

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Action for ME	General	General	Action for M.E. welcome updated guidance on the integrated health and social care support. M.E. is a disability under the Equalities Act so will be affected by the decisions made in the Scope. We therefore want consideration brought to fluctuating conditions. The scope will cover children and young people with disabilities and severe complex needs. People with M.E. will often fluctuate between moderate and severe and lengthy processes to determine their eligibility for support may not reflect the condition they have at the initial point of application.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that myalgic encephalomyelitis is a condition to which the principles of integrated care should apply. The scope also emphasises that changing (fluctuating) conditions will be of relevance in this guideline
Action for ME	General	General	We would also like attention on the transitional arrangements of children and young people when they reach an age whereby they transfer to adult services.	Thank you for this comment. The importance of transition arrangements has been emphasised in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Action for ME	General	General	We would like attention brought to the joined up working of services. One in four of those with M.E. are classed as severely affected. These children are often bed-bound, home-schooled and frequently on a reduced timetable altogether. Because of this, any provision would need to take additional steps to ensure children are accessing services they are entitled to, with the support to ensure they can do this in a way appropriate to their needs. Communication is referred to in this scope and we would like it to be a priority between services.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that myalgic encephalomyelitis is a condition to which the principles of integrated care should apply. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). The scope also emphasises the importance of communication between services

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Allergy UK	General	General	We feel that the draft scope has the potential to exclude a small but significant proportion of the population it aims to serve – those young people who are aged 18-25, cared for within adult services who have complex health needs but ALSO have capacity. There seems to be a question mark in the scope over having capacity but not being “complexly disabled enough” because of their cognition, therefore not entitled to the SAME care and attention an individual without capacity has. Physical needs in this population are often the same or similar to those in individuals registered as not having capacity. We would like to see recommendations providing the same access to cross service teams/funding and support with a recognition of this need within this population. We meet many clients experiencing this exact struggle and feel they are frequently overlooked because of challenges with identification and engagement. Having the capacity is very different from having the ability to care for all your needs.	Thank you for this comment. It has been agreed that the age range of the guideline population will be 0 to 25 years. This is consistent with the age range for access to an education, health and care plan. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). The reference to lack of mental capacity no longer appears in the introduction to the scope and in any case the guideline population includes children and young people with capacity to make decisions (provided they meet the criteria for needing support from all 3 sectors)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Association for Family Therapy and Systemic Practice	General	General	We note a focus on the individual child's concerns, experiences, needs, wants etc., within the documentation. We would encourage NICE to consider the context in which children with learning disabilities live in, from an early age. Emerson and Hatton (2007) discuss the risk factors for children with LD. More children with LD than non-LD come from single parent households, have income poverty, more than two negative life events, poor family functioning, primary carer with no educational qualifications, no adult in paid work, child's mother with mental health issues and/or poor physical health. If we can target those factors, we can make positive changes for children with LD's mental health. We need to target help at family stressors, family patterns of interaction, hardship and family adversity, parents' emotional distress and parenting. Mental health of children and adolescents with intellectual disabilities in Britain. Emerson, Eric; Hatton, Chris: British Journal of Psychiatry, Vol. 191, 12.2007, p. 493-499.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that learning disability is an area in which the principles of integrated care should apply. The scope also emphasises that learning disability will be of relevance in this guideline, and the equalities impact assessment summarises related considerations that will be important in ensuring equality of access to services
British Academy of Childhood Disability	General	General	This guideline is very welcome, as children and young people with complex, disabling conditions are amongst the most vulnerable of all.	Thank you for this comment in support of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	General	General	This guideline has massive scope and will have impact on a large population of children, families and young adults. It is absolutely essential that the guideline development group has representation from all sectors; including Adult and Children's LD psychiatry, general practitioners, paediatricians and adult physicians from a medical point of view. A range of therapists should also be included, YP, carers and charitable organisations are essential. Whilst we understand that it NICE cannot develop social care guidance, health based social care workers should be included in the guideline development. Commissioners are also integral to ensure that the recommendations will be supported and deliverable.	Thank you for this comment. The developers have considered feedback from stakeholders on the committee composition and the final committee composition includes most of the professionals (including those in working in the third sector) mentioned in the comment. The committee will include social workers because NICE does have a remit to develop social care guidelines

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Challenging Behaviour Foundation	General	General	<p>We welcome the development of this guidance. We have some comments on the overall approach. For disabled children with complex needs the range of interventions and support will necessarily look very different for each individual and will include treatment and support for some rare or low incidence conditions. Although individual interventions may look very different, the approach services taken to organise and deliver that care and support can be very consistent and should be 1) personalised to each child's needs and those of their family and 2) integrated in the way it is delivered. A personalised, integrated approach is relevant whether you are talking about tube feeding, physiotherapy, behaviour support, constipation or any of the many other needs a child or young person may have. It would be helpful if this were clearly explained up front, drawing on the best practice developed over the years. We recommend that some areas only touched on lightly in the current scope are covered in greater depth. Early Intervention. Our consultations with families have resulted in clear feedback that early identification of needs, early diagnosis and an early response make a huge difference, both in terms of meeting a child's needs and enabling a family to support their child more effectively. Specifically around behaviour, early intervention was recommended by the CBF academic expert group. (Early Intervention for children with learning disabilities whose behaviours challenge, CBF 2014) Challenging behaviour. The briefing paper referenced above found that "children displaying challenging behaviours are at greater risk of social exclusion, institutionalisation, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions.[1] Poor outcomes are experienced not just by children themselves but by their families too. Carers face an increased risk of physical and mental-ill health, physical injury, increased financial burdens, and reduced</p>	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that challenging behaviour is an area in which the principles of integrated care should apply and the potential equalities considerations mentioned in the comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). The revised scope highlights the importance of providing consistency in the delivery of services, regardless of geographical location, and the importance of mental health is now more prominent. The guideline committee will include a parent or carer with personal experience in the context of access to health, social care and education services for disabled children and young people with severe complex needs</p>
----------------------------------	---------	---------	---	---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

		<p>quality of life.[ii] Challenging behaviour is generally an indication of an unmet need and we support families whose children are regularly failed by services. Often even the most basic needs are not met eg– to learn communication skills, to be kept safe, to have basic health needs met. Many examples of restrictive practice or out of area placements could be avoided if children were supported effectively in the community. Positive Behaviour Support has been shown to improve outcomes, reduce behaviours that challenge and to cost less than the alternatives. We would welcome the inclusion of challenging behaviour more explicitly within the guidance. Although the guidance may be only have scope over physical health and social care – education and mental health services are both key to effective, integrated support for disabled children with complex needs. We would recommend greater focus on the interface with these services. Families of the most vulnerable children are often those who find it the hardest to engage with forums of support groups or to engage with consultations. Families provide the majority of the care for the group of children considered by this guideline. Please take forward a focussed, inclusive consultation with family-carers, who will be able to share a huge amount of lived experience to advise on the development of this guideline.</p>	
--	--	--	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	General	General	<p>I understand we and DHSC commissioned the guidelines but can you clarify the purpose of them? Defining the problem/issue at the outset will help focus the guidelines and improve the impact on children with disabilities. In particular including the role of education so that it is seen as an essential element alongside health and social care. Is it to identify effective practice and reflect that back to readers? make an assessment of how the system is working? support peer review and self assessment? What do you want to achieve? There is no mention of improving outcomes. A diagram highlighting where this fits in to the wider health / care context in the guideline scope would be very helpful. In particular, clarity on the importance of education in improving outcomes for disabled children. I would have expected to see greater focus on services working effectively together to deliver outcomes, best use of funding, better joint commissioning, etc. Helpful to think about achieving outcomes related to many of the questions set out in the scoping paper. Principle of better outcomes whether in education, work, independence, health or care improves overall outcomes and wellbeing meeting all the services aims and saves money overall preventing crisis. [All for one and one for all J] We discussed via telekit that this guidance should be aimed at strategic leadership rather than an operational "How to guidance" at the rock face, nevertheless collecting evidence on what work – case studies – are helpful in persuading readers about the possible. Hence, we thought beginning with some of the best performing areas (LAs working with health areas) may help illustrate the art of the possible. Nigel Rayner at Mott MacDonald has offered to point you</p>	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). The aim of the guideline is to improve outcomes through better integration, delivery and organisation of services. There is a section in the scope headed 'main outcomes' which will guide the committee in the evaluation of evidence; specific outcomes for the individual review questions to be addressed in the guideline will be agreed by the committee during the guideline development process. The suggestion to develop a diagram summarising the integration of health, social care and education services will be shared with the committee when the guideline enters the development phase</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			in the direction of the better performing areas following Ofsted and CQC SEND inspections.	

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	General	General	Scope remains a bit imprecise – some sections cover a great deal of ground (and I appreciate that we might want to keep our options open), but without defining explicitly the cohort, and without indicating clearly what is the objective. Is this primarily guidance to deliver joint commissioning? Or integration between services (and with commissioners). Probably both are within scope.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). The aim of the guideline is to improve outcomes through better integration, delivery and organisation of services. The cohort (guideline population) is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	General	General	No mention of autism – I appreciate desire to avoid specifying conditions, but it is essential to indicate that this is within scope. I would also recommend that challenging behaviour is explicitly referenced in the body of the scope.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that autism is a condition to which the principles of integrated care should apply. The scope also emphasises that challenging behaviour will be of relevance in this guideline, and the equalities impact assessment summarises related considerations that will be important in ensuring equality of access to services
Department of Health	General	General	I think part of the purpose of this work – which is alluded to in passing – would be to ensure commissioners can agree on who is responsible for what, with particular reference to the school environment / ensuring access to education.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). The aim of the guideline is to improve outcomes through better integration, delivery and organisation of services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	General	General	It is not clear why this guidance is entitled health and social care and reference is made throughout to health and social care; for example it will provide guidance on 'integrated health and social care support'. What's the rationale for only referencing health and social care and not education considering SEND reforms are about all 3 and arguably education is the greatest most consistent player? A lot of the aims mentioned would not be possible without effective engagement with schools and education services – their role and effective fulfilment of their responsibilities should therefore be more prominent in the scope.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Essex County Council	General	General	It should be more clearly defined what this guidance is intending to offer on top of the myriad of other existing guidance e.g. all the guidance around the SEND Code of Practice, transition, management of autism and Id etc. Could the interface between this and other guidance be explained? It might be helpful to review existing guidance to identify gaps which could be filled with work.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline will add value by providing guidance on how existing legislation and statutory guidance should be put into practice
Essex County Council	General	General	The phrase “disabled children and young people with severe complex needs” could generate confusion because you have separated 'disabled children' from 'young people with severe complex needs'. Do you mean children and young people who are disabled and have severe complex needs? If so, where does this leave children and young people who have severe complex needs (as defined on page 5 lines 19-20) but no formal diagnosis of disability?	Thank you for this comment. The guideline population is disabled children and young people with severe complex needs. The guideline title has been amended to provide greater clarity, and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	General	General	Use of plain English: e.g. avoid terms such as facilitate, accessibility, disparate, self-efficacy, social capital, attainment etc.g. Page 9 lines 23-25 phrase is unhelpfully complicated rather than in everyday language.	Thank you for this comment. This review question (and others) have been redrafted. The word accessibility has been retained as it refers the degree to which services are available to disabled children - a key part of this guideline
Essex County Council	General	General	The term "acceptable" is used throughout this document; this is very subjective to whoever is quantifying it – consider either amending the term or providing some kind of quantification about what "acceptable" is to ensure that it is understood by all parties.Likewise with 'effective' – should there be further clarification on how a service would be termed 'effective'? It might be helpful to include guidance for services on identifying and monitoring effectiveness?	Thank you for this comment. The main outcomes section lists outcomes that could be used to determine whether approaches to integrating services are effective and acceptable. The revised scope emphasises that evidence related to the experience of service users and their families and carers will be taken into account in developing the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	General	General	Genetic Alliance UK welcomes the development of a guideline on integrated health and social care support for children and young people with disabilities and severe complex needs. This is an important topic substantial scope for quality improvement. In order for the guideline to have a chance of improving the experiences of service users and their families and carers, it is vital that the guideline consider not only which interventions and strategies are effective in each area of care, but also how services should be delivered to ensure that service users and families are able to access these effective interventions and strategies. For this reason we consider that all of the proposed review questions should consider barriers to and facilitators of care (question 2). We would also support the alternative title 'Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation' (question 5) as it strengthens the emphasis on this aspect of unmet need.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities
Lancashire Care NHS Foundation Trust	General	General	This client group require an integrated approach that includes education and the voluntary sector as well as health and social care.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline committee will include members with expertise in the education and voluntary sectors in the context of disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Lancashire Care NHS Foundation Trust	General	General	Challenges also include health professionals from several NHS Trusts being involved. e.g. I had a case recently that had professionals from 4 hospital trusts plus LCFT. This meant 5 separate healthcare records.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes a reference to planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services
Lancashire Care NHS Foundation Trust	General	General	I believe there would be value in scoping the journey of Children and Young people in different regions by getting services and families together to create a map of when and who was involved. This would answer many of the questions.	Thank you for this comment. The suggestion to scope the journey of children and young people will be shared with the committee when the guideline enters the development phase and be considered from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Mencap	General	General	<p>A good practice example of cost saving interventions is the Early-positive Approaches to Support (E-PAtS) programme. There are currently no parent support programmes available to support the specific needs of families of children with a learning disability. Mencap is working with the Tizard Centre at the University of Kent to trial a new parent support programme called E-PAtS (Early-Positive Approaches to Support). E-PAtS comprises 8 x 2.5-hour sessions<sup>20</sup> for family caregivers of children (0-5 years) with a learning disability or developmental delay. Its main aim is to meet the needs of families at an early stage, prior to or just after the development of early behaviour difficulties. The programme provides parents with information and practical skills to minimise risks associated with challenging behaviour, and support their child’s development and life chances. Key Features are:Co-produced over a period of 5 years by professionals in the learning disabilities field and family caregiversRoutinely co-facilitated by trained family caregivers and professionals working in partnershipProvides an emotionally supportive and sensitive group process that attends closely to care-givers’ emotional needs.Utilises high quality, evidence-based information and strategies specific to the needs of families raising a child with learning disabilities.Can be implemented in a range of settings, is fully manualised and free to use for all organisations who have trained facilitators.Mencap has been trialling this approach in Northern Ireland and in London with some promising results to date. The vast majority of participants said they found the various elements of the programme – looking after yourself, sleep, communication, life skills, challenging behaviour and information on local support – useful or very useful.“What the session taught me is 2 things; one is I have to look after myself, cause who is going to look after [name of child], it isn’t about just me soldiering on. I actually have to look after myself cause I have got somebody</p>	<p>Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services</p>
--------	---------	---------	--	---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

		else to look after as well and for your own mental wellbeing you've got to"	
--	--	---	--



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	General	General	It would be beneficial for the questions asked regarding methodologies which are 'effective and acceptable' to be supported through links to evidence of what is effective in personalisation and person centered planning e.g– these approaches support the understanding of preferences and observation of communication of views and interests/preferences for people with greater needsThe PfA pathways reference many of the 3.6 life outcomes, in a more accessible language- is the guide for families too?	Thank you for this comment. One of the key areas identified in the scope was ensuring children and young people are involved in planning and reviewing, and know about, their combined health and social care and education. This covers person-centred planning and personalisation. Thank you for drawing our attention to the PfA pathways. NICE editors work to ensure that NICE guidelines and information on the NICE website are straightforward to read and free from jargon
National Development Team for Inclusion	General	General	A visual depiction- flow chart- would be most welcome, to enable understanding in familiesThis should be co-produced with families to ensure that the interventions meets family needs in enabling independencePerhaps developing a similar website to the 'What Works' website in education, could provide evidence of effective practice, not least using language and visual information accessible to families	Thank you for this comment and the information about related resources. The suggestion to develop a visual depiction of the integration of health, social care and education services will be shared with the committee when the guideline enters the development phase. The committee will include a parent or carer with personal experience in the context of access to health, social care and education services for disabled children and young people with severe complex needs
National Development Team for Inclusion	General	General	It would be beneficial to see more on Positive Behaviour Support for children and young people who need it.	Thank you for this comment and the example of a specific approach. The suggestion will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	General	General	Section 3.2 notifies that all settings, including educational settings, are 'covered'- settings in education will require specificity about whether this is legal guidance, and will require a clear notification when the final document is released as a guide	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline will add value by providing guidance on how existing legislation and statutory guidance should be put into practice. All NICE guidelines include a disclaimer stating that the recommendations represent the view of NICE, arrived at after careful consideration of the available evidence, and that professionals are expected to take guidelines fully into account, alongside needs, preferences and values of individual patients or service users. The disclaimer continues by highlighting that recommendations in NICE guidelines are not mandatory and guidelines do not override the responsibility of professionals to make decisions appropriate to the circumstances of the individual patient or service user, in consultation with that person and/or their carer or guardian

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	General	General	This scoping document seems to be based on the medical model from the use of the term severe complex needs. It needs to take account of all the current legislation that refers to partnership working across Education Health and Care rather than just focus on integrated health and social care.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We appreciate that the guideline will need to be developed in the context of current legislation that is relevant across the 3 sectors. The guideline will add value by providing guidance on how existing legislation and statutory guidance should be put into practice. The guideline population is disabled children and young people with severe complex needs and this is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
National Development Team for Inclusion	General	General	The review questions are really difficult to answer and need simplifying. For example, you could embolden key words such as identification in 1.1 and assessing in 1.2 and so on. The language needs to be made much easier for many of the target group who will have difficulty understanding.	Thank you for this comment. NICE editors work to ensure that NICE guidelines and information on the NICE website are straightforward to read and free from jargon. A short version of the guideline will be made available which is easier to digest
Newlife	General	General	This draft guideline scope is an incredible opportunity to ensure that disabled children's services can be truly integrated with the child and family at the heart. The guideline is ambitious in its aims and has the ability to transform the lives of the most vulnerable children in our society. We look forward to supporting NICE in the development of this guideline and its implementation.	Thank you for this comment in support of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	General	General	With reference to the proposed, alternative Guideline title "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation", we would recommend not using this and staying with the original title that starts (appropriately) with Children...	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities
Norrie Disease Foundation	General	General	This guideline is very welcome, as children and young people with severe complex needs such as Norrie disease are very vulnerable. Being a rare disease, it is a condition most professionals never come across in their career.	Thank you for this comment in support of the guideline
Royal College of Occupational Therapists	General	General	In response to question 1 on the comments form: We would suggest considering inclusion of the innovative Changing places initiatives including modular facilities to allow toilet and changing access to community events and leisure attractions, e.g. at a music festival or theme parks.	Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Occupational Therapists	General	General	In response to question 1 on the comments form:A complex young person in local academy mainstream school (now 15) is allocated 3 teaching assistants for care needs (changing and gastrostomy fed) communication (uses eye gaze technology) and curriculum differentiation. She has an EHCP.	Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services
Royal College of Occupational Therapists	General	General	Although specific health interventions are not being described, a basic standard of service delivery would be beneficial as this client group often receive no more than equipment/ orthotics provision from AHPs , further distancing them from accessing leisure, independence or employment	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice. Specifically, this guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis)
Royal College of Occupational Therapists	General	General	Models of service delivery such as Person Centred Active Support, and the Primary Provider Model are having a significant impact for this client group and should be referenced as exemplars of good practice - they are not specific health interventions	Thank you for this comment and the examples of specific approaches. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice. Specifically, this guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). The examples provided will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Paediatrics and Child Health (with BACD input)	General	General	The reviewer is happy with the draft scope.	Thank you for this comment in support of the guideline
Royal College of Physicians	General	General	The RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our Young Adult and Adolescent Standing Committee and would like to make the following comment. In general, the guidance will be welcome, however the age range of 0-25 may present some logistical problems to secondary care should young people with complex needs access acute health care, especially for the 16-18 year olds where there may be confusion as to point of admission. We are concerned that there is no mention of forward planning and ceiling of care in the case of severe life threatening illness ( although this may be considered outside the realm of this guidance)	Thank you for this comment. It has been agreed that the age range of the guideline population will be 0 to 25 years. This is consistent with the age range for access to an education, health and care plan. The importance of transition arrangements and end of life considerations have been emphasised in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Royal College of Psychiatrists	General	General	The draft scope refers to "health" and it seems implied that this means physical health only, however mental health should be clearly included in "health" The document emphasis on the need of integration of physical health and social services. There is a risk of missing the opportunity of promoting integration of all three aspects of needs (including mental health) in the same person (under 25s with disability and severe complex needs). Guidance on integration of mental and physical care is currently in progress and should be acknowledged. Ideally this should be reflected in the title..." integrated physical and mental health and social care support" to avoid confusion and risk of discrimination.	Thank you for this comment. It was always the intention that health would refer to both mental and physical aspects of health. The importance of mental health has been made more prominent in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Psychiatrists	General	General	In view of the above the mental health commissioning needs to integrate and commissioners in all three domains should be encouraged by these guidelines to collaborate. It needs to be considered that patients continue to have all other aspects of their complex needs even though temporarily a physical health need or mental health needs take priority.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The importance of mental health has been made more prominent in the revised scope
SeeAbility	General	General	SeeAbility attended the scoping workshop in December to contribute to the scoping consultation. At that event there were a number of representations about the role of education in this guideline, particularly as for most children with severe complex needs they should be in receipt of an Education, Health and Care Plan, and their school setting will be providing input to a variety of health needs in the school environment. It is still unclear how much the Department of Education will be involved in co-producing this guideline and how it will cross over with current guidance such as the government's guidance on supporting children with medical conditions in school, the SEND code of practice, etc as this might be helpful context for the scope.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	At first glance the scope seems to focus more on complexities relating to physical health rather than also considering complexities relating to mental health.	Thank you for this comment. It was always the intention that health would refer to both mental and physical aspects of health. The importance of mental health has been made more prominent in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	Would it be possible to clarify whether the guidance is for: Young people with learning disability. Young people with severe and complex needs. Young people with both learning disability and severe complex needs. This distinction can be important for access to support. For example, we know that however badly affected a young person is by autistic spectrum disorder and any complexities which arise from this, if they do not have a learning disability, they are not accepted by the disability team for social care support.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	Would it be possible to clarify the age group the guidance applies to? Different children and young people's services may serve different age groups. For example: Health service provision may be for under 16s or under 18s. Education and Local Authority provision may be for under 19s. Education, Health and Care (EHC) Plans apply to under 25s.	Thank you for this comment. It has been agreed that the age range of the guideline population will be 0 to 25 years. This is consistent with the age range for access to an education, health and care plan
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	The guidance should fit with Education, Health and Care (EHC) and Care Education and Treatment Review (CETR) processes. These are not explicitly referred to in the scope.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	Given that the main issue in providing care for this group of young people is resource based, is the assumption that the guideline will be mainly values focused? If there are quality standards linked to service provision, one unintended consequence could be pressure to 'diagnose' young people with LD so that they can receive a service. Waiting lists for autistic spectrum disorder assessment are very long; is there potential for long waits to receive confirmation of 'complex needs'?	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice. Specifically, this guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). The aim of the guideline is to improve outcomes through better integration, delivery and organisation of services. There is a section in the scope headed 'main outcomes' which will guide the committee in the evaluation of evidence; specific outcomes for the individual review questions to be addressed in the guideline will be agreed by the committee during the guideline development process. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services) and children and young people's needs will be addressed in this guideline in that context
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	A 'passport of care' approach would be very helpful.	Thank you for this comment and the example of a specific approach. The suggestion will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Tees, Esk and Wear Valley's NHS Foundation Trust	General	General	List of relevant documents could include NICE guidance on post diagnosis autistic spectrum disorder.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, and the other NICE guidelines that contain recommendations specific to particular conditions are too numerous to mention in this section. We will, however, keep in mind that autism spectrum disorder is a condition to which the principles of integrated care should apply

