Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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Ace Centre	Guideline	037	002	1.10.1 Emphasis is needed on the importance of having a local AAC service to provide independent AAC and Assistive Technology advice and information, awareness raising about the identification of need for AAC, assessment, training and ongoing support. To deliver this, a local AAC service needs a competent workforce, clearly defined care pathway and annual recurrent equipment budget to maintain assessment and loan AAC equipment as described in this document: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf Freely available AAC assessment tools are also available here: https://iasc.mmu.ac.uk/resources/	Thank you for your comment. The existing guidance from NHS England on commissioning AAC services and equipment, that you cite in your comment, is already cross-referenced in recommendation 1.10.6. As there is existing guidance the committee have not made recommendations about commissioning local AAC services.
Ace Centre	Guideline	037	008	1.10.2 NHSE specialised AAC services are not commissioned to provide training for all children and young people who need / use AAC. The training that is available from these services is specific to the prescribed equipment for children and young people who are eligible for their services only. We welcome the additional guidance detailed in this section and would recommend that further consideration should be given by local commissioners to the potential cost efficiency savings of improving how AAC equipment is managed in their area. Increasingly, Individual Funding Requests	Thank you for your comment. The NHSE 2016 Guidance for Commissioning AAC Services and Equipment, paragraph 16 states that "A local AAC service would provide: • training of the those around an individual being provided with AAC such as family members and carers". The committee have amended the wording of the recommendation to clarify that the local AAC service can provide training in collaboration with the specialist hub where needed.

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				are made for AAC equipment provision for anyone who needs AAC and does not meet NHSE specialised AAC service eligibility criteria. This strategy results in further inequity in AAC provision, as there is no opportunity to identify, plan for and prioritise meeting this need more widely and no opportunity to re-issue AAC equipment that has been provided and is no longer needed. In addition, this is not an effective use of public funds	
Ace Centre	Guideline	037	021	1.10.3 We welcome the identification of AAC training for families and carers and would like to have added the need for families to have information about who to contact if their child / young person's communication aid ceases to be functional, including emergency / out of hours contact details	Thank you for your comment. This is already covered by the second bullet point of recommendation 1.10.2
Ace Centre	Guideline	037	023	1.10.4 As Education, health and social care commissioners still have limited understanding about AAC services and provision, it may be helpful to add some weblinks to voluntary or public sector organisations that can assist individuals who use AAC and their families, such as: https://www.communicationmatters.org.uk/ https://acecentre.org.uk/ https://assistivetechnology.org.uk/	Thank you for your comment. The committee have not added links as you suggest because the guideline has not assessed the content of these links.
Ace Centre	Guideline	038	001	1.10.5 There are still very few areas in England where there are commissioned local AAC services to support children and young people who do not (or do not yet)	Thank you for your comment. Commissioners have a responsibility to commission services that meet the needs of their population. If that population have communication needs then they should commission these services.

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				meet regional NHSE specialised AAC service eligibility and we are concerned that this guidance infers that these exist across the country. It would be more helpful to state "where these exist" or describe plans for how this provision will be developed. A description of a local AAC service is included within Sections 5 – 7 in this guidance document: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf	These services might not be always be called 'local AAC services', for example they could be being provided by community SLT services. However in the committee's view the services are being provided.
Ace Centre	Guideline	038	004	1.10.6 The terminology used to describe AAC services in sections 1.10.5 and 1.10.6 are very similar and need to be clarified. Describing the NHSE specialised AAC services as "local specialised augmentative and alternative communication services" is confusing. Access to regional NHSE Specialised AAC services is dependent on the referrer evidencing that the person being referred meets the defined eligibility criteria. This website gives details of the criteria (that are more helpful than the link to the D01 S/b service specification), the NHSE specialised AAC and EC services and how to contact them so would be worth referencing in the guidelines: https://assistivetechnology.org.uk/	Thank you for your comment. The committee have reviewed the wording of the recommendations to be clearer on the distinction between local AAC services and NHSE specialised AAC services. The committee have retained the existing reference to the NHSE service specification as this is the guidance produced by NHSE.
Ace Centre	Guideline	038	008	1.10.7 It would be helpful in this section to add that referrals to regional NHSE specialised AAC services can be made by professionals working in publicly funded positions and it is advisable for referrers to contact the NHS specialised AAC service in their region in	Thank you for your comment. This is covered by the existing wording to follow the referral process and eligibility criteria specified in the Guidance for commissioning AAC services and equipment. Continuing, co-ordinated input from practitioners across all 3 sectors is integral to providing care for disabled children and young

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				advance of making a referral to ensure that they provide sufficient evidence of eligibility. Details about how to contact each regional NHSE specialised AAC service can be found here: https://assistivetechnology.org.uk/ Input from local Education, Health and Social Care practitioners should continue before, during and after referral to Specialised AAC Services has been made.	people with severe complex needs and is a central theme running throughout this guideline. The committee have therefore not repeated this here.
Ace Centre	Guideline	051	002	1.15.20 There is an AAC competency framework that has been developed by NHS Education for Scotland and may be useful to reference here in order to provide professionals with a resource to assist in the identification of their training needs: https://www.aacscotland.org.uk/files/cm/files/ipaacks.pdf	Thank you for your comment. The bullets in recommendation 1.15.17 were based on areas identified by the evidence reviews. The AAC competency framework was not identified by the evidence as an area where further training was needed and so the committee have not added it to the recommendation.
Ace Centre	Guideline	059	002	1.17.15 It would be helpful to add another bullet here referencing details of local AAC and Assistive Technology services within their Local Offer, including eligibility criteria and the care pathway to NHSE specialised AAC services	Thank you for your comment. The bullets in this list were based on things that are supposed to already be included in the SEND Local Offer (if available) but evidence indicated that this wasn't the case. Details of AAC and Assistive Technology services were not identified as things that were missing and so the committee have not made your suggested change.
Ace Centre	Guideline	061	005 - 008	This section should be expanded to describe the need for local AAC services to be commissioned to provide services and equipment for children and young people who do not / do not yet meet NHS specialised AAC service eligibility criteria.	Thank you for your comment. This is a definition of a term used within the guideline, not a recommendation. As such the committee have not made the change you suggest.
Ace Centre	Guideline	105	016 - 020	This should clarify that the need for maintenance, insurance and support relates to local AAC	Thank you for your comment. The committee have made this change.

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				services. This is already in place for any child / young person who receives communication aid equipment from NHSE specialised AAC services.	
Ace Centre	Guideline	105	022 - 024	The line of responsibility should be clarified here to state commissioners of local AAC services, which may include ICS / CCG / Children's Services	Thank you for your comment. This text is describing the evidence found about communication aids and the committee's deliberations on this when making recommendations. The committee are not in a position to specify who should be responsible for maintenance and insurance, only that it should be agreed who is responsible. Therefore the committee have not made your suggested addition.
Ace Centre	Guideline	105	012	This should read occupational therapists not occupational health	Thank you for your comment. The committee have made this change.
Ace Centre	Guideline	106	026 - 029	It may be worth adding that all NHSE specialised AAC services have facilities and processes to manage equipment and may be worth approaching to support local AAC equipment management.	Thank you for your comment. This text is describing the evidence found about communication aids and the committee's deliberations on this when making recommendations. The committee have included NHSE specialised AAC services in the text.
Achieving For Children	Comments form	Q4	Q4	COVID The absence of considering covid is something that should be resolved by recognising the impact of covid and any future disaster/pandemic on disabled children and their access to services, likelihood of poverty etc. All professionals working in this area must consider this and any potential increase in severity of need.	Thank you for your comment. The committee agree that the pandemic has reduced the capacity and ability to access services. This may impact the implementation of the guidance. As a result, the committee have passed your comment onto the NICE team, which plan implementation support. It is beyond the scope of this guideline to comment on any future pandemic and the potential impact it may have on such issues as poverty. However, the comittee have acknowledged that the population in question has changing needs. Hopefully, services being more joined-up, tailored, and informed by children and young people and their families and carers

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					will make services more resilient to any future variation in severity of needs and enable practitioners to address these needs. The committee agree that any systemic increase in severity will need additional funding to meet the demand. However, NICE does not have a remit to make recommendations on funding decisions.
Achieving For Children	Guideline	General	General	From a Participation perspective, this is great guidance. It has a very strong rights and participation ethos and starting with the principles for children and young people's involvement is really great to see. There are lots of barriers and it requires local commitment, time and resource - and will be a long way from how most local areas are working in practice. But the principles are right and just because it's hard, doesn't mean it shouldn't be done.	Thank you for your comment and your support of the guideline
Achieving For Children	Guideline	General	General	We are concerned about the lack of reference to emotional and mental health - this is as significant an issue for children and young people with severe complex needs as other young people, and perhaps more so because it is often unrecognised / undiagnosed	Thank you for your comment. The committee have added a recommendation about recognition of emotional and mental health needs at the start of section 1.2
Achieving For Children	Guideline	General	General	A significant number of Young People who we support in transition have Learning Disability and this doesn't seem to be mentioned.	Thank you for your comment. The recommendations in this guideline focus on integrated service delivery and organisation across education, health and social care. The recommendations apply to all disabled children and young people from birth to 25 years who need education, health and social care support (unless otherwise specified) and so the committee have not cited specific groups within the recommendations.

