some boroughs operate a screening process to check eligibility for CHC before making referrals whereas others have made large numbers of unsuccessful referrals with a majority being rejected. The CHC process is long and intrusive and adds considerably to the uncertainty and distress experienced by the adult social care user. We would therefore recommend that all Local Authorities have in place a screening system for checking eligibility before making CHC referrals. We would also recommend that they ensure adequate support is in place for the individual while health and social care negotiate funding. Again this is clear in the Care Act but in practice is still a problem.	care could inform future arrangements for Continuing health care (CHC). We have revised text in 1.3.6 that the person is given details of the nature and the purpose of the assessment and in 1.2.1, in line with the Care Act, that local authorities must provide information about people’s rights and entitlements to care and support services.
Inclusion London	Short	8	8 - 13	We would welcome the inclusion of two additional bullet points within this section recommending that a care and support needs assessment should: Aim to assess need without being subject to an over-riding agenda to make predetermined levels of savings to the value of a support package. Evidence including findings from the recent Community Care survey as well as Disabled people’s own lived experience shows that this is now common practice, however it is not in line with the Care Act. Be carer-blind. Although it is clearly stated in the Care Act that this should be the case, evidence on the ground that this is not happening is so overwhelming that this needs to be clearly spelled out within these recommendations.	Thank you for your comment. Recommendation 1.3.3 that Local authorities must ensure that care and support needs assessments focus on the person’s needs, how this impacts on their wellbeing and the outcomes they want to achieve in the day to day life, is a strong recommendation based on the duties set out in the Care Act. Recommendation 1.3.4 has been revised to state that care and support needs assessments should take a whole family approach and take into account the needs of carers.
Inclusion London	Short	8	17 - 24	We would welcome the inclusion of two additional bullet points within this section recommending that Local Authorities should ensure that: The person is informed whether it is an assessment or a review that is being undertaken. We have evidence from Community Care solicitors as well as anecdotal evidence from Disabled people who were previously recipients of the Independent Living Fund that this is frequently not the case. In some cases, it appears that the social worker is themselves not clear which it is which is a cause for even more concern. Inclusion within this guideline would encourage Local Authorities to understand the need to be clear on the difference. The person is informed who is coming to the assessment, particularly for elements of the assessment process where the person will be observed receiving personal care. This is a very practical way of ensuring that assessments are carried out in ways that respect the dignity of the individual. We very much agree with and welcome the inclusion of “dignity” under 1.4.4, however Local Authorities do need further guidance to understand straightforward ways such as this as to how they can implement that.	Thank you for your comment. We have revised this recommendation based on your suggestion to state that local authorities should ensure that the person is given the details of the nature and purpose of any assessment.
Inclusion London	Short	9	6	We are concerned that there currently no recommendations within this section specifying that care and support plans need to respect the wishes and preferences, and also the well-being and dignity of the person. Increasingly adult social care users are having plans forced on them which contravene their wishes, threaten their well-being and deny dignity, for example expecting people who are not incontinent to wear incontinence pads or use penile sheaths in order to cut support while claiming this will “increase independence and autonomy”. Where the person does not consider their care and support plan to reflect the best way to meet their needs while maintaining well-being this should be stated objectively within the care and support plan setting out the reasons given by the person without use of derogatory language: “non-compliant” and “uncooperative” are phrases we see written in plans used to negate the individual’s valid concerns about how their support needs are going to be met.	Thank you for your comment. The Guideline Committee considered that the care and support needs assessment, on which the care and support plans are based, include reference to promoting the interests and independence of people who use services and also to be respectful of their dignity. Recommendation 1.3.8 has been revised to make clear that the care and support needs assessment documentation should make clear what assessed needs will be met and how. In terms of delivering on this, we have revised recommendation 1.4.1 on providing care and support to say that service providers should foster a culture that enables practitioners to respect people’s choices and preferences in all settings where care is delivered.
Inclusion London	Short	10	1	We are concerned about Local Authorities not paying enough to enable people to meet their legal obligations as employers, for example according to the National Living Wage, case law on night shifts and pensions regulations. Where the law has changed, Local Authorities will frequently refuse to increase Direct Payment rates	Thank you for your comment. While it is beyond the remit of NICE guidance to make recommendations about funding of care and support, this was an issue of concern raised by the Guideline Committee. We have revised recommendations 1.3.24 that in line with the Care Act statutory guidelines local authorities should

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				accordingly, forcing the person to either breach employment legislation or reduce the hours of support they receive from the amount they were assessed as needing in order to make up the difference in pay. We would urge a recommendation in this section that responds to these concerns.	ensure that support is available and inform people where to get support with their role and responsibilities as an employer, including terms and conditions. We hope that the guideline will inform good practice in this area.
Inclusion London	Short	10	2 - 6	We would welcome inclusion of an additional bullet point within this section recommending that Local Authorities should inform people of their right to alternative options where pre-payment cards are given as default. We are aware that this is not happening in practice.	Thank you for your comment. We have added a bullet to this recommendation stating that local authorities should inform people of the different payment systems available.
Inclusion London	Short	10	21	Within this section on Personal Assistants we would welcome additional recommendations that: Local Authorities should have in place policies concerning redundancies and contingencies. We have come across practice where LAs have not had these in place and this has caused considerable difficulties for people in the management of their Direct Payments, or for family members where a relative in receipt of a DP has died and they have been left liable for the redundancy payments of PAs over what the insurance will cover. Local Authorities should ensure their staff have training in and understand the employment legislation to which those people who employ Personal Assistants are subject. This would avoid situations where changes to support packages are made in ways that leave the person in violation of employment law, for example cuts to hourly rates made with immediate effect without recognition that Personal Assistant contracts specify notice periods for any changes to their terms and conditions.	Thank you for your comment. The Guideline Committee recognises the current complexities of being an employer of personal assistants and people’s legal obligations in that regard. We have revised recommendation 1.3.20 to say that the direct payment process should be ‘able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants to prevent such situations when payments are reviewed without taking their legal obligations as employers into account. We have also revised recommendation 1.3.24 that local authorities should support people to access support on their roles and responsibilities as an employer, including redundancy and contingency planning, (in line with the Care Act statutory guidance 12.29).
Inclusion London	Short	10	25	We are concerned that this recommendation does not make sufficiently clear Local Authorities’ responsibility to not only inform people where to get support but to ensure that support is available in the first place. In some cases Personal Budget/Direct Payment Support Services are only providing minimal support which is failing to provide the support people need in order to stay in line with employment legislation changes.	Thank you for your comment. We have revised recommendation 1.3.24 to include the text: ‘in line with the Care Act statutory guidance, local authorities should ensure support is available for people employing personal assistants, and that they are told about where to get support with:: • recruitment and retention of staff • their role and responsibilities as an employer (for example, payroll, and terms and conditions, redundancy and contingency planning).
Inclusion London	Short	14	20	We are concerned at the wording of this recommendation to “prevent” behaviour that challenges. Behaviour that challenges is a form of communication used by people who are not able to verbalise their wishes and feelings. Rather than focusing on simply stopping behaviours (which can be achieved by means such as physical or chemical restraint, causing harm and breaching a person’s human rights without facilitating communication), service provision should focus on understanding and meeting the needs of the person in order that behaviour that challenges does not occur.	Thank you for your comment. We have revised recommendation 1.4.15 to say ‘Ensure that support in residential care is based on a good understanding of people's needs, including behaviour that challenges as communication’. We have added an additional bullet point to say that people should have access to community health teams and specialist supports.
Inclusion London	Short	15	13	Under staff skills and experience we would welcome a recommendation that staff should receive user led training in the social model of disability and independent living philosophy.	Thank you for your comment. Although the recommendation does not use the term “social model of disability”, the view of the Committee was that the recommendations had been developed from this perspective, and therefore provided examples of putting this in practice. Recommendations in the staff skills and experience section includes making sure that staff have right the personal attributes identified from values-based interviewing (1.5.1) , and that service providers should consider involving people who use services and their carers (as experts by experience) in the recruitment and training of staff and supporting and training others to be experts by experience (1.5.3)
Kent County Council	Full	General		Should there be some reference to safeguarding adults	Thank you for your comment. We have revised recommendation 1.2.1 to specify that in line with the Care Act local authorities must provide information on local safeguarding procedures and how to raise safeguarding concerns or make a complaint.
Kent County Council	Full	General		Should there be some reference to safeguarding children	Thank you for you for your comment. Children who use social care services are out of scope for this guideline on adults who use social care services.

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Kent County Council	Full	8	18	Should this read, actively involve the person in 'all decisions' and not 'all key decisions'	Thank you for your comment. We have revised this text as you suggest
Kent County Council	Full	11	25-29	Is this talking about developing an information sharing agreement and having Standard Operating Procedures, which is what the ICO and the IG toolkit require? Do not omit to mention the Health and Social Care Act 2015 provides a duty to share information for the purposes of Direct Care. Also The GDPR will bring additional transparency requirements and improve Privacy Notices.	Thank you for your comment, Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that the guideline is relevant to a diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation. The main emphasis of the recommendation was to support collaborative working, and we have revised the recommendation to make this clearer. We have added reference to the Health and Social Care (Safety and Quality) Act 2015 in recommendation 1.4.10.
Kent County Council	Full	12	10-11	What does 'control their own funding' mean? Does it mean provide care and support planning to advise on appropriate care and support or does it mean provide financial advice – which is covered in 7-8	Thank you for your comment. This recommendation (1.2.1) has been revised for greater clarity and now reads: 'local authorities must provide information about personal budgets and what all the options are for taking a personal budget e.g. local authority managed, Individual Service Fund, or Direct Payment as well as rights and entitlements to assessments and care and support services'.
Kent County Council	Full	12	17-18	LAs should provide (not consider) information about vol orgs etc as part of the prevention requirements of the Care Act	Thank you for your comment. We have revised this recommendation as you have suggested
Kent County Council	Full	13	7-11	Should this also state needs assessment should be strengths based	Thank you for your comment. The Guideline Committee were cautious about stating a person's strengths and assets should be used in assessments for care needs, or that a person's strengths, defined by an assessor could be a means of determining eligibility for services. We have revised the text to make clear that we mean self-defined strengths and outcomes that a person wants to achieve in their day to day life.
Kent County Council	Full	13		There is no reference to providing the eligibility determination to ensure there is transparency in decision making	Thank you for your comment. We have revised this recommendation to include information on a person's rights and entitlements.
Kent County Council	Full	14	4-7	Should this also include a direct reference to contingency planning	Thank you for your comment. We have revised this recommendation as you have suggested.
Kent County Council	Full	14	23	This should read Care and support plans not care plans	Thank you for your comment. We have revised this recommendation as you have suggested.
Kent County Council	Full	15	22	Should read care and support planning stage	Thank you for your comment. We have revised this recommendation as you have suggested.
Lifeways Group	Short	General	General	Lifeways are broadly supportive of the recommendations within the guideline and would be pleased to see them implemented as the industry standard. In particular, Lifeways support and commend efforts to improve people's experiences of social care services. The overarching principles to treat people who use services as individuals and to support them to maintain their independence as far as possible should be adopted as best practice. In the learning disabilities sector, it is positive that there is consensus regarding the need to transition people into a community setting. For too long, individuals have been forced to live in settings and receive care that does not meet their needs or wishes. The Government and NHS England have undertaken important work to improve care since the Winterbourne View scandal, although progress admittedly remains too slow. All the evidence from the Care Quality Commission (CQC) is that small scale community settings are a key factor in driving up the quality of services and delivering much better outcomes for people with disabilities. Supported living services are an entirely personalised, locally-focused model which can be used as a method to accelerate integrated care services. We believe that supporting people to live independent lives has wider benefits for our whole society in promoting community cohesion, and in reducing demand on health care services.	Thank you for your comment. We are glad that these recommendations will support developments in this area. The Guideline Committee considered it very important that people should be supported to live the life that they choose.