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	General	General	<p>Thomas Pocklington Trust is a charity committed to increasing awareness and understanding of the needs of people with sight loss and to developing and implementing services which meet their needs and improve their lives. The charity seeks to champion needs, provide change leadership, seek out gaps in service provision and with the cooperation of like-minded partner organisations, prioritise actions aimed at addressing identified deficiencies. We have responded in relation to the experiences of healthcare for vision impaired (VI) children and young people plus those with additional disabilities. This group is very much a minority group within childhood disability (approx. 26K (Ref 1) children/young people in the UK though this is an underestimation as many children are undiagnosed/not registered and the true figure is thought to be closer to 34K) but their needs are very specific. Within all areas of need – healthcare, education and social care, the lack of expertise and experience has negative consequences to their provision. The low numbers of VI children/young people mean that it would cost very little for their healthcare experience to be improved and we recommend that the NHS should work with existing experts within some of the major VI organisations, so that the experience of this group could be improved at minimal cost. There is little if any research, evidence or information about best practice in relation to VI children/young people accessing healthcare but information related to VI adults can provide useful insights into this issues. Ref 2, Ref 3. Ref 1. <a href="https://www.rnib.org.uk/nb-online/eye-health-statistics">https://www.rnib.org.uk/nb-online/eye-health-statistics</a> Ref 2. <a href="https://hgs.uhb.nhs.uk/wp-content/uploads/Sensory-Impairment-">https://hgs.uhb.nhs.uk/wp-content/uploads/Sensory-Impairment-</a></p>	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that visual impairment is a condition to which the principles of integrated care should apply. The scope also emphasises that sensory impairments (which include visual impairment) will be of relevance in this guideline, and the equalities impact assessment summarises related considerations that will be important in ensuring equality of access to services</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			Meeting-the-needs-of-visually-impaired-people-1.pdf Ref 3. <a href="https://www.abilitynet.org.uk/news-blogs/5-ways-nhs-disables-blind-people-and-5-ways-it-could-help">https://www.abilitynet.org.uk/news-blogs/5-ways-nhs-disables-blind-people-and-5-ways-it-could-help</a>	

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
 Consultation on draft scope  
 Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Thomas Pocklington Trust	General	General	<p>Although NICE can only deal with the integration of health and social care, it is vital that when working with children and young people under the age of 25 with severe and complex needs that these needs are also integrated with those of education. Health and social care play such a vital role in the education of disabled children and young people and full integration is vital to ensure the child/young person's well being in all areas of their life.</p> <p>****<a href="https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/children">https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/children</a>****Currently VI children/young people without additional needs are attaining at a lower level than their sighted peers, are more likely to be NEET (Not in Education, Employment or Training) and more likely to be long term unemployed. The outlook for VI children with complex needs is even bleaker.<a href="https://www.rnib.org.uk/knowledge-and-research-hub/research-reports/education-research/sight-impaired-7">https://www.rnib.org.uk/knowledge-and-research-hub/research-reports/education-research/sight-impaired-7</a>****<a href="https://www.rnib.org.uk/information-everyday-living/education-and-learning/learning-complex-needs">https://www.rnib.org.uk/information-everyday-living/education-and-learning/learning-complex-needs</a>The EHCP (Education and Health Care Plan) which are the backbone on which support for children with disabilities is built includes all aspects of educational, health and social care so it would make sense for this to be reflected in all aspects of the child/young person's life.****<a href="https://www.ipsea.org.uk/pages/category/education-health-and-care-plans">https://www.ipsea.org.uk/pages/category/education-health-and-care-plans</a>The attendance of professionals from either social or health care at school meetings is very low due to a number of factors including lack of time, not being informed, education and either health or social care provision falling under multiple local authority areas. This can lead to significant gaps in the understanding of provision for the child/young person.****<a href="https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Health%20Advice.pdf">https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Health%20Advice.pdf</a></p>	<p>Thank you for this comment and the information about related resources. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)</p>
--------------------------	---------	---------	---	---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	General	General	<a href="https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Core-Care-Pathway.pdf">We would like to draw your attention to Together for Short Lives' 'A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions', available to download here: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Core-Care-Pathway.pdf</a> The pathway proposes a core framework for professionals working with children and young people to support the local development of an integrated care pathway for children diagnosed or recognised as having a life-threatening or life-limiting condition and following the child and family's unique care journey. The pathway puts children and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.	Thank you for this comment, the example of a specific approach and information about related resources. The suggestion will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services. The revised scope also highlights the importance of end of life considerations. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Bristol NHS Foundation Trust</a>	General	General	I welcome this document, as a manager of a service which supports children with complex needs. We have been experiencing issues with support in providing care to children based in special schools regarding monitoring anthropometry and clinical reviews. We believe that assessing and reviewing these children who have nutritional needs should be based in the schools. This not only ensures good levels of communication with professionals who know the child and family well but also, prevents the need for taking the child out of school to another appointment. Unfortunately due to the cut backs, we are finding it more difficult to direct the school based nursing teams with regard to weighing and measuring the children; a fundamental need and essential to be able to assess health, well-being and growth. This directive is coming from the commissioned health care providers who are pulling the nursing teams out of the special schools and into a central base. This effects all aspects of health care for these children. A clear guidance within the document promoting close health monitoring based within the school is essential for this vulnerable group of children.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that health monitoring is an area in which the principles of integrated care should apply. Education is also referenced throughout the revised scope
Challenging Behaviour Foundation	Specific question response	Specific question response	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? The use of local "positive behaviour support" or "intensive support teams" to provide local behaviour support. This has offset the cost of out of area placements and we can share evidence of this.	Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	Specific question response	Specific question response	Which, if any, of the proposed review questions should consider barriers to care? This is an overarching issue, so all of them.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate
Challenging Behaviour Foundation	Specific question response	Specific question response	For which questions would views and experiences of service users be most important to consider? All of them and particularly the ones about involving children and families and which interventions and approaches deliver good outcomes.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate
Challenging Behaviour Foundation	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?" It depends whether this guideline will be able to clarify how services should be organised? The usual terminology would be "disabled children and young people with severe complex needs..."	Thank you for this comment. The guideline short title has been changed to disabilities and severe complex needs in children and young people up to 25. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Essex County Council	Specific question response	Specific question response	<p>· Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Examples of Essex integrated health and social care support: Essex Joint Area Panels (health, education and social care) meet monthly to agree joint packages for children with complex needs. This ensures that plans for children with continuing care, social care and education needs are coherent, resourced and regularly reviewed. The integrated Essex Child and Family Wellbeing Service highlights what can be achieved through genuine joint planning and commissioning. There is provision in this contract for other Essex CCGs to join the commission and ECC continue to promote this possibility to partner agencies in pursuit of more joined up services. A key feature the Essex Child and Family Wellbeing service (ECFWS) is the integration of professionals from Children’s Centre, Health Visiting and School Nursing Teams to deliver a new service focused on improving outcomes for children, young people and their families. In West Essex, this integration includes the paediatric health provision commissioned by West Essex CCG. ECFWS is a holistic service with a partnership approach at the centre of the delivery model. ECFWS has 29 multidisciplinary Healthy Family Teams across the County as well as a Healthy Schools and Public Health Team that service local communities across Essex. Healthy Family Teams consist of a Team Leader, Health Visitors, School Nurses, Healthy Family Support Workers, Healthy Family Support Assistants and Administrators. The jointly commissioned Specialist Healthcare Tasks service ensures there is safe delegation of healthcare tasks, training and competency review and sign off for professionals across Education, Health and Care. This has enabled children and young people with medical needs to travel safely to and attend school, engage in the community and access care. In 2016/17, 1868 professionals across education, health, social care and short</p>	<p>Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services</p>
----------------------	----------------------------	----------------------------	---	---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

<p>breaks providers were trained in Specialist Healthcare Tasks. An area of best practice is the specialist healthcare task provision in Mid special schools. We have brought all our therapy provision under a single provider and contract and a joint review of children's therapies is underway with health, education and social care. Delivery of therapies across the county previously was disjointed and had an impact upon parental confidence in the local area's ability to meet their children and young people's needs. Pooling resources, less individualised responses and increased competition has enabled us to be more efficient and provide a quicker response. The Essex All Age Partnership Group has active membership from health and social care alongside families living with autism. Its role is to set and oversee delivery of priorities to improve the lives of children, young people and their families by identifying and building on good practice. The children's Autism strategy is in draft form and an adult strategy is in place. We are considering now how we can bring these strategies together and have one co-ordinated action plan. Care Education Treatment Reviews (CETR) as part of the NHSe project initiative: the focus is on progress for vulnerable children with escalating needs (Learning Disability and Autism) who may be at risk of hospital admittance. The CETR has external input from other parents who have had similar experiences and some external clinicians to bring challenge and perspective. We have most partners signed up to taking the requests for these conversations seriously and accepting the need to consider additional and or different support. The ambition is to establish over the next 12 months the impact that we can have in working more intensively with these cases, agreeing the financial impact and then securing the funds going forward. Multi stakeholder SEND Work Groups enable health, social care and education to work collaboratively to address local issues relating to progressing the SEND agenda.</p>
---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

<b>Stakeholder</b>	<b>Page no.</b>	<b>Line no.</b>	<b>Comments</b>	<b>Developer's response</b>
Essex County Council	Specific question response	Specific question response	Which, if any, of the proposed review questions should consider barriers to care? Commonly health and social care IT systems are different/independent of one another, creating challenges to adopting a 'tell it once' approach, or working in a joined up/collaborative way across areas outlined in Q1, Q2, Q3. Barriers are referenced on page 10 line 19.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate
Essex County Council	Specific question response	Specific question response	· For which questions would views and experiences of service users be most important to consider? Section 3.5: Q1.1; 1.2; 1.3; 2.1; 3.1; 4.1; 5.1; (possibly 5.2); 6.1; 7.1; 7.2; Service Users should be meaningfully involved in the co-production of elements outlined in Q8, including at strategic levels. Section 3.6: Service Users should be given opportunity to review and contribute to the list of outcome themes.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate
Essex County Council	Specific question response	Specific question response	What in your opinion are the most important and least important of the proposed review questions? Most important Q: 2; Least important Q: 8.2	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"We would prefer the term '0-25' to 'under 25s' – however, using a quantified age range is more helpful than 'children and young people' – as this can be misinterpreted as under 18s. See comments elsewhere as to why education is not listed alongside health and social care.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"FSRH would support use of the alternative title "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation" as above.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities
National Development Team for Inclusion	Specific question response	Specific question response	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?There is evidence of cost benefits associated with people with severe learning disabilities being employed through good (evidence based approaches) See Beyer and Robinson (2009) plus we have some costed case studies from Kent and soon, others will be available from Wolverhampton. There is evidence about the costs associated with providing short breaks in universal settings and the less expensive options but this is quite old. (Children's society- Witney scheme). There may well have been something more recently produced associated with the Aiming High for Disabled Children programme.	Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

<b>Stakeholder</b>	<b>Page no.</b>	<b>Line no.</b>	<b>Comments</b>	<b>Developer's response</b>
National Development Team for Inclusion	Specific question response	Specific question response	Which, if any, of the proposed review questions should consider barriers to care? The ones associated with access to health and social care services, plus short breaks, education (health and social care at school & college) and employment (5.2, 6.1, 7.1, 7.2, 7.3)	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate
National Development Team for Inclusion	Specific question response	Specific question response	For which questions would views and experiences of service users be most important to consider? Lived experience of support where health and social care input could have yielded better outcomes (in other words, most aspects of life across Education, Health and Care. It needs to be made very concrete for many children and young people.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate
National Development Team for Inclusion	Specific question response	Specific question response	What in your opinion are the most important and least important of the proposed review questions? Ones related to co-production and personalisation as they are generic.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"NO, it is good that it specifies under 25s but the disabilities and severe complex needs is not acceptable- needs to separate out into severe and complex and relate to people not labels. How about: Integrated health and social care for disabled children and young people under 25: Improving service delivery and coordination in all settings.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Occupational Therapists	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"We would support the alternative title of Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities
Royal College of Psychiatrists	Specific question response	Specific question response	Which, if any, of the proposed review questions should consider barriers to care?We would suggest review question 4.1 should consider barriers to care	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate
Royal College of Psychiatrists	Specific question response	Specific question response	For which questions would views and experiences of service users be most important to consider?We would suggest review questions 1.2, 1.3, 2.1, 3.1, 4.1, 5.1, 7.1, 7.2 and 7.3	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Psychiatrists	Specific question response	Specific question response	What in your opinion are the most important and least important of the proposed review questions? Review question 8.1 is most important. We did not identify any questions that were unimportant	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly
Royal College of Psychiatrists	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?" We believe that the term 'children and young people' should still be present so we would suggest the alternative title: "Children and Young People under age 25 with Disabilities and Severe Complex Needs: integrated health and social care support and service delivery and organisation.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Speech and Language Therapists	Specific question response	Specific question response	<p>Specific Questions: Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Which, if any, of the proposed review questions should consider barriers to care? For which questions would views and experiences of service users be most important to consider? All of them. Children and young people should be being consulted on ways of identifying and choosing intervention, and monitoring of their care and needs. Particularly they should be involved in the planning, including what strategies are effective for them (as an individual), and their priorities for how their care is managed. What in your opinion are the most important and least important of the proposed review questions? 2 Ensuring children and young people are involved in planning, Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?" Yes.</p>	<p>Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated but will still maintain a focus on the views and experiences of service users where appropriate. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	Specific question response	Specific question response	<p>Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Engaging voluntary sector organisations to work with the family to provide mental health support which also integrates services which facilitate relationships between the child and family and the social care, education care services to ensure that everyone works well together to the best interest of that child and family. See working model of The Maypole Project. "facilitating the role of parents and carers" This is almost impossible to answer as each area has equal import, but in order to provide a response: 1 Most important – facilitating the role of parents and carers as they provide the secure base emotionally and physically for the child from diagnosis through to young adulthood. 2 – ensuring children and young people are involved in planning 3 ID assessing monitoring – CHANGING NEEDS of disabled children and young people (more cyp are being kept alive through enhanced treatments, this must be supported and reflected by understanding how this changes their needs, and the impact of a potentially increasing number of cyp affected. 4. managing health and social care needs – re changing and developing as above. 5. accommodation – as having an appropriate roof over one's head is the basis for safety and security and ability to reach full potential. 6. education, social and leisure.</p>	<p>Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"We would support this alternative title but we would also encourage the integration of support, including mental health support, here as services which provide to wellness of mind and body should be an integrated provision as a holistic approach is advocated.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. However, other areas of the scope have been amended to emphasise that both mental and physical health conditions will be of relevance in this guideline
Thomas Pocklington Trust	Specific question response	Specific question response	Which, if any, of the proposed review questions should consider barriers to care?All of them	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. For the updated review questions we will consider 'barriers to and facilitators of care' where appropriate
Thomas Pocklington Trust	Specific question response	Specific question response	For which questions would views and experiences of service users be most important to consider?2 Ensuring children and young people are involved in planning, and know about, their combined health and social care.5 Facilitating the role of families and carers	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	Specific question response	Specific question response	What in your opinion are the most important and least important of the proposed review questions? Most important: 8 Ensuring effective commissioning, integration and joint working between practitioners across health and social care services****Least important (BUT STILL IMPORTANT): Enabling education, social and leisure activities and preparation for employment	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery for the guideline. The review questions have been updated accordingly
Thomas Pocklington Trust	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?" Cannot see any particular advantage to this title and it is very long winded.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
University Hospitals Birmingham NHS Foundation Trust	Specific question response	Specific question response	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Collaborative commissioning for children's continuing care between health and social care and collaborative procurement of service providers could offer overall cost improvement, improved compliance and clinical reassurance of agencies used, streamlined service provision to children and young people, streamlined assessment and review of needs will improve patient and family experience and consequently improved communications develops between health, education and social care professionals.	Thank you for this comment and the examples of cost saving approaches. The suggestions will be considered further during development of the guideline from the perspective of cost effective integration of health, social care and education services
University Hospitals Birmingham NHS Foundation Trust	Specific question response	Specific question response	For which questions would views and experiences of service users be most important to consider? All questions in 'Integrated health and social care support for individual children and young people and their families and carers', questions 8.3 8.4 and 8.5 in 'Service delivery and organisation'	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate
University Hospitals Birmingham NHS Foundation Trust	Specific question response	Specific question response	What in your opinion are the most important and least important of the proposed review questions? All questions are valuable to ensure effective review and should be considered a whole response.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery for the guideline. The review questions have been updated accordingly

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
University Hospitals Birmingham NHS Foundation Trust	Specific question response	Specific question response	Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?" Prefer a title that identifies 'children and young people' but do think inclusion of 0-25 criteria in title adds clarity.	Thank you for this comment. The guideline short title has been changed to disabled children and young people up to 25 with severe complex needs. This emphasises that people aged 25 are included in the guideline population. The phrase children and young people has been retained in the short title because stakeholders felt that it was important to refer to the people and not only their disabilities and needs. The subtitle has also been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities
Department for Education	1	7	Replace integrated health and social care with integrated health, education and social care. All services need to be integrated to make a difference. The Children and Families Act 2014 is a very important piece of legislation and it requires health, care and education services to work together on Education, Health and Care plans (EHC plans). Good liaison early on can prevent crisis and lead to savings in care and residential placements. Helpful to refer to this early on. Similarly Care, Education and Treatment Reviews (CETR). Personal Education Plans, Children in Need assessments and any other plans or assessments for children with disabilities.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	1	15	Add "severe" in front of complex	Thank you for this comment. We were advised to mirror the exact wording of the proposed quality standard title and this is why 'severe' is not specified before the phrase 'complex needs'
British Academy of Childhood Disability	1	18	Many children with complex needs do not meet the threshold for accessing Social Care even though they and their families really need help and support. Rather than 'travelling long distances' to access respite, in many cases they just don't get respite meaning that parents become increasingly exhausted. This can contribute to parental mental health issues as well as long term problems with being physically able to provide care. This issue recurs regularly in my practice; I probably see families in this situation at least once a fortnight (at a conservative estimate).	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). The importance of mental health has been made more prominent in the revised scope
Disabled Children's Partnership	1	18	There needs to be definition at the start of this document on what are complex severe needs, including progressive conditions, children and young people who acquire additional support needs, including defining that complex needs is about the complexity of the need and not the number of disabilities, to make this a person centred definition, including what 'ongoing requirement' is defined as.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Mencap	1	18	This section would benefit from explicitly clarifying disabled children's rights to a Child in Need assessment – an automatic entitlement to an assessment for all disabled children	Thank you for this comment. This part of the scope has been revised considerably and the reference to the right to access health, social care and education services has been deleted as it applies to all children and young people. Relevant legislation is listed in a later section of the scope and the guideline committee will refer to this throughout the guideline development process