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Achieving For Children	Guideline	General	General	There does not seem to be any mention about the Mental Capacity Act and need for assessment and for training for parents to understand.	Thank you for your comment. The Mental Capacity Act is referenced in recommendation 1.1.50. It is not the purpose of this guideline to be a comprehensive repository of all legislation that is relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions.
Achieving For Children	Guideline	General	General	The document is well written, child centred and includes key information from other documents and guidance	Thank you for your comment and your support of the guideline
Achieving For Children	Guideline	General	General	Pros of this integrated guideline - Equal representation of all teams/ agencies Limits repetition for family / joint working share information collaborative working supports good communication with aim for better outcomes Each team should feel valued and have a voice identifies Key workers	Thank you for your comment and your support of the guideline
Achieving For Children	Guideline	General	General	There is a huge challenge around shared IT systems, IG and information sharing which needs to be tackled to enable integrated working to function optimally.	Thank you for your comment. The review questions investigated by this guideline did not identify any evidence to support making a recommendation about shared IT systems, especially given that this would likely have significant resource implications. The guideline has made recommendations in section 1.1. about information sharing which, if implemented, should make these processes more efficient.
Achieving For Children	Guideline	016		Referral to social services - suggests a social care assessment but if the request is for family support this	Thank you for your comment. The committee have added introductory text to this section to clarify that all disabled

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				may go directly to them within the referral pathway unless there is safeguarding concern of high level need. The notes relating to this area talks about stigma for families accessing social services so this document tends to continue with that stigma; if we are more open about the options of family support for the lower level need and social care for the higher level need plus safeguarding this may help.	children are defined as in need under section 17 of the Children Act 1989 and are entitled to an assessment of need. However some social care support for families may be available without an assessment
Achieving For Children	Guideline	017	017	1.3.4 Annual review plans – there is no clear guidance as to how they should happen	Thank you for your comment. The committee have removed this bullet point from the recommendation as it had been included in error - this recommendation is about EHC needs assessment and therefore commenting on EHC plan reviews is not appropriate.
Achieving For Children	Guideline	018	005	1.3.10 There needs to be a mechanism for CAMHS advice to routinely form part of the EHCP information; this is currently a challenge	Thank you for your comment. If a child or young person going into SEND assessment has an open referral to any health service (including CAMHS), than that service would input into EHC needs assessment. It would not be appropriate for CAMHS advice to routinely form part of the EHC needs assessment for all children and young people as not all of them have mental health needs.
Achieving For Children	Guideline	020	003	1.3.12 The commissioning arrangements for paediatric advice for EHCPs varies and needs to be consistent	Thank you for your comment. The guideline did not identify any evidence to support making recommendations about the commissioning arrangements for paediatric advice.
Achieving For Children	Guideline	029	020	1.6.7 Providing training for parents and carers – there are cost implications when considering this refers to tailoring the training for each parent/carers.	Thank you for your comment. The committee have amended the text to be about ensuring the training is appropriate to the needs of families, in recognition of the fact that some people will want more in-depth training straight away, whilst others will not. This has also been clarified in the text of the rationale and impact section.

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Allergy UK	Guideline	006	012	It is important to use appropriate health literacy, pitched at the correct age and understanding of the intended audience and provide explanations and examples where necessary especially when using health care terminology. The broad age range that the document applies to may mean one format/version would not be suitable to the broad range of age's that it is referring to. The easy to read format will help in part with this but consideration of children who are visually impaired is also important. An audio version could be made available to ensure inclusivity.	Thank you for your comment. The recommendation is to enable children and young people to communicate their views in a way that is appropriate for their age, developmental level and ability to communicate. The committee have not specified any particular formats.
Allergy UK	Guideline	007	012	1.1.16 It would be valuable to add an additional bullet point that mentions signposting to support organisations of relevance. Support/Patient organisations like Allergy UK can provide a valuable life line to those in need offing advice and support parents and/or carers as well as organisations to better understand the needs of those they are helping.In the past Allergy UK have supported schools/social and childcare settings to better understand the complex needs of children with multiple and complex allergies this helps to foster improved relationships between organisations and the individual and /or family and ultimately leads to improved outcomes for the children with allergies.	Thank you for our comment. Signposting to support organisations would be covered by the second bullet 'specialist national or local support groups'.
Allergy UK	Guideline	015	018	Underlying health conditions: Children with complex needs may also require special diets due to food allergy or reasonable adjustments to their care because of another allergic condition.	Thank you for your comment. This recommendation is about referring to the appropriate service for assessment, not making a diagnosis or developing a treatment plan.

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				In the UK allergic disease is very common in children. 6-8% of children up to the age of three years have a food allergy. Allergic disease is a widespread and often complex problem: there is estimated to be 20 million people living in the UK with allergy. The most common allergic conditions in children and young people are food allergies, eczema, asthma and hay fever of which 1 in 4 people in the UK have hay fever also called seasonal allergic rhinitis is greatly under recognised and poorly managed and can have significant impact on quality of life due to sleep disturbance, lack of concentration due to allergic symptoms -which can impact on school work. Some of these conditions may require treatment with medication and/or possession of life saving medication in the event of a severe allergic reaction e.g. an adrenaline auto-injector (AAI) for the treatment of a severe allergic reaction) also called anaphylaxis pronounced (ana-phy-laxis). Children with food allergies should have a written plan of care also called an allergy action plan completed and signed by a Health Care Professional that documents the particular food(s) they are allergic to and lists any prescribed medications and advice on what to do in the case of an allergic reaction. This contributes to maintaining good standards of care of children with allergies.	
Allergy UK	Guideline	018	017	Health care specialists working with people who have allergies for example allergy consultants/dietitian's,	Thank you for your comment. Input from specialists in allergies would be encompassed by the existing wording.

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				gastroenterologists and dermatologists may need to provide advice and recommendations to inform assessments and advocate for any necessary accomodations that need to be made or put in place to safeguard children with allergies. Allergy is a complexed area and requires specilaist care often provided in secondary and tertiary care unfortunately there is a significant demand for these services and for some children and families depending on their geographical location this may mean a delay in getting a diagnosis as waiting lists to access services may have long wait lists.	This guideline is focussed on providing integrated care and as such has not highlighted any specific practitioners in the recommendations.
Allergy UK	Guideline	023	012	Allergy management is age appropriate and some children are able to manage their allergies very well and others need help and support- this should be guided by the parent/carer where possible and it should be noted that children with allergies face the same social difficulties as adults but lack the maturity and emotional response, and awareness of consequences to deal with them. Younger children and those with complex health needs/disability will need someone to advocate for them with regards to allergen avoidance, making safe food choices, and being in the care of someone who is able to administer their allergy medications who have received appropriate training. Children with allergies may also be subject to bullying of various forms which has in the past led to a death from a food related anaphylaxis where a known food allergen trigger was deliberately exposed to a food allergic individual.	Thank you for your comment. The second bullet of recommendation 1.4.12 should ensure that if a disabled child or young person with severe complex needs has allergies, a practitioner with knowledge of these needs would inform development of the EHC plan.

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Allergy UK	Guideline	029	003	It is important to communicate with the child and families of those living with allergy-they are often experts in their conditions have to live with them day to day. Establishing what level of involvement (if any) the child has in making decisions about their care. As their is no cure for allergy it can be a chronic/life long condition so empowerment is important.	Thank you for your comment. The committee agree it is important to involve both the child and their families in communication. Recommendations about communicating with the child or young person are made in section 1.1. of the guideline.
Allergy UK	Guideline	038	013	1.11 Environmental adaptations may be needed when accomodating the needs of an allergic child. An example of this could be not sitting a child who has hay fever near an open window during the summer months when the grass outside is being cut, or considering what alternatives could be an incentive to food treats that may pose a risk to a child with a food allergy e.g. reward chart with stickers. Physical adaptations may include access to medication (having a secure area/cabinet in a classroom or setting that is accessible) and within close proximity to the person who may need the medication.	Thank you for your comment. The review questions investigated by the guideline focussed on integrated service delivery and organisation across education, health and social care. As such evidence about the effectiveness of specific environmental adaptations was not looked at and the committee have not made any recommendations in this area. However where environmental adaptations are cited in the recommendations, these would, where relevant, apply to adaptations related to allergies
Allergy UK	Guideline	043	016	There is no cure for food allergy to date and for other types of allergy including asthma, eczema and hay fever whilst they can be out grown they are in general persistent in nature and chronic conditions where the main stay of management involves trigger avoidance for example in a cow's milk allergic child avoiding cow's milk in all its forms in their diet and having suitable alternatives that a nutritionally complete. Allergy training and awareness to support the allergic child's need is key to this including allergen awareness	Thank you for your comment. The bullets in this recommendation relate to support that is needed in relation to employment. Allergy training and awareness is not the focus of this recommendation.