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Lifeways Group	Short	General	General	Pooled budgets hold much promise, however have to-date not been entirely effective. The Better Care Fund (BCF) is an enabler to ensuring that individuals have access to services based on their needs, but thus far this money has been subsumed into the acute sector. The ethos of pooled budgets must be embraced given the current interdependence of the NHS and care sector; however there are question marks over the extent to which social care providers and our commissioners see the benefits of the BCF initiative. This is even more of an issue with the recent announcement that access to BCF money will be based on whether local authorities are successful in reducing delayed transfers of care. The BCF must be successful for the purpose for which it was intended, that is to drive the transformation of local services to ensure that people receive better and more integrated care and support.	Thank you for your comment. We hope that by making recommendations for good practice that these recommendations will support developments in this area.
Lifeways Group	Short	General	General	Lifeways strongly supports the use of personal budgets as an innovative approach to the design and delivery of adult social care. One of the most important contributions personal budgets have made is that all providers of social care services now have to consider much more carefully what we offer and how we communicate with the people we support and their families. The enhanced choice for service users through personal budgets has made social care a public service that is genuinely accountable to and controllable by the people being supported; this is essential to a high quality and responsive social care system. We firmly believe personal budgets have helped to instil a strong culture across the social care system that puts the needs and wishes of service users front of mind for commissioners and providers. It is with this in mind that personal budgets should be emphasised in the guidance as an important step to improving the experience of care for people using adult social care services.	Thank you for your comment. We hope that by making recommendations for good practice in the use of different kinds of personal budgets that these recommendations will support developments in this area.
Lifeways Group	Short	General	General	Lifeways are enthusiastic about the development of new models of care, particularly the work underway in Greater Manchester and the employment of multidisciplinary teams working across health and social care. Lifeways is also fully supportive of the devolution agenda as an opportunity for local areas to make local decisions based on local need and to do things differently. For this guideline to be successful in improving care for people with learning disabilities, there needs to be a central focus on ensuring that the sector continues to promote good practice and innovation. Attention must be given to important new approaches to care provision, as it presents an invaluable opportunity to do things differently in a sustainable way.	Thank you for your comment. The methods of systematically reviewing research literature on the views and experiences of people who use adult social care services will necessarily look backwards in time for examples of good practice and what people value in adult social care services. The Guideline Committee support the guideline’s role in promoting good practice and where there was a gap in the evidence the committee was able to make research recommendations.
Lifeways Group	Short	7	2	There is real value in information sharing, however we are concerned that the schism between health and social care is a barrier to ensuring that this guideline is adopted as effectively as possible across the board. The current lack of integration and information sharing between health and social care means that care is not person-centred and people with learning disabilities are often subject to a fragmented care pathway, which serves as an impediment to holistic care. In order for this guideline to become best practice, it is important that it takes into consideration the barriers to implementation and places greater emphasis on closer working between health and social care partners. It is a recurring theme from the families and carers of the people we support, that they recognise and value the work done by individual people, but are profoundly frustrated by the complexity of systems, and the apparent inability of health and social care to work together.	Thank you for your comment. The Guideline Committee also considered the integration of health and social care, as well as other services important to adults who use social care services to meet their needs and preferences in a holistic way. The recommendations on information have been revised and more detail added to ensure that it is clear that information has to be provided on all health, social care and health-related services, in line with the Care Act and in line with the Accessible Information Standard. The research evidence highlighted, and Guideline Committee recognised, the complexity of systems and the committee suggested that good practice would include a named worker whose role would be to signpost and navigate across services. We hope these recommendations will enable closer working between health and social care and other services.

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Lifeways Group	Short	7	5	Proper implementation of the Care Act presents a genuine opportunity to improve people's experiences of adult social care. We feel that some local authorities are not meeting their obligations under the Care Act, particularly around market shaping and developing new services. Although there are often reasons why this could be the case, more needs to be done to enable councils to play their part in ensuring individuals are supported to maintain their independence as far as possible. Given that the financial pressures on local authorities are likely to continue, it is our view that there will be more and more challenges to local authorities over failures to meet Care Act obligations.	Thank you for your comment: the Guideline Committee agree it is useful to highlight how the guideline relates to other guidance and legislation and includes references to the Care Act where the Guideline Committee and the research evidence suggested that particular provisions were not happening in practice, or were of particular importance to people's experiences of care. The Guideline Committee gave careful consideration to the resource impact of their recommendations and was aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They hope that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services.
Lifeways Group	Short	10	21	Linked to the more general point above on personal budgets, Lifeways would like to highlight the employment of Personal Assistants as an area that should be given greater consideration. These individuals operate in an entirely unregulated world, so local authorities and the CQC are not in a position to monitor quality or whether taxpayers are getting value for money. It is with this in mind that we would call for NICE to specifically highlight the need for greater oversight of the role and responsibilities of Personal Assistants.	Thank you for your comment. The views and experiences of people who use adult social care also highlighted some issues regarding the rights and responsibilities of people who employ personal assistants. Unfortunately, whether greater oversight would overcome these challenges and issues, what form that oversight would take and by whom it would be carried by, was out of scope for this guideline on the experience of adults who use social care services. We hope that the good practice identified in the views and experiences evidence, Guideline Committee discussions and expert witness testimony on what is most valued about personal assistants and the recommendations based on this evidence will lead to greater efficiencies in stable placements, by recommending supports for fulfilling employers' responsibilities and contingency planning.
Lifeways Group	Short	11	12	As an experienced provider of supported living services to over 5300 individuals, we have developed a well-rounded approach to providing care and support. We pride ourselves on delivering high-quality, local services, personalised to meet individual needs and aspirations. Lifeways are therefore supportive of the guidelines calling on a greater degree of respect for people's individual choices and preferences; integral to our philosophy is ensuring the people we support are treated with respect, dignity and in line with their wishes. We firmly believe that models that give vulnerable adults more choice and control over their environment to enhance their quality of life, such as supported living services, should be embraced and supported by NICE. Supported living services provide a range of complex care in one location. Lifeways work with a number of Housing Associations to develop purpose new built accommodation and tailored packages for service users. We understand that people have different needs and preferences, which requires a flexible approach to developing bespoke solutions. This model of care means people can be supported to move out of hospital into the community in line with their specific care need for an undefined period of time. Lifeways are able to offer clinical support in the community that consists of behavioural nurses and psychologists and will also include support from a Consultant Psychiatrist, who can work independently or supplement the local NHS clinical teams. The model incorporates the use of assistive technology and other vital adaptations.	Thank you for your comment. The importance of supporting people in their individual choices and preferences came out strongly in the research evidence and the Guideline Committee's expertise and experience. We have reflected this in the recommendations and as a general principle. Where we do not specify a setting, such as a supported living environment, we mean this recommendation and/or overarching principle applies in all settings where care is delivered. We have described supported living in the terms used section of the guideline. We did not find research evidence on the views and experience of people who used assistive technology. For this reason the Guideline Committee considered this a gap in the evidence and suggested a research recommendation in this area.
Local Government and Social Care Ombudsman	Full	General	General	In response to your third question, we have some free resources available on our website that aim to help care providers improve the way they handle complaints. These include template complaint procedures, letters, and general guidance and information sheets.	Thank you for your comment and for the link to resources.

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				We also provide training courses aimed at supporting care providers to handle complaints effectively. Courses are tailored to frontline staff or complaint managers. In partnership with the Parliamentary and Health Services Ombudsman (PHSO) and Healthwatch England, we have published a framework to help improve the way complaints are handled across the NHS and social care. My Expectations was produced in consultation with over 100 patients and service users and over 40 organisations to describe people's expectations of good complaint handling. The CQC adopted this work as a tool for determining what 'good' looks like in complaint handling when inspecting services. We publish an annual Review of Adult Social Care complaints, which makes available our data for complaints about councils and care providers to support transparency and accountability across the social care sector. And, when we identify common or systemic issues, we publish focus reports to share learning and promote best practice among service providers. Those relevant to adult social care include: • Working together to investigate health and social care complaints (December 2016); and • Counting the cost of care: the council's role in informing public choices about care homes (September 2015). We also publish our decisions, which can be searched by organisation and subject. These can help councils and care providers to: • learn from the mistakes of others and ensure they aren't repeated; and • understand whether we're likely to find fault in various situations and, if so, how we might suggest an appropriate remedy for any subsequent injustice. Our decisions could also contribute to a range of information used by commissioners and providers to inform service improvement (Page 18, lines 18-20).	
Local Government and Social Care Ombudsman	Full	46 104 119 120	5-11 15-17 28-29 1-13	You may be aware that our colleagues at the Parliamentary and Health Services Ombudsman (PHSO) published a report in December 2015 that looked at the barriers older people face when raising concerns or complaints about their care, in any setting. The research identified a number of recognisable themes: lack of information about how to complain, feeling like complaining would make little difference, a lack of support to complain, not wanting to make a fuss, and worrying about what will happen if they do. We recognise these barriers apply equally to social care settings. Indeed, these themes closely reflect the findings from the literature review described in the full version of your draft guideline. Note, for example: • Page 46, lines 5-11 • Page 104, lines 15-17 Page 119, lines 28-29; Page 120, lines 1-13	Thank you for your comment. We note the barriers identified to raising concerns and complaints for older people and also for adults who use social care services. We have therefore revised text in recommendation 1.2.1 on providing information and added that local authorities should provide information about how to raise concerns or make a complaint.
Local Government and Social Care Ombudsman	Full	133 134	6-18 7-12	A robust complaints procedure is an absolutely essential mechanism for empowering people to overcome the barriers related to improving their experience of social care services. So it is concerning that one study, cited in your literature review, found an "absence of clear processes for redress" in care homes and that "none…had a formal complaints procedure in place" (Page 133, lines 6-18).	Thank you for your comment. NICE supports the Quality Matters initiative. We note the barriers identified to raising concerns and complaints for older people and also for adults who use social care services. We have therefore revised text in recommendation 1.2.1 on providing information and added that local authorities should provide information about how to raise concerns or make a

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				Indeed, we have a longstanding concern that many people may be unaware of their right to seek independent redress from the Ombudsman. However, ensuring the complaints system works well is not only about process; it is largely about culture – the way in which frontline staff respond to initial concerns from care users and families, and the attitude to and ownership of concerns and complaints by managers, and their willingness to learn from them. People who raise concerns and complaints should have the confidence that they will be heard, understood and responded to appropriately, and staff should be equipped with the tools they need to respond to concerns and complaints confidently and be empowered to resolve matters quickly, where appropriate to do so. Indeed, this is recognised by the authors of that study when they note that care providers must learn "how to encourage and attend to dissenting as well as majority voices" (Page 134, lines 7-12). This is also recognised by the Quality Matters initiative currently being led by the CQC and involving a range of partners across the social care sector (including us). That work focuses on six priorities to improve the quality of adult social care, the first of which is to ensure that: ☐ people who use services, their families and carers receive information that is clear and standardised, and that complaints are handled quickly and effectively; and there is a strong approach to the duty of candour so there is a culture of being open and honest when something goes wrong (Quality Matters, p9).	complaint and use records of complaints as a source of information to improve services (1.7.4). Also recommendation 1.4.1 recommends that service providers should foster a culture in their staff to ensure that that there are open channels of communication between practitioners and people who use services.
Local Government and Social Care Ombudsman	General	General	General	The Local Government and Social Care Ombudsman investigates complaints about councils and some other authorities and organisations, including independent adult social care providers in England. It is a free service. Our role is to investigate complaints in a fair and independent way – we do not take sides. Our jurisdiction spans the whole adult social care sector; we are the single point of independent redress for complaints about adult social care, irrespective of whether that care is arranged and funded privately or through a local authority.	Thank you for your comment.
Local Government and Social Care Ombudsman	General	General	General	Complaints and enquiries about adult social care account for the second largest category of our work (behind Education and Children's Services). In 2016-17, we received 3,061 cases about adult social care – an increase of 3% on the previous year. It is often more valuable to look at complaint outcomes, rather than case volumes alone. Where we find fault in the way councils or care providers carry out their duties, we will uphold a complaint. In 2016-17, we upheld 63% of the detailed investigations we completed into adult social care complaints. This compares with 53% for all complaint types within our jurisdiction. In fact, adult social care had the highest uphold rate of all complaint types. This means we were more likely to identify fault in how adult social care services are delivered compared with all other complaint types we investigated.	Thank you for your comment. Recommendation 1.6.4 also identifies complaints as an important source of information.
Local Government and Social Care Ombudsman	General	General	General	Our experience, of dealing with situations where things have gone wrong, puts us in a unique position to provide insight into what could be done to improve adult social care services. We publish an annual Review of Adult Social Care Complaints, which makes available our data for complaints about councils and independent care providers, and supports transparency and accountability across the whole adult social care complaints system.	Thank you for your comment. Recommendation 1.6.4 also identifies complaints as an important source of information.