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	1	18	We ask that, throughout the scope, NICE specifies that it applies to infants in addition to children and young people. This would help to make the guideline consistent with NG61 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.	Thank you for this comment. It has been agreed that the age range of the guideline population will be 0 to 25 years. This is consistent with the age range for access to an education, health and care plan
Disabled Children's Partnership	1	19	This should reflect that disabled children have greater entitlements to social care than other children and young people as they are defined as 'Children in Need' by the Children Act 1989	Thank you for this comment. This part of the scope has been revised considerably and the reference to the right to access health, social care and education services has been deleted as it applies to all children and young people. Relevant legislation is listed in a later section of the scope and the guideline committee will refer to this throughout the guideline development process
Department for Education	1	21	Add "consistent" after "integrated, inter-agency". Families would like to see consistent provision wherever they live.	Thank you for this comment. The scope now highlights the importance of providing consistency in the delivery of services, regardless of geographical location
Epilepsy Action	1	21	We strongly agree that a joint, integrated, inter-agency approach at the point of delivery of both healthcare and social care is needed, and would welcome seeing more details about how this would work	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice
Cardiff and Vale University Health Board	1	22	This interagency approach should start at the point of referral if possible, combining assessments/ meetings in order to enable joint approach to delivery.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	1	22	This interagency approach should start at the point of referral if possible, combining assessments/ meetings in order to enable joint approach to delivery.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice
Disabled Children's Partnership	1	22	Insert 'Education' before health and social care. Health and social care need to be applied within an educational context, in accordance with the Children and Families Act 2014. It is vital that education is included here in order to integrate services to get the best outcomes for the child or young person	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Newlife	1	22	We ask that education is added to ensure this is truly an "integrated, inter-agency approach"	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
The Maypole Project	1	22	Due attention should be given to mental health issues which are caused or exacerbated by the child's condition	Thank you for this comment. The importance of mental health has been made more prominent in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	1	23	We suggest that this line reads "with advances in medicine and technology"	Thank you for this comment. The suggested change has been made
Bradford District Achievement Partnership	1	24	To add the following: '...severe complex needs are living fulfilling lives which includes accessing education and are surviving to adulthood.' Rationale: To recognise that most children and young people with complex care needs access education which considering the significant amount of time for that child or young person spends within an education setting, makes the school their secondary place of care. During this time, education providers are responsible and accountable 'in loco parentis' and therefore the employers of education staff delivering Royal College of Nursing delegated tasks are the accountable public bodies for the delivery of this care.	Thank you for this comment. The final phrase in this paragraph has been simplified to refer to improving the lives of disabled children and young people and their families and carers. This broad statement encompasses the detail suggested in the comment
Royal College of Speech and Language Therapists	1-2	27-1	Why is communication disorder itself not an item in the list, communication disorders are a disability with their own complex consequences, and should be recognised in their own right here. We strongly acknowledge the inclusion and amendment to read as the following: Survival with physical disability, cognitive impairment, behavioural challenges, communication disorders including social communication difficulties, learning disability or sensory impairment.	Thank you for this comment. This sentence has been simplified to refer to living with disability in combination with a mental or physical health condition, which may lead to increasingly severe, complex and changing needs. The importance of communication disorders is emphasised elsewhere in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	1	26	Suggest replacing sentence beginning 'survival with', with "Living with, and often a combination of, physical disabilities, cognitive impairments, behavioural and social communication disorders, learning disabilities and or sensory impairments, in combination with a health condition may lead to increasingly severe and complex ongoing needs".	Thank you for this comment. The phrase 'survival with' has been replaced by 'living with' as suggested. The remainder of the sentence has been simplified to refer to living with disability in combination with a mental or physical health condition, which may lead to increasingly severe, complex and changing needs
Newlife	1	27	We welcome the inclusion and recognition of "behavioural and social communication disorders"	Thank you for this comment in support of the guideline
Together for Short Lives	1	27	We ask that this list includes life-limiting and life-threatening conditions.	Thank you for this comment. This sentence has been simplified to refer to living with disability in combination with a mental or physical health condition, which may lead to increasingly severe, complex and changing needs. The importance of degenerative conditions and end of life considerations is emphasised elsewhere in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	2	8-30	<p>We suggest including the following in the list of challenges: lack of appropriate training and awareness of complex needs in order to make the right decisions about education, health and social care of children and young people with complex needs. roles and responsibilities of professionals in different settings, such as health care professionals in educational settings only carrying out their specific roles, and not supporting the needs of the whole child, leading to multiple staffing to support one child or young person. Services operating in isolation are not supporting the child or young person and their family as a whole. accessing Education Health and Care Plans to ensure that all three needs are assessed, recorded, met and regularly assessed according to guidelines. Additionally those without an Education, Health and Care Plan are often not able to access combined and integrated personalised support across education, health and social care. there is often insufficient consideration of the educational/ social care implications for planned long-term medical interventions, for example, operations that remove the child or young person with severe and complex needs from education for an extended period. issues with integrating staff from services within settings such as the family home and educational facilities. a postcode lottery of services, with some local authorities not providing certain support, including blanket bans on equipment. issues with a 'drop off' of support when the young person is transitioning from child services to adult services. a postcode lottery of services, with some local authorities not providing certain support, including blanket bans on equipment.</p>	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services; providing training and development opportunities for professionals involved in delivering integrated health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools); managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services; and providing transparency and consistency in arrangements for transition between children's and adults' services</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	2	8-30	This seems a bit of an odd list of challenges, some challenges listed are very broad / strategic – e.g. lack of local service provision, and some much more specific and individual – e.g. problems coordinating appointments. Not sure what value this adds to the scope because of this. To be useful it would be helpful for this list to be longer and more comprehensive. It's not clear how these challenges have been identified.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges; it is not possible to provide a comprehensive list in terms of very specific challenges

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	2	8-30	Given that a significant proportion of children and young people with severe complex needs have those needs as a result of having a rare or undiagnosed genetic condition, it would be appropriate for the section on challenges faced in the care of disabled children and young people to acknowledge some of the challenges experienced as a consequence of having a rare or undiagnosed genetic condition, for example that many professionals lack understanding of how specific rare conditions impact those affected, or the unpredictability and lack of prognosis that comes with being undiagnosed. We would also welcome a more overt statement in this section about how children and young people are falling through the cracks in the system. Many undiagnosed children and young people that we support are being told that they do not meet the very specific criteria for support from health services, despite having substantial health needs that social care is unwilling or unable to provide for. An additional challenge we feel should not be omitted from this list is the difficulties many families face accessing training and/or trained staff for support at home.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as genetic conditions) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools). The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Psychiatrists	2	11-30	Another suggestion for an example of a significant challenge faced by children and young people with severe complex needs includes 'development of mental health disorders such as anxiety and depression due both as their direct experience of their own needs, as well as a response to how carers and the environment responds to their needs'.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as mental health conditions) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to considering the relevance of mental health conditions and/or challenging behaviour, including aspects that affect communication with the child or young person

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Psychiatrists	2	11-30	Another suggestion for an example of a significant challenge faced by children and young people with severe complex needs includes 'development of behaviours that challenge as a result of communication frustration or other emotional responses to their needs'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as mental health conditions) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to considering the relevance of mental health conditions and/or challenging behaviour, including aspects that affect communication with the child or young person

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	2	11-30	We ask that this list includes an inability to access short breaks for respite because their local NHS clinical commissioning group and their local authority:do not jointly commission themdisagree with each other about which of them is responsible for commissioning them; and/or do not recognise the need to commission specialist short breaks which meet disabled children's complex health needs and which are different to short breaks needed by those with less complex needs.We ask that it also includes an inability to choose how and where they receive care because (i) there is a limited range of care settings to choose from within their local area and/or (ii) they are not given the opportunity to discuss their preferences and record them in a plan.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: ensuring the voice of the child or young person is heard, and that they are able to influence how and where their care is provided; and planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services, communication between services, and avoiding the need to travel long distances to access care and services, including residential services, education and short breaks (respite care)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	2	24-29	The challenge of changing health needs is not one only found in neuromuscular conditions requiring ventilator support, so it is odd that this bullet specifically focusses on that group. Children and young people with rare or undiagnosed genetic conditions often have fluctuating and unpredictable health needs which can present challenges to health and social care services.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as genetic conditions) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering changing, evolving and emerging needs and their impact on the integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	2	20-23	Only mentions the impact on the child and young person, the prolonged periods in hospital can have a detrimental impact on the family carers, resulting in potentially having to give up work or have reduced hours, and preventing them from having any recreation or dedicated time with any other siblings and friends.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	2	17-19	This is two issues in one, some parents are over-protective and so do not enable their children to access some community resources (although this may be because the resources are not appropriate for complex needs). Childrens voices may not be heard because, outside of education, partner agencies do not always have the technology/skills set to communicate effectively with those with limited verbal communication or those that rely on body language to communicate.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	2	17-19	This is two issues in one, some parents are over-protective and so do not enable their children to access some community resources (although this may be because the resources are not appropriate for complex needs). Children's voices may not be heard because, outside of education, partner agencies do not always have the technology/skills set to communicate effectively with those with limited verbal communication or those that rely on body language to communicate.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	2	5-7	This should say explicitly that the young person must always be involved in decisions about their care, and children and young people must always have information in a format that they can access with communication support where appropriate. This should also include involving parent-carers (and reflect the Mental Capacity (Amendment) Bill once that has been enacted).	Thank you for this comment. The reference to lack of mental capacity no longer appears in the introduction to the scope. The revised list of challenges in the next section of the scope (under the heading Current practice) refers to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	2	17-19	We consider it wrong single out carers as a potential barrier to children and young people's voices being heard. In most cases carers will have a key role in enabling the child or young person's views and wishes to be heard; and there will be other barriers that should be overcome, such information not being provided in a format that they can access independently or appropriate communication support not being provided.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	2	17-19	Is carers being over-protective really the most important issue to pick out in respect of children and young people's voices not being heard? It would seem that there are perhaps greater barriers to this occurring which may be more useful to list as examples	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	2	17-19	This bullet appears to suggest that overprotective carers are the primary barrier to children and young people's voices being heard, whereas we know from many of the families we support that a key issue is that arrangements are not being made to appropriately support the involvement of young service users in their own care.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	2	17-19	Children and young people's voices may also not be heard because the professionals (doctors, therapists, etc.) do not create opportunities to ask and/or listen to their views, or adapt how they ask if the child/young person has communication disorders. Sometimes the team around a child with dual sensory needs can mother the child/young person and have low expectations for them. This results in not only the children and young people's voices not being heard, but also the voice of the family. Being over protective of children/young people can lead to very low expectations and low feelings of self worth, as the children are waiting/expect for things to be done for them. This makes them stand out from their friends even more, as well as stopping them from accessing broader and richer life/school experiences which gives them better chances for the future.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes references to: ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and overcoming barriers related to attitudes to service provision among professionals, and setting expectations that support involvement and independence of the child or young person

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	2	17-19	To add the following: 'It is important that health services, social care services and education providers work together to meet these needs.'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. The previous reference to over-protective parents has been deleted and instead this section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	2	12-13	Additional bullet point: 'Schools admit pupils with complex health care needs. Commonly, this is reliant on education staff delivering a range of recognised nursing tasks without national guidance for education providers on the governance framework.'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services, and communication between services; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	2	17-18	These should be two separate points. Children and young people's voices are often not heard as nobody asks them their views. A separate point is that children often do not have access to the same experiences as other children, due to a lack of reasonable adjustments or the attitudes of those supporting them. It sounds a bit judgemental to say carers are "overly" protective.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and making reasonable adjustments to support and promote access to and integration of health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	2	11-12	Move this 1st bullet to 4th bullet as primarily a health and social care guidance and this item is too high. Tone it down as most children with SEND do attend mainstream schools and LAs provide additional high need funding to cover the cost of needs that a school cannot meet from its normal SEND resources. Perhaps "Some schools were unable to provide school places as they did not feel they could meet children and young people's needs. Some admit children but do not have a sufficiently good accessibility strategy and/ or fail to make sufficient reasonable adjustments to support children's needs and inclusion. Schools do not always appreciate that needs change during the course of children and young people's development in the education system "	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to: ensuring access to education services, overcoming barriers to offering school places and activities, and considering the impact of part-time attendance patterns due to health and care needs. Moreover, this reference to education services has been moved down the list of challenges as suggested

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	2	9-10	We suggest that additional challenges should include: interface with mental health services and reasonable adjustments to enable children with specific conditions including LD and/or autism to access CAMHS; and:Multi agency support for children with behaviour that challenges in order to support them to stay within the community and not escalate to higher tier provision	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as mental health conditions) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: making reasonable adjustments to support and promote access to and integration of health, social care and education services; and considering the relevance of mental health conditions and/or challenging behaviour, including aspects that affect communication with the child or young person

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	2	11-12	Seems fairly contentious way to phrase this and also ambiguous – if there are generally issues about reasonable adjustments to enable children to take up a place at a school, couldn't it be phrased in this way? Need also to consider related but different challenges about multi agency support for children on part-time time tables	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: making reasonable adjustments to support and promote access to and integration of health, social care and education services; and ensuring access to education services, overcoming barriers to offering school places and activities, and considering the impact of part-time attendance patterns due to health and care needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	2	24-25	It seems odd to pick out specific issues around respiratory failure and not mention other well-known areas of struggle e.g. managing behaviour that challenges, sleep, more broadly support around multi agency response to children with complex health needs; not sure these points need to be so specific?	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as challenging behaviour) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	2	13-14	This bullet should also recognise that lack of local service provision is meaning that many children and young people are having to go without much needed support.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services, communication between services, and avoiding the need to travel long distances to access care and services, including residential services, education and short breaks (respite care)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	2	11-12	There is a need to tackle the issue of schools not wanting to enrol children and young people who have additional needs. The Norrie Disease Foundation regularly speaks with families who have visited schools which clearly did not want the child/young person to enrol. Reasons for this include where the school is obviously concentrating on academic targets, and had little experience of pupils with Health & Education Care Plans. Often these children/young people end up in schools which are unable to meet their needs, resulting in the child/young person having to move schools, which is very damaging for the child/young person and stressful for the family unit. This results in them travelling very long distances to school which is expensive for the local authority, and makes it difficult for the child/young person to have local (or any) friends.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that Norrie disease is a condition to which the principles of integrated care should apply. Education is referenced throughout the revised scope
Norrie Disease Foundation	2	13-14	Children and young people with Norrie disease have dual sensory needs; however their families are not recognised in terms of needing respite. They spend time and energy applying for respite from charities which are under resourced. This puts an enormous strain on the family unit, causing family break ups and stress and anxiety for the siblings. Parents worry about the long term prospects for their children with Norrie disease, and need much greater help in navigating the social service system. For example, the majority of Norrie families don't know how to access the social services system, or what they are entitled to. The Norrie Disease Foundation also gets contacted regularly by individuals with Norrie, and from their parent/carers, who cannot get social service help,	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that Norrie disease is a condition to which the principles of integrated care should apply

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			despite being blind and deaf themselves or caring for someone who is, and are unable to work.	
Disabled Children's Partnership	2	1	Change 'impairment' to 'impairments' as people might have more than one impairment.	Thank you for this comment. The word impairment no longer appears in this text but the later references (under equalities considerations) have been revised to state the plural as suggested
The Maypole Project	2	3	Ongoing needs ... Including mental health needs.	Thank you for this comment. This sentence has been simplified to refer to living with disability in combination with a mental or physical health condition, which may lead to increasingly severe, complex and changing needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	2	3	We ask that NICE specifies that this could include infants, children and young people who have degenerative conditions, who are likely to lose skills and will need to be regularly reassessed.	Thank you for this comment. This sentence has been simplified to refer to living with disability in combination with a mental or physical health condition, which may lead to increasingly severe, complex and changing needs. The importance of degenerative conditions and end of life considerations is emphasised elsewhere in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Department for Education	2	4	Add after "work together to meet these" " in a consistent way wherever people live."	Thank you for this comment. The preceding paragraph has been revised to emphasise the importance of consistency in the delivery of care and services, regardless of geographical location

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	2	6	We welcome proposals to involve the young person in decisions made on their behalf. We also however suggest that the young person's family are included in this process especially where the young person lacks mental capacity.	Thank you for this comment. The reference to lack of mental capacity no longer appears in the introduction to the scope. The revised list of challenges in the next section of the scope (under the heading Current practice) refers to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used
Paediatric Continence Forum	2	6	We agree that the young person should be involved as far as possible in decisions made on their behalf. However good practice is that parents/carers who have known the young person well throughout early life should also be consulted and their views considered in decision making. Richard Handley's untimely death from complications of constipation shows what can happen if families are excluded (Public Health England 2016 'Making reasonable adjustments for people with learning disabilities in the management of constipation')	Thank you for this comment. The reference to lack of mental capacity no longer appears in the introduction to the scope. The revised list of challenges in the next section of the scope (under the heading Current practice) refers to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Mencap	2	7	It will be important to be aware of the changes to the Deprivation of Liberty Safeguards (DoLS) system – the new Liberty Protection Safeguards (LPS) system will, subject to Parliamentary approval, now apply to 16 and 17 year olds and may be relevant when it comes to a health/social care placement that gives rise to a deprivation of their liberty and where the individual lacks capacity	Thank you for this comment. While we appreciate the relevance to this guideline of legislation and policy documents that are in the process of being developed or updated, it is not feasible to list all of these in the scope and so the suggested change has not been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Allergy UK	2	10	Allergic disease is not mentioned in this document or specific section. Supporting information to evidence the need for allergy to be included in this document: Allergic disease accounts for the most prevalent chronic childhood disease in Europe children and young people bear the burden of this epidemic. (Allergic disease is an umbrella term that encompasses asthma, eczema, hay fever, food allergy are other types of allergy including drug allergy). A diagnosis of food allergy has a considerable impact on a child and the everyday life of their whole family. Allergic reactions are often mild, but they can sometimes be very serious and on rare occasions can result in death. Allergies commonly start in childhood and are lifelong conditions with no cure. The younger a child is when the first allergic condition appears is more likely to develop other allergic conditions (Pawankar 2012) accessed online 28/01/2019 <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3488929/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3488929/</a> Multiple and complex allergies are becoming more common. Unfortunately whilst rates of other allergic conditions have stabilised the prevalence of food allergy	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that allergic disease is a condition to which the principles of integrated care should apply

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			has increased with estimates of between 5-8% of children in the UK have a food allergy.	

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Mencap	2	10	Under these examples there should be reference to increased demand on safeguarding services which has reduced resource and provision for preventative and support services which disabled children access most – clearly this has implications for meeting needs before they escalate	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need while giving due consideration to potential safeguarding issues

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Speech and Language Therapists	2	10	We would strongly encourage the inclusion of an additional point, in the list of challenges faced in the care of disabled children and young people. This is around the difficulties in gaining the child and young person's perspectives on their care, and challenges in obtaining their preference due to communication challenges. For example:Difficulties in ensuring the C&YP has been provided with and has an understanding of information about their healthcare, and challenges in eliciting their own views and preference about their care.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	2	11	If schools do not provide access to places they may not provide a suitable alternative acceptable to the young person either, resulting in severely curtailed participation.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Department for Education	2	11	Insert a new bullet into the list of current practice. Lack of transparency and consistency in entitlement, especially for support provided to cover the transition from children's services to adult social care and health services.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to providing transparency and consistency in arrangements for transition between children's and adults' services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	2	11	In addition to schools not allowing access to places, for children with epilepsy there are problems with access to rescue medication. We are aware of instances of schools being reluctant to take responsibility for administering this medication	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities (such as epilepsy) highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes references to: providing training and development opportunities for professionals involved in delivering integrated health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools); and ensuring access to education services and overcoming barriers to offering school places and activities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	2	11	Children are excluded from school both because schools don't think they can meet their needs and also because schools cannot manage some of the behavioural issues that are part of a complex needs condition.**** <a href="https://www.theguardian.com/education/2018/oct/23/send-special-educational-needs-children-excluded-from-schools">https://www.theguardian.com/education/2018/oct/23/send-special-educational-needs-children-excluded-from-schools</a>	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
The Maypole Project	2	12	Schools allowing access to places without due understanding or resources to fit the child's needs in place.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Thomas Pocklington Trust	2	13	Particularly serious problem in very rural areas.	Thank you for this comment in support of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	2	14	In reality, travelling long distances is most often required to access appropriate education/residential services & not so often for respite care. However there is a lack of appropriate respite provision (day services & overnight) for those with complex physical or behaviour needs	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services, communication between services, and avoiding the need to travel long distances to access care and services, including residential services, education and short breaks (respite care)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	2	14	In reality, travelling long distances is most often required to access appropriate education/residential services & not so often for respite care. However there is a lack of appropriate respite provision (day services & overnight) for those with complex physical health or behaviour needs	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical locations, including joint commissioning and coordination of services, communication between services, and avoiding the need to travel long distances to access care and services, including residential services, education and short breaks (respite care)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	2	15	Discrimination based on lack of appropriate provision – such as limited stock of accessible houses	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	2	15	Discrimination based on lack of appropriate provision – such as limited stock of accessible council houses	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Speech and Language Therapists	2	15	Add 'employment' as an example	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities. The section of the scope that lists key areas that will be covered by the guideline refers to enabling education, social and leisure activities and preparation for employment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	2	15	Also in accessing benefits	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities
Allergy UK	2	16	Allergy may lead to themes of discrimination in daily life examples of these pertinent to the allergic child or young person include exclusion from: Educational opportunities for example a school tripAn activity involving exposure to an allergen e.g. a craft/art sessionA Child with a food allergy unable whose dietary needs are not able to be accommodated for in the educational setting. This type of social exclusion can lead to psycho-social stress and difficulties in coping. DunnGalvin et al (2015) accessed	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that allergic disease is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			<p>online 28/01/2019  <a href="https://www.karger.com/Article/Abstract/375106">https://www.karger.com/Article/Abstract/375106</a></p>	
The Maypole Project	2	16	Additional of physical activities	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	2	17	Children and young peoples' voices may equally not be heard because professionals do not create opportunities to listen to their views or understand how they communicate.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	2	17	We are aware and concerned of children and young people's voices not being heard, and this is a particular issue for people with epilepsy. We would welcome measures to ensure that children and young people with epilepsy are able to have the same experiences as other children or young people	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	2	17	Voices also not being heard because of lack of suitable training, time and equipment (tactile, audio, signing, braille etc) for the child to express themselves and be understood	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	2	17	Children and young peoples voices are often not heard because of communication difficulties – supporting children and young people to communicate in any way that they can should be included	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	2	19	Children and young people's voices not being heard because, for example, the system focuses on the voices of their adult parents/carers	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to ensuring the voice of the child or young person is heard, that they are able to influence how and where their care is provided, are involved in their care, and that communication focuses on the child or young person, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests) and is adapted appropriately in terms of skills and technology used; and providing training and development opportunities for professionals involved in delivering integrated health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	2	20	Children and young people are often sent home from school to recover from a seizure, rather than being provided with a safe space in the school to recover from the seizure, and return to lessons when they are able. Sending children home instead leads them to losing valuable learning time at school, and repeated absences lead to poorer outcomes (social and educational).	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	2	21	It should also be recognised that setting up home parenteral nutrition can be a very slow process while financing is organised, resulting in unnecessarily long stay in hospital	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	2	22	"often without education or recreation": All children and young people who require lengthy stays in hospital should be provided with education, preferably by the hospital school or their own schools. It should also be noted that some children may require home schooling because of the complexity of their health needs	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services
Newlife	2	23	We welcome the recognition of the importance of equipment in the safe discharge of children from hospital.	Thank you for this comment in support of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	2	23	Add: safe discharge requires ... adequate services and support to be available in their community	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	2	24	The comment about 'neuromuscular' could be amended as this issue is not limited to those young people but any child/young person who require respiratory support/ventilation needs and/or changes to their physical condition.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	2	24	The comment about 'neuromuscular' could be amended as this issue is not limited to those young people but anyone with ventilation needs and/or changes to their physical condition.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	2	28	We ask that education is included here to mirror the difficulties families face in securing funding for their EHC Plans across the settings.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Cardiff and Vale University Health Board	2	29	Education are a partner agency which can cause delay – i.e. training school staff to manage ventilation needsAlso Continuing Care guidance in Wales (2012) suggests that provision of services should not be delayed whilst funding discussions take place	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Cardiff Council	2	29	Education are a partner agency which can cause delay – ie training school staff to manage ventilation needsAlso Continuing Care guidance in Wales suggests that provision of services should not be delayed whilst funding agreements discussion take place	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Allergy UK	2	30	Supporting evidence of time away from Health/Social care settings specific to children who have allergic conditions: Children's with different manifestations of allergic disease will be referred for specialist care from a wide range of Health Professionals for example (Allergy specialists, Dermatologists, Dietitian's and Specialist Nurses and have a need to attend both planned and unplanned Health appointments. If a child's allergic condition is not well controlled or their condition flares then a visit to their GP or A&E Department presentation may be warranted.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that allergic disease is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services
Norrie Disease Foundation	2	30	Parents/carers need much more help coordinating the numerous health appointments - this is a contributing factor towards mental health issues in the family unit. Children/young people with Norrie disease have appointments with numerous different clinics, e.g. visual impairment, audiology, autism, etc., often at hospitals a considerable distance from home. If appointments for different clinics at the same hospital could be arranged for the same day (or even as joint clinics) that would help enormously both in terms of time away from home/ school/ work/ alternative childcare for siblings as well as the financial cost of travelling to the clinics.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that Norrie disease is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	2	30	, without appropriate support	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need (while giving due consideration to potential safeguarding issues), including supporting parents and carers in coordinating multiple health, social care and education appointments