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				and first aid management of allergic reactions. Not all first aid courses cover the management of allergy and with allergy prevalence high this should be a priority for training needs across health, education and social care settings.	
Allergy UK	Guideline	046	010	when organising interagency teams effective leadership is required to bring about the change needed to ensure children with complex health needs can fully participate.	Thank you for your comment. The committee agree that effective leadership is important but the guideline review questions did not look for evidence on what makes leadership effective and therefore are not able to make recommendations in this area.
Allergy UK	Guideline	048	008	It is not possible to achieve effective policy or practice unless those with lived experiences of the conditions/complexities this document refers to are given the opportunity to share these experiences and those in positions to influence policy and guidelines listen to, acknowledge and act upon these. These collective experiences can inform insights and knowledge and help identify where changes/improvements are needed. For those living with allergy there is often not just the physical entity of the disease but also the psychosocial burden and this can extend to parents (anxiety/fear of their child being exposed to their trigger allergen).	Thank you for your comment. Getting input from those with lived experience is a central component of the statutory guidance in the SEND code of practice. Therefore the committee have not repeated it here.
Allergy UK	Guideline	051	021	Safe food choices are key for children with food allergies. Staff training on allergen management is vital to ensure that staff preparing, cooking and serving food understand the difference between an allergy and intolerance and the consequences.	Thank you for your comment. This is a recommendation about improving staff understanding of EHC plans. As such it would not be appropriate to include anything about staff training on allergen management.

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				Children with multiple food allergies is not uncommon and will need particular care when planning and providing for meals, snacks and drinks in different settings. Training priorities include catering staff having food allergen awareness training and Health and Social Care having undertaken a course in first aid that includes allergy management (that covers use of adrenaline auto-injectors e.g. EpiPen). The emphasis should be on a whole organisational approach to allergen awareness and individual risk assessments undertaken and guidelines established. Nut or allergen free environments are not advisable or practicable.	
Allergy UK	Guideline	055	002	Positive experiences can be life changing and transformational whilst negative experiences can have a detrimental impact on families and lead to break down in relationships/communication and trust between care providers and families. It is important that all service providers seek to promote positive experiences and advocate for those with allergies.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health.
Association for Dance Movement Psychotherapy UK	Guideline	005	015	Rec 1.1.5 notes that children and young people should be encouraged to 'give their views on their care, education and support, and express what they want and need.' However, we note that there is no provision within the guidelines to make any recommendations for the therapies that have been shown to support children and young people's communication skills. We are concerned that the recommendation will be	Thank you for your comment and the references you have provided. The committee drafted this recommendation in response to qualitative evidence indicating that support for a child or young person to express their wishes is sometimes inadequate. A systematic review focusing on strategies to involve children and young people in the planning of their care and education was conducted however, the articles to which you refer would not have been included in this for the following reasons: Aithal, et

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				implemented to varying degrees across services if no evidence base for suitable interventions to aid communication is offered in the guideline. In particular there is an absence of any links to other NICE guidelines for reference to interventions. We would like to highlight the evidence that demonstrates how Dance Movement Psychotherapy has been shown to help children and young people with SEN to improve social communication with a randomised controlled trial by Aithal et al (2021a) next to other qualitative studies (Wengrower, 2010; Samaritter, 2015; Devereaux, 2017; Athanasiadou & Karkou, 2017). Moreover, studies have shown promising results on the social wellbeing of children with ASD irrespective of whether they preferred verbal or non-verbal mode of communication. Eight out of nine studies mentioned the effects of Dance Movement Psychotherapy on improving different social and communication skills in the systematic review conducted by Aithal et al., (2021b). Positive impact on awareness of personal boundaries, relationship with the therapist, entering group relationship, understanding of social dynamics and social relatedness were noted in many studies	al., (2021a); Aithal, et al., (2021b); DeJesus, et al., (2020); López-Ortiz, et al., (2019); Morris, et al., (2021); Samaritter (2015); and Sharda, et al., (2018) focus on the impact of dance movement psychotherapy on wellbeing rather than its use as a communication tool in the context of care and education planning. In addition, they do not report on any of the outcomes specified in the review protocol. Athanasiadou, et al., (2017); Devereaux, C. (2017); Houghton, et al. (2016); and Wengrower (2010) would not have been included, as they do not report quantitative effectiveness data on interventions.

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				(Samaritter, 2015; Houghton & Beebe, 2016; Athanasiadou & Karkou, 2017; Devereaux, 2017). Significant improvement in Social Engagement and Attunement Movement (SEAM) observation scale and scores obtained on a social questionnaire administered pre-post therapy in Samaritter (2015) thesis. The measurement of social behaviours through questionnaires and self-report indicated that improvement was not limited just to the therapeutic setting; instead the participants were able to generalise it to their real life as well. Another systematic review with 11 studies focusing on children with cerebral palsy indicated the potential for dance and movement to have positive impacts on emotional expression, social participation, and attitudinal change (Lopez-Ortiz et al., 2018). Overall, the findings from a range of studies reflect that regardless of the heterogenous spectrum of abilities presented by children, Dance Movement Psychotherapy has been successful to further social and communication aspects of the children within a short period. This is likely because the non-verbal elements promoted in Dance Movement Psychotherapy cannot only enhance non-verbal	

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				expressions but can facilitate verbal communication as well. Furthermore, specific elements of Dance Movement Psychotherapy have been shown to be particularly effective for communication and social development including mirroring- and rhythm-based interventions (Morris et al., 2021). The results are coherent with the notion that the creative arts, in general, encourage social communication, which may otherwise be impeded by sensory, motor and social difficulties (Sharda et al., 2018; DeJesus et al., 2020). Aithal, S., Karkou, V., Makris, S., Karaminis, T., & Powell, J. (2021a). A Dance Movement Psychotherapy Intervention for the Wellbeing of Children With an Autism Spectrum Disorder: A Pilot Intervention Study, Frontiers in Psychology,12. https://doi.org/10.3389/fpsyg.2021.588418 Aithal, S., Moula, Z., Karkoum V., Karaminis, T., Powell, J. & Makris, S. (2021b). A Systematic Review of the Contribution of Dance Movement Psychotherapy towards the Wellbeing of Children with Autism Spectrum Disorder. Frontiers in Psychology (Accepted). doi: 10.3389/fpsyg.2021.719673.	

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				Athanasiadou, F., & Karkou, V. (2017). Establishing Relationships with Children with Autism Spectrum Disorders through Dance Movement Psychotherapy: A Case Study using Artistic Enquiry. The Rhythm of Relating in Children's Therapies, 272–292. DeJesus, B. M., Oliveira, R. C., Carvalho, F. O., Jesus Mari, J., Arida, R. M. & Lavinia Teixeira-Machado. (2020). Dance promotes positive benefits for negative symptoms in autism spectrum disorder (ASD): A systematic review. Complementary Therapies in Medicine. 49. https://doi.org/10.1016/j.ctim.2020.102299. Devereaux, C. (2017). Educator perceptions of dance/movement therapy in the special education classroom. Body, Movement and Dance in Psychotherapy, 12(1), 50–65. https://doi.org/10.1080/17432979.2016.1238011 Houghton, R., & Beebe, B. (2016). Dance/Movement Therapy: Learning to Look Through Video Microanalysis. *American Journal of Dance Therapy*, *38*(2), 334–357. https://doi.org/10.1007/s10465-016-9226-0	

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				López-Ortiz, C., Gaebler-Spira, D.J., Mckeeman, S.N., Mcnish, R.N. and Green, D. (2019), Dance and rehabilitation in cerebral palsy: a systematic search and review. Dev Med Child Neurol, 61: 393-398. https://doi.org/10.1111/dmcn.14064 Morris, P., Hope, E., Foulsham, T. et al. (2021). The Effectiveness of Mirroring- and Rhythm-Based Interventions for Children with Autism Spectrum Disorder: a Systematic Review.Rev J Autism Dev Disorders. https://doi.org/10.1007/s40489-021-00236-z Samaritter, R. (2015). Inside the Mirror: Effects of attuned dance-movement intervention on interpersonal engagement as observed in changes of movement patterns in children and adolescents with autism spectrum disorder. Dissertation. [Doctoral Thesis]. Edge Hill University. Sharda, M., Tuerk, C., Chowdhury, R. et al. (2018) Music improves social communication and auditory–motor connectivity in children with autism. Transl Psychiatry 8, 231. https://doi.org/10.1038/s41398-018-0287-3	