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				We also identify thematic issues and publish focus reports that draw together the learning from the complaints we see, highlighting the issues and making best practice suggestions for councils and providers.	
Local Government and Social Care Ombudsman	Short	General	General	In terms of the recommendations outlined in your draft guideline, there are a number of places where reference to effective complaint handling could be made more explicit. Given the findings from your literature review, and our own experience of the impact on people when things go wrong, there are strong reasons to include clear expectations on complaint handling for those who implement the guideline. The rest of our response offers suggestions to consider about how this could be achieved.	Thank you for your comment. The Guideline Committee agree that being able to raise concerns and make complaints is an important part of good practice and improving services, We have therefore revised text in recommendation 1.2.1 on providing information and added that local authorities should provide information about how to raise concerns or make a complaint and in recommendation 1.6.4 on using records of complaints as a source of information to improve services.
Local Government and Social Care Ombudsman	Short	3		As an overarching principle A third principle might be included to encourage people to give honest feedback about their care, whether informally or formally through complaints and compliments. This recommendation adapts a number of points from the NICE guideline on service user experience in adult NHS services (see 1.2.4, 1.3.4, 1.3.6, 1.3.7, 1.3.8, 1.3.12, and 1.3.13).	Thank you for your comments and suggestions of recommendation that may also be relevant to this guidelines from the complementary NICE guidelines on service user experience in adult NHS services. We have adapted relevant recommendations from the Adult NHS services guidelines in the general principles section and referred to the relevant section of the guidelines by hyperlink.
Local Government and Social Care Ombudsman	Short	7		In the context of the provision of information A sixth recommendation might be added to this section that local authorities and care providers should provide information about how someone can complain about issues related to their care. This should include a clear signpost to the Ombudsman once the local complaints process is exhausted. As outlined in comment 6 (above), resources are available on our website to help care providers improve the way they handle complaints.	The Guideline Committee agree that information provided should also include information on how to raise safeguarding concerns or make a complaint and have revised the recommendation accordingly to include this.
Local Government and Social Care Ombudsman	Short	11	22-23	While providing care and support This point could be expanded to include putting systems in place for making complaints, including the right to escalate such complaints to the Ombudsman. In its present form, the existing point might be taken to refer to safeguarding concerns only.	Thank you for your comment. The Guideline Committee agree that information provided should also include information on how to raise safeguarding concerns or make a complaint and have revised the recommendation on providing information (1.2.1) to include this.
Mencap	Short	5		Co-production It would be helpful to define the meaning of co-production here, so that there is genuine co-production and not just consulting.	Thank you for your comment, we have included a definition of co-production in the 'Terms used in this guideline' section based on the Think Local Act Personal definition.
Mencap	Short	6		Coordinating care It would be helpful to include that the named coordinator needs appropriate knowledge and skills to coordinate care for the individual in question. Housing can be a key issue for people with a learning disability and other people using services. It is important that any named coordinator has the specialist housing expertise required or is closely linked to someone with the relevant expertise. The points highlighted in 1.2.3 are key and should absolutely be implemented to encourage joint working. It would be helpful to include that all types of collaborative working should involve people and families where appropriate.	Thank you for your comment. We have revised recommendation 1.3.10 based on your suggestions to ensure that the named coordinator is competent to coordinate and access services including housing, and that they should be able to liaise and work with the person, their families, carers and advocates.
Mencap	Short	10		Personal budgets and direct payments It is very important people with a learning disability and families get the support needed to use direct payments and these support services, including local peer support services, are sufficiently resourced.	Thank you for your comment. The Guideline Committee also agrees that people should be supported to use personal budgets and direct payments. The recommendation on personal budgets and direct payments has been revised to say that people should be made aware of all options and formats for personal

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					budgets and direct payments, and that local authorities should resource and connect people to peer support services.
Mencap	Short	5,6		Involving carers, families and friends In line with the Mental Capacity Act, families and those who know the person well should be involved in decisions where a person lacks capacity to make that decision. It is important that families are able to be fully involved and their expertise and knowledge recognised and valued. Too often we hear about situations where families are not being involved effectively and are not having their expertise about their family member recognised.	Thank you for your comment. The Guideline Committee recognises the importance of involving families and carers. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people's views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Mencap	Short	12		Continuity and consistency It would be helpful to include that oversight and adequate funding are needed from commissioners.	Thank you for your comment. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about oversight and funding of care and support.
Mencap	Short	7,8		Care and support needs assessment and care planning It would be helpful to include that there should be a holistic approach to assessment which aims to bring together all of the person's needs and this may need the input of different professionals such as adult care and support, children's services, housing (Care Act statutory guidance). The LA should consider what adaptations to the needs assessment process are needed to make it as person-centred as possible. For example, allowing more time, enabling video to be shown which can help the person share their needs and preferences.	Thank you for your comment. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people's views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Mencap	Short	15		End of life support in residential settings It is important people with a learning disability and staff in residential settings can access support from health professionals in the community with expertise around end of life care. Commissioners need to ensure that end of life care for people with a learning disability is appropriately resourced.	Thank you for your comment. We have revised the recommendation on 1.4.15 on understanding people's needs to include a statement that everyone in residential care settings should have access to community health teams and specialist support. It is beyond the remit of NICE guidance to make recommendations about funding of care and support.
Mencap	Short	17		Using people's views to improve services It is important that all people with a learning disability are supported to give their views, share preferences and wishes and be involved in and influence decisions around services. If people with the most complex needs are not able to influence and be involved in decisions around services (because they are not supported to do so/ more creative approaches are not used) their needs may not be properly thought about in service design and development and as a consequence they are likely to miss out. Creative approaches can be used to enable people who don't use formal communication to share their experiences and preferences, for example the use of video of people's experiences. Mencap and BILD's Involve Me project looked at involving people with profound and multiple learning disabilities in decision-making. Link to summary booklet with key messages from the project: https://www.mencap.org.uk/sites/default/files/2017-05/Involve%20me%20Summary%20Booklet.pdf It is important to remember that families often have crucial knowledge about their loved one's needs and preferences and insight into how services are supporting their family member, particularly where their family member has complex needs	Thank you for your comment. It was important to the Guideline Committee to make recommendations in this area, reflecting the research evidence that making adaptations to tools to gather people's views were more effective in including people's views with a view to improving services. We did not find research evidence on particular tools that could be shown to be more effective. We have revised recommendation 1.6.8 for organisations who conduct research to make sure all groups can participate, including people with different communication needs, and this may involve adapting different methods. We have also added text that reasons for low response rates should be investigated and adaptations should be made to increase participation. We have also stated that independent advocacy should be provided where necessary to ensure participation if that person wishes to use an advocate to assist them. We have revised the text in 1.6.2, which now says that activities to gather views of people using care and support and their carers should be co-produced.

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				and does not use formal communication. Their expertise and knowledge should be valued and used to inform service development.	
Mencap	Short	11,12		Providing care and support It would be helpful to highlight the importance of understanding the person’s means of communication and ensuring that communication needs are met, in line with the accessible information standard. Meeting communication needs is a fundamental part of providing care and support. 1.5.5 - commissioners must ensure there is adequate funding to enable providers to offer a choice of activities that are led by the person’s needs, preferences and interests.	Thank you for your comment. We have revised recommendations 1.1.5, 1.1.7, 1.4.1 and 1.6.7 to make sure that people’s communication needs are identified, recorded and met, in line with the Accessible Information Standard. It is beyond the remit of NICE guidance to make recommendations about funding of care and support.
Mencap	Short	13,14		Residential settings 1.5.13 As well as maintain personal relationships and friendships, people with a learning disability may need support to develop personal relationships and friendships, which are a crucial part of wellbeing. It is important that there is a good understanding of people’s needs including behaviour that challenges. It is important that people who display behaviour that challenges get the support they need, and they are able to get this early on to help stop needs escalating and crisis situations. It is important there are good links with professionals in community health teams and that people and staff in residential settings can access the support needed from these teams in a timely way.	Thank you for your comment. We have revised recommendation 1.4.15 to say that people should be supported to take part in social groups as well as activities. We have further revised this recommendation to say that people in residential care settings should have access to community health teams and specialist support.
Mencap	Short	15,16		Staff skills and experience A workforce with the right skills for the people they support is key to ensuring good lives. To this end, it is important that recruitment processes involve the person and their family (where appropriate) and that innovative ways of doing this are implemented where required. It would be helpful if the guideline could be stronger than asking service providers ‘to consider’. It would be helpful if the guideline could say that people who use services - and families - should be involved in the recruitment of staff. For people with a learning disability who have complex needs and don’t use formal communication, families can be particularly important in ensuring their needs and preferences are understood – they should be recognised as valuable partners in the recruitment and training of staff.	Thank you for your comment. We have revised the text for recommendation 1.5.3 to include people who use services and their carers in the recruitment and training of staff.
Motor Neurone Disease Association	Full	8	14-18	We support the draft guideline’s emphasis on enabling people to make decisions about their care. This should include a strong focus on effective communication and information provision. Patient experience data suggests that there is room for improvement in this area. The MND Association’s 2016 Improving Care Survey found that 18% of respondents disagreed that “different options for my social care are explained to me in a way that I understand”, with 29% unsure (n=587 responses total). 59% agreed that “I make key decisions about my social care and determine what I receive”, but 27% were unsure and 14% disagreed. Social care service providers should give particular consideration to the communication and information needs of people living with severe disability.	Thank you for your comment. The Guideline Committee also state that information provision should take into account people’s communication needs and preferences, in line with the Accessible Information Standard. We have revised recommendations 1.1.5, 1.1.7, 1.4.1, and 1.6.7 to make this clear. We have also revised text in recommendation 1.1.12 to include commissioners and service providers should consider seeking advice from disabled people’s organisations and user led organisations to ensure they can deliver services that are appropriate to needs and preferences.

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				Particularly in the case of severely disabling conditions such as MND, social care services should consider working with third sector organisations with experience and expertise in working with particular patient groups to develop an effective communication plan and to disseminate relevant information.	
Motor Neurone Disease Association	Full	9	1-11	We welcome the draft guideline's focus on the right to advocacy. For people living with severely disabling conditions such as MND, an advocate can be a vital source of help to understand and navigate the complex social care system, and to communicate the person's needs and wishes. Survey data suggests that access to advocacy remains lower than it should be. The MND Association's 2016 Improving Care Survey found that 26% of respondents were unaware of their right to an advocate. In addition, 31% did not know how to access an advocate, compared to 30% who did. It is essential that social care services clearly inform all service users of their right to an advocate and how to access one.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
Motor Neurone Disease Association	Full	9	17	Survey data suggests that the majority of social care users with MND believe they can access the care they need, but a substantial minority are not positive about their social care experience. 14% of survey respondents to the 2016 Improving Care Survey disagreed with the statement "I receive the social care I need when I need it", while 27% were unsure. Provisional data from the (not yet published) 2017 survey suggests that patient satisfaction has declined over the past year. Given the ongoing funding crisis surrounding social care, many people are concerned that access to social care services may be reduced over the coming years, for example through more stringent eligibility requirements, reductions in hours of care or the quality of care packages. Patient choice may also be affected by a shrinking provider market. In this context it is essential that people's access to vital care services is protected. For people with a severely disabling condition such as MND, any reduction in access to or quality of care can have major consequences for that person's wellbeing, independence and quality of life, and that of their family and carers.	The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Motor Neurone Disease Association	Full	10	21	Support for families and unpaid carers is one of the weakest performance areas for social care services according to the MND Association's survey data. Of respondents to the 2016 Improving Care Survey, 23% disagreed that their family members and family carers are well supported by social care, with 32% unsure. In addition, the MND Association Carers Survey 2015 found that only a third of carers had received an assessment for support, and 38% were unaware of their right to one. This echoes research by Carers UK which found that 39% of people caring for someone at the end of life waited 6 months or more for a carer's assessment. For many people, caring is a full time job. 56% of carers spend more than 100 hours a week caring, according to Caring for Carers, a report by the MND Association. MND Costs, a recent report published by Demos on behalf of the MND Association, showed that four-fifths of people living with MND who live at home rely on their partner or spouse to be their main carer, with the majority receiving at least 35 hours of care a week from that person. 46% of carers took no planned breaks from caring, and 42% of those that did relied on family and friends to do so. It is essential that the needs of carers are given full consideration as a key aspect of social care services. This should include provision of respite care to enable	Thank you for your comment. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people's views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15. We have also amended text in 1.3.7 to make sure that it is checked when the person who is being assessed has caring responsibilities, to establish whether the person they care for cared for is a carer themselves. We have revised text in 1.1.13 to include respite care as an example of information that should be provided to people with caring responsibilities