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	2	30	Additional point: social care agencies being ill-equipped and trained to demonstrate an understanding of the severe stress and mental anguish caused to families ....	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need (while giving due consideration to potential safeguarding issues), including supporting parents and carers in coordinating multiple health, social care and education appointments

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	2	30	Additional point: Social care agencies at times failing to differentiate their language and terminology between identifying family/parental stress factors which need to be alleviated and safeguarding issues.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need (while giving due consideration to potential safeguarding issues), including supporting parents and carers in coordinating multiple health, social care and education appointments

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Thomas Pocklington Trust	2	30	Parents/carers not only coordinating health and social care appointments but also frequent educational appointments.****Also the term parent/carer rather than parent covers the large number of people who adopt/foster children/young people with complex needs.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering the impact on families and carers, and the training and support they might need (while giving due consideration to potential safeguarding issues), including supporting parents and carers in coordinating multiple health, social care and education appointments

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	2	30	Additional comment – lack of suitable adapted accommodations (private and social housing developments) to meet physical and sensory complex needs significantly delays discharge from hospitals and often means families having to move away from their local communities	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities. The reference to accommodation is broad enough to include consideration of physical and sensory complex needs. The section of the scope that lists key areas that will be covered by the guideline refers to ensuring suitability and accessibility of accommodation

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	2	30	Additional comment - limited resources in terms of community paediatric palliative care consultants significantly affects daily management of complex children and young people and their families and can affect facilitation by community nursing teams and palliative care teams to offer support during end of life in the home	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to meeting the needs of children and young people with life-limiting conditions, including provision of palliative and end of life care
Disabled Children's Partnership	3	16-29	Additional relevant policy/guidance – NHS England Accessible Information Standard- Working Together to Safeguard Children (2018) – Department for Education- Supporting pupils at school with medical conditions (2015) – Department for Education- Care and Support for Deafblind Children and Adults Policy Guidance (2014) – Department of Health- Short Breaks for Carers of Disabled Children (2011) – Department for Education- Safeguarding the Welfare of Disabled Children (2010) – Department for Children, Schools and Families	Thank you for this comment. Supporting pupils at school with medical conditions 2015 and Working together to safeguard children 2018 are now included in the list of legislation and statutory guidance. The Department for Education guidance on short breaks for carers of disabled children and the Department of Health policy guidance on care and support for deafblind children and adults are now included in the list of national guidance. However, it is not feasible to provide an exhaustive list of guidance relevant to this guideline. Legislation, statutory guidance and other national policy and guidance documents mentioned by multiple stakeholders have been prioritised for inclusion in the lists

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	3	17-29	Update list of references several DH documents are older than January 2018 when the Department became DHSC, these should be referred to as Department of Health documents. Line 17 should read "Good intentions, Good enough (2017) Dame Christine Lenehan Council for Disabled Children commissioned by Department for Education" Line 18 should read "These are our children (2017) Dame Christine Lenehan Council for Disabled Children commissioned by Department of Health"	Thank you for this comment. The suggested changes have been made
Together for Short Lives	3	17-29	We ask that the following are added to this list: Children Act 1989 Chronically Sick and Disabled Persons Act 1970 NHS Long Term Plan (2019) NHS England Universal Personalised Care (2019) NHS England Short breaks for carers of disabled children (2011) Department for Education.	Thank you for this comment. The Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 are now included in the list of legislation and statutory guidance. The NHS long term plan and the Department for Education guidance on short breaks for carers of disabled children are now included in the list of national guidance. However, it is not feasible to provide an exhaustive list of guidance relevant to this guideline. Legislation, statutory guidance and other national policy and guidance documents mentioned by multiple stakeholders have been prioritised for inclusion in the lists
Disabled Children's Partnership	3	11-15	Other legislation that should be included here: The Chronically Sick and Disabled Persons Act 1970; Children Act 1989; and Breaks for Carers of Disabled Children Regulations 2011. It would also be helpful to include relevant case law such as the Nascot Lawn judgment last year <a href="https://www.bailii.org/ew/cases/EWHC/Admin/2018/267.html">https://www.bailii.org/ew/cases/EWHC/Admin/2018/267.html</a>	Thank you for this comment. The suggested changes in the list of legislation have been made. It is not feasible to refer to all relevant case law and so this suggestion related to case law has not been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	3	1-5	The Norrie Disease Foundation strongly supports this. However, many families within the Norrie community find that there are no links between health and social care, meaning they can't access social care and that they don't know who their 'inter-agencies' are.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that Norrie disease is a condition to which the principles of integrated care should apply. The guideline recommendations will identify how this should work in practice
Department for Education	3	19-20	May be useful to mention Chapter 3 of the SEND Code: "Chapter 3 on Working Together is especially helpful"	Thank you for this comment. While we appreciate the particular relevance to this guideline of chapter 3 of the Special educational needs and disability code of practice in explaining the duties of local authorities and partner commissioning bodies for developing joint arrangements for commissioning services to improve outcomes for children and young people with special educational needs or disabilities (including those with an education, health and care plan), it is not feasible to highlight the most pertinent parts of all the legislation and guidance in the guideline scope and so the suggested change has not been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	3	1	health, social care and education	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
The Maypole Project	3	1	Providing APPROPRIATE, improved ...	Thank you for this comment. The phrasing has been revised to state that delivering integrated health, social care and education services for disabled children and young people with severe complex needs, tailored to the needs of the individual child or young person, involving them in decisions about their health and social care and education, and incorporating support for their families and carers, will improve the lives of the children and young people and their families and carers. It is implicit that integrated care should be appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	3	2	We suggest changing to: 'with severe and complex needs, ensuring that children and young people and their families and carers are at the heart of decision making, and providing support for...'	Thank you for this comment. The phrasing has been revised to state that delivering integrated health, social care and education services for disabled children and young people with severe complex needs, tailored to the needs of the individual child or young person, involving them in decisions about their health and social care and education, and incorporating support for their families and carers, will improve the lives of the children and young people and their families and carers
British Academy of Childhood Disability	3	1+2	Strongly support	Thank you for this comment in support of the guideline
<a href="#">London North West Healthcare NHS Trust</a>	3	3	Carers... during transition...	Thank you for this comment. The phrasing has been revised to state that delivering integrated health, social care and education services for disabled children and young people with severe complex needs, tailored to the needs of the individual child or young person, involving them in decisions about their health and social care and education, and incorporating support for their families and carers, will improve the lives of the children and young people and their families and carers. The importance of transition from children's to adults' services has been emphasised elsewhere in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning,

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
				integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
The Maypole Project	3	3	Providing support, including awareness of mental health issues which may face families and carers ...	Thank you for this comment. The phrasing has been revised to state that delivering integrated health, social care and education services for disabled children and young people with severe complex needs, tailored to the needs of the individual child or young person, involving them in decisions about their health and social care and education, and incorporating support for their families and carers, will improve the lives of the children and young people and their families and carers. The relevance of mental health and behavioural conditions has been emphasised elsewhere in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	3	3	Inclusion of quality of experience of end of life care should be considered here	Thank you for this comment. The phrasing has been revised to state that delivering integrated health, social care and education services for disabled children and young people with severe complex needs, tailored to the needs of the individual child or young person, involving them in decisions about their health and social care and education, and incorporating support for their families and carers, will improve the lives of the children and young people and their families and carers. The preceding list of challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes a reference to meeting the needs of children and young people with life-limiting conditions, including provision of palliative and end of life care
Cardiff and Vale University Health Board	3	5	This will also allow suitable access to community resources & enable the young person to feel part of their local community.	Thank you for this comment. The final phrase in this paragraph has been simplified to refer to improving the lives of disabled children and young people and their families and carers. This broad statement encompasses the detail suggested in the comment
Cardiff Council	3	5	This will also allow suitable access to community resources & enable the young person to feel part of their local community.	Thank you for this comment. The final phrase in this paragraph has been simplified to refer to improving the lives of disabled children and young people and their families and carers. This broad statement encompasses the detail suggested in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	3	6	The Chronically Sick and Disabled Persons Act 1970 is missing here.	Thank you for this comment. The Chronically Sick and Disabled Persons Act 1970 is now included in the list of legislation and statutory guidance
Norrie Disease Foundation	3	8	How will you tell whether 'what works' for families is really reaching them and working for them? How will the families be asked whether they are seeing an improvement in their services? How will 'what works' be evaluated? What happens if something isn't working for the family - who should they approach to rectify?	Thank you for this comment. NICE guidelines are based on the best available evidence which will include evidence drawn from published research studies and be supplemented by the experience and expertise of the multidisciplinary guideline committee. The committee will include a parent or carer with personal experience in the context of access to health, social care and education services for disabled children and young people with severe complex needs. The NICE guideline development process also incorporates methodology for assessing the quality of the available evidence as part of the evaluation of what works. Specifically, this guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	3	10	Other relevant legislation to consider including in this list:Chronically Sick and Disabled Persons Act 1970 (Section 2)Children Act 1989 & 2004Relevant Codes of Practice and Guidance Children and Young Persons Act 2008Crime and Disorder Act 1998General Data Protection Act 2018Disabled Persons (Services, Consultation and Representation) Act 1986Education Act 1996Education and Inspections Act 2006Equality Act 2010Health and Social Care Act 2012Legal Aid, Sentencing and Punishment of Offenders Act 2012Local Government and Public Involvement in Health Act 2007Local Government Act 1974Mental Capacity Act 2005National Health Service Act 2006Tribunals, Courts and Enforcement Act 2007United Nations Convention on the Rights of Persons with DisabilitiesUnited Nations Convention on the Rights of the ChildOther relevant regulations to consider including in this list:Breaks for Carers of Disabled Children Regulations 2011Children Act 1989 Representations Procedure Regulations 2006Community Care Services for Carers and Children's Services (irect Payments) Regulations 2009Designated Teacher (Looked after Pupils etc) Regulations 2009Education (Independent School Standards) Regulations 2010Education (Pupil Information) Regulations 2005Other relevant guidance to consider including on list:16 to 19 funding guidance (DfE)Alternative provision guidance (DfE)Mental Capacity Act Code of Practice: Protecting the vulnerable 2005Ordinary Residence Guidance 2013Participation of young people in education, employment and training (DfE guidance)Reasonable adjustments for disabled pupils 2012Social	Thank you for this comment. The Children Act 1989, the Chronically Sick and Disabled Persons Act 1970, Supporting pupils at school with medical conditions 2015, and Working together to safeguard children 2018 are now included in the list of legislation and statutory guidance. The Department for Education guidance on short breaks for carers of disabled children and the Department of Health policy guidance on care and support for deafblind children and adults are now included in the list of national guidance. However, it is not feasible to provide an exhaustive list of guidance relevant to this guideline. Legislation, statutory guidance and other national policy and guidance documents mentioned by multiple stakeholders have been prioritised for inclusion in the lists

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			Care for Deafblind Children and Adults guidance 2009 Supporting pupils at school with medical conditions 2014 Working Together to Safeguard Children 2015 & 2018	

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	3	13	Also the Mental Capacity Amendment Bill (when passed) and the resulting code of practice will include 16-18 year olds (and of course up to 25)	Thank you for this comment. While we appreciate the relevance to this guideline of legislation and policy documents that are in the process of being developed or updated, it is not feasible to list all of these in the scope and so the suggested change has not been made
Department for Education	3	13	Add reference to current Mental Capacity Amendment Bill <a href="https://services.parliament.uk/bills/2017-19/mentalcapacityamendment/documents.html">https://services.parliament.uk/bills/2017-19/mentalcapacityamendment/documents.html</a>	Thank you for this comment. While we appreciate the relevance to this guideline of legislation and policy documents that are in the process of being developed or updated, it is not feasible to list all of these in the scope and so the suggested change has not been made
Cardiff and Vale University Health Board	3	15	Social Services & Wellbeing (Wales) Act 2014 is integral for those in Wales as well as the Additional Learning Need and Education Tribunal (Wales) Act 2018(taking into account page 4 line 18, if this is relevant for Wales ministers are more likely to incorporate it)	Thank you for this comment. Section 2 of the scope includes the standard text stating that NICE guidelines cover health and care in England and that decisions on how NICE guidelines apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. It is not feasible to include all legislation from the other UK countries in the list referred to and so the Welsh legislation mentioned in the comment has not been included

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	3	15	Social Services & Wellbeing (Wales) Act 2014 is integral for those in Wales as well as the Additional Learning Need and Education Tribunal (Wales) Act 2018The Additional Learning Needs and Educational Tribunal (ALNET) Act 2018, which is now law (implementation from Sept2020 to Aug 2023). The ALNET sets out duties for all three statutory agencies, which are consistent with/ complementary to SSWB. The ALN Code, currently under formal consultation, is due to be published in final form before the end of 2019. In contrast, the 2015 document referred to on page 3 has no formal status: Other national policy and guidance relevant to this guideline includes: Special educational needs and disability (SEND) code of practice: 0 to 25 years (2015) Department for Education and Department of Health and Social Care(talking into account page 4 line 18, if this is relevant for Wales ministers are more likely to incorporate it)	Thank you for this comment. Section 2 of the scope includes the standard text stating that NICE guidelines cover health and care in England and that decisions on how NICE guidelines apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. It is not feasible to include all legislation from the other UK countries in the list referred to and so the Welsh legislation mentioned in the comment has not been included
Department for Education	3	15	Add <a href="https://www.gov.uk/government/publications/visiting-children-in-residential-special-schools-and-colleges">https://www.gov.uk/government/publications/visiting-children-in-residential-special-schools-and-colleges</a> (Statutory visits to children with special educational needs and disabilities or health conditions in long-term residential settings) (2017)	Thank you for this comment. The suggested change has been made
Department for Education	3	15	Include Children Act in list of legislation, and 'Working Together to Safeguard Children (2018) in list of guidance	Thank you for this comment. The suggested changes have been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	3	16	Additional guidance to be added to 'National policy and guidance relevant to this guideline includes:'Department of Health, 'Getting it right for children, young people and families', 2012.(Rationale: This guidance sets out the four levels of school nursing services to support children and young people in school including Universal Partnership Plus i.e. complex care needs.)Royal College of Nursing, 'Meeting Health Needs in Education and other Community Settings', 2018.(Rationale: This guidance for nurse registrants covers delegation of nursing tasks to support workers. Support workers are defined as non-health workers and include education, social care or thirds sector support workers. The guidance refers to the delegation of nursing tasks to support workers as 'an integral component of supporting health and social care needs in educational and other community settings'.Department for Education, 'Supporting Pupils at School with Medical Conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England,' 2015. (Rationale: Statutory guidance for Section 100 of the Children and Families Act 2014, places a legal duty on school governing bodies and proprietors to make arrangements for supporting pupils at their school with medical conditions.	Thank you for this comment. Supporting pupils at school with medical conditions 2015 is now included in the list of legislation and statutory guidance. However, it is not feasible to provide an exhaustive list of guidance relevant to this guideline. Legislation, statutory guidance and other national policy and guidance documents mentioned by multiple stakeholders have been prioritised for inclusion in the lists

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	3	16	Other Policy documents to include: The NHS 10 year plan which includes a priority on children with learning disabilities The National service Framework for children, young people and maternity services – standard 8, disabled children and young people and those with complex health needs (DH, 2004) The NSF is old now, so the legislative framework is different, but much of the best practice is worth revisiting as that document is focussed on the same group of children.	Thank you for this comment. The NHS long term plan is now included in the list of national guidance. As the comment mentions, the National Service Framework for children, young people and maternity services relates to an older legislative framework and so this has not been listed
Cardiff and Vale University Health Board	3	17	Welsh Government have incorporated the UN Convention of the Rights of the Child into all new legislation on Wales.	Thank you for this comment. Section 2 of the scope includes the standard text stating that NICE guidelines cover health and care in England and that decisions on how NICE guidelines apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. It is not feasible to include all legislation from the other UK countries in the list referred to and for the same reason the international legislation mentioned in the comment has not been included
Cardiff Council	3	17	Welsh Government have incorporated the UN convention of the rights of the child into all new legislation on Wales.	Thank you for this comment. Section 2 of the scope includes the standard text stating that NICE guidelines cover health and care in England and that decisions on how NICE guidelines apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. It is not feasible to include all legislation from the other UK countries in the list referred to and for the same reason the international legislation mentioned in the comment has not been included

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	3	22	Delete "Aiming High for Disabled Children 2007" - no longer policy	Thank you for this comment. The suggested change has been made
Department for Education	3	30	Add the Mental Health Green paper as a relevant reference as it too encourages collaboration and joint working between health and education <a href="https://www.gov.uk/government/consultations/transforming-children-and-young-peoples-mental-health-provision-a-green-paper">https://www.gov.uk/government/consultations/transforming-children-and-young-peoples-mental-health-provision-a-green-paper</a>	Thank you for this comment. While we appreciate the relevance to this guideline of legislation and policy documents that are in the process of being developed or updated, it is not feasible to list all of these in the scope and so the suggested change has not been made
Royal College of Speech and Language Therapists	4	General	Again, as recommendation in comment 1 to include communication disorders as a separate example: physical disability, cognitive impairment, behavioural challenges, communication disorders including social communication difficulties, learning disability or sensory impairment.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that communication disorders (including behavioural and social communication disorders) are an area to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	4	3-17	We ask that this list includes voluntary sector children's palliative care provider organisations, including children's hospices.	Thank you for this comment. The scope specifies that the guideline is for a wide-ranging audience, including providers of care and support for disabled children and young people with severe complex needs (including third sector and voluntary organisations). This would include voluntary sector children's palliative care provider organisations, such as children's hospices. It is not possible to give an exhaustive list of health professionals for whom the guideline would be relevant, but the importance of end of life considerations has been emphasised elsewhere in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Bradford District Achievement Partnership	4	9-10	Reference to 'practitioners' working with disabled children and young people with severe complex needs is vague. Our interpretation of this point is that this applies to education staff therefore, could this explicitly state 'education staff' rather than 'practitioners'.	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	4	17-18	Additional bullet point: School governing bodies and proprietors. This is because of the legal duty on school governing bodies and proprietors outlined in point 4. The RCN's guidance (Jan 2018) to its registrants explicitly identifies "support workers" employed in schools, to whom qualified nurses will provide training in delegated medical tasks, subject to these staff being suitably employed with liability insurance arrangements in place. The RCN guidance does not suggest any suitable governance structure for this employment, and the DfE's 2015 publication for school governing bodies predates the RCN document and does not have the specificity to respond to the new care requirements.	Thank you for this comment. The scope now specifies that the audience for the guideline includes providers of health, social care and education for disabled children and young people with severe complex needs (including third sector and voluntary organisations). This would include schools and providers of education and also school governing bodies
Action for ME	4	1	We would like the inclusion of teachers and education providers to this list to ensure that those in charge of welfare are aware and the needs of children are met in an education setting.	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers. The revised scope also specifies that the audience for the guideline includes providers of health and social care and education for disabled children and young people with severe complex needs (including third sector and voluntary organisations). This would include schools and providers of education and also school governing bodies

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	4	2	Suggest adding to the listHeadteachers, teachers, SENCOs and education staffMental health/CAMHS practitioners	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers. The health professionals mentioned in the comment are covered elsewhere in this section by the inclusion of health professionals working with disabled children and young people with severe complex needs
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	4	5	Health professionals working with young adults in adult health care services for transition and transfer of care should be included as different services may have different completion of transition age specifications – 18 years/ 19 years/ 21 years/25 years	Thank you for this comment. The scope specifies that the guideline is for a wide-ranging audience, including providers of care and support for disabled children and young people with severe complex needs (including third sector and voluntary organisations). This would include voluntary sector children's palliative care provider organisations, such as children's hospices. It is not possible to give an exhaustive list of health professionals for whom the guideline would be relevant, but the importance of transition arrangements has been emphasised elsewhere in the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	4	9	For clarity, we suggest changing to 'practitioners, teaching and support staff, and educational advisory services working with disabled children and young people with severe complex needs in education services'	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers
Paediatric Continence Forum	4	9	Please clarify "practitioners"; teachers should be specifically mentioned	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers
Department for Education	4	10	Replace "in education services" with "in education settings and services. Professionals such as Educational Psychologists, local authority SEND officials, SENCOs in schools".	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers. The health professionals mentioned in the comment are covered elsewhere in this section by the inclusion of health professionals working with disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	4	11	We should probably also include schools and providers of education – mainstream and special schools; they are key players in integrated support, and can be commissioners of some services (e.g. speech and language therapy).	Thank you for this comment. The scope now specifies that the audience for the guideline includes providers of health and social care and education for disabled children and young people with severe complex needs (including third sector and voluntary organisations). This would include schools and providers of education
Epilepsy Action	4	11	We are concerned that schools and academies, and school nurses and Special Educational Needs Coordinators (SENCOs) have not been mentioned alongside local authorities, given their close interaction with children and young people	Thank you for this comment. The scope now specifies that the audience for the guideline includes teaching and support staff working with disabled children and young people with severe complex needs in education settings and services. This would include special educational needs coordinators (SENCOs) as well as head teachers. The health professionals mentioned in the comment are covered elsewhere in this section by the inclusion of health professionals working with disabled children and young people with severe complex needs. Schools and academies are now covered by providers of health and social care and education for disabled children and young people with severe complex needs (including third sector and voluntary organisations)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	4	17	Would like to see a role for primary care, and this reflected in the bullets on page 4. GPs have a potential role in relation to children's complex needs.	Thank you for this comment. The scope specifies that the guideline is for a wide-ranging audience, including health professionals, and allied health professionals, working with disabled children and young people with severe complex needs. This would include professionals in primary care such as GPs. It is not possible to give an exhaustive list of health professionals for whom the guideline would be relevant. The relevance of the guideline for GPs is reflected in a GP being prioritised for inclusion in the guideline committee as a co-opted member