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				Wengrower, H. (2010). I am here to move and dance with you' dance movement therapy with children with autism spectrum disorder and pervasive developmental disorders. In In V. Karkou (Ed.), Arts therapies in schools (pp. 179–196). Jessica Kingsley	
Association for Dance Movement Psychotherapy UK	Guideline	014	011	Rec 1.2 makes no mention of the point of diagnosis and how this is delivered to caregivers. Furthermore, there is no mention of the kinds of language that is used, for example, the damaging medicalised language around disability. There is a body of qualitative evidence that makes recommendations for good practice (Hallberg et al, 2010; Acharya, 2011), and evidence of how this can be implemented in Dance Movement Psychotherapy practice (Frizell 2017; Frizell 2020). Acharya, K. 2011. "Prenatal Testing for Intellectual Disability: Misperceptions and Reality with Lessons from down Syndrome." Developmental Disabilities Research Reviews 17 (1): 27–31. doi:10.1002/ddrr.135. Frizell, C. (2017) Entering the World: Dance Movement Psychotherapy and the Complexity of Beginnings with Learning Disabled Clients. In, Unkovich, G., Buttee C. and Butler, J. (eds.) (2017) Dance Movement Psychotherapy with People with Learning Disabilities:	Thank you for your comment and the references you have provided. The committee agree that communication around diagnoses, and the language used in this context is important and have made recommendations on this in the section on 'Communication formats and providing information. NICE guidelines are developed using the methods described in the 2018 NICE guidelines manual. The recommendations in section 1.2 ('Identifying needs and involving other services') were drafted by the committee after considering the evidence presented to them in two systematic reviews evidence review C: combined approaches to identifying, assessing and monitoring needs and evidence review K: barriers and facilitators of joined-up care. Studies are included in systematic reviews according to pre-specified criteria regarding a number of characteristics such as study objectives, methodology, population, outcomes reported, etc. The papers that you have cited would therefore not have been included, as they do not address the research questions agreed by the committee for either of these reviews. Frizell C (2020) and Hallberg U (2010) both report on parental views regarding the diagnosis of their child with Down's syndrome, which is not within scope for this guideline. In addition, Acharya K (2011) and Frizell C (2017) would not have been included in any of the

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				Out of the Shadows, into the Light. Abingdon, Routledge, pp. 9-21. Frizell, C. (2020): Learning disability imagined differently: an evaluation of interviews with parents about discovering that their child has down's syndrome, Disability & Society, DOI: 10.1080/09687599.2020.1816904 Hallberg, U., S. Oskarsdottir, and G. Klingberg. 2010. "22q11 Deletion Syndrome—The Meaning of a Diagnosis. A Qualitative Study on Parental Perspectives." Child: care, Health and Development 36 (5): 719–725. doi:10.1111/j.1365-2214.2010.01108.x.	reviews, as they do not report primary research (or a systematic review of primary research).
Association for Dance Movement Psychotherapy UK	Guideline	019	006	Rec 1.3.10 notes that during EHC assessments, practitioners 'take into account the child or young person's age, level of 7 understanding, communication needs and specific circumstances.' There is no mention of specialised services that can support assessments where verbal communication is more difficult or links to other NICE guidelines that can advise. Dance Movement Psychotherapy can be particularly valuable in assessment when verbal communication is more difficult to access. This is evidenced particularly in Hoo (2017) & Lebre et al, (2020).	Thank you for your comment and the references you have provided. The committee recognise the importance of adapting communication styles when working with a child or young person during an EHC assessment, particularly when verbal communication is difficult. No evidence was identified (meeting the pre specified inclusion criteria) which evaluated the use of dance therapy as part of the EHC needs assessment process and therefore the committee are not able to recommend it. NICE guidelines are developed using the methods described in the 2018 NICE guidelines manual. The recommendations in section 1.2 ('Identifying needs and involving other services') were drafted by the committee after considering the evidence presented to them in two systematic reviews evidence review C: combined approaches to identifying, assessing

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				Hoo, F. (2017) DMP assessments for children and young people with learning disabilities and special needs. In Unkovich, G., Buttee C. and Butler, J. (eds.) (2017) Dance Movement Psychotherapy with People with Learning Disabilities: Out of the Shadows, into the Light. Abingdon, Routledge Lebre, P., Dunphy, K., & Juma, S. (2020). Exploring use of MARA (Movement Assessment and Reporting App) to establish group objectives for psycho-motor interventions, *Body, Movement, Dance and Psychotherapy.* https://doi.org/10.1080/17432979.2020.1806926	and monitoring needs and evidence review K: barriers and facilitators of joined-up care. Hoo (2017) would not have been included in these reviews, as it does not report primary research. Lebre, et al. (2020) would not have been included in these reviews as it does not report on the identification, assessment, or monitoring of combined health, social care and education needs that is required as part of the EHC process and is not comparative.
Association for Dance Movement Psychotherapy UK	Guideline	022	016	Rec 1.4.9 notes that 'practitioners should distinguish between what therapeutic support is needed' although makes no mention of what therapeutic support is shown to be effective nor makes any recommendations or links to other NICE guidelines that do. There is a whole body of evidence of how Dance Movement Psychotherapy can enhance the lives of disabled people and their families (Unkovich et al, 2017). In particular we would like to highlight a recent RCT (Cofini et al, 2021) that offers strong evidence to	Thank you for your comment and the references you have provided. The committee recognise the positive impact that therapeutic support can have on the lives of children and young people with severe complex needs. However, this guideline focuses on integrated service delivery and organisation between health, social care and education. As such, looking at the effectiveness of specific interventions, such as Dance Movement Psychotherapy, does not fall within the scope of this work and the papers you have referenced would not therefore have been included in the systematic reviews that the committee used as the basis for their recommendations.

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				show that Dance Movement Psychotherapy can improve quality of life and psychological wellbeing, increase self-esteem, concentration and attention and improve emotional recognition in children with SEN. There is also evidence to show that Dance Movement Psychotherapy can improve vocabulary, social communication and self-regulation (Wengrower, 2010; Samaritter, 2015; Devereaux, 2017; Athanasiadou & Karkou, 2017; Leung 2021; Aithal et al, 2021) Aithal, S., Karkou, V., Makris, S., Karaminis, T., & Powell, J. (2021). A Dance Movement Psychotherapy Intervention for the Wellbeing of Children With an Autism Spectrum Disorder: A Pilot Intervention Study, Frontiers in Psychology,12. https://doi.org/10.3389/fpsyg.2021.588418 Athanasiadou, F., & Karkou, V. (2017). Establishing Relationships with Children with Autism Spectrum Disorders through Dance Movement Psychotherapy: A Case Study using Artistic Enquiry. The Rhythm of Relating in Children's Therapies, 272–292. Cofini, V., Cianfarani, A., Cecilia, M. R., Carbonelli, A., & Di Giacomo, D. (2021). Impact of dance therapy on children with specific learning disability: A two-arm	

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				cluster randomized control study on an Italian sample. Minerva Pediatrics, 73(3), 243-250. doi:10.23736/S2724-5276.18.05249-0 Devereaux, C. (2017). Educator perceptions of dance/movement therapy in the special education classroom. Body, Movement and Dance in Psychotherapy, 12(1), 50–65. https://doi.org/10.1080/17432979.2016.1238011 Leung, A. (2021). The Impact of a Movement-based Emotional Self-Regulation Programme on Adolescents with Special Educational Needs During the Transition Period from School to Post-School in Hong Kong. PhD Thesis., Available at: http://hdl.handle.net/2299/23940 Samaritter, R. (2015). Inside the Mirror: Effects of attuned dance-movement intervention on interpersonal engagement as observed in changes of movement patterns in children and adolescents with autism spectrum disorder. Dissertation. [Doctoral Thesis]. Edge Hill University. Wengrower, H. (2010). I am here to move and dance with you' dance movement therapy with children with autism spectrum disorder and pervasive	

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				developmental disorders. In In V. Karkou (Ed.), Arts therapies in schools (pp. 179–196). Jessica Kingsley Unkovich, G., Buttee C. and Butler, J. (eds.) (2017) Dance Movement Psychotherapy with People with Learning Disabilities: Out of the Shadows, into the Light. Abingdon, Routledge	
Association for Dance Movement Psychotherapy UK	Guideline	023	001	Rec 1.4.10 notes that 'Commissioners must use the information in sections F, G and H of the EHC plan to commission the services the child or young person needs.' We are concerned that no mention is made in the guideline for the provision of any services that have been shown to support the educational, health and social needs of children and young people with disabilities.	Thank you for your comment. The focus of this guideline is about providing integrated care. It is therefore not within the scope to recommend particular interventions.
Association for Dance Movement Psychotherapy UK	Guideline	023	017	Rec 1.4.13-1.4.15 states that children's and young peoples' views should be recording using 'their preferred communication format'. We would like to highlight that all Dance Movement Psychotherapists are trained to have the skills to listen to communication other than the verbal and so have a clear role to play in these processes.	Thank you for your comment and providing this information.
Association for Dance Movement Psychotherapy UK	Guideline	028	020	1.6.1 'Direct families and carers to sources of emotional and practical support, to help them come to terms with their child's needs and diagnosis (or lack of diagnosis).'	Thank you for your comment and the references you have provided. The committee made this recommendation as they agreed on the importance of practical and emotional support for parents. However, this guideline focuses on integrated service delivery and organisation between health, social care and education, and the intent of the

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				At early years of the child's development, the process of obtaining a diagnosis, understanding and accepting the diagnosis, looking for suitable interventions, attending frequent appointments, and dealing with the child's communication and behaviour difficulties can be painful and a major source for stress among primary caregivers (Greeff & van der Walt, 2010). Previous studies and systematic reviews in Dance Movement Psychotherapy show that it has the potential to encourage clients to discover their innate strengths and resources toward achieving personal growth and recovery (Shim et al., 2017; Athanasiadou & Karkou., 2017; Wengrower, 2015; Samaritter, 2015; Harris, 2007) and many other researchers in Dance Movement Psychotherapy have described improvements in resilience in a wide range of client population. A study conducted by Ayvazoglu et al. (2015) on the physical activity levels of parents of children on the autism spectrum indicate that they were largely inactive due to the physical and emotional demands of the family. Parents reported that they did not manage to find time to be physically active because of the time spent commuting from one therapy to another for their children. At the same time, as relevant research literature suggests (Tomporowski, 2003; Pan et al.,	recommendation is to ensure that practitioners consider whether this type of support is needed and direct parents to it where it is available. Therapy for parents is not within the scope of this guideline and the committee did not review evidence on the effectiveness of specific interventions in this context. As a result, the references you have cited on Dance Movement Psychotherapy would not have been included in the systematic reviews that the committee used as the basis for their recommendations. For more information regarding the evidence underpinning these recommendations please see the three systematic reviews presented to the committee - evidence review A: views and experiences of service users; evidence review D: supporting families and carers; and evidence review K: barriers and facilitators of joined-up care.