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				people to take much-needed breaks from what can be a very demanding and challenging role.	
Motor Neurone Disease Association	Full	14	26	Survey data from the 2016 Improving Care Survey suggests that the financial aspect of social care is relatively poorly communicated and understood. When asked their view of the statement "the cost of my social care and how much I need to contribute has been explained in a way that I understand" 29% of respondents disagreed, and 32% were unsure. This is particularly concerning when people are increasingly being asked to contribute more to their social care. When responding to the 2016 Improving Care Survey, a third of people who contribute towards the cost of their own care said they saw the cost rise over the past 12 months. Social care services should work with third sector organisations to develop comprehensible and accessible information on the funding options available for social care users.	Thank you for your comment. We have added more detail in the recommendation 1.2.1 about providing information about care and support services to include information on rights and entitlement and how to access support including eligibility criteria. The intention was to provide greater transparency in how decisions are made about providing care and support.
Motor Neurone Disease Association	Full	19	24	As MND is a progressive and terminal condition in all cases, planning for end of life must be seen as a key aspect of care and support planning. Families should always be encouraged to discuss end of life decisions with relevant health and social care professionals, but often these conversations are difficult and painful for the individual concerned as well as their carers and their families. The MND Association produces a guide to help facilitate these challenging conversations and support health and social care professionals to raise this issue sensitively, available via http://www.mndassociation.org/careinfo. We suggest that social care professionals draw on resources produced by patient advocacy organisations within the third sector to help them understand how best to address this difficult topic.	Thank you for your comment. We have revised the recommendation on end of life care to be more inclusive of families and carers (1.4.18) and also to access independent patient advocacy organisations to discuss end of life care if this is what people want (1.4.19).
National Collaborating Centre for Mental Health	Full	5	16	This line is slightly awkward to read – could possibly amend to "18% said they had some, but not enough, control and 6% had no control at all."	Thank you for your comment. We have revised the text to be clearer as you suggest.
National Collaborating Centre for Mental Health	Full	8	1	Within the box, should the term 'your care' be capitalised and written within apostrophes so that it is clearer that this is another source of info? Although it has a hyperlink, it reads strangely as it is.	Thank you for your comment. We have revised the text to be clearer as you suggest.
National Collaborating Centre for Mental Health	Full	8	10 + 11	If the final part of this paragraph is amended slightly it might read clearer. Possible suggestion: '…and providing the support and assistance they require to fulfil this.'	Thank you for your comment. We have revised the text to be clearer as you suggest.
National Collaborating Centre for Mental Health	Full	10	25	Every 6 to 12 months sounds like a long time to review this – family/carer dynamics can change in shorter time periods and a person might not feel comfortable to initiate the conversation with a professional about not involving (or involving) their family/carers otherwise. Would suggest up to 3 months unless there is a reason for the initial proposition.	Thank you for your comment. We have revised the text in this recommendation to make sure this is the minimum, and should be reviewed when circumstances change or when a review is requested (1.1.14).
National Collaborating Centre for Mental Health	Full	13	21	Really great to see this included	Thank you for your comment.
National Collaborating Centre for Mental Health	Full	19	25 + 26	This sentence is a little bit unclear. Might it be worth rephrasing to the following: "Managers in residential settings should co-produce a police on end of life care with people who use services. This includes:.."	Thank you for your comment. Thank you for your comment. We have revised the text to be clearer as you suggest.

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National Collaborating Centre for Mental Health	Full	20	4	Might read easier if this says "… making someone available…" but is also fine as it is if you disagree.	Thank you for your comment. Thank you for your comment. We have revised the text to be clearer as you suggest.
National Collaborating Centre for Mental Health	Full	22	25	Really great	Thank you for your comment. For information, this recommendation (now 1.6.8) has been amended to make clear that advocacy should be offered when it would help the person to take part, or if the person expresses a preference to use advocacy.
National Collaborating Centre for Mental Health	Full	45	16	'reality sis' - is this a typo or [sic]?	Thank you for your comment. Thank you for your comment. We have revised the text to be clearer as you suggest.
National Collaborating Centre for Mental Health	Full	190	2	Should this be 'disjoint'?'	Thank you for your comment. We have revised text as you have suggested.
Relatives Support Group	DRAFT			We think the overall intentions of this document are excellent but often Health and Safety regulations, financial pressures and 'red tape' stop Care Workers and Nursing Staff implementing service user choices across a broad range. Please note we have used the term Carer a lot in our comments when we really men 'Relative'. Our loved ones are in residential nursing care but we still regard ourselves as 'Carers'.	Thank you for your comment. The Guideline Committee gave careful consideration to possible barriers to implementation of the recommendations, including widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Relatives Support Group	DRAFT	4	1.1.8	Services need to be published more widely; cultural and religious needs are often overlooked, carers/relatives are often told what is available without feeling adequately consulted - their expertise by experience can be overlooked.	Thank you for your comment. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people's views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
Relatives Support Group	DRAFT	8	1.4.4	If a professional is going to such lengths to listen to people's needs then these needs have to be respected. Often in practice they are overlooked due to financial pressures and over ruling by management decisions due to factors outside the service user's knowledge or control..	Thank you for your comment. The Guideline Committee agreed that it was important to involve people and their families when listening to people's needs and the recommendation 1.3.4 has been revised. The recommendation also makes it clear that there should be transparency on why decisions are made.
Relatives Support Group	DRAFT	9	1.4.12	Time needs to be given to reviewing care and support needs. 'Matching' is essential but there is little evidence on the ground of this happening.	Thank you for your comment. The Guideline Committee agree that time should be allowed for reviewing care and support needs and have revised recommendation 1.1.8 in general principles of care that time should be given for people to express their views and preferences. We hope that recommendation 1.3.13 will encourage matching to happen more frequently in practice.
Relatives Support Group	DRAFT	11	1.5.1	Little evidence of co-producing policies or protocols. We may see a social worker once a year when they initiate a Deprivation of Liberty Assessment or Continuing Health Care Assessment but there it is little evidence of any 'open communication' in between times.	Thank you for your comment. We hope this recommendation will encourage more meaningful co-production of policies and protocols.
Relatives Support Group	DRAFT	12	1.5.6	Staff change constantly and residents do not always have a 'special person' (keyworker) to relate to. This is very distressing for relatives and service users alike. With no one person to share issues with the carer/relative can end up speaking to any number of staff and feeling sidelined. Individual staff can be very caring but don't have the time for forming relationships with residents in depth even	Thank you for your comment. Recommendation 1.4.7 provides suggestions for how continuity and consistency in care can be provided. Recommendation 1.3.10 also recommends that each person should have a named co-ordinator. The Guideline Committee agreed that delivery of better services often does not require additional resource but more efficient practice.

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				though they may be supplied with Life Stories and information about the resident's likes and dislikes. This does not necessarily require additional staffing but how staff are used does need addressing as well as staff training about dementia, for example.	
Relatives Support Group	DRAFT	13	1.5.10	Providing a sense of community and mutual support requires a member of staff to build relationships with the community which managers often don't have the time for. Volunteers could readily be recruited if there is a system set up including DBS checks and training.	Thank you for your comment. We did not find research evidence of people's views and experiences on the use of volunteers specifically. However, the recommendations allow for some flexibility in service delivery, which could include the use of volunteers and support in accessing groups. We have also added that service providers should know about and support access to services provided by the voluntary sector (1.5.5).
Relatives Support Group	DRAFT	13	1.5.11	Space in residential settings needs to be set aside for positive interactions. Having a Relatives Support Group within a residents' lounge is unsatisfactory due to noise levels and the invasion of the residents' space so we meet in a local restaurant for coffee.	Thank you for your comment. We have revised recommendation 1.4.14 to say that residential care settings should be welcoming to visits from family, friends and advocates.
Relatives Support Group	DRAFT	15	1.6.1	Involvement of people who use services (experts by experience) is essential but requires funding, training and support for Carers/Relatives which is sadly lacking. While we have our own Relatives Support Group this is held outside the home (due to lack of space) and neither managers nor staff have the time to join us.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning and support for carers and relatives in local areas to ensure capacity to deliver the recommendations.
Relatives Support Group	DRAFT	17	1.7.2	Service users and carers/relatives should be involved with any research. Relatives have experience of being consulted about Care Plans, for example, but not about research. Without feedback or understanding about how any research will be used we feel powerless.	Thank you for your comment. We have revised recommendation 1.6.2 to say that research should be coproduced.
Relatives Support Group	DRAFT	17	1.7.7	Little evidence of the views of service users being sought either directly or through their Relative or an Advocate. Moreover there is little feeling of it being 'safe' to express our views especially if they may appear critical.	Thank you for your comment. The Guideline Committee also agree that people should feel that they can safely express their views and this is addressed in recommendation 1.6.7. We have revised recommendation to 1.6.2 to say that research should be coproduced.
Relatives Support Group	DRAFT	18	1.7.10	'Experts by experience' are an excellent idea but funds will be needed to recruit, train and support.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Relatives Support Group	DRAFT	18	1.7.12	Publishing the results of any research needs the full backing of management who may feel criticised. An open forum for free discussion in residential nursing and care homes is urgently needed.	Thank you for your comment. We hope that these recommends will encourage good practice in these areas, noting some of the current obstacles that exist.
Royal College of Nursing	Full	General	General	In principle, we do not believe that there are many healthcare professionals who would disagree with the aims of the guidelines. Individualized care and planning is probably the most significant element in these guidelines. The challenge for implementation, however, relate to capacity, i.e. the ability of healthcare professionals who are involved to find the time to deliver these recommendations. Shortages of staff within health and social care teams and the increasing complexity of people's needs have resulted in challenges for professionals attempting to deliver this level of care. In some ways the same issue arises with cost pressures, as in practice there is an increase in the numbers of older people needing complex care and this has additional cost implications for both the NHS and local authorities.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable. The committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.
Royal College of Nursing	General	General	General	The Royal College of Nursing welcomes proposals to develop these guidelines. The RCN invited members who care for older people to review and comment on the draft documents on its behalf.	Thank you for your comment.

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				The comments below reflect the views of our reviewers.	
Royal College of Nursing	General	General	General	There are positives to gain from working with colleagues in the voluntary sector who can support or share responsibilities with complex assessment. The Organisation Help and Care Support in Bournemouth is a good example of this in practice as they have managed to provide 'needs led' assessments that are not caught up with service criteria in the same way that is often seen in the NHS or social services. Also if integration can be realised then duplication can be avoided which should free up necessary resource to see more people with complex needs.	Thank you for your comment and the case study example. We have revised some recommendations (1.1.12, 1.2.4, 1.5.5,) to make sure the voluntary sector is represented as an available resource. The Guideline Committee agree that more efficient use of resources recommended here would lead to savings elsewhere in the system.
Sense	Full	General	General	Sense is a national charity, supporting people with complex communication needs. We work closely with a number of local authorities across the country to provide high quality care and support to people with complex communication needs and long-term disabilities. We took a leading role in supporting NHS England to develop the Accessible Information Standard. From March 2016 it has been a requirement for all health and social care providers, as well as commissioners to comply with the standard. As such, our response to this consultation will focus exclusively on how NICE's guidance can support providers and commissioners of adult social care to fully comply with the Accessible Information Standard. We welcome the fact that NICE have made explicit reference to the Accessible Information Standard in this guideline. However, we believe that NICE should further embed reference to the standard in this guideline, pointing out the stages within a person's journey through the social care system that the Accessible Information Standard will embed their rights. For example section 1.1.6 of the draft guideline makes reference to organising an independent interpreter, a process that should comply with the Accessible Information Standard. However, no reference is made to the Standard in this section, we believe this is a missed opportunity to highlight when, where and how the Standard must be applied. Further to this we recommend that the NICE guideline offers further practical support to providers and commissioners of adult social care to ensure that the Accessible Information Standard is implemented consistently and correctly on a national scale. This will greatly improve people with sensory impairments and complex communication needs experience of using adult social care services. We believe that NICE should make reference to the following steps and requirements to achieve this: 1. Support for adult social care providers There are five steps that providers need to take to implement the standard: ☐ Identify the communication and information needs of those who use their service ☐ Record the communication and information needs they have identified: clearly and consistently on the person's record, recording their needs not why they have those needs i.e. "requires BSL interpreter" not "person is d/Deaf". ☐ Have a consistent flagging system so that if a member of staff opens the individual's record it is immediately brought to their attention if the person has a communication or information need. ☐ Share the identified information and communication needs of the individual when appropriate. ☐ Meet the communication and information needs identified. For example, send an appointment letter in Braille or book an interpreter for an appointment. 2. Support for commissioners of adult social care For providers to meet and exceed these standards, commissioners of adult social care must facilitate providers to do so. In order to do so commissioners (namely clinical commissioning groups, local authorities and NHS England) must:	Thank you for your comment. The Guideline Committee agreed that there were more opportunities to recommend practice to support implementation of the Accessible Information Standard and have amended recommendation 1.1.5 in the 'Enabling people to make decisions about their care' section, which now includes text to ask to identify and record the person's communication requirements. This gives examples of environmental conditions to support communication. With reference to support for commissioners of adult social care, recommendation 1.4.1 has been revised to make reference to the Accessible Information Standard as part of fostering a culture that respects people's preferences and choices. As specific steps in implementation are described in the Accessible Information Standard, we have linked to this document: it has not been repeated in full in the recommendations. Commissioning and conditions of contracts are not in scope for the guideline.