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Mencap	4	26	<p>These inequalities should include: Mental health inequalities (Ref: NICE guidelines: Mental health problems in people with learning disabilities: prevention, assessment and management) Poverty (Ref: Public Health England. The determinants of health inequities experienced by children with learning disabilities. 2015. Gateway number: 2014725. <a href="https://www.gcad.info/media/294672/determinants_of_child_health_inequalities.pdf">https://www.gcad.info/media/294672/determinants_of_child_health_inequalities.pdf</a>) Family breakdown (<a href="https://www.relate.org.uk/policy-campaigns/publications/under-pressure-relationships-uk-parents-who-have-child-learning-disability">https://www.relate.org.uk/policy-campaigns/publications/under-pressure-relationships-uk-parents-who-have-child-learning-disability</a>) Attainment (<a href="https://www.gov.uk/government/statistics/level-2-and-3-attainment-by-young-people-aged-19-in-2017">https://www.gov.uk/government/statistics/level-2-and-3-attainment-by-young-people-aged-19-in-2017</a>) Physical health (Ref: Public Health England. The determinants of health inequities experienced by children with learning disabilities. 2015. Gateway number: 2014725. <a href="https://www.gcad.info/media/294672/determinants_of_child_health_inequalities.pdf">https://www.gcad.info/media/294672/determinants_of_child_health_inequalities.pdf</a>) Employment (<a href="https://www.mencap.org.uk/sites/default/files/2016-10/2016.126%20Employment%20vision%20statement.pdf">https://www.mencap.org.uk/sites/default/files/2016-10/2016.126%20Employment%20vision%20statement.pdf</a>)</p>	<p>Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that the mental health conditions and disabilities mentioned in the comment are areas to which the principles of integrated care should apply. In addition, the importance of mental health conditions has been emphasised in the revised scope and in the equalities impact assessment</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Psychiatrists	4	26	It is not clear whether cognitive impairment, behavioural and social communication disorders, learning disability and sensory impairment are considered to be Mental Health issues. Patients are regularly disadvantaged when these impairments and disorders are categorised as Learning disability and not addressed separately as possible Mental health disorders such as autism, ADHD, anxiety disorders and or depression. Disabled patients are often discriminated and do not receive Mental Health support in addition to their physical healthcare and social care. In particularly challenging behaviour in patients with disability require collaboration between physical health clinicians, mental health clinicians and social	Thank you for this comment. The scope has been revised to highlight that the disabilities listed as examples may manifest through, or occur in combination with, mental health and behavioural conditions or physical health conditions. Examples of conditions and disorders of relevance when considering principles that should be applied to integrate health, social care and education services for children and young people with severe complex needs have been added, including several mental health and behavioural conditions
Department for Education	4	28	Add a new sentence after "sensory impairment." "It will also look at inequalities in provision between different locations so that people can be clearer on the minimum entitlement wherever they live."	Thank you for this comment. A reference to the importance of consistency in the delivery of care and services, regardless of geographical location, has been added in an earlier section of the revised scope
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	4	29	Protected characteristics should be considered relevant as each has significant impact on severe and complex needs and can be comorbidities	Thank you for this comment. The scope has been revised to highlight that the disabilities listed as examples may manifest through, or occur in combination with, mental health and behavioural conditions or physical health conditions. Examples of conditions and disorders of relevance when considering principles that should be applied to integrate health, social care and education services for children and young people with severe complex needs have been added

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	5	16-23	These definitions seem problematic – what is our definition here of an ongoing requirement for integrated health and social care support and services? Some might interpret this to mean continuing care, but we are not presumably limiting this to continuing care. The document very conspicuously doesn't mention continuing care, which might confuse people.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Genetic Alliance UK	5	17-20	In specifying that the guideline will only cover those with 'an ongoing requirement for integrated health and social care support and services', it will be important for the guideline to clearly state how this requirement should be established. Many children and young people with undiagnosed genetic conditions clearly have health needs, but find themselves unable to meet the very specific criteria for services due to the uncertainties of their condition.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Department of Health	5	25-27	Should this be clarified – that we mean where health and social care services are supporting a child with complex needs in an educational setting, because presumably NICE's remit doesn't extend per se to educational settings?	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	5	1	Consider adding attachment disorder as this presents as complex needs but not as a mental health condition	Thank you for this comment. The scope has been revised to highlight that the disabilities listed as examples may manifest through, or occur in combination with, mental health and behavioural conditions or physical health conditions. Examples of conditions and disorders of relevance when considering principles that should be applied to integrate health, social care and education services for children and young people with severe complex needs have been added, and these include attachment disorder
Cardiff Council	5	1	Consider adding attachment disorder as this presents as complex needs but not as a mental health condition.	Thank you for this comment. The scope has been revised to highlight that the disabilities listed as examples may manifest through, or occur in combination with, mental health and behavioural conditions or physical health conditions. Examples of conditions and disorders of relevance when considering principles that should be applied to integrate health, social care and education services for children and young people with severe complex needs have been added, and these include attachment disorder
Paediatric Continence Forum	5	1	Under "invisible disabilities" continence problems and patients with stomas should be specified	Thank you for this comment. This sentence now references continence problems as an example of a disability or impairment that is not immediately apparent

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Speech and Language Therapists	5	2	We are pleased to see communication highlighted as a protected characteristic here. However we feel it would be more beneficial to rephrase this as a more encompassing characteristic as communication is not just verbal- difficulties with comprehension and need for assistive devices for example need equal consideration. For example: Having a difficulty with communication including understanding, verbal expression and communication differences (e.g. AAC).	Thank you for this comment. The reference here to communication has been deleted as there is a general reference earlier in this section to communication problems and disorders
Mencap	5	5	This list should also include family breakdown and bullying as additional characteristics	Thank you for this comment. The suggested changes have been made
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	5	5	Additional characteristics are relevant here as significantly impact on outcomes for all children and young people; in children with complex needs are likely to be even more difficult to overcome	Thank you for this comment in support of the guideline
Challenging Behaviour Foundation	5	6	Add to the characteristics associated to vulnerability "displaying behaviour described as challenging"	Thank you for this comment. A reference to challenging behaviour has been added earlier in this section

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	5	8	It is not clear whether "not attending school" refers to truancy, or children missing school due to being in hospital, or frequent doctor's appointments. We would welcome clarity about this matter	Thank you for this comment. The phrasing has been revised to clarify that this refers to being unable to attend school rather than truancy

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

British Academy of Childhood Disability	5	19	<p>Definition of Severe complex needs has to be better defined. I think that current wording: 'ongoing requirement for integrated health and social care support and services' is vague and not specific enough for both professionals and families, and is dependent on interpretation as to whether integrated health and social care support and services are deemed to be required. The experience of many paediatricians working in the field, evidenced by surveys of the impact of austerity on services for disabled children, young people and their families [Impact of Austerity Measures on families with Disabled Children: Survey of BACCH and BACD members and Child Development Team leads November 2014 and January 2015 <a href="https://www.bacdis.org.uk/policy/documents/ImpactofAusterityMeasuresonfamilieswithDisabledChildren16Jan2015.pdf">https://www.bacdis.org.uk/policy/documents/ImpactofAusterityMeasuresonfamilieswithDisabledChildren16Jan2015.pdf</a>; Horridge KA et al, Austerity and families with disabled children: A European Survey. Dev Med Child Neurol. 2018; <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/dmcn.13978">https://onlinelibrary.wiley.com/doi/abs/10.1111/dmcn.13978</a>] is that thresholds for accessing particularly social care support for disabled children and young people are increasing in many areas, making it much more difficult for families to get all the needs of their children, young people and themselves adequately met. It would be preferable to define complexity of needs by enumerating the number of needs, for example, using the Disabilities Complexity Scale. [Horridge KA et al. Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale. Dev Med Child Neurol. 2016;58 (6):570-580; Horridge KA et al. Prospective pilots of routine data capture by paediatricians in clinics and validation of the Disabilities Complexity Scale. Dev Med Child Neurol. 2016;58(6):581-588] How will an 'ongoing requirement for social care' be classified? There may be an ongoing requirement for social care that is being met, or an ongoing requirement for social</p>	<p>Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)</p>
---	---	----	--	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support**  
**Consultation on draft scope**  
**Stakeholder comments table**

**08/01/2019 to 05/02/2019**

		care which has not met threshold for Children's Services involvement. Will the scope of the guideline take in this much larger group of children and consider their needs?	
--	--	--	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	5	19	Suggest amending final sentence to read "severe complex needs refer to a lifelong need for support to access ordinary activities". The current definition would include almost all disabled children and we understand that this guidance is intended to apply to those with more complex needs.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Disabled Children's Partnership	5	19	It is not clear who identifies the on-going requirement; we suggest listing the groups who are responsible for identifying integrated health and social care support	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Epilepsy Action	5	20	It is not clear whether "social care support" means that the children or young people would need to have a support worker to qualify	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Epilepsy Action	5	22	We are concerned about the ambiguity around the phrase "severe complex needs". Complex needs is defined as an "illness, disability or sensory impairment and needs a lot of additional support on a daily basis". However, it is not clear what the definition of "severe complex needs" is, and we are concerned that this would preclude some children and young people who would need this support.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	5	23	This should include children and young people with progressive conditions where the child or young person will develop needs that are severe and complex, but this should also discuss changing and fluctuating levels of need or capacity. This point links to P1 L18-22 that a definition of severe complex needs is required at the start of the document. We suggest including 'unless they currently have a diagnosis of a progressive condition that is known to cause complex needs'	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). This could include children and young people with progressive conditions and also those with changing (fluctuating) needs
Action for ME	5	27	We would like this reaffirmed as per comment 2.	Thank you for this comment. The importance of transition arrangements has been emphasised in the revised scope. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Challenging Behaviour Foundation	5	27	We support the inclusion of educational settings, therefore points 2 and 8 above should be taken on board to be consistent.	Thank you for this comment and the examples of cost saving approaches and relevant legislation and policy in earlier comments. We are not sure how these are relevant in specifying the settings to be covered by the guideline but the section of the scope describing settings that will be covered has been revised to state all settings in which health and social care and education are provided for children and young people from birth to 25 years

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	5	27	Helpful to define severe complex needs.	Thank you for this comment. The guideline population is now defined with reference children and young people needing support from all 3 sectors (health, social care and education services)
Epilepsy Action	5	27	It is not clear whether "educational setting" refers to mainstream schools, academies, special educational needs schools or all of the above	Thank you for this comment. The section of the scope describing settings that will be covered has been revised to state all settings in which health and social care and education are provided for children and young people from birth to 25 years

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	6	6-onwards	Add to the list "Diagnosis, early identification and early intervention"	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the overarching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes identifying, assessing and monitoring combined health, social care and education needs, including changing needs, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	6-18	We suggest an additional point 8 in this list, 'Ensuring suitability and accessibility of information and communication with children and young people, in order to facilitate person centred care and support'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes ensuring children and young people are involved in planning, and know about, their combined health and social care and education, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Together for Short Lives	6	7-18	We ask that this list includes initiating conversations with children and families about personal budgets – as personal health budgets, integrated personalised commissioning and/or education, health and care (EHC) plan personal budgets.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes ensuring children and young people are involved in planning, and know about, their combined health and social care and education, which is broad enough to include the suggestions in the comment
Royal College of Occupational Therapists	6	7-17	In response to question 3 on the comments form: Views and experiences of service users would be most important to consider in all the points listed under 3.3.	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. The review questions have been updated accordingly but will still maintain a focus on the views and experiences of service users where appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	6	5-9	Integrated health care and education support etc - mention Education, Health and Care plans (EHC plans) as well as other relevant plans Care Education and Treatment Reviews (CETR) etc.	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services), and so this will guide considerations regarding identification assessment and monitoring of needs
Together for Short Lives	6	25-28	We ask that this list includes 'End of life care for infants, children and young people with life-limiting conditions: planning and management' (2016) NICE guideline NG61.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, however, the suggested addition to this list relates to a NICE guideline covering over-arching principles of care and so the suggested change has been made
Bradford District Achievement Partnership	6	5-6	This section covers integrated health and social care support for individual children and young people and their families and carers. Consideration should be given to including a bullet point about using Education, Health and Care Plans (EHCPs) which is the key driver for integrated delivery of services introduced in the Children and Families Act 2014	Thank you for this comment. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services), and so this will guide considerations regarding identification assessment and monitoring of needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	6	20-21	Effective commissioning, integration and joint working section. In addition to health and social care services this section should include reference to local authorities as commissioners of the education High Needs Local Offer, acknowledging education staff as core delivers of health interventions.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account refers to education services as well as health and social care services. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). This could include considerations related to staffing, for example skills, mix and experience of staff, training requirements of staff, and staffing levels (numbers and staff mix)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	6	17-18	Employment is not always appropriate, so suggest a change of working to "...preparation for employment (where appropriate).There doesn't appear to be much mention in regards to the Social Care Workforce (social care workers and healthcare workers), who may also be involved.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account already includes the specific edit suggested in the comment. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). This could include considerations related to staffing, for example skills, mix and experience of staff, training requirements of staff, and staffing levels (numbers and staff mix)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Genetic Alliance UK	6	22-23	As discussed in some of the above points, we have concerns about how this restriction will work in practice, particularly in cases of some of the families we support who have been told by social care that they have an exclusively health need, but who don't qualify for support from health services.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. Moreover, the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services). As such, the list of areas that will not be covered has been amended to clarify that interventions that do not relate to integration of health, social care and education services will not be covered in this guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	6	10-11	Whilst we support this statement and involving children and young people in decision making, communication disorders, which affect a high proportion of those with Norrie disease, must be considered. Ensuring children and young people are involved in planning and listening to their voices and aspirations, and setting positive expectations, is important. However, the quantification of services e.g. hours of therapy support, number of clinics per year, and outcomes such as expected milestones to be achieved (e.g. improved muscle strength, raising head, finger strength) is also very important so that families have something concrete and, ideally legally binding, to refer to when they don't receive the services that their children are entitled to.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the overarching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes ensuring children and young people are involved in planning, and know about, their combined health and social care and education, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	6	12-13	Often when their children's needs change, families do not know that they should be notifying anyone, and if they should who it should be, or that they are entitled to receiving different or increased levels of support. Families also need better information provided so that they can be aware of probable changes or implications to their health and condition.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the overarching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes: identifying, assessing and monitoring combined health, social care and education needs, including changing needs; ensuring children and young people are involved in planning, and know about, their combined health and social care and education; and facilitating the role of families and carers. Together these are broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	6	20-21	Norrie families tell us that they experience very little or no integration between health and social care because having a dual sensory loss plus other conditions associated with Norrie means they don't qualify for social care. Families also really struggle between the lack of communication between schools, health and social care, and find themselves continually updating all the parties involved which is exhausting and frustrating for families who are already time and emotionally stressed.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that Norrie disease is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services
Disabled Children's Partnership	6	6	Include the age young person covers up to	Thank you for this comment. It has been agreed that the age range of the guideline population will be 0 to 25 years. This is consistent with the age range for access to an education, health and care plan
Paediatric Continence Forum	6	8	"of disabled children" should be expanded to acknowledge the needs of children and young people with continence as a hidden disability. For instance their need to use toilets for "disabled" because of the need for suitable disposal facilities for stoma bags, disposable catheters and continence pads, which is a particular problem for boys and young men. Also their need for Changing Places as they may require a hoist and changing bench.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	6	10	Needs to take into account additional communication needs, and there needs to be a qualifying statement, to cover those children and young people who are not able, because of the complexity of their needs, to meaningfully contribute to service planning. For these children and young people, the views of their families and other carers who know them best must be taken into account.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes: identifying, assessing and monitoring combined health, social care and education needs, including changing needs; ensuring children and young people are involved in planning, and know about, their combined health and social care and education; and facilitating the role of families and carers. Together these are broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	6	10	Add: Planning & review, not just planning	Thank you for this comment. The suggested change has been made
Cardiff Council	6	10	Add: Planning & review, not just planning	Thank you for this comment. The suggested change has been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	6	10	Young people should be engaged in planning their own care needs whatever their capacity, but this must be done by someone skilled in working with children who do not have capacity or who use alternative methods of communication	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes: identifying, assessing and monitoring combined health, social care and education needs, including changing needs; ensuring children and young people are involved in planning, and know about, their combined health and social care and education; and facilitating the role of families and carers. Together these are broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	11	Change to 'their combined health, social care, and educational support'	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	6	12	This needs to acknowledge the realities of rising thresholds and budget constraints and provide guidance on minimal, reasonable, support required whatever the constraints	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). This could include considerations related to resource constraints (including capacity, queues and waiting lists)
Department for Education	6	12	Yes, this is helpful, good to pick up that needs change and there needs to be continuous review.	Thank you for this comment in support of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	12	Change to 'managing health, social care, and educational needs in an integrated way, including changing and evolving need'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes meeting health, social care and education needs, including changing and evolving needs, which is broad enough to include the suggestions in the comment considering the entire context for the guideline is integration of services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	6	14	Change 'Promoting and maintaining independence and wellbeing' to 'Promoting and maintaining independence, wellbeing and quality of life.'Also needs to take into account those children and young people whose complexity of needs prevent them from being meaningfully involved in planning their own health or social care. In addition the needs of children and young people who will not ever be able to gain independence or achieve employment must be recognised.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes promoting and maintaining independence and wellbeing, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	6	14	Quality of life and raising expectations of what their children can achieve with the right support is also important.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes promoting and maintaining independence and wellbeing, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff Council	6	15	Facilitating the role of families and carers", as the family are normally the ones who are there 24 hours a day, 365 days a year. I would suggest "Support the role of families and carers".	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes facilitating the role of families and carers, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	15	Include 'including preparation and support for when families and carers are no longer able to support the child or young person'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes facilitating the role of families and carers alongside many other factors which together are broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	6	15	"Facilitating the role of families and carers.". ADD especially where the young person's involvement may be limited by the nature of their needs, and in this situation the role of families and carers should continue to be facilitated after the young person's 16 <sup>th</sup> birthday	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes facilitating the role of families and carers alongside many other factors which together are broad enough to include the suggestions in the comment
Challenging Behaviour Foundation	6	16	This suggest the guidance should also apply to housing leads in LAs and DFG assessors as health and social care will not have control of decisions about accommodation	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. As such, it is aimed at professionals, commissioners and providers of such services, rather than wider authorities

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	6	16	We ask that this line reads "ensuring the assessment, suitability and accessibility of accommodation and equipment".	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes ensuring suitability and accessibility of accommodation, which is broad enough to include the suggestions in the comment since ensuring an assessment would be a prerequisite for ensuring suitability and accessibility

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	6	17	Also needs to take into account those children and young people whose complexity of needs prevent them for employment.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes enabling education, social and leisure activities and preparation for employment. The phrasing with regard to employment was suggested by other stakeholders as being broad enough to encompass considerations as to whether employment will be feasible

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	6	17	after "for" add "a meaningful adult life, including employment". Not everyone will find employment, but everyone can have a meaningful life.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the overarching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes enabling education, social and leisure activities and preparation for employment. The phrasing with regard to employment was suggested by other stakeholders as being broad enough to encompass considerations as to whether employment will be feasible

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	6	17	Transition should be specified – and I would recommend that we allude to the Preparing for Adulthood outcomes for SEND, as relevant to any young person with complex needs.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account now includes planning and managing transition from children's to adults' services in accordance with the suggestions in the comment. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	6	17	Enabling education, social and leisure activities and preparation for employment is a priority for Epilepsy Action and people with epilepsy and we welcome this proposal	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	6	17	We ask that included in here is being aspirational with disabled children and supporting them to be the best that they can be.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account includes promoting and maintaining independence and wellbeing, which is broad enough to include the suggestions in the comment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	18	Include additionally 'or future adult social care services, including transition across to these'	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account now includes planning and managing transition from children's to adults' services in accordance with the suggestions in the comment. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
British Academy of Childhood Disability	6	20	Change 'Ensuring <u>effective</u> commissioning, integration and joint working between 20 practitioners across health and social care services' to 'Ensuring <u>effective/joint</u> commissioning, integration and joint working between 20 practitioners across health and social care services.	Thank you for this comment. The suggested change has been made

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line_no.	Comments	Developer's response
Challenging Behaviour Foundation	6	20	The Children and Families Act requires joint commissioning across education, health and care. It would be good to x-ref and be consistent here.	Thank you for this comment. The suggested change has been made
Disabled Children's Partnership	6	21	Again, this should include education: we suggest changing to 'practitioners across health, social care, and educational services'	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	6	23	Interventions that relate exclusively to healthcare, insert ' <i>social care, or education</i> '	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. As such, the list of areas that will not be covered has been amended to clarify that interventions that do not relate to the integration of health and social care and education will not be covered in this guideline. Other NICE guidelines provide recommendations for specific aspects of, for example, health or social care, and these recommendations will not be reiterated in this guideline because the focus will be on approaches for ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	6	23	Not sure what this means – that we're not interested in health services, or that we're not interested in health services which are not integrated with other forms of support like social care. I presume it means that the delivery of health services, their provision etc. is not a focus, as covered elsewhere, but it's a bit abrupt as it stands, and probably needs a bit of explanation.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. As such, the list of areas that will not be covered has been amended to clarify that interventions that do not relate to the integration of health and social care and education will not be covered in this guideline. Other NICE guidelines provide recommendations for specific aspects of, for example, health or social care, and these recommendations will not be reiterated in this guideline because the focus will be on approaches for ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	6	23	As health care interventions usually always have a social care impact too, we would welcome clarification on what this sentence means	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health and social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. As such, the list of areas that will not be covered has been amended to clarify that interventions that do not relate to integration of health and social care and education will not be covered in this guideline. Other NICE guidelines provide recommendations for specific aspects of, for example, health or social care, and these recommendations will not be reiterated in this guideline because the focus will be on approaches for ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
SeeAbility	6	23	Although the scope says that it will not cover areas that “relate exclusively to healthcare”, at the workshop this was brought up as an issue and it was felt it was unclear what was meant by a combination of ‘health and social care interventions’ – as it often these are funded in very different ways, sometimes in their entirety by health, sometimes in their entirety by social care, although the aim is to provide integrated support. In some cases health and social care needs are being picked up by education by virtue of the intervention being placed in the ‘Education’ section of an EHCP – again an issue raised at the scoping workshop. We feel it would be helpful to have a better definition in the scope, or examples, of the types of intervention covered by this guideline.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health and social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. As such, the list of areas that will not be covered has been amended to clarify that interventions that do not relate to the integration of health and social care and education will not be covered in this guideline. Other NICE guidelines provide recommendations for specific aspects of, for example, health or social care, and these recommendations will not be reiterated in this guideline because the focus will be on approaches for ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	6	27	The transition from children's to adult's services is vitally important and we welcome this guidance being included	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health and social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account now includes planning and managing transition from children's to adults' services. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Cardiff and Vale University Health Board	6	17 & 18	Employment is not always appropriate, so suggest a change of working to "...preparation for employment (where appropriate).	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. We will not be able to formulate recommendations specific to particular health conditions or disabilities, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. Moreover, the previous list of areas under the heading integrated health and social care support for individual children and young people and their families and carers has been incorporated into the over-arching area relating to service delivery and organisation as factors to be taken into account, rather than defining specific areas (or review questions) themselves. The list of factors to be taken into account already includes the specific edit suggested in the comment. The guideline will be developed using the approaches described in appendix A of the NICE guidelines manual (service delivery – developing review questions, evidence reviews and synthesis). This could include considerations related to staffing, for example skills, mix and experience of staff, training requirements of staff, and staffing levels (numbers and staff mix)
Mencap	7	27	Mencap believes there is a real need for a robust cost-benefit analysis of early intervention for children with complex needs as, currently, no such evidence exists	Thank you for this comment. We have noted the lack of published economic evidence in this area and will highlight this to the economists working on the guideline and at NICE