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				2005; Lubans et al., 2016; Yeh et al., 2016), physical activity levels can be directly linked with the overall wellbeing of a person. Therefore, dance movement psychotherapy, a movement-based psychological intervention, can play a role in supporting parents. A study in India (Aithal et al., 2020, Aithal et al., 2019) identified reduction in stress and depression measures and also provided a theoretical framework to identify the process of resilience enhancement through Dance Movement Psychotherapy in parents of children with ASD. The model that emerged from the study, consisted of multiple themes which traced the journey of the participants (6 themes); therapeutic and contextual factors (10 themes); and perceived outcomes of Dance Movement Psychotherapy (11 themes). The key take away message from the responses of the caregivers was that, in addition to psychoeducational aspects, interventions like Dance Movement Psychotherapy that can promote self-care, relationship with their children and emotional wellbeing are very necessary. In the doctoral thesis (Aithal et al., 2020), that involved 37 SEN teachers, teaching assistants and parents achieved Minimal clinically important differences (MCID) was achieved for both outcome measures used in the study i.e. Parenting Stress Index-Short Form (PSI-SF) and Adult Wellbeing	

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				Scale (AWS) in the Dance Movement Psychotherapy intervention group but not the control group. Aithal, S., Karkou, V., Kuppusamy, G. & Mariswamy, P. (2019) Backing the backbones—A feasibility study on the effectiveness of dance movement psychotherapy on parenting stress in caregivers of children with Autism Spectrum Disorder. The Arts in Psychotherapy, (64), pp.69-76. https://doi.org/10.1016/j.aip.2019.04.003. Aithal, S., Karkou, V., & Kuppusamy, G. (2020). Resilience enhancement in parents of children with an autism spectrum disorder through dance movement psychotherapy. The Arts in Psychotherapy, (71). https://doi.org/10.1016/j.aip.2020.101708. Athanasiadou, F., & Karkou, V. (2017). Establishing Relationships with Children with Autism Spectrum Disorders through Dance Movement Psychotherapy: A Case Study using Artistic Enquiry. The Rhythm of Relating in Children's Therapies, 272–292. Ayvazoglu, N. R., Kozub, F. M., Butera, G. & Murray, M. J. (2015). Determinants and challenges in physical activity participation in families with children with high	

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				functioning autism spectrum disorders from a family systems perspective. Research in Developmental Disabilities. 47, pp93-105. https://doi.org/10.1016/j.ridd.2015.08.015. Greeff, A., & Van der Walt, K. (2010). Resilience in Families with an Autistic Child. Education and Training in Autism and Developmental Disabilities, 45(3), 347-355. Retrieved September 13, 2021, from http://www.jstor.org/stable/23880109 Harris, D. A. (2007). Dance/movement therapy approaches to fostering resilience and recovery among African adolescent torture survivors. *Torture: Quarterly Journal on Rehabilitation of Torture Victims and Prevention of Torture*, *17*(2), 134–155. Lubans, D., Richards, J., Hillman, C., Faulkner, G., Beauchamp, M., Nilsson, M., Kelly, P., Smith, J., Raine, L., & Biddle, S. (2016). Physical Activity for Cognitive and Mental Health in Youth: A Systematic Review of Mechanisms. *PEDIATRICS*, *138*. https://doi.org/10.1542/peds.2016-1642 Pan, C.-Y., Frey, G. C., Bar-Or, O., & Longmuir, P. (2005). Concordance of Physical Activity Among	

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				Parents and Youth with Physical Disabilities. *Journal of Developmental and Physical Disabilities*, *17*(4), 395–407. https://doi.org/10.1007/s10882-005-6622-7 Samaritter, R. (2015). Inside the Mirror: Effects of attuned dance-movement intervention on interpersonal engagement as observed in changes of movement patterns in children and adolescents with autism spectrum disorder. Dissertation. [Doctoral Thesis]. Edge Hill University. Shim, M., Johnson, R. B., Gasson, S., Goodill, S., Jermyn, R., & Bradt, J. (2017). A model of dance/movement therapy for resilience-building in people living with chronic pain. *European Journal of Integrative Medicine*, *9*, 27–40. https://doi.org/10.1016/j.eujim.2017.01.011 Tomporowski, P. D. (2003). Cognitive and Behavioral Responses to Acute Exercise in Youths: A Review, Pediatric Exercise Science, 15(4), 348-359. Retrieved Sep 13, 2021, from https://journals.humankinetics.com/view/journals/pes/15/4/article-p348.xml Wengrower, H. (2010). I am here to move and dance with you' dance movement therapy with children with	

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				autism spectrum disorder and pervasive developmental disorders. In In V. Karkou (Ed.), Arts therapies in schools (pp. 179–196). Jessica Kingsley Yeh, H.-P., Stone, J. A., Churchill, S. M., Wheat, J. S., Brymer, E., & Davids, K. (2016). Physical, Psychological and Emotional Benefits of Green Physical Activity: An Ecological Dynamics Perspective. *Sports Medicine*, *46*(7), 947–953. https://doi.org/10.1007/s40279-015-0374-z	
Birmingham Women's and Children's Hospital	Guideline	General	General	I think it's a really good document, I like the level of detail in terms of putting it into practice. I think it will be a challenge in Birmingham as we are nowhere near there yet.	Thank you for your comment and your support of the guideline
Birmingham Women's and Children's Hospital	guideline	General	General	The layout could be more user friendly and involve colour and segmentation.	Thank you for your comment. The guidance has been broken up into sections, as demonstrated by the contents page. It is not NICE style to use colour in the recommendations.
Birmingham Women's and Children's Hospital	guideline	004 onwards		Section 1 Really like the focus on involving the child and young person at the start of the guidance	Thank you for your comment and support for the recommendations.
Birmingham Women's and	Guideline	004	General	Working together and MDT is key and vital in being able to make any progress with families	Thank you for your comment and your support for the recommendations.

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Birmingham Women's and Children's Hospital	Guideline	004	General	Working together and MDT is key and vital in being able to make any progress with families	Thank you for your comment and your support for the recommendations.
Birmingham Women's and Children's Hospital	Guideline	005	General	Consider different ways to involve the family, technology, writing, face to face. Use of an interpreter or an advocate (ideally independent) to support the family. Where possible face to face meetings, but consider if technology could be used if a meeting is needed sooner. If the family have legal teams involved along with PALS and complaints where do they fit into this?	Thank you for your comment. The committee have amended recommendation 1.1.4 to reflect getting the input of children and young people in the format that is most suitable for them (including virtual meetings and other accessible options). It is not possible for the guideline to make recommendations on all possible eventualities and so the committee have not added anything about when legal teams or PALS are involved. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
Birmingham Women's and	Guideline	005	General	Consider different ways to involve the family, technology, writing, face to face. Use of an interpreter or an advocate (ideally independent) to support the	Thank you for your comment. The committee have amended recommendation 1.1.4 to reflect getting the input of children and young people in the format that is

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Children's Hospital				family. Where possible face to face meetings, but consider if technology could be used if a meeting is needed sooner. If the family have legal teams involved along with PALS and complaints where do they fit into this?	most suitable for them (including virtual meetings and other accessible options). It is not possible for the guideline to make recommendations on all possible eventualities and so the committee have not added anything about when legal teams or PALS are involved. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
Birmingham Women's and Children's Hospital	Guideline	006	General	Consider if LD is needed and involved. Independent advocate might be useful. MDT meetings which start on a journey of a patient and then continue until the end and then follow on into the community. Notes are important to summarise meetings and ensure dissemination of them. Parents having copies of notes of meetings- Do they need to be transcribed? Who does this and How?	Thank you for your comment. The committee are not clear what you are referring to when you cite 'consider if LD is needed and involved'. If you mean that the child or young person or their parents have learning disabilities/difficulties, such instances would be covered by the recommendations about establishing the child or young persons preferred communication format and using it and a new recommendation raising awareness that parents may have communication difficulties of their own. The committee are also not clear of the relevance of your comment about MDTs in relation to recommendations about communication formats.