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				Ensure that their commissioning and procurement processes support providers to implement the standard, following the processes listed above. This must be evidenced in contract terms. Contract terms should seek assurances from providers of their compliance with the standard. This should include evidence of identifying, recording, flagging and meeting needs.	
Skills for Care	Short	General	General	There seems to be far more references to local authority responsibilities than those of the care providers, something that could cause confusion where the task is likely to be undertaken at the provider level. There may be some merit to produce two separate recommendation documents. 1) key recommendations for local authorities and 2) key recommendations for care providers Some of the residential setting advice could be adapted and made relevant to care at home services,	Thank you for your comment. The Guideline Committee gave considerable thought to who recommendations should be addressed to, and the majority of recommendations relating to service provision are addressed to providers. Given the close interdependence between provider and commissioner roles, we think there is value in all recommendations being presented together rather than producing separate documents. With regard to recommendations on residential settings, these were based on the research evidence. The committee considered whether these could be extrapolated to cover other settings, but decided that the evidence did not support this.
Skills for Care	Short	5	25 / 26	The recommended timeframe seems prescriptive, perhaps add… “Review this regularly are required (e.g. every 6 to 12 months)”	Thank you for your comment. We have amended recommendation 1.1.14 to read ‘Review this regularly (at least every 6 to 12 months), or when requested.’
Skills for Care	Short	7	3 / 4	This section seems to be written primarily for the Local Authority but would equally apply to providers. Would be helpful to include a few provider related examples of what this should include e.g. care plan, reporting abuse etc.	Thank you for your comment. The evidence reviewed related primarily to information that would help people to access and make use of care.
Skills for Care	Short	12	1 / 2 / 3	Would benefit from explicit reference here to all adult social care settings, including care at home	Thank you for your comment. We have revised the text to say ‘in all settings where care is delivered’, in line with your suggestion.
Surrey County Council	Full	General	General	We are concerned by the length of this guidance and volume of appendices. Although a short version has been produced it is unclear whether this is a set of principles that service providers should consider or whether it is likely to become a mandatory principle that providers must follow.	Thank you for your comment. There is a short version of the guideline which is the version NICE would expect practitioners to refer to. The longer version provides full details of all the evidence reviewed for those wishing to know more.
Surrey County Council	Full	General	General	We are unclear whether this guidance will be the successor for the variety of self-assessment frameworks currently being used, such as the ‘Think Local Act personal, Making it Real ‘I statements’, the ADASS (Association of Directors of Adult Social Service) /LGA (Local Government Association) Adult Social Care Risk awareness tool and the Local Account.	Thank you for your comment. NICE guidelines are evidence-based guides intended to be read alongside existing guidance. We have updated the introduction to explain how our recommendations build on, rather than replicate or replace, existing guidance and legislation.
Surrey County Council	Full	General	General	We are unclear how this guidance impacts on the annual Adult Social Care Survey that Local Authorities undertake on behalf of the Department of Health.	Thank you for your comment. The guideline gives examples of good practice including the Adult Social Care survey. The guideline should complement the Adult Social Care survey guidance for local Authorities by giving examples of good practice in data collection, including maximising response rates and achieving representative samples by making adaptations to data collection tools and involving people in their design.
The Alzheimer’s Society	Short version	p.3 - p.4	P 15 – 15	Alzheimer’s Society welcomes the recommendation to enable people to make decisions about their care. As an organisation, we strongly advocate that people with dementia and their families should be able to make decisions about the care they receive. It should not be assumed that people do not have capacity nor that they do not have specific needs or wants that should be respected by adult social care providers. We welcome the recommendation to support people to express their views and be engaged throughout the service design, delivery and evaluation process to ensure	Thank you for your comment. We agree that allowing additional time to understand and process information is an important part of people’s communication preferences and we have revised the text in recommendations 1.1.5 and 1.1.7 to reflect this.

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				that services meet their needs and aspirations. Collecting feedback of experience is a key component to delivering quality care and it is particularly important to support people with dementia, who often struggle with communication (as this is one of the symptoms of the condition). Therefore, supporting them to continue communicating their views, preferences and needs will be key to ensuring that their care is tailored to them and is person-centred. In addition to the recommendation to use communication aids, plain language and advocacy support, we would recommend ensuring that staff members allocate additional time to discuss someone's care as this may be key to involving someone with dementia (please see section 8 for more practical guidance.	
The Alzheimer's Society	Short version	p.10	1-6	We welcome the recommendation that local authorities should inform people about personal budgets and give people as much choice and control over the way to use these funds to purchase care. While section 26 of the Care Act sets out local authorities' duties in promoting transparency and access to personal budgets, Alzheimer's Society undertook mystery-shopping exercises with local authorities to find out about the availability and accessibility of information available to people with dementia about personal budgets and found that this is often lacking. Therefore, any measure to increase the information available to people about a system that offers many additional choice and control over their care is positive, as it will lead to more people with dementia using such budgets. Through this research, we also found that people with dementia were often not given enough control over how they could use the budgets in order to live well (which negates their purpose), and we therefore welcome the recommendation to ensure as much control as possible is provided about how someone can use the funds. This will ensure more personalisation and that peoples' individual needs are truly reflected.	Thank you for your comment. The Guideline Committee agreed that it was important for people to have choice over their personal budgets and have made some revisions based on your suggestions for greater clarity. In recommendation 1.2.1 we have added text on the different types of personal budgets there are and in 1.3.19 added text to make clear that people should be supported to choose the option that suits them best and the different payment systems that are available. There is a related NICE guideline CG42 Dementia: supporting people with dementia and their carers in health and social care.
The Alzheimer's Society	Short version	p.11	12-27	Alzheimer's Society supports the recommendation to build a culture that enables practitioners to respect people's individual choices, as this is key to people with dementia having positive experiences of care, which meet their needs. The recommendation to promote co-production of policies and protocols with people who use services is positive and necessary, as it helps to ensure that these services are set up with the needs, experiences and views of the people using the services at the forefront. At Alzheimer's Society, we have co-production groups led by people with dementia present across the country, who feedback to us about our services, our direction and policies and procedures. This is central to guaranteeing that the latter work for people with dementia and that everything is put in place in a way that enables them to engage, participate and live well with the condition. We also support the recommendation to train and support practitioners to work in a way that enables people with lived experience to be engaged, and believe that appropriate training is absolutely key to enabling personalised high quality care to be delivered to people with dementia. Our research shows that nearly 40% of home care workers receive no dementia training.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
The Alzheimer's Society	Short version	p.15	13-14	Alzheimer's Society welcomes the recommendation that practitioners should be able to take part in learning and development and believes that the Government must commit funding to providing social care staff involved in the care of people with dementia with appropriate training. Our Fix Dementia Care Homecare report (2016), found that almost 40% of home care workers were not receiving any form of dementia training, which detracts from their ability to provide personalised and high quality care. In order to provide	Thank you for your comment. We are glad that these recommendations will support developments in this area.

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				appropriate and needs-based care, such training must be provided across the board. As staff retention is also a major issue within the adult social care sector, we support professional development as this could be a contributing factor to retaining staff better (which in turn creates consistency that is beneficial to people with dementia). The "Dementia Core Skills Education and Training Framework", developed by Skills for Health and Health Education England in partnership with Skills for Care, sets out the essential skills and knowledge necessary to support people with dementia throughout the health and social care spectrum and is a valuable tool that should be shared across the sector (please see full report here: http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf?s=cw1)	
The Alzheimer's Society	Short version	p.4	17-19	We welcome the recommendation to ensure that everyone with social care needs has access to services based on their needs, as people with dementia have specific needs that need to be considered within a care setting. We know anecdotally that people with dementia have been provided with generic social care support in the community, which has not taken into account the specific needs they may have and therefore has not provided them with personalisation they are entitled to through the Care Act. In order to continue to live well with dementia, it is imperative that social care providers take into account the particular challenges created by the condition, but that the local authorities also consider this when placing people to ensure people are able to get the care that they need.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
The Alzheimer's Society	Short version	p.6	7-16	Alzheimer's Society supports the recommendation that local authorities and providers should consider providing people with a named coordinator who can act as first point of contact, can contribute with the assessment process and liaise and work with health and social services involved in care. As an organisation, we know that people with dementia currently have to navigate a complex and often disjointed health and care system (which is challenging due to their condition), which involves up to 20 different professionals at any given time. By having a named coordinator/advisor present throughout someone's journey to help them, the person would have more confidence and be more able to navigate the complex web of care – which is why Alzheimer's Society's new five year strategy aims to ensure that everybody living with the condition would be able to access such support. In addition, Alzheimer's Society believes that there is significant cost benefit to the system of having such a coordinator in place (see our "Dementia Advisers: A cost-effective approach to delivering integrated dementia care" report).	Thank you for your comment. We are glad that these recommendations will support developments in this area. We have revised recommendation 1.3.10 on coordinating care to include that the named person has to be competent and has to liaise and work with the person, their family and carers. We have added housing as a service sector the named person should be able to liaise with as well as with health and social care.
The Alzheimer's Society	Short version	p.7	2 – 12	We welcome the recommendation to provide people with information they can easily read and understand in line with the Accessible Information Standard. We know (from speaking with people affected by dementia) that they struggle to access the right information about their care. In 2015-2016, we carried out a mystery shopping exercise of local authorities and the information they held about personal budgets to find out how accessible and dementia friendly this was - our resulting report with findings can be found at:	Thank you for your comment. The Guideline Committee agreed that there were more opportunities to recommend implementation of the Accessible Information Standard and have amended recommendation 1.1.5 in the 'Enabling people to make decisions about their care section' now includes text to ask to identify and