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	7	28	Will this section also look at identifying the need for Education/Health/Social Care to work alongside each other to ensure effective economic delivery? We suggest including 'Effective economic delivery also relies on identifying the need for education, health, and social care to be properly integrated'	Thank you for this comment. All NICE guidelines have a strong economics component. The guideline committee and economist working on the guideline will decide which review questions to prioritise for economic analysis. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery. Therefore looking at effective economic delivery will be an important part of this guideline
Challenging Behaviour Foundation	8	13	This section includes lots of questions which ask "which interventions are effective and acceptable..?" and refer to "joint health and social care needs". Needs are needs – they are only defined as "health" or "social care" needs by the various systems in place – often when they are trying to pass the budgetary buck from one service to another. Eg "is that a health bath you need or a social care bath?" A better way to approach this list of questions would be to ask "What are the best approaches to enable health and social care to work together to deliver good outcomes in (add list, including, early identification, assessment, consultation of children and families and provision)	Thank you for this comment. We included health and social care in the questions to make it clear that we are covering both of these aspects. When answering the questions we will not look at health or social care in isolation but try to look at care holistically. Please also note that following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery
Challenging Behaviour Foundation	8	13	This also asks which interventions are "acceptable". To help answer that it may also be worth looking at the evidence around what interventions are "not acceptable". There will be more evidence of the harm caused by unacceptable interventions – there is less research around what works and best practice.	Thank you for this comment. For each review question we will be looking at specific outcomes relevant to that question, these could include both positive and negative outcomes (benefits and harms)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Challenging Behaviour Foundation	8	13	There will be a range of interventions, depending on a child's needs. If the guidance does not want to get into specific interventions, it would make more sense to focus on HOW to work together to deliver person-centred approaches to support.	Thank you for this comment. Although we will still be looking at interventions, please note that following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery (that is, how services across the health, social care and education sectors should work together)
Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit	8	15	This section concerns "Identifying, assessing and monitoring combined health and social care needs, including changing needs, of disabled children and young people with severe complex needs." Sexual health needs of this group of young people can be overlooked, misunderstood or neglected; assessment should explicitly include sexual health needs, which change and evolve over time. Assessment needs to include discussion regarding confidentiality and respect the fact that young people may not wish to discuss sexual health and relationships with (or in the presence of) parents/ carers.	Thank you for this comment and for drawing attention to this specific issue which has been noted. The draft review questions are fairly general but when we carry out these reviews our protocols will contain more details on what the guideline committee via consensus thinks needs to be covered by each review
Mencap	8	15	It will be important for this section to include reference to how health and social care (and education) agencies can work together to help identifying someone's cognitive needs in the early years as well as their health needs	Thank you for this comment. Following the scope consultation various changes have been made to the scope to emphasise a focus on service delivery (that is how the health, social care and education sectors should work together). Thank you for highlighting the importance of identifying cognitive needs in the early years. There is a review question on identifying needs which we think would encompass this

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	8	15	The term "severe complex" is not used in any other context. It might be useful to be more specific about the children we are including. Section 1 attempts a definition but this could include a very wide range of children who would not necessarily have severe and complex needs. Is the group specifically those who are the most at risk of being placed in restrictive environments – the "Transforming Care" group?	Thank you for this comment. Due to the complexity of the population attempting a definition has its challenges. However, making the definition too narrow runs the risk of excluding children and young people who may benefit from the guideline. Therefore a pragmatic approach has been taken and the guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Paediatric Continence Forum	8	16	"...changing needs, of disabled children... with severe complex needs". See comments 5 and 6 above. Those with continence as a hidden disability also need <i>integrated health and social support</i> yet might not be included under the <i>severe complex needs</i> heading.	Thank you for this comment. The scope has been updated and continence problems have been included as an example of a disability or impairment that is not immediately apparent
<a href="#">London North West Healthcare NHS Trust</a>	8	17	.. across transition from children's to adult services..... and the specific interventions that need to take place	Thank you for this comment. By including transition from children's to adults' services within the first review question, the question risks becoming too complex. We will include a question on the transition from children's to adults' services and the impact of interventions designed to improve this. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	8	18	I am not sure about use of the word 'intervention' in the following context: 'What interventions are effective and acceptable in early identification of combined health and social care needs'. It would be more precise to use 'approach' or 'methodology'. Identifying, assessing and monitoring combined health and social care needs can be done quite easily in a thorough community paediatric assessment; finding services prepared to meet the holistic needs is much more difficult. Combined Social Care/ Paediatric/ Education meetings e.g. Team around the Child/ Child in Need etc are also highly effective once appropriate services are involved.	Thank you for this comment. We agree that using the word 'approaches' would be more suitable so we have reflected this in the review questions
Epilepsy Action	8	18	Early identification and intervention is vitally important and can make a huge difference to people with epilepsy. Quickly and effectively establishing a person's combined health and social care needs should be prioritised	Thank you for this comment. We will have a review question focused on finding the most effective approaches to identifying, assessing and monitoring combined health, social care and education needs, including changing needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Faculty of Dental Surgery	8	18	Children with disabilities have been found to have significantly higher oral health needs compared with the wider population. Refs: Ivancić Jokić N, Majstorović M, Bakarčić D, Katalinić A, Szivoczka L. Dental caries in disabled children. Coll Antropol. 2007;31:321-4. O'Leary I, Kinirons M, Stewart C, Graham F, Hartnett C. Levels of oral disease in a sample of children with disability; a study carried out prior to comprehensive dental treatment under general anaesthesia. Eur Arch Paediatr Dent. 2007;8:150-2. Dental caries is currently the most common single diagnosis leading to hospital care in 5-9 year old children in England (NHS HES data 2017-18). Ensuring children with disability have early access to oral health assessment and appropriate preventive dental care is an essential component of integrated care. Access to appropriate preventive oral health advice can have a significant impact. For example, using an appropriate fluoride containing toothpaste can reduce dental caries by 27-36% (Fluoride toothpastes of different concentrations for preventing dental caries in children and adolescents Information. Cochrane Database: DOI:10.1002/14651858.CD007868.pub2). Once appropriately instructed, such advice can be delivered by various health and care professionals, including dental health professional, health visitors and even school teachers.	Thank you for this comment. We understand the increased importance of oral health need in this population compared to the wider population, however this issue is too specific to be included in the scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Action for ME	8	18-20	<a href="#">We would like the word “fluctuating” inserted into this section. A consensus document produced by the International Alliance for M.E. and backed by researchers and charities around the world, agree that M.E. is a ‘serious, chronic and fluctuating illness’. Because of the fluctuating nature of this condition, needs can change frequently and urgently.</a>	Thank you for this comment. The revised scope refers to changing conditions, which includes fluctuating conditions
Royal College of Paediatrics and Child Health (with BACD input)	8	18-24	The word ‘intervention’ in the following context may perhaps be inaccurate: ‘What interventions are effective and acceptable in early identification of combined health and social care needs’. It would be more precise to use ‘approach’ or ‘methodology’. Identifying, assessing and monitoring combined health and social care needs can be done quite easily in a thorough community paediatric assessment; finding services prepared to meet the holistic needs is much more difficult. Combined Social Care/ Paediatric/Education meetings e.g. Team around the Child/Child in Need etc are also highly effective once appropriate services are involved.	Thank you for this comment. We agree that using the word approaches would be more suitable so we have reflected this in the review questions
British Academy of Childhood Disability	8	21	I am not sure about use of the word ‘intervention’ in the following context: ‘What interventions are effective and acceptable in assessing combined health and social care needs’. It would be more precise to use ‘approach’ or ‘methodology’.	Thank you for this comment. We agree that using the word approaches would be more suitable so we have reflected this in the review questions

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	8	21	New q: What strategies allow agencies to work together to consider and address any risks facing a child inside and outside the home?	Thank you for this comment. We have included a review question to reflect this, on assessing which service delivery models offer best outcomes including independence and wellbeing
Epilepsy Action	8	21	Epilepsy is a variable condition, impacting differently at different times of the day, week or month and thought needs to be given to how this and other such variable conditions are assessed	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. The scope also emphasises that changing (fluctuating) conditions will be of relevance in this guideline
National Development Team for Inclusion	8	21	The whole point of early intervention should be to minimise crisis intervention later on and keep children in ordinary settings and to avoid segregated provision being made. It is important that identification and assessment do not lead to labelling which puts the child at risk of being placed in a cycle of restrictive environments. Early intervention needs to lead to support but not dependency.	Thank you for this comment. We agree that early intervention is vital to ensure inclusion of disabled children and young people with severe complex needs. We will have a review question focused on finding the most effective approaches to identifying, assessing and monitoring combined health, social care and education needs, including changing needs
British Academy of Childhood Disability	8	24	I am not sure about use of the word 'intervention' in the following context: 'What interventions are effective and acceptable in monitoring combined health and social care needs'. It would be more precise to use 'approach' or 'methodology'.	Thank you for this comment. We agree that using the word approaches would be more suitable so we have reflected this in the review questions

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	8	24	It is unclear whether technological interventions could be considered as a way of monitoring need. There are a number of technological devices for people with epilepsy, such as seizure alarms, which we believe should be included	Thank you for this comment. The precise details of the review questions will be clarified through preparation of review protocols. We will make the guideline committee aware of the suggestions in your comment when they are discussing review protocols
National Development Team for Inclusion	8	24	Interventions need to be related to outcomes arrived at following person-centred planning meetings. It is not acceptable to have blanket provision based on crude labelling but tailored to the aspirations, desires and needs of individuals in their ordinary environments. Person-centred planning enables children, young people and their families to determine the right support for them in partnership with the relevant professionals. Person-centred planning also promotes holistic assessment and monitoring as the plan is constructed around questions that need a collective response and holistic responsibility for delivery support. See these websites for more information: <a href="https://www.thinklocalactpersonal.org.uk">https://www.thinklocalactpersonal.org.uk</a> / <a href="https://www.england.nhs.uk/personalisedcare/what-is-personalised-care/">https://www.england.nhs.uk/personalisedcare/what-is-personalised-care/</a> <a href="http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/">http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/</a>	Thank you for this comment. We have ensured the review questions focus on person-centred outcomes. For example, we have a review question about supporting the involvement of children and young people in planning and reviewing their health, social care and education needs; and promoting and maintaining independence and wellbeing further emphasises the importance of person-centred planning and involvement in planning
Royal College of Physicians	8	24-25	What interventions are effective and acceptable in monitoring combined health and social care needs, including changing needs, of disabled children and young people with severe complex needs? We would like to see a line acknowledging the need for forward planning in the event of life threatening illness.	Thank you for this comment. We agree life-threatening illness should be acknowledged therefore we have included a specific question related to planning and managing palliative and end of life care for children and young people with life-limiting conditions. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
				between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Disabled Children's Partnership	8	26	Insert 1.4 "What interventions are effective in assessing the sensory and communication support needs of the child or young person with severe complex needs"	Thank you for this comment. The review question on assessment and monitoring has been redrafted - it now covers general health, social care and education needs. When planning the evidence review the guideline committee will prioritise which needs to focus on - this may include sensory and communication needs
Disabled Children's Partnership	8	26	Insert "1.5 What interventions are effective in addressing behaviour that can challenge and positive behaviour support"	Thank you for this comment. The review questions have been redrafted and rather than focusing on specific interventions they now address the overall organisation of health, social care and education services. The issue of challenging behaviour is covered (for people with learning disabilities) in NICE guideline NG93

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Faculty of Dental Surgery	8	27	Where appropriate oral health services are available and accessed, children with disability report positive experiences of their oral health and the services they accessed. Ref: G Yesudian, M Hall, J Owens, H D Rodd and Z Marshman. The oral health experiences of children with learning disabilities in special schools in Sheffield. Journal of Disability and Oral Health (2012) 13/2 45-50 It is therefore important that these children are able to access appropriately commissioned and provided oral health services, which may be either through a family dentist (GDS) or Specialist Paediatric Dentistry services within either the Community Dental Services (CDS) or Hospital Dental Services, depending on the child's needs. Where specialised oral health care is needed, transition from Paediatric Dental Care to Adult Special Care Dental Services needs to be appropriately managed (Commissioning Standards for Paediatric Dentistry, NHS England 2018)	Thank you for this comment. We understand the increased importance of oral health need in this population compared to the wider population, however this issue is too specific to be included in the scope of this guideline
Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit	8	27	This section concerns "Ensuring children and young people are involved in planning, and know about, their combined health and social care." Young people and their families/carers need to know where and how to access information about their sexual health, to include issues surrounding consent, contraception, management of problems such as heavy, painful menstrual bleeding and sexually transmitted infection.	Thank you for this comment. The importance of considering sexual health for disabled children and young people with severe complex needs has been emphasised earlier in the revised scope. The exact details to be covered in each review question will be clarified by the guideline committee through the preparation of review protocols and the suggestions in your comment will be raised with the committee when review protocols are being discussed

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	8	28	Change to 'their combined health, social care, and educational needs'	Thank you for this comment. We have changed this to reflect your suggestion by including educational needs, and also reflected this through the other review questions
Department for Education	8	29	New q: What communication strategies are effective for ensuring continuity of sharing information across health, social care, education and other services, where a child resides in an out of area placement?	Thank you for this comment. The review questions have been redrafted and the issue of strategies for joined up working across services is now covered in several questions
Disabled Children's Partnership	8	29	Change to 'including communication and access to information, are effective'	Thank you for this comment. The review question on participation in enabling education, social and leisure activities and preparation for employment has been redrafted (there are now separate questions for education and social/leisure activities as compared to preparation for employment). When planning the evidence review the guideline committee will prioritise which strategies to focus on - this may include communication needs and access to information
National Development Team for Inclusion	8	29	<a href="https://www.preparingforadulthood.org.uk/">All of the legislation covering disabled children and young people expects co-production and the voice of children and young people and yet evidence would suggest that progress in this area is slow and inconsistent across the country, thus leading to inequity. The Preparing for Adulthood website has many examples of co-production</a> <a href="https://www.preparingforadulthood.org.uk/">https://www.preparingforadulthood.org.uk/</a>	Thank you for this comment. The review question on participation in enabling education, social and leisure activities and preparation for employment has been redrafted (there are now separate questions for education and social/leisure activities as compared to preparation for employment). When planning the evidence review the guideline committee will prioritise which strategies to focus on - this may include co-production initiatives

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	8	29	As above, person-centred planning is essential if children, young people and their families are going to have their voices heard. There are a range of person-centred tools and approaches that support the communication of children and young people with complex communication barriers including those who do not use words: communication passport, decision-making agreement, vocational profile, inclusion web, peer support, technology (e.g. personal wiki) and advocacy.	Thank you for this comment and providing the list of person-centred tools and approaches. We will keep these in mind during development of the guideline
Royal College of Speech and Language Therapists	8	29	We are pleased to see communication highlighted here. We would like to make a note that these strategies will be highly variable and dependent on an individual therefore we would encourage the scope and forthcoming guideline to address this more in depth. Speech and Language Therapists should be consulted on such strategies, for each child or young person.	Thank you for this comment and support for this review question. We will keep your suggestions in mind during the development of the guideline. We have advertised for a speech and language therapist to join the guideline committee so we will have specialist input in this area
Department for Education	8	30	New q: What features of practice ensure that safeguarding risks are identified by specialist and non-specialist disabled children practitioners, particularly where a child has communication difficulties?	Thank you for this comment. The review questions have been redrafted with a focus on service delivery and joined-up working. When planning the evidence review the guideline committee will agree the most useful outcomes. Safeguarding is a potential outcome that could be used to evaluate the relative effectiveness of service models and strategies

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	8-9	15-301-8	1 and 1.1 - 3.1 should each say health, social care and education needs - all three need to be integrated. Children spend a good amount of their time at school or in alternative education so it is essential to work with educators when assessing and meeting children's health and care needs as well as their educational needs.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Challenging Behaviour Foundation	8-10	15	See comments 12-17 above which also apply to this section	Thank you for this comment which has been addressed through reference to the other comments cited
Department for Education	9	1	New q: What features of practice, and models of delivery, allow multi-agency safeguarding partners to promote the safety and stability of children and young people with disabilities and severe complex needs?	Thank you for this comment. The review questions have been redrafted with a focus on service delivery and joined-up working. When planning the evidence review the guideline committee will agree the most useful outcomes. Safeguarding is a potential outcome that could be used to evaluate the relative effectiveness of service models and strategies
Together for Short Lives	9	3	We ask that the list includes a new question: 2.2 What strategies are effective in initiating conversations with children and families about personal budgets – as personal health budgets, integrated personalised commissioning and/or education, health and care (EHC) plan personal budgets?	Thank you for this comment. The review question about supporting families and carers has been redrafted. When planning the evidence review the guideline committee will prioritise which issues to focus on - this may include personal budgets

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">London North West Healthcare NHS Trust</a>	9	4	Across transition developmental milestones (at 16years old and 18 years old) in which service provision and legislation overlaps between childhood and adulthood.	Thank you for this comment. We will include a question on joined up working as part of the transition from children's to adults' services and the impact of interventions and approaches designed to improve this. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
National Development Team for Inclusion	9	5	All interventions need to be based on holistic planning which starts with a person-centred conversation leading to high quality planning. A typical person-centred conversation explores the following:What do people like and admire about you?Who are the important people in your life?What is important to you now and in the future?What is important for you now and in the future?What is working well in your life now?And not so well?What support do you need?From who and how will it be provided?This conversation needs to be supported by a confident and trained facilitator who can enable participants to freely express their views and feelings. The central purpose of this type of planning is to focus on the individual rather than on stereotypical ideas about interventions related to labels. In our experience, children and young people and their families do not form a homogenous group but have individual life stories and needs. The idea is to develop holistic outcomes which all professionals can support and which inform the commissioning of services.	Thank you for this comment and providing the detailed description about person-centred conversations to help place focus on the individual. We will keep these in mind during the development of the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	9	5	These children and young people will almost certainly be receiving high needs education funding and any health and social care interventions must be jointly planned across all agencies. The Children and Families act 2014 requires integrated working, holistic person-centred planning, joint commissioning of provision, all with a focus on life outcomes not service inputs. The Education, Health and Care plan provides the perfect opportunity to have an overarching high quality plan which informs all work with the individual young person.	Thank you for this comment. We acknowledge that educational needs should be considered equally alongside health and social care needs. As a result, we have reflected this element throughout the revised scope
Department for Education	9	8	New question: How should health, care and education services work together to plan for and subsequently support transitions into and between settings and from child to adult services and from family to independent living? Or break these key transitions into separate research questions.	Thank you for this comment. There is already a NICE guideline on transition from children's to adults' services, therefore this scope will not focus specifically on this aspect. However, we acknowledge the importance of planning and managing transition and have included a review question on interventions and approaches to ensure joined up working in this area. However, this guideline will not duplicate or replace existing guidelines but will focus specifically on the context of ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services for disabled children and young people with severe complex needs
Challenging Behaviour Foundation	9	9	Add 4.2 "Ensuring an evidence-based and consistent approach to supporting children who display behaviours described as challenging and reducing restrictive interventions."	Thank you for this comment. The review questions have been redrafted following consideration of all the stakeholder comments. The importance of challenging behaviour is now emphasised in the scope and the guideline committee will decide whether to prioritise this for specific consideration in any of the review questions

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	9	9	An essential part of "...promoting independence.." is the availability of adequate PUBLIC toilet and changing facilities (including Changing Places for those who require hoists and changing benches), with appropriate waste disposal (for stoma bags, pads etc) otherwise even children and young people with continence problems as a hidden disability will be severely restricted in public areas that they can access with confidence	Thank you for this comment and highlighting the importance of adequate public toilet and changing facilities to give children and young people with incontinence problems access. However, public toilets are outside the scope of this guideline which is limited to settings in which health, social care and education is provided
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	9	9	To give consideration of role of continuing care framework for supporting and enabling independence and well being and how collaborative working and funding between health and social care could improve outcomes for children and young people	Thank you for this comment and for making us aware of this framework. We will review the evidence to determine the most effective service models to deliver joined-up health, social care and education services for this population and this will address this issue

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	9	10	As in our comment above, the provision of equipment and assistive technologies should be a priority for people with epilepsy	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health and social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services
National Development Team for Inclusion	9	10	The most important intervention to promote independence for children and young people with severe complex disabilities is to be included in their communities, including mainstream schooling. Being immersed in an inclusive environment is the best way for a disabled child to develop independence in terms of generational norms. Developing circles of friends supports the individual and provides strong role models of behaviour and communication. All interventions, including assistive technology and equipment should enable this inclusion and independence and should seek to remove barriers to ordinary life	Thank you for this comment. Promoting and maintaining independence has been identified as a key area in the scope and will be examined during the guideline development. Inclusion, participation, wellbeing and independence have also been added as potential outcomes, and the guideline committee will consider these and decide on which specific outcomes to include for each review question. A review question has been added to examine the evidence and determine the best approaches for health, social care and education services to promote inclusion, independence and wellbeing

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	9	10	There are issues in obtaining equipment for school via OT's e.g. toileting equipment and then getting similar equipment for home which comes under a separate budget - often resulting in delays in the ability to commence a timely and co-ordinated programme both at home and at school	Thank you for this comment. A review question has been included on ensuring the suitability and accessibility of the environment in which disabled children and young people with severe complex needs receive health, social care and education, which will address the issue of equipment. Issues around budgeting will be taken into consideration when deciding upon the economic priority topics in the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