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					Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard. The section on 'Planning and running meetings' already contains recommendations about recording meetings and action points and sharing these with the child or young person and their family. It will be a matter for local implementation to determine if these need to be transcribed and how this will happen if so.
Birmingham Women's and Children's Hospital	Guideline	006	General	Consider if LD is needed and involved. Independent advocate might be useful. MDT meetings which start on a journey of a patient and then continue until the end and then follow on into the community. Notes are important to summarise meetings and ensure dissemination of them. Parents having copies of notes of meetings- Do they need to be transcribed? Who does this and How?	Thank you for your comment. The committee are not clear what you are referring to when you cite 'consider if LD is needed and involved'. If you mean that the child or young person or their parents have learning disabilities/difficulties, such instances would be covered by the recommendations about establishing the child or young persons preferred communication format and using it and a new recommendation raising awareness that parents may have communication difficulties of their own. The committee are also not clear of the relevance of your comment about MDTs in relation to recommendations

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					about communication formats. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard. The section on 'Planning and running meetings' already contains recommendations about recording meetings and action points and sharing these with the child or young person and their family. It will be a matter for local implementation to determine if these need to be transcribed and how this will happen if so.
Birmingham Women's and Children's Hospital	Guideline	006	019	Not enough to simply translate, we need to be advocating for the parents with limited language skills to be improving verbal and written English as this has a direct impact on outcomes. There is an evidence base for this when I last looked in diabetes for adults. I am not sure of the strength of evidence but I see it in practice and it makes sense as accessing support for health, education and social support often is impacted by literacy and verbal language skills in any setting.	Thank you for your comment. The guideline literature searches identified evidence (Evidence report K, subtheme 2.2) that language barriers made it difficult for parents to find out about available services. However, the guideline did not look for evidence on the effectiveness of parents and carers learning English if this is not their first language and therefore the committee are not able to make recommendations in this area.

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Birmingham Women's and Children's Hospital	Guideline	008	General	Consider Interpreter, clear TOR, Agenda, Where it needs to be held and Who needs to be there?, Does an advocate need to be present?, Key worker or not-Do the patient and family need one??	Thank you for your comment. Where meetings should be held, who needs to attend, what to think about when planning meeting agendas are covered in other recommendations in this section. Recommendations about providing key working support are in section 1.15. The committee have covered the potential need for an interpreter in the section on 'Communication formats and providing information'. Having a clear Terms of Reference would be part of standard practice and the committee do not think it needs to be included here. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
Birmingham Women's and Children's Hospital	Guideline	008	General	Consider Interpreter, clear TOR, Agenda, Where it needs to be held and Who needs to be there?, Does an advocate need to be present?, Key worker or not-Do the patient and family need one??	Thank you for your comment. Where meetings should be held, who needs to attend, what to think about when planning meeting agendas are covered in other recommendations in this section. Recommendations about providing key working support are in section 1.15. The committee have covered the potential need for an interpreter in the section on 'Communication formats and providing information'. Having a clear Terms of Reference

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					would be part of standard practice and the committee do not think it needs to be included here. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
Birmingham Women's and Children's Hospital	Guideline	009	009	Include the option of a virtual appointment via video or telephone if available. This can be done from school if permission is sought.	Thank you for your comment. The committee have added the option for virtual appointments.
Birmingham Women's and Children's Hospital	Guideline	010		There is a standard that all children who are able be offered a confidential consultation on their own +/- chaperone. I do this for all children above 13. The parents are asked to consent and the consultation is confidential and not disclosed to the parent unless there are safeguarding issues. This understanding is discussed before seeing the young person on their own. (perhaps can incorporate to 1.138	Thank you for your comment. The committee have added to the recommendation that practitioners should support the child and parent to understand each others perspectives, but not been prescriptive about how this could happen. A confidential consultation could be a method that is uses.
Birmingham Women's and	Guideline	012	General	Does PALS, Complaints or legal team have a role within this?	Thank you for your comment. PALS, Complaints or a legal team would be involved if someone had done something wrong. These recommendations are trying to make sure

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Children's Hospital					things are done correctly from the start so involvement from PALS, Complaints or a legal team shouldn't be needed. Therefore the committee have not amended the recommendation. However it should be noted that even though the guideline doesn't refer to these services, this would not stop parents or children and young people from accessing them if they wanted to.
Birmingham Women's and Children's Hospital	Guideline	013	General	Secure source of information sharing- NHS.Net accounts etc, clear purpose discussion in email for parents viewing. Upload correspondence to a central point so it's clear for information sharing between professionals. Highlight any information that is of a sensitive nature.	Thank you for your comment. The evidence reviews conducted for this guideline did not support making recommendations about the use of specific systems to share information.
Birmingham Women's and Children's Hospital	Guideline	014		I would recommend additional detail about Children's social care responsibilities and the role of SC Children's Disability teams. I also think there needs to be reference to the thresholds for section 17 assessments and plans, and what that means for children and families.	Thank you for your comment. Not all local areas will have a SC Children's Disability Team and thresholds for provision under section 17 and the Chronically Sick and Disabled Persons Act 1970 vary according to area so the guideline cannot provide additional detail. Responsibilities for children's social care are covered by statutory guidance.
Birmingham Women's and Children's Hospital	Guideline	014	013	Section 1.2.1 We have looked at a toolkit to identify additional needs	Thank you for your comment and providing this information.
Birmingham Women's and Children's Hospital	Guideline	016	General	Early referals to relevant or anticpated teams. Consider processes such as EHelp or social care. Information sharing with teams to ensure that external agencies are part of the discussion.	Thank you for your comment. Early referrals to other teams are covered by recommendations 1.2.3 and 1.2.5. No evidence on EHelp was identified by the literature searches conduced for this guideline and therefore is not able to make any recommendations about it.

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Birmingham Women's and Children's Hospital	Guideline	027	General	Challenge when referral is refused or questioned and escalate. Consent must be required and obtained Clear sentence at start of the referral for the reason for the referral	Thank you for your comment. The committee consider that the points you raise are covered within the existing wording.
Birmingham Women's and Children's Hospital	Guideline	028	General	What support does the family need- Advocate, FSW? Does the family need a broker to support with the PHB if I the family need assistance with the direct payment or PHB? Is there a role for psychology? Is an advocate useful? Is there a role of a family support worker to assist with navigation? Key worker?	Thank you for your comment. The exact support that will be needed will depend on the family and their individual circumstances and it is not possible to cover all possibilities in a recommendation. This is why the committee have recommended directing families to relevant sources of support.
Birmingham Women's and Children's Hospital	Guideline	028	General	Who is responsible for training? Bespoke needs of families- LD or not? What ways can training be given?- Simulation, training rooms? Bespoke trainers who can give time and focussed attention? Face to face or virtual is there a need or a preference? Bespoke- one size doesn't fit all	Thank you for your comment. Who would need to lead the joint development of training would depend on what the training covered. It is not possible to specify this in a recommendation. Ensuring the training is appropriate to the needs of the family is already covered in recommendation 1.6.7. Flexibility in training formats is already covered in recommendation 1.6.11. Using different teaching styles is already covered in recommendation 1.6.8.
Birmingham Women's and Children's Hospital	Guideline	032	General	Who leads on this? Specialised person or team or is it the home team? MDT approach need to work together, any fragmentation causes big issues in trying to transition a child with multiple services What is the voice of the CYP?- What do they want? What works for them?	Thank you for your comment. The committee did not find any evidence to support making a recommendation about specialised roles, teams, home teams or MDTs in relation to transition from children's to adults' services. However, the recommendations made in the guideline should help to make the approach to transition more co-ordinated. The

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					recommendations in section 1.1. already cover finding out what children and young people want.
Birmingham Women's and Children's Hospital	Guideline	035	General	Consideration of the main focus and issue Work with the socio economic factors (i.e- housing, finance etc) Don't loose the main focus of the discharge of the patient and their wishes and desires Is there a role of a play worker, FSW?	Thank you for your comment. The focus of this review question was establishing what combined health, social care and education service delivery arrangements can best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance care plan, and for the needs of their families and carers. Recommendations 1.9.4 and 1.9.5 already cover the need to focus on what the child or young person wants. The role of play workers and FSWs are outside the protocol for this review question and so the committee cannot make recommendations about them. No evidence was found by the guideline literature searches on housing and finance in relation to palliative and end of life care and so the committee have not made any recommendations about these.
British Academy of Audiology	Easy Read	General	General	We worry this document is too complex for the intended audience. Many children or young adults with severe complex needs might not be able to understand this document.	Thank you for your comment. The committee have passed your comment on to the NICE publishing team for further consideration.
British Academy of Audiology	Easy Read	008	Last bullet	"Communicate" means how you share information. It includes **listening**, speaking and writing.	Thank you for your comment. The committee have passed your comment on to the NICE publishing team for further consideration.
British Academy of Audiology	Easy Read	018		The sentence at the top is too long and complex.	Thank you for your comment. The committee have passed your comment on to the NICE publishing team for further consideration.