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				https://www.alzheimers.org.uk/downloads/file3217/dementia_friendly_personal_budgets_guide . .We found that accessibility of information was a major issue in this area of social care and have been told since that there are wider issues around people affected by dementia wishing to find out about what kind of support is available, how they can access this and about the financial aspects of care and support. This is in spite of the fact that as set out in section four of the Care Act, local authorities have a duty to provide comprehensive and accessible information about the support available. Within this context, it is absolutely key that NICE puts forward recommendation with the intent that ease and accessibility of information throughout the social care sector is improved, as this will empower people with dementia to make appropriate choices and understand the financial impact of care, which we know is an issue due to lack of transparency. We also welcome the specific recommendation for local authorities to provide information about support on offer through voluntary organisations, as this may play a key role in helping people with dementia to remain independent and live well within their community for as long as possible.	record the person’s communication requirements and gave an example of environmental conditions to support communication. Recommendation 1.4.1 has been revised to include the Accessible Information Standard when fostering a culture that respects people’s preferences and choices. We agree that the role of voluntary sector is an important one and have revised recommendations 1.1.12 that these should include user-led organisations and disabled people’s organisations. We have revised recommendation 1.2.4 to include reference to providing people information about community resources and support, including voluntary organisations and in 1.5.5 suggested that service providers should understand arrangement for and the function of local services they may need to work with, including those in the voluntary sector.
The Challenging Behaviour Foundation	Full	General	General	It would be helpful to include the full range and complexity of the issues faced by people with complex needs. Adults with severe learning disabilities are amongst the most disadvantaged members of our society. They can expect to achieve less than other people, to face more barriers and discrimination and to struggle to become socially integrated. 1 The addition of severe challenging behaviour greatly increases the obstacles to their development and integration. Individuals with learning disabilities and behaviour perceived as challenging are likely to: □ Live in places or with people they don’t like, often a long way from their family home 2 □ Be given too much medication, or inappropriate medication 3 □ Be subjected to restraint 4 □ Be secluded and have their movement restricted 4 1Mansell, J. (2010). Raising our sights: services for adults with profound intellectual and multiple disabilities. 2Department of Health (2015). Government response to No voice unheard, no right ignored. 3 Public Health England (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. 4 Care Quality Commission (2014). Review of Learning Disability Services.	Thank you for your comment. There is a separate NICE guideline on people with learning disabilities and behaviour that challenges. We have also amended recommendation 1.4.15 to make reference to viewing behaviour that challenges as communication.
The Challenging Behaviour Foundation	Full	General	General	There is little explanation throughout how to ensure family members and carers are alongside the individual at the centre of their care. Engagement with family carers is especially important in the care of someone with a severe learning disability who may struggle to communicate their views and needs themselves. Family carers and other people who know the individual well can be invaluable resources regarding communication, behaviour and choice.	Thank you for your comment. We have revised recommendations and in the general principles (1.1.5, 1.1.7), in co-production (1.1.9), coordinating care (1.3.10), needs assessment (1.3.4, 1.3.9) , personal assistants (1.3.26), providing care and support (1.4.1), end of life support in residential settings (1.4.18), staff skills (1.5.3) , using people’s views to improve services (1.6.2), to make clear that families should be involved at every step if that is what the person wants, and if the person lacks capacity then the provisions in the Mental Capacity Act 2005 should be followed (1.1.16). We have added a reference to

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					the forthcoming NICE guideline on Provision of support for adult carers as a footnote to recommendation 1.1.15.
The Challenging Behaviour Foundation	Full	9	12	It would be helpful to include how the complex communication needs of someone with severe learning disabilities could be met to enable them to be involved in their care. Approaches to seeking the views of people with a severe learning disability will need to be personalised and with the support of people who know the individual well.	Thank you for your comment. We have revised recommendation 1.1.7 to make reference to using plain language and also personalise the communication approach and to take time and check with a person that knows them well to understand what is being said. We have also revised the recommendation on conducting research (1.6.6) to say that all groups should be able to participate, including people with different communication needs and to investigate reasons for low response rates and increase participation by adapting response formats.
The Challenging Behaviour Foundation	Full	10	22	It would be helpful to include that some people with learning disabilities lack capacity to decide how they wish their carers / family to be involved in their care. Family carers often have a wealth of information and knowledge about a person’s health and medical history and consideration should be made of their inclusion where an individual lacks the capacity to decide who should be involved.	Thank you for your comment. We have created a new recommendation that says if a person lacks capacity to make a decisions about who they want involved the Mental Capacity Act should be followed (1.1.16).
The Challenging Behaviour Foundation	Full	16	5	Consideration should be given to ensure all people who use social care services (including those with severe learning disabilities and challenging behaviour) are included, not just those whose responses are easy to access.	Thank you for your comment. We have revised the recommendation on conducting research (1.6.6) to say that all groups should be able to participate, including people with different communication needs and to investigate reasons for low response rates and increase participation by adapting response formats.
The Challenging Behaviour Foundation	Full	16	2	It would be helpful to include that co-production needs to include all people who use services including those who can be difficult to engage with details on how this might be achieved.	Thank you for your comment. We have revised our definition of co-production to make clear that families and carers should be effectively involved in co-production with the consent of the person who uses services.
The Challenging Behaviour Foundation	Full	19	16	It would be helpful to provide greater detail on the need to understand why people have behaviours that challenge, the reasons and purposes for the behaviour and the need to use this knowledge to support individual’s behaviour positively. Challenging behaviour is often perceived as a ‘problem’ or ‘illness’ to be ‘treated’, ‘cured’ or ‘stopped’. The problem is seen as being part of the person rather than focussing on what needs to change around the person, such as their environment or how people support them. This is unhelpful and potentially damaging for these individuals. It is important to look beyond the behaviour and provide appropriate person centred, holistic support to enable individuals to achieve their full potential.	Thank you for your comment. The overall recommendation was about understanding people, and this includes behaviour that challenges. We have revised the text of recommendation 1.4.15 to clarify that staff should understand behaviour that challenges as a communication and not something that needs “preventing” but being understood and responded to appropriately.
The Challenging Behaviour Foundation	Full	19	19	Consideration should be given to ensure participation in tasks and activities is purposeful promoting the maintenance / development of skills	Thank you for your comment. Recommendation 1.4.5 has been strengthened to say that people should be encouraged to take part in activities.
The Challenging Behaviour Foundation	Full	21	14	It would be useful to include how all people including those with complex needs (people with severe learning disabilities) should be given the opportunity to be involved in decision making about services design and how this may be achieved.	Thank you for your comment. The evidence suggested that methods for involvement were highly varied depending on the needs of a particular group. Recommendation 1.6.6 makes a high level recommendation about adapting methods of involvement to ensure wide participation.
The National LGB&T Partnership	Full	general	Appendix A	Regarding the methods for developing guidelines: Suggest NICE add National LGB&T Partnership and/or LGBT Foundation’s Evidence Exchange to their list of website and database sources for this and other guidelines.	Thank you for your comment. We will share this information with the technical leads at NICE.
The National LGB&T Partnership	Full	5	13	Contrast the findings in the ASCOF LGBT Companion (based on the largest overview of LGB&T experiences of social care to date): the majority (53%) of LGBT people felt choice was limited, 33% rated their care as poor and a further 35% described the standard of care as mixed.	Thank you for your comment. The Guideline Committee noted that people from the LGBTQI community may face additional barriers to receiving good care. Recommendation 1.1.10 notes that there should be equal access to care for a range of groups, and recommendation 1.3.15 notes that equality and diversity issues should be recorded in people’s care plans. It was raised during consultation that people from LGBTQI community may be estranged from their families and that the assumption that families are always supportive or should be automatically assumed to be appropriate to be involved in a person’s care may disadvantage people from LGBTQI community. For this reason, we have added advocates to the list of people who may be in the person’s supporting network of

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					people that should be involved in their care if that is what they wish (recommendations 1.1.14, 1.1.15, 1.1.16, 1.3.1, 1.3.2, 1.3.10, 1.4.2, 1.4.14).
The National LGB&T Partnership	Full	7	5	The guidelines could refer to the Implementation chapter (PAGE 389) which has useful tips.	Thank you for your comment. We feel the text here is sufficient in terms of context.
The National LGB&T Partnership	Full	7	11	Should the list of legal duties also include the Social Value Act 2013 as it should also consider local authority procurement principles?	Thank you for your comment. Commissioning and procurement are outside the scope of this guideline.
The National LGB&T Partnership	Full	10	17	Local authorities and providers should also work with people who use (and may use adult social care services in the future) to co-produce the services themselves, as well as information, policies and training. (This is mentioned in 1.7 but no harm specifying it here too).	Thank you for your comment. The Committee agreed that the level of detail in this recommendation was sufficient, as co-production of services is noted in recommendation 1.6.2. We have also added detail on the definition of co-production in the terms used section.
The National LGB&T Partnership	Full	10	23	The guidelines should also refer to advocates when discussing 'carers, family and friends' since many LGBT people do not have a relationship with family and they rely on LGBT support groups who play an advocacy role in engaging with providers. (This is also a general point throughout the whole document).	Thank you for your comment. We agree that people may rely on advocates, rather than families or unpaid carers. For this reason, we have added advocates to the list of people who may be in the person's supporting network of people that should be involved in their care if that is what they wish (recommendations 1.1.14, 1.1.15, 1.1.16, 1.3.1, 1.3.2, 1.3.10, 1.4.2, 1.4.14).
The National LGB&T Partnership	Full	14	12	The guidelines should also explain how someone can review their care worker's performance and request a change at any time.	Thank you for your comment. We believe this is covered in recommendation 1.3.16 that suggests discussions and decisions about care should be reviewed when required.
The National LGB&T Partnership	Full	15	15	Some peer support services for some groups who share protected characteristics may not be local so local authorities should ensure these are resourced too (in collaboration with neighbouring authorities) and ensure access to such groups.	Thank you for your comment. We have included the text on disabled people's and user led organisations on seeking advice on equality and diversity issues, including sexual orientation and sexuality in recommendation 1.1.12.
The National LGB&T Partnership	Full	16	5	Local authorities should also review the demographic breakdown of personal assistants to ensure they reflect all the communities that they serve.	Thank you for your comment. As personal assistants are directly employed by people who use services, this appears to be out of the remit of local authorities.
The National LGB&T Partnership	Full	16	13	Providers should co-produce the services on offer with people who use services as there may not be sufficient choice for those who share protected characteristics.	Thank you for your comment. Co-production of services is noted in recommendation 1.6.2.
The National LGB&T Partnership	Full	17	19	Providers should also monitor the sexual orientation and gender identity of staff and service users to ensure they are meeting the needs and representative of communities.	Thank you for your comment. The Committee discussed this, but thought that the level of detail in the recommendation about matching staff was sufficient in this case.
The National LGB&T Partnership	Full	18	24	Residential settings should also reflect the histories and experiences of all communities with imagery that makes people feel welcome (e.g. positive images of LGB&T people, posters advertising Pride events).	Thank you for your comment. We believe that the recommendation 1.4.14 sufficiently captures positive expression based on people's choices
The National LGB&T Partnership	Full	18	8	Practitioners should also involve community groups in residential settings, making people aware of cultural groups that may exist locally and further afield.	Thank you for your comment. Based on your suggestions, we have revised the text of recommendation 1.4.15 to say supporting people to take part in activities and groups that they want to be involved in.
The National LGB&T Partnership	Full	20	8	Providers should also monitor the sexual orientation and gender identity of staff to ensure they are representative of the communities they aim to serve.	Thank you for your comment. The Committee discussed this, but thought that the level of detail in the recommendation about matching staff recommendation was sufficient in this case.
The National LGB&T Partnership	Full	21	4	Service providers should ensure practitioners are also aware of voluntary sector and community services.	Thank you for your comment. We have revised the text of recommendation 1.5.5 to include voluntary services. We have also included reference to voluntary and community organisations such as disabled people's organisations and user-led organisations in recommendations 1.1.12 and 1.2.4.
The National LGB&T Partnership	Full	21	18	Involvement in service design should also include identifying gaps in services.	Thank you for your comment. We agree that monitoring should identify gaps in services and have revised the text in this recommendation.
The National LGB&T Partnership	Full	391	8	To implement the guidelines organisations may need to reach out to partners who are not local but who have the expertise of working with groups that share protected characteristics.	Thank you for your comment. Recommendation 1.1.12 refers to seeking advice from voluntary and community sector organisations such as disabled people's organisations and user-led organisations. This could include national organisations.