SeeAbility	9	10-13	<p><a href="#"><u>We would like to see the guideline feature the case for special schools sight testing, provision of glasses and embedding of vision in EHCPs and an understanding of a child’s visual needs in the classroom as an example of where children’s independence and wellbeing can be maintained. SeeAbility has been undertaking this work in special schools. We and a number of researchers and clinicians have reported on providing specialist sight tests and glasses in special schools to children with profound and complex needs, including those with cerebral palsy, severe autism and global developmental delay. 4 in 5 children with the most severe learning disabilities attend special schools. Over the past five years the SeeAbility project has enabled us to provide nearly 2500 sight tests, for over 1200 children and dispense nearly 1000 pairs of glasses. We have also helped train 637 teachers, teaching assistants and support staff, presented or exhibited at 20 conferences for paediatricians, QTVIs, optometrists and provided new resources on how children see, and we have published a new mini guide with the National Association on Special Educational Needs (nasen) which provides practical resources on how to make sure children make the most of their vision. We have found that half of the children have a problem with their vision, a third need glasses, and yet</u></a></p>	<p>Thank you for this comment. We are aware that sight testing in special schools is an important service for this population. Although this will not be covered specifically in this guideline, the evidence will be reviewed during development to determine which service delivery arrangements are most effective in meeting health, social care and education needs, including changing and evolving needs</p>
------------	---	-------	--	---

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

[only 7% had any history of going to a community optician for an NHS sight test \(despite all children having the right to an annual NHS sight test\). 44% had no history of eye care at all. The rest of the children we see have some history of eye care, but it is through hospital eye clinics, due to the lack of accessible community schemes. In our research \(and that of others in special schools\) we estimate a quarter to a third of children have such poor vision they would be classed as visually impaired by the World Health Organisation. It is estimated that around 80% of our learning is through vision and during formative childhood years vision continues to develop. If children are not accessing eye care then it stands to reason that their education, wellbeing and ability to socialise and play may be affected if they cannot make the most of their potential vision. Their behaviour might be deemed 'challenging' when in fact it may be frustration at not being able to see properly. We have examples of children who just needed a high spectacle prescription and whose 'unengaged' behaviour had been put down to autism; children whose parents had been told their child would never get on with glasses, who now totally benefit from them; children whose only way to communicate is through eye gaze but had never had a sight test to check if they could see the technology;](#)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

[children whose behaviour has totally changed because their visual status is now known. In rarer cases the ability to easily access sight tests in school has led to sight threatening conditions being identified and referred for treatment, saving a child's sight. The importance of testing runs from the early years, when visual pathways are developing, to teenage years. Recently we have worked with the Royal College of Ophthalmologists, British and Irish Orthoptic Society and College of Optometrists, amongst others, to set out a clinical framework of the recommended vision testing protocols for children in special schools. This can be found here with the full range of suggested tests and how to embed the results in a child's education, health and care plan and with teaching staff. The framework is research based and evidence/clinically led, and has recently been endorsed by Public Health England as an alternative to child vision screening which should be available in special schools \[www.rcophth.ac.uk/2016/07/seeability-provides-framework-for-provision-of-eye-care-in-special-schools-in-england/\]\(http://www.rcophth.ac.uk/2016/07/seeability-provides-framework-for-provision-of-eye-care-in-special-schools-in-england/\) .The proposal is now part of the NHS Long Term Plan and NHS England is preparing plans to commission this at a national level \(as it is responsible for primary eye care\).We believe special schools sight testing is a good example of an](#)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support**  
**Consultation on draft scope**  
**Stakeholder comments table**

**08/01/2019 to 05/02/2019**

	<p><a href="#"><u>intervention that exists to promote and maintain independence and wellbeing in children, for the reasons given above. As a mixed methods approach is taken by NICE to evidence, there is both qualitative and published evidence that this is welcomed by children and young people and their families. We hope that this intervention could be included in the guideline.</u></a></p>	
--	--	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	9	15-18	Ensuring that the whole team around the child is informed about the child/young person's condition, progress made, wishes, etc/ is vital. Often Norrie families spend a good portion of a clinic with a new professional teaching them about the condition and answering the same questions previous professionals have asked. It would be helpful for parent/carers to have a designated lead who they can contact if they have any questions (e.g. by email).	Thank you for this comment. We have amended the guideline to focus on service delivery and have included two additional review questions which will look at the most effective models to deliver joined-up health, social care and education services, and the facilitators and barriers of continuity of care across these services, which will address this issue
British Academy of Childhood Disability	9	11	Good teamwork e.g. keeping in touch by email, prompt responses to parents' questions and needs, appropriate team member contacting parents with response when they ask a question to a less suitable team member (e.g. mentioning feeding problems at a physio appointment). Appropriate allocation of time to this joined up kind of care as it can be very time consuming for professionals. Collecting data about whether it makes a difference to families.	Thank you for this comment. We have amended the guideline to focus on service delivery and have included a review question which will look at the effect of joined-up working for health, social care, and education practitioners on the success of services, which will address this issue
Disabled Children's Partnership	9	11	As well as being provided with equipment, people need to be given the skills to use it – we suggest, therefore, changing to 'assistive technologies and access to training and support to use these, are effective'	Thank you for this comment. We agree that training is an important issue and have added a review question which will look at how health, social care and education professionals can be enabled to meet combined health, social care and education needs, which will address this issue

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Newlife	9	11	We welcome with the inclusion of equipment in supporting independence.	Thank you for this comment. As part of the guideline development process the evidence will be reviewed and a question has been included on ensuring the suitability and accessibility of the environment in which disabled children and young people with severe complex needs receive health and social care and education, which will address the issue of equipment. Independence has been suggested as an outcome and the guideline committee will agree which outcomes are appropriate for each review question
Royal College of Occupational Therapists	9	11	Necessary special equipment (beds, hoisting, toileting and showering equipment, wheelchairs) are expensive and needs to be assessed for and provided in a timely manner to home, respite, education and the work place. Funding is complex coming from from health, social care education and charities with inequalities and differences across areas. Any servicing and replacement needs to be timely. Risk assessments need to be completed and signed off with yearly reviews	Thank you for this comment. Your suggestion will be taken into consideration when deciding upon the economic priority topics in the guideline. A question has been included on ensuring suitability and accessibility of the environment in which disabled children and young people with severe complex needs receive health and social care and education, which will address the issue of necessary special equipment
Royal College of Occupational Therapists	9	11-33	Provision of equipment and assistive technologies including maintenance and review and access to social and leisure activities are the most important review questions.	Thank you for this comment. We agree that these are priority areas and as such they are included in the guideline scope. As part of the guideline development process the evidence will be reviewed in these areas

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	9	12	Change to 'accessible in reducing isolation, and promoting inclusion and learning'	Thank you for this comment. Your suggestion will be considered and the guideline committee will agree on the final wording of each review question during development
<a href="#">London North West Healthcare NHS Trust</a>	9	13	... complex physical and mental health needs	Thank you for this comment. The terminology 'severe complex needs' includes children and young people with severe complex mental and/or physical health needs
British Academy of Childhood Disability	9	15	Direct email access between families and professionals can be really useful (but again potentially extremely time consuming for professionals- needs to be carefully managed)	Thank you for this comment. The review questions include an evaluation of what interventions and approaches will be effective models of joined-up working for health, social care, and education practitioners, which will address this issue
Epilepsy Action	9	15	Enabling families and carers to be involved in the care of disabled children and young people is vitally important, especially in cases where the disabled children and young people lack mental capacity. Unfortunately we are aware of cases where families or carers are not involved, and wishes or information about the child or young person have been ignored	Thank you for this comment. A review question has been included to determine which interventions are effective in enabling families and carers to be involved in the planning and delivery of care of disabled children and young people with severe complex needs, which will address this issue

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	9	15	Families are the prime carers of disabled children and young people with severe complex needs. In our experience parents, brothers and sisters, grandparents and friends are the experts and need to be seen as such. The role of professionals should be to share their expertise and knowledge with families so that they are as confident as possible in supporting their family member with a disability. All interventions should be focused on supporting the family to have the best possible life. Perhaps developing a similar website to the 'What Works' website in education, could provide evidence of effective practice, not least using language and visual information accessible to families	Thank you for this comment. One of the key areas identified in the scope is supporting the role of families and carers. This area will be covered during the development of the guideline. A review question has also been added to the scope which will examine which interventions, including communication, are effective in enabling families and carers to be involved in the planning and delivery of care
Paediatric Continence Forum	9	15	We welcome this question as a very positive contribution	Thank you for this comment in support of the guideline
British Academy of Childhood Disability	9	17	Adding the word 'empowering' to the current wording, e.g. 'are effective and acceptable in <u>empowering and</u> enabling families and carers to be involved'.	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question
Disabled Children's Partnership	9	17	We do not think that 'involved' is the right word here: families should be more central than simply 'involved'	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
The Maypole Project	9	17	Families and carers “to be involved in the care of...” uncertain about language here. Is this about “involvement” as sometimes families and carers feel totally alone and without support to help them in their role – leaving them so totally” involved” that they may feel totally overwhelmed. Alternatively we have seen the care system working to take over the care of a child/young person when families/carers are deemed not to be appropriately involved using language which alienates them from the system which should be there to help and “facilitate” them in their very difficult and stressful role. Training in communication and use of language, and even of the system appears to break down at times.	Thank you for this comment. We will consider the use of the term 'involvement' during development and the guideline committee will agree on the final wording of each review question. We have amended the scope to include a review question which will examine how health, social care and education professionals can be enabled to meet combined health, social care and education needs of disabled children and young people with severe complex needs, which will address the issue raised about training in communication and use of language

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	9	19	Short breaks should be part of holistic planning and should be determined by children and young people themselves as far as possible. The break should not be seen as something just for the family carers (although the legislation is framed in this way). For all children and young people the aim should be to provide home based and inclusive support. For example, for a younger disabled child having a sleep over with friends should be the aim and a short break budget can provide support for this to happen. If a family are thinking about the future accommodation needs of their older son or daughter then a night away with support in a place of the young person's choice is a stepping stone to independent living. For all children and young people, if they were enabled to be included in local activities such as clubs and societies, there would be less demand for expensive residential stays. This means staff working in universal settings need to be supported to understand how to be confident and competent in welcoming disabled children into their setting. I.e. They need disability awareness training and in particular, to understand how to make reasonable adjustments. This needs to be viewed as a rights based area of development.	Thank you for this comment. Promoting and maintaining independence and wellbeing, ensuring the suitability and accessibility of accommodation, and supporting the role of families and carers have been identified in the scope as key areas for this population. These will be covered during the guideline development process, which will address these issues
National Development Team for Inclusion	9	19	Short breaks should be jointly funded for children and young people with ongoing healthcare needs. Currently funding arrangements are often solely based on social care funding. Keeping costs down involves use of existing provision that is already adapted but could be used by anyone. E.g. adapted holiday cottages, accessible rooms in hotels	Thank you for this comment. This will be taken into consideration when deciding upon the economic priority topics in the guideline

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Paediatrics and Child Health (with BACD input)	9	19	Suggest adding the word 'empowering' to the current wording, e.g. 'are effective and acceptable in <u>empowering and</u> enabling families and carers to be involved'.	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question
The Maypole Project	9	19	How can health and social services work together to facilitate accessible, acceptable quality and quantity of short breaks ...	Thank you for this comment. We have added accessibility, availability and timeliness as outcomes, which will address these issues. The included outcomes for each review question will be decided by the guideline committee during development
Together for Short Lives	9	19	We ask that the word 'specialist' is inserted before short break on page 19. We believe it is important for this guideline to make it clear that children with complex health needs need specialist short breaks which include some element of healthcare assessment and/or intervention. Specialist care is provided by a multi-disciplinary team of specialist staff, all working closely together to ensure seamless support to the entire family. Specialist care could include: physiotherapy, complementary therapies, play and music therapy. The provision of this specialist medical and nursing support during short breaks is vital in creating a service that parents have confidence in and therefore meaningfully benefit from. The inclusion of 'specialist' in this context differentiates this group of infants, children and young people from those with less complex needs.	Thank you for this comment. The scope includes a review question which will examine the evidence on the effectiveness of interventions such as short breaks in enabling families and carers to be involved in the planning and delivery of care for this population, which will also encompass the issue of specialist short breaks. Your suggestion to amend the wording will be considered during development when the guideline committee agrees the final wording of each review question

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Essex County Council	9	19-21	Consider adding: 'within the locality of the family'	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question
Essex County Council	9	22	Consider adding: 'within the locality of the family'	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question
Newlife	9	22	We ask that this line reads "ensuring suitability and accessibility of accommodation and specialist equipment".	Thank you for this comment. Your suggestion will be considered during development and the guideline committee will agree on the final wording of each review question
National Development Team for Inclusion	9	23	Person-centred planning will explore housing and support gradually from the year 9 annual review of the Education, Health and Care plan. In year 9 it is important to give young people and their families information about local housing and support options, including information about the local housing register, housing benefit, local social landlords, local supported living schemes and inheritance and housing trusts. At each subsequent review the conversation will explore emerging ideas about future accommodation. Health and social care interventions will be determined by the individual's plan but should focus on providing the support needed for the young person to have an as ordinary life as possible. At the same time it is essential that the local area uses the information about young people's future housing and support needs to inform commissioning	Thank you for this comment. Ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services, and the suitability and accessibility of accommodation, have been included as key areas in the scope and will be examined during the guideline development process. Barriers to and facilitators of ordinary life have also been identified as key issues and will be considered during development

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	9	24	In providing "suitability ...accommodation" for children with complex needs, including continence, note it must be recognised that adequate storage space is essential for example for continence pads, stoma bags, parenteral nutrition equipment, hoists etc.	Thank you for this comment. Ensuring suitability and accessibility of accommodation has been identified in the scope as one of the key areas and will be examined during the guideline development process, which will address this issue
Epilepsy Action	9	27	Enabling education, social and leisure activities and preparation for employment should be a priority, in order to allow people to life as independently as possible	Thank you for this comment. Enabling education, social and leisure activities and preparation for employment has been identified in the scope as one of the key areas and will be examined during the guideline development process
Thomas Pocklington Trust	9	27	<a href="https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment">A number of children and young people with complex needs will not go into employment – do we need to adjust this therefore to say employment and/or adult life?****https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment</a>	Thank you for this comment. We have amended the wording to reflect that not all disabled children and young people with severe complex needs will enter employment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	9	27	To give consideration of role of education and health care plans/planning in enabling access to education and the community	Thank you for this comment. Education, health and care plans have been identified as integral in supporting health, social care and education needs for this population and will be considered throughout the guideline development process. Access has been added to the scope as one of the key areas to be covered
Essex County Council	9	27-28	Consider adding: 'within the locality of the family'	Thank you for this comment. All the review questions have been redrafted, including the question pertaining to education, social and leisure activities and preparation for employment. We understand the view that such services should be provided within the locality of the family. However, including this in the review question would pre-empt the answer to the question and so the question has been kept generic at this stage
Epilepsy Action	9	29	Promoting inclusion and learning for disabled children and young people with severe complex needs is vitally important and should be prioritised	Thank you for this comment. This was identified as a priority and the scope already covers inclusion and learning for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	9	29	<p>All services within a local area should promote inclusion. It is important that a local area has a vision which drives policy and strategy. It is not possible for health and social care to promote inclusion if all children with severe complex needs are being directed to special schools. It is important to have transparency about the legal right that families and young people have to attend mainstream education – we find that many parents are not aware of their legal rights and even when they are, they are often aware that many local schools will not admit children with severe complex needs. This situation is not acceptable and each local area should explain clearly on the Local Offer website and in all communications: What is the local vision for inclusion? Is the vision articulated in policy and strategy documents? Are all schools aware of best practice in teaching, learning and support for children and young people with severe complex needs? Is support for disabled children commissioned jointly across education, health and social care (children and adult services)? Are support services equally available to children and young people attending mainstream settings and special schools?</p>	<p>Thank you for this comment. This was identified as a priority and the scope already covers inclusion and learning for disabled children and young people with severe complex needs. The issues that you raise will be explored as part of the guideline development process and the committee will attempt to make recommendations pertaining to these</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	9	32	Life outcomes in person-centred Education, Health and Care plans are essential for preparing young people for adulthood. Section E of the plan should be constructed using the Preparing for Adulthood pathways from year 9 at the latest. These are: Employment Independent Living Friends, Relationships and Community Good Health As part of a person-centred planning or review conversation, outcomes will be arrived at which will take the young person towards their aspirations in these areas. Health and care interventions will be determined by the provision and inputs required to enable the young person to achieve their outcomes. Joint planning will ensure that leisure, social and employment outcomes will be supported holistically through health, care and education interventions. It is important that all staff across education, health and care are aware of the evidence base of what works to support young people with severe complex needs to achieve these life outcomes. So, for example a vocational profile needs to be developed for young people from year 9. This may need to be developed by a job coach in conjunction with a range of other professionals such a speech and language therapist and an occupational therapist. In the same way a circle of friends can be supported by a range of professionals – the exact way will be determined through high quality planning	Thank you for this comment. The outcomes that you mention are already included in the scope. As part of the guideline development process we will look at how these outcomes could be best achieved for disabled children and young people with severe complex needs (that is, models of care, integration of health, social care and education services, joint commissioning and planning, employment, etc)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Occupational Therapists	9	32	Access to and inclusion within leisure should be able to assist services delivering against agreed standards - aspirations for inclusion are very low.	Thank you for this comment. Access to and inclusion within leisure was identified as a priority and is already included in the scope. The guideline will attempt to make evidence-based recommendations pertaining to best practice in this area. It is beyond the scope of the guideline to impose standards on services, although the guideline may inform a NICE quality standard in this area
British Academy of Childhood Disability	9	33	Specialist groups e.g. sports groups overseen by a physio can be really beneficial	Thank you for this comment. As part of the guideline development process, the committee will look at different evidence-based ways of promoting social and leisure activities for disabled children and young people with severe complex needs, which may include sports groups overseen by a physiotherapist
Epilepsy Action	9	33	Promoting social and leisure activities is an important issue for children and young people with epilepsy. Many children and young people with epilepsy feel that they are often prevented from taking part in such activities due to concerns about them having a seizure. Better training and awareness to ensure that people are aware of what to do in the event of a seizure would help address this problem	Thank you for this comment. As part of the guideline development process, the committee will look at evidence-based ways of promoting social and leisure activities for disabled children and young people with severe complex needs. We will also look at how practitioners could be best supported to enable social and leisure activities for disabled children and young people with severe complex needs

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	27-34 1-8	27-34 1-8	Likewise, 7.1-8.1 should each say health, social care and education needs - all three need to be integrated.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Royal College of Occupational Therapists	10	General	Acknowledging that EHCPs have not achieved service integration and standards and a commissioning framework is required to remove or at least reduce the artificial barriers between health education and social care.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice. The guideline population is now defined with reference to children and young people needing support from all 3 sectors (health, social care and education services)
Essex County Council	10	1-3	Consider adding preparing them for the next important life transition.	Thank you for this comment. However, life transition is too generic a term. In this instance we are specifically interested in finding out what approaches to joined up services are most effective in preparing disabled children and young people with severe complex needs for employment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	10	1-3	Schools/universities linking up with organisations/charities which may offer internships or paid work experience, with a view to employment.	Thank you for this comment. As part of the guideline development process we will look at evidence-based ways of promoting employment opportunities for disabled children and young people with severe complex needs, which may include your suggested approaches, that is, schools and universities linking up with organisations and charities that may offer internships or paid work experience, etc
British Academy of Childhood Disability	10	3	In the past I have been part of working groups combining myself (paediatrician), Special School Nurses, Social Care and Connexions Education Services looking at opportunities for young people on leaving school, promotion of ambitious plans e.g. residential colleges/ vocational training, roadshows in schools with stands from local colleges etc. Latterly I haven't had time due to the pressure fo clinical commitments and also the provision of residential places is much diminished in number. My subjective impression is that there are less opportunities for independence now and a greater reliance on (ageing) parents providing ongoing care.	Thank you for this comment. As part of the guideline development process we will look at evidence-based ways of promoting employment opportunities for disabled children and young people with severe complex needs, which may include schools and universities linking up with organisations and charities that may offer internships or paid work experience. Also, as outlined in the scope we will look at approaches to promote independence and ways to facilitate the role of families and carers
Thomas Pocklington Trust	10	3	As 9/27 above.	Thank you for this comment. We have amended the wording to reflect that not all disabled children and young people with severe complex needs will enter employment

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department of Health	10	4	Is there something to be specified here about ensuring training and skills of workforce to support integrated support; making reasonable adjustments?	Thank you for this comment. All the review questions have been revised and we will be looking at how health, social care and education staff can be enabled to meet combined health, social care and education needs of disabled children and young people with severe complex needs
Essex County Council	10	4	This section could include something more specific around managing across complex systems, when there may be a number of commissioning authorities (e.g. multiple CCGs and schools) all commissioning to different criteria – something on maintaining the balance between locally responsive services and consistent, transparent and fair offer would be helpful -it's one of our biggest struggles	Thank you for this comment. The review questions have been revised and will capture joint commissioning of health, social care, and education services for disabled children and young people with severe complex needs
Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit	10	5	This section concerns "Ensuring effective commissioning, integration and joint working between practitioners across health and social care services." Key workers (education/social/health) who have regular contact with these young people need to be able to identify sexual health needs and give basic information. In addition, clear referral/ self-referral pathways based on local provision need to be in place to minimise barriers to the full range of sexual and reproductive health services. Local Sexual and Reproductive Health services should be funded to facilitate access for this group of young people to appropriately-trained healthcare professionals who are able to offer, for example, all suitable contraceptive options.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health and social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that sexual health is an area to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	10	5-25	This should include a specific reference to joint commissioning	Thank you for this comment. The review questions have been revised and will capture joint commissioning of health, social care, and education services for disabled children and young people with severe complex needs
Disabled Children's Partnership	10	6	Change to 'across health, social care and educational services'	Thank you for this comment. This change was made throughout the scope
National Development Team for Inclusion	10	7	Our experience shows that it is not necessarily the structure of services (including co-location) which lead to the best outcomes for children and young people with severe complex needs but having shared values, a shared vision, strong leadership of clear strategies across education, health, care and other relevant services (such as employment and housing). Accountability is key and requires high quality planning, reviewing plans and using the information in plans to inform joint commissioning. It also requires a strong leadership and management culture with senior leaders working together to understand the tasks in hand and empower front line staff to work well across professional boundaries.	Thank you for this comment. This was identified as a priority and as part of the guideline development process we will look at factors that facilitate the strategic oversight to ensure effective commissioning, integration and joint working between practitioners across health, social care and education services. These factors may include: shared values and vision across education, health, care and other relevant services; accountability; strong leadership; etc
National Development Team for Inclusion	10	7	The use of CQUINS can raise performance and help improve the quality of care. A requirement to report in the JSNA on:the numbers of children and young people with the most complex and severe impairments and how many are being supported by which agencies and in what ways would help to prioritise planning for these disabled children	Thank you for this comment. However, these are implementation issues and as such are beyond the scope of this guideline. It will be the responsibility of commissioners to ensure that best practice recommendations are followed up and implemented