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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British Academy of Audiology	Guideline	General	General	Many of the recommendations made in this document would support improved experiences for all adults in a health and social care setting to promote shared decision making.	Thank you for your comment. The scope of this guideline restricts it to making recommendations for Disabled children and young people up to 25 with severe complex needs. Therefore the committee are not able to make recommendations for the group you suggest even though many of our recommendations may also be appropriate for that group.
British Academy of Audiology	Guideline	General	General	This is a great and much needed guideline. However, we worry that already overstretched social and health services will struggle to meet these recommendations. Could NICE and other organisations share information, knowledge, templates, protocols etc to help teams follow the guideline? Could webinars be arranged to support a better understanding of different roles of professionals? Could patient experiences be shared to provide motivation for a service to prioritise making changes to comply with these guidelines?	Thank you for your comment. The committee have passed your comment onto the NICE team, which plan implementation support.
British Academy of Audiology	Guideline	037	Section 1.10	It would be helpful if the term "communication aids" could be defined at the start of this section, as to some health care practitioners, this may have other connotations. For example, from an audiological standpoint, a hearing aid (or hearing aid-compatible accessory) would constitute a "communication aid". Perhaps some consideration of hearing aids (or visual aids) is warranted here. Maybe this could be mentioned in the document at some point with links to the NICE adult hearing loss guideline and/or National Deaf Children's Society (NDCS) guides? Staff and parents need training in the maintenance of these	Thank you for your comment. The committee have added a definition of a communication aid to the terms used section of the guideline. The relevant recommendations about communication aids are intended to apply to all aids, which would include hearing aids.

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				devices in the same way as other communication aids, so many statements in this section are relevant to hearing aids.	
British Academy of Audiology	Guideline	037	Section 1.10	Receptive communication is as important as expressive communication. Could there be a more explicit bullet on receptive communication, possibly with a statistic about the prevalence of hearing or vision difficulties in children with complex needs (see https://www.ndcs.org.uk/media/1829/ear_foundation_additional__disabilities-_literature_review.pdf)? This would be a good opportunity to remind practitioners/staff involved in care for this group of the strong link to vision and hearing issues.	Thank you for your comment. The review question investigated by the guideline was 'What are the most effective practices (for example, environmental assessments and use of equipment such as assistive technology across different contexts) to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education?'. The guideline review questions did not look for evidence on receptive communication or strategies for dealing with vision/hearing issues. Therefore the committee are not able to make recommendations in these areas.
British Academy of Audiology	Guideline	051	Section 1.15.20	Could the list include an additional recommendation of training on the prevalence of sensory loss, available referral options to various sensory services, adaptions and support mechanisms (e.g., hearing aids)?	Thank you for your comment. The areas for training covered in this recommendation were identified by the reviews of the qualitative evidence (see evidence reports A, K and M). The areas you cite in your comment were not identified by the evidence and so the committee have not made this change.
British Academy of Childhood Disability	Guideline	General	general	BACD welcomes this document, to highlight key issues in providing interagency care for CYP with complex needs	Thank you for your comment and your support of the guideline
British Academy of Childhood Disability	Guideline	General	general	Development of the principles of CYP and their parents as equal partners in care cordinations, with all agencies is valuable, please ensure that the equality extends to not expecting parent-carers to be able to do more than professionals involved, especially when they	Thank you for your comment. The committee think that implementation of the recommendations made in this guideline should resolve the issue you describe.

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				may be sleep deprived, and being expected to do highly skilled cares and medical interventions.	
British Academy of Childhood Disability	Guideline	General	general	The training sections for parents and professionals need to emphasise, the role of parents and CYP in training others, resources should be co-produced with expert parents and carers, and 3rd sector charitable organisations. Families will have expertise and lived experience, highly valuable for training professionals. Families will likely benefit from learning from other families as well as professionals.	Thank you for your comment. The committee have revised the recommendations where necessary to emphasise the need for children and young people and their families and carers to be involved in the development of training.
British Academy of Childhood Disability	Guideline	029 - 030	general	The comments in the guidelines on accessibility of training are helpful. Online formats, such as pre-recorded videos and training sessions, and interactive group videos calls should be considered as they can help make training more accessible to busy families, save time for professionals and may make it easier for more than one parent/carer to attend. Families can also re-watch training videos as needed in the future.	Thank you for your comment. The recommendations on training are not prescriptive about the format that should be used which allows flexibility to use the format that best meets the needs of families and carers.
British Academy of Childhood Disability	Guideline	032 - 033	021 – 002	Transition plans should also be planned with children, young people, and families, not just practitioners. Further there needs to be clearer emphasis on delineation and identification of who the adult providers will be; from health, education and social care; and who has full legal or otherwise advocacy for the YP. There is no transition if it is not clear to whom the care is transitioned to.	Thank you for your comment. The committee were aware that services often complete their sections of the transition plan independently and that this can lead to a lack of alignment across sections and a transition plan that is not practical to implement. This was supported by qualitative evidence that transition lacked coordination and was experienced as a period of uncertainty and stress (see evidence report A, sub-themes 4.2 and 11.5; evidence report K, sub-theme 16.2). They therefore focussed the recommendation on practitioners to address this issue.

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British Academy of Childhood Disability	Guideline	004	015	1.1.1 Needs an additional bullet point: For children and young people with the most complex needs who are not able to actively participate in planning or decision-making, the views of those who know them best should also be taken into account, to ensure that the perspective of the child or young person is fully represented.	Thank you for your comment. The committee have added a recommendation about taking into account the views of those who know the child or young person best.
British Academy of Childhood Disability	Guideline	005	002	1.1.2 Again, needs a caveat to ensure that those with the most complex needs who cannot actively participate in discussions and decision-making have their views considered in a holistic way. Being present in a meeting may not be appropriate for all young people, who may find being in such a meeting distressing. This needs to be adequately acknowledged.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual. The committee have also added a new recommendation about taking into account the views of those who know the child or young person well in the section on 'Principles for working with children and young people and their families'
British Academy of Childhood Disability	Guideline	005	005	1.1.3 Whilst of course family members should be consulted and involved in decision-making, for children and young people with the most complex needs, the views of those who know the child or young person best should also be taken into account, i.e. a wider group than those with parental responsibility.	Thank you for your comment. This recommendation covers situations where it may not be appropriate to have a family member present (for example family breakdown). The committee have therefore not included a wider group as you suggest. However the reasons behind this recommendation have been clarified in the related rationale and impact section.
British Academy of Childhood Disability	Guideline	005	015	1.1.5 This is great for those who can be involved in expressing their views, but not all children can. This should be acknowledged and a statement should be	Thank you for your comment. The committee have added a new recommendation about taking into account the views of those who know the child or young person well in

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				included to ensure that for the group of children and young people who are not able to express their views, the views of those in the health and care team who know them best should be sought, along with the views of parent carers and those with parental responsibility, to ensure a full perspective is presented i.e. what the child or young person would have expressed for themselves, had they been able to do so.	the section on 'Principles for working with children and young people and their families'
British Academy of Childhood Disability	Guideline	008	002	1.1.20 This section should include a statement about the importance of assessing the appropriateness (or not) of the child or young person being present during meetings about them. Would being present cause them distress? Would being present lead to more meaningful ascertainment of their views (or not)? The current wording in the guideline assumes that the child or young person being present is always the right thing, but in reality for those with the most complex physical and/or emotional and/or sensory needs, this may not be the case. It is very important for this to be carefully considered ahead of any meetings, not just wheeling in the young person as a way of ticking a box about inclusion, as the child or young person may not be being included in reality and may find the experience negative and distressing.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involved attending meetings).
British Academy of Childhood Disability	Guideline	009	005	1.1.23 All of this is great, but not very practical for those who need to plan meetings for multiple children and young people, e.g. in special school settings. The way this is written, practice will 'fall short' more than it will reach	Thank you for your comment. This recommendation is to consider the preferences of the child or young person as far as possible. It may well be the case that it is not possible to deliver their preferences because of practical reasons, but consideration should at least be given to

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				the stated standard, as it will be impossible to arrange all meetings in the place of the child's choosing and out of school time. This recommendation needs to be reconsidered and written in a way that is more practical to deliver	seeing if it possible. There are also other recommendations in this section which cover what to do if practitioners cannot attend.
British Academy of Childhood Disability	Guideline	015	013	1.2.3 If you think a child or young person may have a special educational need, think more broadly about their circumstances and decide whether they need to be referred to other services. For example: • Could there be an underlying health condition, and do health services need to be involved? On this point, I would argue that it will only be known if the child or young person has health needs (or not) if a health assessment is completed by a health practitioner. It is not reasonable to expect education practitioners to assess as to whether a child *may* have health needs (or not). All children and young people who are suspected to have special educational needs should have access to a health assessment, e.g. with a paediatrician with expertise in SEND.	Thank you for your comment. The staff in question are not being asked to diagnose but to refer to the appropriate service for assessment. Educators are quite often the first professionals to pick up traits that turn out to have medical or health causes and they already identify possible health issues and make referrals.
British Academy of Childhood Disability	Guideline	021	003	1.4.1 In this section, for children and young people with the most complex needs who cannot express their own views or engage actively in discussions and decision-making, there should be consultation and engagement with all those who know the child or young person	Thank you for your comment. The committee have added a new recommendation to the section on 'Principles for working with children, young people and their families' about taking into account the views of those who know the child or young person well, for those who are not able to actively participate in planning or decision making. This is