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Think Local Act Personal	Short	General	General	We have some concerns that the draft guideline does not sufficiently cover a number of areas that are likely to directly impact on people's experience in adult social care services and we would recommend consideration is given to strengthening the following areas: 1. Given the wellbeing principle within the Care Act, it is surprising that so little reference is made to promoting wellbeing within the guideline and what that might mean in practice for local authorities commissioning wise and for practitioners working with and alongside people. 2. The importance of information, advice and support to assist people to keep well, active and engaged - covering both those people who are eligible for local authority support and those below the eligibility threshold. This is part of the prevention duty on local authorities. The guideline could be read as only applying to people receiving local authority for eligible needs. 3. It does not feel as if the guideline has adequately captured the ambition and intention to join up care and support around the needs of individual's i.e. the integration agenda with the NHS, housing and other public services. 4. That greater emphasis should be placed on strengths-based and asset based approaches to commissioning and delivering care and support. 5. There is little reference to safeguarding and developing personalised approaches to this. 6. There is a case for reviewing whether the co-production aspects should be strengthened - both co-production when working with individuals to arrange care and support, but also the requirement and opportunity to involve people with lived experience in the shaping and design of local care and support at both a strategic and operational level . 7. The content in and around personal budgets should be re-visited to reflect that they are a legal requirement (for those eligible) and to make sure the guideline covers all of the deployment options (i.e. not just Direct Payments), making clear that all options should provide opportunities for choice and control. It would help if the guideline made clearer that the primary purpose of personal budgets (all deployment options) is as a means to assist people to meet their needs and chosen outcomes rather than to receive services per se. All services should work at assisting people to meet these needs and outcomes: a life, not a service.	Thank you for your comment. 1. We have made a strong recommendation in 1.3.4 for local authorities to ensure that the care and support needs assessment focuses on people's needs, and how they affect their wellbeing. 2. The focus of the guideline is on people's experience of using adult social care services, including those who are not eligible for local authority funding, and fund themselves. We have now made this clearer in the introduction to the guideline. However, it does not cover other kinds of services, 3. We have clarified the direction of travel towards the integration of health and care services in the introduction section. We have also added reference to housing as a health related service in line with the Care Act in recommendations 1.2.4 on the provision of information 1.3.10 on coordinating care, , and 1.3.4 on taking into account a person's housing status in a care and support assessment in recommendation. This guideline has been developed to sit alongside existing NICE guidelines CG138 Patient experience in adult NHS services and CG136 Service user experience in adult mental health services. 4. The Guideline Committee were cautious about stating a person's strengths and assets should be used in assessments for care needs, as this can sometimes mean determining that people do not require services. We have revised the text of recommendation 1.3.3 to make clear that the focus should be on the person's needs and the outcomes they want to achieve in their day-to-day life. 5. We have revised the recommendation on providing information to include information on safeguarding procedures and how to make a complaint. In relation to taking a personalised approach, recommendation 1.4.1 on providing care and support includes that people should be supported to take managed risks to achieve their goals. 6. We have strengthened the definition of co-production and included TLAP's 6 principles of co-production. We have also revised text on using people's views to improve services in 1.6.2 to make sure the research design of people who use care and support and also carers are co-produced at all stages to refine quality indicators, monitoring tools or to identify gaps in services. 7. We have added a new recommendation (1.3.18) to make clear that the personal budget must be included in a person's care and support plan. We have revised the text of recommendation 1.3.19 to make clear that the purpose of the budget is to meet the person's needs and chosen outcomes – not to purchase services. Recommendation 1.3.19 also recommends that people should be given information about all available payment systems. Recommendation 1.3.20 refers to direct payments as these are the Government's preferred mechanism for personalised care and support (see Care Act statutory guidance). Also, note that in the Introduction to the guideline, 'Who is this guideline for'?, we have made specific reference to self-funders in the bullet 'People using services, including those who fund their own care and support, and their families, carers, advocates and the public.'
Think Local Act Personal	Short	General	General	Some of the language and definitions should be reviewed and/or clarified. For example: - That the guideline is cast very much in the language of people receiving services that are provided to them. Whilst people do get services, the intention of the Care Act is more along the lines of arranging care and support to meet people's needs and chosen outcomes. Consider therefore using the term care and support.	Thank you for your comment. We have revised where appropriate to care and support, including the title of the guideline, as you have suggested. We have deleted the term service users, except when this is included in the title of a NICE guideline that we refer to. We have revised the definition of voluntary sector in the terms used section, and retained the voluntary sector in the recommendations for ease of reading.

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				The term 'service user' is not now a preferred term. Voluntary and community sector now tends to be referred to as 'voluntary and community social enterprise sector' (VCSE)	
Think Local Act Personal	Short	General	General	We strongly recommend that when producing the final guideline account is taken and use made of the revised Making it Real that is being produced by Think Local Act Personal Partnership in partnership with the Coalition for Collaborative Care and National Voices. This will set out what good personalised and joined up care and support looks like from the perspective of people with lived experience. A draft should be available by December 2017 and a final version in March 2018.	Thank you for your comment and for signposting the forthcoming revised 'Making it Real' resources. The current Making it Real resources were used to help develop the framework for evidence review and analysis for the guideline. As this work is now complete, we will unfortunately not be able to incorporate the new resources. However, the new resources should be noted if the guideline is updated in the future.
Think Local Act Personal	Short	5	1.1.11	Disabled people's organisations and User Led Organisations may also be sources of advice and expertise in these areas. Also faith groups.	Thank you for your comment. We have revised recommendations 1.1.12 and 1.2.4 to include your suggestions of user-led and disabled people's organisations.
Think Local Act Personal	Short	5	1.1.12	Co-production - Whilst the areas identified are important, what is most important is that people receiving care and support are able to play a full role (insofar as they wish) in co-producing (deciding and designing) their own care and support.	Thank you for your comment. The recommendations in the guideline are based on the evidence reviewed. We have amended the introductory principles to make clear that we refer to individual as well as strategic co-production. We have renamed the sub-section 'Co-production and enabling people to make decisions' and now includes the recommendations relating to enabling people to have choice and control, and make their own decisions. We have also strengthened the definition of co-production in the term used section, including TLAPs 6 principles.
Think Local Act Personal	Short	6	1.2.1	Named Co-ordinator Should be clearer whether the intention of the guideline is that all people receiving care and support should have a named co-ordinator. Possible confusion in role with a named co-ordinator in the local authority and one with the provider Need to take into account that a named co-ordinator role might be fulfilled by someone else e.g. a NHS professional such as a community nurse.	Thank you for your comment. The decision of the Guideline Committee, based on the evidence reviewed and their expert advice, was that local areas should consider offering people a named coordinator (1.3.10). The strength of the recommendation reflect the evidence available. The recommendation has been revised to make clear that this should be part of care and support planning under the Care Act 2014, which would be undertaken by the local authority. The Guideline Committee noted the potential resource impact of recommendation 1.3.10 if this role does not already exist within a local authority area. However, the Committee noted that that a 'single named contact' is also specified in the guidance supporting the Care Act 2014, so this should be in the process of being implemented already. In addition, we have revised the terms used section and clarified that this is a function, not a post and could be undertaken via a NHS professional or a member of social care staff, via for example, a nurse or a named social worker respectively.
Think Local Act Personal	Short	7	1-6	Are there others that guideline should be for: - Disabled people's organisations and user led organisations? - The Voluntary and Community Social Enterprise Sector (VSCE)? - Commissioners and practitioners/professionals working in allied areas such as the NHS and housing, including where this is integrated commissioning? - Older people are not referenced in the document - People who fund their own care and support are not referenced in the document It is not clear what is meant by 'care managers' in this context (not defined in the Terms Used).	Thank you for your comment. We have included disabled people's organisations, user-led organisations and voluntary organisations. Although we have defined the term The Voluntary and Community Social Enterprise Sector (VSCE) in terms used. Older people are assumed to be included in reference to the population of the guideline of all adults using social care services, and there was a good amount of research evidence from this population that informed the recommendations. The Guideline Committee considered evidence from older people and considered whether these views and experiences could be extrapolated to other

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				The term practitioner is used elsewhere in the guideline (also not defined in the Terms used)	populations and settings. We have included a definition of practitioner in the terms used. The term 'care managers' has been used only in narrative summaries of studies, and reflects the terminology used in the studies.
Think Local Act Personal	Short	7	1.3.2 - 1.3.5	Information & Advice We are not sure whether the guideline adequately reflects the Care Act (and guidance) which is that local authorities: "establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers". Also whether the preventative nature of information and advice should be conveyed. 1.3.2 - LAs should also provide information about options available to control their own funding should be re-phrased along the lines of information about personal budgets and what all the options are for taking a personal budget (local authority managed, Individual Service Fund, or Direct Payment). 1.3.5 It is not clear what is meant by the term 'providing comprehensive information about **other support groups...**. This should be more about making sure people have access to information about all the community resources and forms of support that they can access that might assist their health and wellbeing.	Thank you for your comment. Recommendation 1.2.1 is intended to build on the Care Act and associated guidance in relation to provision of a service for providing information and advice. The recommendation details the types of information and advice that should be provided. It has been amended to include further detail on accessing care, rights and entitlements. Regarding personal budgets, reference to this and the particular funds you mention have been added to recommendation 1.2.1 Recommendation 1.2.4 has been reworded as you suggest to make reference to community resources and support.
Think Local Act Personal	Short	8	1.4.6 (20)	Suggest re-word 'the person is able to bring someone they choose with them', as it could be taken to imply that they have to go somewhere to receive an assessment. It is more about having someone present at the assessment that they have chosen to have there.	Thank you for your comment. The relevant bullet point in recommendation 1.3.6 has been rephrased so that it does not imply that the person has to go somewhere to receive their assessment.
Think Local Act Personal	Short	9	1.4.8	Assessment - The current wording reflects a rather restricted view of an assessment which, according to the Care Act Guidance should be proportionate and "is to identify the person's needs and how these impact on their wellbeing, and the outcomes that the person wishes to achieve in their day-to-day life. Consider changing the guideline to reflect this. Eligibility should also be mentioned, not everyone will be eligible for of PB, but may be able to access community resources to meet their needs. In addition some people may fund their own services. The tone of the wording feels as if assessments are done to, rather than with the involvement of the person. Suggest the wording is re-visited.	Thank you for your comment. The wording of recommendation 1.3.3 reflects that of the Care Act: 'Local authorities must ensure that care and support needs assessment under the Care Act 2014 for people focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day to day life.' Those who have been excluded by eligibility criteria but are self-funded would be included, but people who do not use services are out of scope of the guideline.
Think Local Act Personal	Short	9	1.4.10 - 1.4.13	Care and support plans - The guideline, as drafted, misses out the central purpose of a care and support plan which is to set out how the needs and outcomes identified through the assessment will be met.	Thank you for your comment. The guideline aims to add to, rather than duplicate, what is in the Care Act. The purpose of care and support plans is therefore not re-stated in these recommendations. However, we have added an introductory sentence saying that all care and support plans must meet the requirements of the Care Act 2014.
Think Local Act Personal	Short	10	1.4.14-14.15	Personal budgets and direct payments - This should be re-drafted to explain all the options that people have to take a personal budget, emphasising that information, advice and support should be provided so that people can choose which option suits them best. All options should offer choice and control. Whilst peer support may be of assistance and of value, what is of at least equal importance is that the local authority makes available to people support to manage their Direct Payment, if that's the option they choose to take. This should include advice and assistance on Personal Assistants, but should encompass assistance with managing a Direct Payment in the round. In addition Individual Service Funds,	Thank you for your comment. Recommendation 1.3.2 has been amended to make reference to the different options for personal budgets – this would include options such as Individual Service Funds. Recommendation 1.3.21 makes reference to local authorities providing information and support for people to use direct payments. It was the view of the Guideline Committee that this should take the form of peer support. Reference to choice and control has been added to recommendation 1.3.17. Reference to control of budgets has also been added to 1.4.18. Peer support for direct payments is covered in recommendation 1.3.21.

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				a personal budget held by a provider on behalf of an individual, should be highlighted as an option.	
Think Local Act Personal	Short	12	1.5.2	Whilst it is helpful to use examples to support the point that practitioners should ‘build rapport with people they support’, care should be taken to avoid examples which might appear patronising.	Thank you for your comment. The examples have now been removed from this recommendation.
Think Local Act Personal	Short	15	1.5.16	All services/settings should have an agreed approach to end of life care.	Thank you for your comment. There is a separate NICE guideline in development relating to end of life care, which is why other settings are not covered here. Residential settings are covered here as we found more evidence on these settings, and they are not covered in detail in the forthcoming guideline on End of life care for adults in the last year of life: service delivery Expected publication date: 18 July 2018
Think Local Act Personal	Short	15	1.15.13	Section on residential care needs to place much more emphasis on interface between care home and local community. Particularly around supporting residents to maintain links with/access community resources activities	Thank you for your comment. The recommendations reflect the evidence reviewed, which did not include links with community.
Think Local Act Personal	Short	19	1.7.3	We have concerns that the term ‘gather views’ does not go far enough to support the principle of power sharing. The emphasis should be on actively co-producing with citizens to plan and develop services/approaches etc. Space needs to be created to support honest, mature and constructive conversations between people with lived experience, commissioners and providers.	Thank you for your comment. Co-production is highlighted in recommendation 1.1.9 as an overarching principle for the whole guideline. Recommendation 1.6.2 also highlights that any research in to people’s views should be co-produced.
Macmillan Cancer Support	Full	10	10	I’m not sure exactly what this line means. Do they mean “receive support to access **carers** support services”? In which case give respite care as an example as well as childcare.	Thank you for your comment. This recommendation refers to people who use services and are also carers, and is intended to convey that their caring responsibilities should not prevent them from accessing the support they need. For people caring for children, they may require childcare to enable them to access some support/appointments. We have added reference to respite care as an additional form of support.
Macmillan Cancer Support	Full	11	5	Could add a further point about signposting carers, families and friends to support if appropriate.	Thank you for your comment. We have not made recommendations relating to carers as there is a separate NICE guideline in development relating to carers.
Macmillan Cancer Support	Full	13	11	Need a further point about taking a whole family approach and ensuring that carers are assessed too?	Thank you for your comment. Reference to taking a whole family approach to assessment has been added to recommendation 1.3.4. Carers’ assessments are referenced in recommendation 1.3.7.
Macmillan Cancer Support	Full	14	2	Care plan should be shared with carer if that is the wish of the person being cared for	Thank you for your comment. This has been added to recommendation 1.3.9.
Macmillan Cancer Support	Full	18	23	Could add an additional point about the residential setting being welcoming and inclusive to visitors eg family and friends. Helping people to maintain their social ties and relationships	Thank you for your comment. Reference to residential environments being welcoming spaces for family, friends and advocates has been added to recommendation 1.4.14
Macmillan Cancer Support	Full	8	3	In overarching principles you start with “Treat each person who uses services as an individual. Use each person’s needs, strengths, preferences and aspirations as the basis on which to provide care and support to live an independent life” Could we make more of verbalising an “asset based approach” which would actually look at strengths first?	Thank you for your comment. Recommendation 1.1.1 now makes reference to ‘self-defined strengths, preferences, aspirations and needs’ to emphasise the importance of an asset-based approach.
Macmillan Cancer Support	Full	10	16	The co-production section could we add “the services and support as far as possible” as it doesn’t make that explicit.	Thank you for your comment. This has been amended as you suggest.
Macmillan Cancer Support	Full	11	11	What about the coordinator liaising with family/friends/carers and the individual themselves	Thank you for your comment. Reference to liaison with the person and their family, carers and advocates has been added to recommendation 1.3.10.