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	10	7	<p>There needs to be co-produced, clear and widely understood strategies for supporting children and young people with severe complex needs. These need to include: All schools understanding their responsibilities for including all children and young people and having access to continuing professional development around best practice in teaching and learning for children and young people with severe complex needs Special schools, mainstream schools, early years settings, colleges and health and social care working in partnership to develop a clear understanding of best practice in pedagogy and health and social care support Integrated services that provide strategic support to schools and other settings around communication, Positive Behaviour Support, Circles of Friends Integrated working across education, health and care and beyond Unbiased information for parents and young people about all aspects of provision and support</p>	<p>Thank you for this comment. This was identified as a priority and as part of the guideline development process we will look at factors that facilitate the strategic oversight to ensure effective commissioning, integration and joint working between practitioners across health, social care and education services. These factors may include: shared values and vision across education, health, care and other relevant services; accountability; strong leadership; etc. As explained in the scope we will also look at the best ways of involving and supporting families and carers, and young people in their care, etc</p>
Royal College of Psychiatrists	10	7-25	<p>Another suggestion of a review question that is in keeping with current national health and social care policy is 'What technological strategies or systems are effective and acceptable in ensuring good quality care across health, social care, education and other services for disabled children and young people with severe complex needs?'</p>	<p>Thank you for this comment. This was identified as a priority and is included in the scope</p>

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Epilepsy Action	10	9	The Epilepsy Care Pathway is a good example of a specific service model for facilitating access to disparate services	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that epilepsy is a condition to which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services
Thomas Pocklington Trust	10	9	Many children/young people with complex needs rely on a parent/carer to be their key worker.	Thank you for this comment. The exact definition of key worker will be agreed with the committee during the protocol drafting stages and as you suggest this may include a parent or carer
British Academy of Childhood Disability	10	10	Would strongly welcome this approach	Thank you for this comment in support of the guideline
Epilepsy Action	10	13	Care planning is a particular concern for Epilepsy Action and strategies to share information across health, social care, education and other services should be a priority.	Thank you for this comment. This was identified as a priority and is already included in the scope

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
National Development Team for Inclusion	10	13	Ultimately we need joint person-centred planning and practice. This requires sharing information and is enabled by the current legislation but it is often misunderstood. The barriers should be addressed through strong action planning led by senior leaders across education, health and care with the involvement of families and young people.	Thank you for this comment. This was identified as a priority and we will be looking at effective communication strategies across health, social care and education services to facilitate joint working. Also, we will be looking at effective ways of facilitating the role of families and carers, and involving children and young people in planning their care
Department for Education	10	15	New q: what arrangements are most effective in enabling health, social care, education and other agencies to work together to ensure staff receive the best training?	Thank you for this comment. All the review questions have been revised and we will be looking at how health, social care and education staff can be enabled to meet combined health, social care and education needs of disabled children and young people with severe complex needs
Paediatric Continence Forum	10	19	<i>A comment for consideration under section 8.5:</i> Different funding streams can make it difficult to access appropriate services and equipment	Thank you for this comment. We will look at all the 'barriers to' in a systematic way and as you suggest these may include different funding streams. However, it is beyond the guideline scope to change the funding arrangements of services and equipment
British Academy of Childhood Disability	10	20	Lack of secure email access between health/ education/ social care is an ongoing (and ridiculous) daily headache- just sorting this out would be a massive step forward.	Thank you for this comment. We will look at all the 'barriers to' in a systematic way and as you suggest these may include lack of secure email access, etc

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Norrie Disease Foundation	10	20	Barriers include lack of joined up commissioning of clinical services, lack of social care funding for family respite, schools unwilling to enrol pupils with complex needs.	Thank you for this comment. We will look at all the 'barriers to' in a systematic way and as you suggest these may include lack of joined up commissioning of clinical services, lack of social care funding for family respite, schools unwilling to enrol pupils with complex needs, etc
Together for Short Lives	10	22	We ask that NICE specifically refers to community nursing support in this section. This can be provided by NHS community children's nurses, voluntary sector hospice at home teams or a combination of both. It has long been recognised that home is usually the best place for children and that they should be admitted to hospital only if the care they require cannot be provided in the community or on a day care basis. Following a diagnosis in hospital it is likely that families will want to return home their community as soon as possible. Hospice at home refers to a service which brings skilled, practical children's palliative care into the home environment and works in partnership with parents, families and carers. Children and young people with disabilities and severe complex needs will receive the bulk of their care at home and often have severe limits on their mobility meaning it is important to acknowledge the role that community children's nursing support can take in their care pathway.	Thank you for this comment. As part of the guideline development process we will look at various models of service delivery across health, social care, education and other services. At this stage the exact service models are unknown. However, we will include all evidence-based models of service delivery that fit the inclusion criteria in the review protocols to be agreed by the committee

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	10	24	Please clarify "virtual" co-location of services, bearing in mind that the number of different services these children and young people needs to kept to a minimum. Also access to and ability to use technology (e.g. Skype if this is an example of "virtual co-location") may not be within the financial or physical cope of children and young people with complex needs and their families.	Thank you for this comment. All the review questions have been revised, including the question on models of timing and location of services. The reference to 'virtual' co-location of services has been removed
Cardiff and Vale University Health Board	10	25	Additional consideration towards commissioning with regards to accessible housing stock and respite facilities	Thank you for this comment. This was identified as a priority and we will be looking at how health and social services can work together to effectively facilitate and commission respite care for families and carers of disabled children and young people with severe complex needs. We will also be looking at approaches that promote accessibility of accommodation (that is, housing) for this population
Cardiff Council	10	25	Additional consideration towards commissioning with regards to accessible housing stock and respite facilities	Thank you for this comment. This was identified as a priority and we will be looking at how health and social services can work together to effectively facilitate and commission respite care for families and carers of disabled children and young people with severe complex needs. We will also be looking at approaches that promote accessibility of accommodation (that is, housing) in this population

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Bradford District Achievement Partnership	10	25-26	Additional question to be included: 'What are the governance arrangements most suitable for reviewing and quality assuring multi-agency delivery of EHCPs by the NHS, Social Care and Education Providers?'	Thank you for this comment. As explained in the scope we will be looking at the strategic oversight of and clear accountability in integrated health and social care, which may include having particular governance arrangements for providers of services for disabled children and young people with severe complex needs
Action for ME	10	26	We would like consideration to go towards the accessibility of services. For many with hidden disabilities like M.E., it may be difficult to obtain the social care people need. In 2015 we had 848 respondents to our 'Access to Care and Support' survey. Although the respondents were not limited to children, only 6% said that they receive a social care package.	Thank you for this comment. This review question has been redrafted to focus on the suitability and accessibility of health, social care and education services rather than just accommodation
Department of Health	10	26	As above, I think the Preparing for Adulthood outcomes framework is a good summary of outcomes relating to transition.	Thank you for this comment. The guideline committee will prioritise outcomes when planning the evidence review. The 4 main outcomes of the Preparing for adulthood outcomes framework (that is, employment, independent living, community inclusion and health) are consistent with our proposed list in the scope
Disabled Children's Partnership	10	26	The outcomes section should include outcomes for parent carers and for siblings.	Thank you for this comment. Depending on the focus of the particular review question the outcomes listed could apply to children and young people or their parents and carers

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Disabled Children's Partnership	10	26	It would be helpful if there was a statement identifying that each of these outcomes are inter-related eg: if social capital is low then this will impact on areas such as communication and quality of life. We suggest additionally including 'Main outcomes are interlinked and the impact of one outcome on another must be considered in a person-centred approach'	Thank you for this comment. We agree that outcomes might be inter-related but not all outcomes in the list will be considered for every review question. The committee will prioritise a smaller list of key outcomes for decision making for each question. The person-centred approach underpins NICE guidelines which recognise that each person has different values and preferences and that recommendations should reflect this
Challenging Behaviour Foundation	10	26	The list of outcomes is helpful and the focus on interventions should consider whether they deliver these outcomes. However, the research is sparse and it will be important to have a full consultation with family-carers to gain a better understanding of which interventions deliver good outcomes. Under the quality of life heading, one of the recognised measures is reductions in challenging behaviour.	Thank you for this comment. The views and experiences of families and carers will be gathered in several ways during guideline development: parents or carers may be part of the guideline committee; we are likely to look at published qualitative evidence about the views of family and carers; and families and carers can contribute their views about the draft guideline through registered stakeholder organisations during the consultation on the draft guideline
Essex County Council	10	27-28	Consider additional bullet points of: Safety Quality of relationships (with family/friends/paid carers) Delivered Locally Should these outcomes also consider outcomes for families / parents and carers? Feeling better supported and empowered etc? It would be helpful to add how these outcomes have been selected?	Thank you for this comment. Depending on the focus of the particular review question the outcomes listed could apply to children and young people or their parents and carers. The main list of outcomes was drafted by the scoping group. The guideline committee will prioritise a smaller set of key outcomes when planning specific review questions and in some cases may choose to look at outcomes not on this list

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
British Academy of Childhood Disability	10	29	Whilst laudable to have quality of life as an outcome measure, it needs to be clear that for those with the most complex needs, this will be as reported by families or other carers, rather than self-reported. It is difficult to measure outcome for this group using 'independence', as only those young people able to gain some control over their environments are likely to achieve this, whilst those with the greatest complexity of needs would be deemed to have 'failed' this test, as they are not able to gain any degree of independence. Similarly, using 'learning or educational attainment' as a measure will only be applicable for those with the potential to gain learning abilities or educational attainments, as those with the most profound learning disabilities and/or progressive, neurodegenerative conditions will not be able to 'score' on such measures and would be deemed to have 'failed' these measures.	Thank you for this comment. This list describes the outcomes that will be used to compare the effectiveness of different interventions or service configurations. These are not necessarily binary pass or fail outcomes - a small incremental improvement in independence may still be important. The measurement of quality of life may be more challenging in children and young people with profound disability but in these cases assessment by a proxy or caregiver is reasonable approach
Together for Short Lives	10	29	We ask that this list also includes: physical and mental health outcomes for parents, carers and sibling the extent to which parental relationships are maintained, and to which the break-up of parental relationships is avoided.	Thank you for this comment. Depending on the focus of the particular review question the outcomes listed could apply to children and young people or their parents and carers
Essex County Council	10	31	Consider adding 'and preparedness for next important transition'	Thank you for this comment. The guideline committee will prioritise a smaller set of key outcomes when planning specific review questions and in some cases may choose to look at outcomes not on this list

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

National Development Team for Inclusion	10	32	<p>In addition to the above, it will be important to instill a belief that children and young people can work even if later for some reason (such as ill health) it does not happen. Research by Marc Gold et al has demonstrated that the severity of a person's impairment is not as good a indicator of ability to get a job as the level of motivation. Hence, starting conversations about work early is important. Good employment support includes:: A presumption that people can work Good vocational profiling that highlights an individual's strengths, interests and preferences and takes account of what is not possible. This informs work experience placements and subject choices Exposure to the world of work through tasters, employer visits, work experience Well- constructed supported internships, traineeships and supported apprenticeships Positive relationships built up with employers- a clear 'ask' from the supporting providers: what is being sought- Is it a taster, a work experience placement or a working interview for a job? A positive match for the employer and the young person that meets a business need Skilled work place and job analysis A skilled Job Coach for many young people who negotiates with the employer and teaches the tasks required to a high and consistent standard. This may involve the use of TSI (Training in Systematic Instruction) A follow on job coach to provide long term support to both employer and the employee An understanding of how to use the different funding sources that exist to best effect e.g. Access to Work Travel training for young people and careful planning for travel to and from work for those who cannot use public transport It is very important to involve families of disabled children and young people from a young age in order to help them understand the support that exists and to reassure them about benefits, bullying in the work place, travel arrangements, etc. There are positive examples of what individuals can achieve when supported effectively on the Preparing for Adulthood website. We can provide</p>	<p>Thank you for this comment. This concept is covered by the outcome 'self-efficacy', that is, the person's belief in their ability to achieve their goals, which could include employment. We intend to review evidence about how health, social care and education services can best support children and young people to participate in education, social activities, and employment</p>
---	----	----	---	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support**  
**Consultation on draft scope**  
**Stakeholder comments table**

**08/01/2019 to 05/02/2019**

		research reviews that provide background evidence. All of this requires positive partnership working, a shared understanding of what is possible and strong leadership.	
--	--	---	--

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Paediatric Continence Forum	10	36	In order that children and young people with disabilities and severe complex needs do not have to limit their activities outside their home or educational environments, we believe that the following should be specified in this section: 1. accessibility throughout the public transport system; 2. ready availability of accessible public toilets with changing and waste disposal facilities;	Thank you for this comment. We have revised the main list of outcomes to include the availability and timeliness of health, education and social care services. The public transport system and public toilets are outside the scope of this guideline which is limited to settings in which health, social care and education is provided
Cardiff and Vale University Health Board	11	1	Add: integration &/ collaboration of services (not just experience of...)	Thank you for this comment. We have revised the main list of outcomes to include joined-up working and cross-sector planning
Cardiff Council	11	1	Add: integration &/ collaboration of services (not just experience of...)	Thank you for this comment. We have revised the main list of outcomes to include joined-up working and cross-sector planning
Essex County Council	11	1	Including the quantity, quality and flexibility of support/intervention provided by services at a LOCAL level and extent to which services adopt to person-centred approaches to the way they work.	Thank you for this comment. We have revised the main list of outcomes to include availability of local services
Essex County Council	11	2-5	Consider adding 'within the locality of the family'	Thank you for this comment. We have revised the main list of outcomes to include availability of local services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	11	2	Consider integration into local community and peer group as well as participation and inclusion	Thank you for this comment. We have revised the main list of outcomes to include availability of local services and the setting of services
Royal College of Speech and Language Therapists	11	6	Again we are pleased to see communication highlighted in the list of evidence. However we do have some concerns regarding how communication will be considered when assessing the evidence, as much research on communication of children and young people with disabilities and complex needs may not specify gains from intervention in terms of traditional 'communication skill'. They may instead be reflected in quality of life etc., but a result of a communication intervention. We would encourage that when evidence is reviewed, expert stakeholders are consulted in this area as evidence around this topic may be less likely to align with that of precise health outcomes.	Thank you for this comment. The guideline committee will prioritise a set of key outcomes when planning specific review questions

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	11	7	Replace “educational attainment” with “educational progress and attainment.” This helps capture ‘activity towards’ and not just final attainment.	Thank you for this comment. We have included the word 'learning' to cover the concept of general learning progress
<a href="#">University Hospitals Birmingham NHS Foundation Trust</a>	11	7	Learning or educational attendance and attainment	Thank you for this comment. We have revised the main list of outcomes to include the availability and timeliness of health, education and social care services
Bradford District Achievement Partnership	11	7-8	Additional bullet points: Children and young people have access to the same high quality standards of care regardless of setting.Effective governance arrangements for healthcare services across all settings.	Thank you for this comment. We have revised the main list of outcomes to include the availability and timeliness of health, education and social care services, the extent of joined-up support, and effective cross-sector planning
Essex County Council	11	10	Consider adding outcome measure: was child/young person and parent/carer satisfied with the speed/pace of progress toward outcomes?	Thank you for this comment. We have revised the main list of outcomes to include the availability and timeliness of health, education and social care services. The guideline committee could specify additional outcomes when agreeing the evidence review plan if they thought that would be appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Department for Education	11	21	Again, "health, social care and education" as it is important that health and social care professionals normalise contact with Local authority special educational needs and disability (SEND) teams for children and young people with severe and complex needs. Also with schools and education providers where necessary, for instance in hospitals. (These are Alternative Provision education providers.)	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope
Department for Education	12	1	Add education to the diagram. See also comment above page 1 concerning the whole document, a diagram to show how these guidelines fit in the wider system of health and social care and SEND education process for support.	Thank you for this comment. The guideline subtitle has been changed to emphasise that the guideline scope has been refocused on integration of services across the health, social care and education sectors. The guideline recommendations will focus on principles of integrating care rather than addressing specific health conditions or disabilities. Education is referenced throughout the revised scope. The suggestion to develop a diagram summarising the integration of health, social care and education services will be shared with the committee when the guideline enters the development phase
Royal College of General Practitioners	General	General	· The guideline producers may find the following RCGP resources to be of interest:Confidentiality and Young People Toolkit <a href="https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/youth-mental-health/the-rcgp-adolescent-health-group.aspx">https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/youth-mental-health/the-rcgp-adolescent-health-group.aspx</a> Safeguarding Children Toolkit <a href="https://www.rcgp.org.uk/-/media/Files/CIRC/Safeguarding-">https://www.rcgp.org.uk/-/media/Files/CIRC/Safeguarding-</a>	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice, and the suggestions and resources referred to in the comment will be taken into consideration

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*



**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			Children-Toolkit-2014/RCGP-NSPCC-Safeguarding-Children-Toolkit.ashx?la=en	
Royal College of General Practitioners	4	2	<a href="#">Health professionals in primary care should be explicitly listed here. Primary care services come in contact disabled children and young people with severe complex needs for the management of their general healthcare needs and comorbid conditions, and can work in collaboration with specialist services to optimise care. Clearer guidance for GPs is needed in this area. 76% of parents reported they find it difficult to take their disabled child to visit the GP, and often end up in A&amp;E instead</a> <a href="https://contact.org.uk/media/609552/gp_briefing_final_proof.pdf">https://contact.org.uk/media/609552/gp_briefing_final_proof.pdf</a>	Thank you for this comment. The scope specifies that the guideline is for a wide-ranging audience, including health professionals, and allied health professionals, working with disabled children and young people with severe complex needs. This would include professionals in primary care such as GPs. It is not possible to give an exhaustive list of health professionals for whom the guideline would be relevant. The relevance of the guideline for GPs is reflected in a GP being prioritised for inclusion in the guideline committee as a co-opted member

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of General Practitioners	8	15	<a href="#">Processes are currently in place to manage people with learning disabilities within primary care. For patients with learning difficulties, there is a Quality Outcomes Framework (QOF) requirement (LD003) to have a named GP who provides a regular check-up looking at all aspects of their lives. GPs must perform an annual health check, create a health action plan, and maintain a learning disability register at the practice level. The guideline developers may find this following report to be useful: <a href="https://www.cqc.org.uk/sites/default/files/documents/health_care_for_disabled_children.pdf">https://www.cqc.org.uk/sites/default/files/documents/health_care_for_disabled_children.pdf</a></a>	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind that learning disability is an area in which the principles of integrated care should apply. We will consider throughout the development of the guideline issues such as those you have mentioned that will be important in ensuring equality of access to services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of General Practitioners	8	27	<u><a href="#">When involving young people in decision making they need to be viewed, as far as is possible, as autonomous adults with needs regarding privacy, confidentiality, consent, their sexuality, services such as GUM and contraception. If the patient has capacity, the consultation should be directed at them, both in terms of directing communication to the patient rather than the carer, and encouraging patient decision-making. It might be beneficial to make a recommendation to explicitly offer the patient some time alone without the carer present to discuss issues. The GMC guidance states "you should make it clear that you are available to see children and young people on their own if that is what they want."</a></u> <u><a href="https://www.gmc-uk.org/-/media/documents/0_18_years_english_0418pdf_489_03188.pdf">https://www.gmc-uk.org/-/media/documents/0_18_years_english_0418pdf_489_03188.pdf</a></u>	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. The guideline recommendations will identify how this should work in practice, and the suggestions and resources referred to in the comment will be taken into consideration
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop NICE children and young people with disabilities and severe complex needs - integrated health and social care support and service guidance. The RCN invited members who work with children and young people with disabilities and severe complex	Thank you for this comment in support of the guideline. Responses to the specific comments raised are provided below

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
			needs to review the draft scope on its behalf. The comments below reflect the views of our reviewers.	
	General	General	Guideline development: it would be important to have both children's/learning disability nursing and adult nursing represented on the guideline development committee as the guidance is from birth to 25 years.	Thank you for this comment. It has been agreed that nursing expertise covering the age range of relevance in the guideline (0 to 25 years) will be included in the guideline committee
Royal College of Nursing	2	23	It is not clear what is meant by meeting "other new needs". Further information to add clarity would be helpful here.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to considering changing, evolving and emerging needs and their impact on the integration of health, care and education services; the phrase 'other new needs' has been deleted

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Nursing	2	30	Add point: Care co-ordination and communication by professionals across the hospital/community interface.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to managing consequences of planned or unplanned health procedures in terms of delivering integrated health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Nursing	2	30	Add point: Meeting the complex physical healthcare needs of the child or young person in the school setting.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to providing training and development opportunities for professionals involved in delivering integrated health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools)

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Nursing	2	30	Add point: Transition to adult services.	Thank you for this comment. It has been agreed that the guideline will cover principles of care in the integration of health, social care and education services. While we will not be able to formulate recommendations specific to particular health conditions or disabilities, we will keep in mind conditions and disabilities highlighted by stakeholders as being relevant to the principles of integrated care. The section of the scope that lists challenges has been revised to remove very specific references to particular conditions and disabilities, and to focus instead on more general and over-arching challenges. This section now includes reference to providing transparency and consistency in arrangements for transition between children's and adults' services
Royal College of Nursing	3	16	Suggest adding United Nations Convention on the Rights of Persons with Disabilities (it includes children and young people).	Thank you for this comment. Section 2 of the scope includes the standard text stating that NICE guidelines cover health and care in England and that decisions on how NICE guidelines apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. It is not feasible to include all legislation from the other UK countries in the list referred to and for the same reason the international legislation mentioned in the comment has not been included
Royal College of Nursing	6	15	Add point: Meeting the information needs of the child or young person and their family. A lack of this or difficulty accessing it continues to feature in research with families.	Thank you for this comment. As explained in the scope we will look at ways of facilitating the role of families and carers

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*

**Children and young people with disabilities and severe complex needs: integrated health and social care support  
Consultation on draft scope  
Stakeholder comments table**

**08/01/2019 to 05/02/2019**

Stakeholder	Page no.	Line no.	Comments	Developer's response
Royal College of Nursing	10	30	Change to 'social and emotional well-being'	Thank you for this comment. The outcome wellbeing covers these concepts; moreover, the guideline committee could specify additional outcomes when agreeing the evidence review plan if they thought that would be appropriate
Royal College of Nursing	11	6	Add point: Information provision for families at points of their journey e.g. at diagnosis, starting school, transition to adult services.	Thank you for this comment. The outcomes experience of services and communication cover this concept; moreover, the guideline committee could specify additional outcomes when agreeing the evidence review plan if they thought that would be appropriate

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.*