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Macmillan Cancer Support	Full	13	7	Doesn’t mention looking at strengths and assets of individuals	Thank you for your comment. The Guideline Committee were cautious about stating a person’s strengths and assets should be used in assessments for care needs, or that a person’s strengths, defined by an assessor could be a means of determining eligibility for services. We have revised the text to make clear that we mean self-defined strengths and outcomes that a person wants to achieve in their day to day life.
Macmillan Cancer Support	General	General	General	Overall good guidance- but would like to see more of explicit reference to asset based approaches and also more emphasis on making sure families and carers are involved (where appropriate)	Thank you for your comment. Additional reference to involving family, carers and advocates has been included in recommendations 1.1.5, 1.1.7, 1.1.9, 1.1.14, 1.1.15, 1.1.16, 1.3.1, 1.3.2, 1.3.4, 1.3.9, 1.3.10, 1.3.26, 1.4.2, 1.4.14, 1.5.3, 1.6.2.
Macmillan Cancer Support	Full	10	10	I’m not sure exactly what this line means. Do they mean “receive support to access **carers** support services”? In which case give respite care as an example as well as childcare.	Thank you for your comment. We have revised text in 1.1.13 to include respite care as an example of information that should be provided to people with caring responsibilities
UK Homecare Association	draft-guideline-2	8 8 9	2 18 17	Reference ‘overarching principles’ We consider that there should be a differentiation between the roles and responsibilities of the commissioners of social care and the expectations placed on providers of that care An example would be page 8 line 18 which states “Actively involve the person in all key decisions that affect them” where the decisions likely to affect them arise as part of the commissioners-of-care needs assessment process rather than the providers of that care, except in cases of self-funding” A further example arise on page 9 line 17 which states “Ensure that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-economic status or other aspects of their identity” which we consider to be wholly the legal duty of local authorities under the Care Act 2014	Thank you for your comment. We agree that both commissioners and providers have responsibilities in relation to these recommendations; the specifics of these are covered elsewhere in the guideline. For example, involving people in key decisions in needs assessment is covered in recommendation 1.4.4. Involving people in decisions about strategic commissioning is covered in recommendation 1.7.1. With regard to recommendation 1.1.10 on access to care, we suggest that providers also have responsibilities in relation to accessibility – for example in relation to location and physical accessibility of their services.
UK Homecare Association	draft-guideline-2 s1.1.2	8	9	Reference statement “…. including participating in their community … “ For the majority of homecare providers there is scant capacity within a local authority funded care package to underwrite the participation in community activities and it would be inequitable to make adverse comment about the providers compliance with these guidelines when the state funded care package is unlikely to recognise this requirement	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of the recommendations throughout the development process. It was the view of the Committee that achieving this recommendation did not necessarily require significant additional resources, and was therefore aspirational but achievable.
UK Homecare Association	draft-guideline-2	8	18	See comments in comment number 1 above	Thank you for your comment. As stated above, we agree that both commissioners and providers have responsibilities in relation to these recommendations; the specifics of these are covered elsewhere in the guideline. For example, involving people in key decisions in needs assessment is covered in recommendation 1.3.4. Involving people in decisions about strategic commissioning is covered in recommendation 1.6.1. With regard to recommendation 1.1.10 on access to care, we suggest that providers also have responsibilities in relation to accessibility – for example in relation to location and physical accessibility of their services.
UK Homecare Association	draft-guideline-2	8	19	We do not consider it helpful to catalogue the necessity to comply with legal requirements: selective choice of which legal requirements to catalogue to the exclusion of others will always be arbitrary and of limited value	Thank you for your comment. People who may lack capacity to make decisions were identified in the Equality Impact Assessment as a group who may be in need of particular support and consideration, particularly given that concerns raised by the Care Quality Commission regarding the implementation of the Mental Capacity Act. We have therefore highlighted the Mental Capacity Act 2005, as this is the key legal framework in relation to this group.

People’s experience in adult social care services: improving the experience of care and support for people using adult social care services

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UK Homecare Association	draft-guideline-2	9	28, 29	We consider these two lines of text to be superfluous	Thank you for your comment. These lines are intended to provide examples of how service providers can provide care that meets cultural and religious needs.
UK Homecare Association	draft-guideline-2	12	29	The statement “joined-up policies, processes and systems” should be elaborated to establish precisely what should be *joined up*, why and what outputs are envisaged	Thank you for your comment. It was the view of the Committee that this recommendation is sufficient to convey that collaborative working between services may need to be supported by integration of policies, processes and systems across services. The detail of this is likely to vary across areas and services.
UK Homecare Association	draft-guideline-2	14	18	We consider that the statement “Ensure care workers are able to deliver care in a way that respects the person's cultural, religious and communication needs” is intangible and lacks definition: we would suggest that this should be elaborated to construct what precisely is expected of care commissioners and how this can be embodied within contracts. We do not consider that “ensure” offers any realistic guidance and is open to broad interpretation.	Thank you for your comment. Recommendation 1.1.11 provides concrete examples of how cultural and religious needs can be met. We have added a cross-reference to recommendation 1.1.11 in to recommendation 1.3.14
UK Homecare Association	draft-guideline-2	14	27	It would be helpful if the specific clauses within the Care Act 2014 were cited to add weight to this statement: this embodies a legal requirement on local authorities and is not a discretionary option for councils	Thank you for your comment. It is not usual NICE house style to cite specific clauses in legislation.
UK Homecare Association	draft-guideline-2	16	11 – 25 22 - 25	There are a number of aspects to this statement that lack clarity and which propose a course of action on both commissioners and providers that under current market and contracting conditions are unlikely to develop in the way envisaged: 1. What would local authority ‘oversight’ look like? Would this be a supervisory relationship? This type of arrangement existed prior to the inception of CSCI and the CQC where there were county based registration system and which was notable for its local community focus, since dissipated by the subsequent model of regulation: are you proposing a reversal to that approach? 2. What criteria could be applied to measure performance against this aspiration? 3. The development of a specified organisational or operational *culture* is rarely a matter of prescription and is a long term venture that requires collaboration rather than direction from a third party. *Culture Change* is a very long term enterprise and research into organisational psychology and operational dynamics*, characteristic of many MBA programmes, would suggest a 4 to 7 year turnaround period is not uncommon: it really is not a prescriptive venture that can be dealt with lightly 4. The co-production of policies and procedures is not a rent free undertaking: it will cost money 5. The co-production of policies and procedures is not a guarantor of success or of achieving *the right thing* and it may not be overly helpful to cite this in a way that could be taken as if it’s a universal panacea The last two bullet-points at lines 22 – 25 are not cost free. It may be helpful to identify as part of these guidelines an operational method by which this could be achieved.	Thank you for your comments. 1 and 2. We have removed reference to local authority oversight from the recommendation. 3. We acknowledge that development of an organisational culture is fundamental to promoting improved service user experience, requiring a range of actions. 4 and 5. We agree that co-production is necessary, but not sufficient, for success, which is why a range of actions have been specified here. However, the statutory guidance on the Care Act identifies that co-production ‘can contribute to developing individual resilience and help promote self-reliance and independence, as well as ensuring that services reflect what the people who use them want’. There is an expectation in the statutory guidance on the Care Act that co-production should be taking place. The Guideline Committee therefore considered that this should not require significant additional resource to what is already required to implement the Care Act.
UK Homecare Association	draft-guideline-2	16 - 17	26 – 29 / 1 -2	Our comments in 9 above apply equally to this clause. The costs of providing the scale of services proposed in the second bullet-point is almost certainly prohibitive within the current financial environment of local authority contracted provision.	Thank you for your comment. The second bullet point in recommendation 1.4.1 has now been removed.
UK Homecare Association	draft-guideline-2	18	9	The repetitious use of ‘appropriate’ within the guidelines leaves some question as to what constitutes *appropriateness* and is too open to interpretation for the purposes of a guidance document.	Thank you for your comment. We have reviewed the usage of the term ‘appropriate’ in the guideline and amended the following recommendations: 1.1.11, 1.1.12, 1.4.15, 1.6.11.

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UK Homecare Association	draft-guideline-2	18 19	24 – 27 01 - 07	This clause concerns the functionality of built assets and is unlikely to be within the remit of care staff or managers. We consider it unlikely that influence over such issues can occur other than at the *health system planning* phase of a newbuild or refurbishment, although we readily support the innovative use of therapeutic geography within the built environment.	Thank you for your comment. We acknowledge that some aspects of the care environment may be determined by the building itself. However, the Guideline Committee intended this recommendation to refer to aspects of the environment such as availability and placement of furniture, making adaptations and so on. It was the view of the Committee that this was within the remit of care staff and managers.
UK Homecare Association	draft-guideline-2	22	1 - 8	This clause forms part of the CQC regulatory and inspection regime	Thank you for your comment. It is helpful to know that implementation of this recommendation is likely to be monitored by CQC inspections.
UK Homecare Association	draft-guideline-2	23	1 - 11	We consider it unlikely that there is sufficient funding *generally* within the provider arena to underwrite this proposal: over 70% of social care is state funded and we have yet to see examples of contracts where there would be sufficient leeway to fund such a scheme	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of the recommendations throughout the development process. It was the view of the Committee that achieving this recommendation did not necessarily require significant additional resources, and was therefore aspirational but achievable.
UK Homecare Association	draft-guideline-2			We are concerned that there are several clauses within the document where there may be value in consolidating items and being less 'granular' in the description, for example items: 1.5.3 1.5.4 1.5.5 1.5.13 1.5.14	Thank you for your comment. The NICE guideline development manual suggests that each recommendation should contain only 1 main action. This is why these recommendations have been separated out in this way.
UK Homecare Association	draft-guideline-2	general	general	The development of guidelines such as this creates an opportunity to adopt one of two models: firstly, an aspirational approach that describes an ideal world. Secondly, to develop guidelines that have very considerable utility because they are grounded in the practicalities of providing care services within the prevailing market disposition and the very real limitations that this environment places on both commissioners and providers. The former model carries the risk of becoming unworldly in its aspiration and ambition but can, if modelled sensitively, provide stimulus and impetus to the market by giving clarity over the best possible route to systemic product improvement over the long(er) term. The latter model has the inherent advantage of demonstrating how to maximise effectiveness and efficiency within existing constraints. We are concerned that there is here an opportunity to be lost.	Thank you for your comment. NICE guidelines are based on the best available evidence, including cost-effectiveness evidence where available, and are developed by a committee of service providers, people who use services and their carers. This approach therefore aims to balance what is known about best practice with implementation and resource impact considerations, and these have been taken in to account throughout the development process. It is the view of the Committee that these recommendations are aspirational but achievable.