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				best, to ensure that their holistic needs are fully represented, not just those with parental responsibility.	intended to apply throughout the guideline and therefore it has not been repeated in section 1.4.
British Academy of Childhood Disability	Guideline	023	003 – 008	What's the timeline for carrying out these plans and ensuring that the support is in place?	Thank you for your comment. Timeframes for producing EHC plans are included in the SEND code of practice so the committee have not repeated this information here. It is not within the remit of this guideline to specify timelines for implementing the required support.
British Academy of Childhood Disability	Guideline	023	022	1.4.15 Whilst this is appropriate for children and young people who have the mental capacity to understand, the statement needs to be more inclusive of children and young people who do not have such capacity, for example, by acknowledging that not all children and young people will have the capacity to understand the outcomes in their EHC plan.	Thank you for your comment. The final sentence of recommendation 1.4.15 already acknowledges that some children and young people may have difficulties in understanding the EHC plan content. However the committee thought it was still important to involve them as far as possible.
British Academy of Childhood Disability	Guideline	025	012 – 016	Parents/Carers/children and young people should be able to request a re-assessment if they feel things have changed.	Thank you for your comment. The committeehave clarified that this is a professional assessment not an EHC plan re-assessment. Therefore your suggested change has not been made.
British Academy of Childhood Disability	Guideline	032	014	1.8.3 This statement needs to be more inclusive of those young people who lack capacity to plan for adulthood, emphasising the importance of engaging with those who know the young person best, including but not restricted to, their parent carers, in the spirit of the best interests decision-making framework of the Mental Capacity Act.	Thank you for your comment. The committee have added another recommendation about those who lack capacity.
British Academy of	Guideline	049	011 – 006	Ensure that this change is communicated to the child, young person, and their family; Assign the new practitioner with child/young person/family input.	Thank you for your comment. The committee have added communicating the change to the recommendation. Getting input from the child or young person on who

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Childhood Disability					should be their new key worker is already covered in the first bullet.
British Association of Social Workers	General	General	General	The title of the document focusses on disability, so by naming it "disabled children" it takes the fact away that they are children first and foremost. It's not their (or shouldn't be) disability that identifies them. It should be children first then disability. So, why not "Children with disabilities…"	Thank you for your comment. The title of the guideline was agreed following consultation on the draft scope and responding to stakeholder feedback. The committee are not in a position to change it now.
British Association of Social Workers	General	General	General	While I appreciate that NICE's main focus is for England, the issues apply across the UK. It would be helpful for practitioners, family/carers, and service users if there could be a reference at the beginning of the guidelines to indicate this and to identify relevant sources in the other countries.	Thank you for your comment. The committee are not able to cite other sources of information as they have not assessed them.
British Association of Social Workers	Guideline	004	003	They also have the legal right to be involved as per The Social Services and Well-Being Act (Wales) 2014	Thank you for your comment. This is standard text that is included in all NICE guidelines. The committee are not able to influence the content of it.
British Association of Social Workers	Guideline	004	019	Should there be some clarification here around where this legal responsibility ends i.e. at age 18, unless they have a Deputyship for health and welfare?	Thank you for your comment. Taking the views of parents into account is a general principle for working with children, young people and their families which applies throughout the guideline. Taking their views into account would apply even after legal responsibility ends (although it may ultimately be decided no action is taken based on these views) and so this change has not been made.
British Association of Social Workers	Guideline	005	005	Should there be some clarification here around where this legal responsibility ends i.e. at age 18, unless they have a Deputyship for health and welfare?	Thank you for your comment. This recommendation covers situations where it may not be appropriate to have a family member present (for example family breakdown). The committee have therefore not made the change you suggest. However the committee have clarified the

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					reasons behind this recommendation in the related rationale and impact section.
British Association of Social Workers	Guideline	006	002	Should you also identify the need to establish which language they use. In Wales we have a statutory obligation to offer a service in Welsh. This might be important for other languages too.	Thank you for your comment. This is covered in recommendation 1.1.21
British Association of Social Workers	Guideline	010	021	Excellent idea to record or video meetings but needs the agreement of all in the meeting and then consideration as to how this is shared. However, it will also be important to ensure that once the individual and their family/carer has had time to listen and absorb the content of the recording, that they can come back with queries or issues for discussion at a later date – but not too far in advance.	Thank you for your comment. The committee have amended this recommendation to clarify that it relates to practitioners recording meetings and needs to be done in accordance with local policies on information governance and consent.
British Association of Social Workers	Guideline	012	008	Or through their behaviour.	Thank you for your comment. The committee have made this change.
British Association of Social Workers	Guideline	014	005	Surely these should also be shared with the child and their family/carer?	Thank you for your comment. The committee have added sharing with the child, young person and their parents and carers to the recommendation.
British Association of Social Workers	Guideline	021	015 - 016	When referring to SEND do you need to be clear that this only applies in England? There is an alternative one for Wales and possibly the other nations of the UK.	Thank you for your comment. NICE guidance only applies to England so this distinction does not need to be made.
British Association of Social Workers	Guideline	028	019	Carers are also legally able to have an assessment in their role as carers – this is enshrined within the Social Services and Well-Being Act in Wales.	Thank you for your comment and providing this information.

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British Association of Social Workers	Guideline	031	007	This should also cover language	Thank you for your comment. Adapting communication formats is already covered in recommendation 1.7.4, which would include language.
British Association of Social Workers	Guideline	042	General	While I am wholly supportive of supporting individuals into employment, there is nothing in this section where it addresses the need for the individual to be aware of how employment will impact on their benefits.	Thank you for your comment. It was the committee's understanding that official position in this matter is that the benefits system is carefully designed to ensure no-one should suffer a financial detriment as a result of getting a job.
British Association of Social Workers	Guideline	067	019 - 021	Research on this will be so important, especially with our experience of moving much of our interaction and contact online as a result of the pandemic.	Thank you for your comment and support for the recommendations.
British Association of Social Workers	Guideline	067	022	Totally agree that more time is needed and should be there. The challenges often are though a busy and usually high caseload with many competing priorities. Change is needed from the top to ensure that practitioners are given lower caseloads and time to spend with children and their families.	Thank you for your comment. These issues will need to be resolved as part of implementation of the guideline.
British Association of Social Workers	Guideline	079	001 - 005	Media has a lot to answer for! Engagement with Social Services, and specifically social workers, carries with it the stereotype that our main role is to take children into care and so break up families, or remove older people into care homes against their wishes. We need to ensure that we do all we can do change society's perception so that those families who need support are happy to engage and see it as a positive experience.	Thank you for your comment. The committee have made recommendations in section 1.2 to try and address this misconception.

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British Association of Social Workers - England	Comments form	Q1	Q1	**Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** The current system is very bureaucratic, things are not so straightforward in real life. Who picks up the early needs and signs – it is often GPs. There can be long waiting lists for help. The needs may not be properly identified – they may not have the skills locally eg sensory needs within autism. What about wider issues like ARFID and autism?	Thank you for your comment. Where possible, the committee have considered and acknowledged implementation challenges when making recommendations for disabled children and young people with severe complex needs. The committee have acknowledged that health services or education services may identify early needs. There are specific recommendations to ensure that health practitioners, which could include GPs, should think about special educational and social care needs. Education, health and social care practitioners will be involved in EHC needs assessments, and the committee would expect that they will seek out appropriate expertise, where this is not locally available, to ensure appropriate assessment and identification of support needs. The guideline has taken a needs-based approach and did not make diagnosis-specific recommendations. However, the committee would expect that those with some form of autism and co-morbidities, would meet the population criteria for this guideline, and the recommendations will be relevant to them. The committee have passed your comment onto the NICE team, which plan implementation support.
British Association of Social Workers - England	Comments form	Q3	Q3	**What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** There is also need to focus on legal literacy for practitioners and family trauma - see BASW resources	Thank you for your comment and for providing the committee with examples of resources to help with implementation. The committee will pass these ideas onto the NICE team who plan implementation support.

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				https://www.basw.co.uk/system/files/resources/role_of_the_social_worker_and_legal_literacy_2.pdf https://www.basw.co.uk/system/files/resources/quick_guide_-_legal_literacy_copy.pdf **BASW England resources relating to autistic adults** **Capabilities Statement and CPD Pathway: Resources** Resources to support autistic people, social workers, social work organisations and educators. **Toolkit for Autistic Adults** Outline of the toolkit and "how to" guide **Post-qualifying training programmes** Resources to develop post-qualifying training programmes **BASW England resources relating to people with learning disabilities** **Capabilities Statement and CPD Pathway: Resources** Resources to support people with learning disabilities, social workers, social work organisations and educators. **Toolkit for people with learning disabilities** Capabilities Statement Implementation Resources for social work with adults with learning disability: further information **Hair tool** The hair tool: a resource for critical friends and social workers to gather feedback	

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				There is also a need to focus on Ask Listen Do and family rights. This comes across as very much done too and not empowering of children and families, which is what is actually needed: https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/	
British Association of Social Workers - England	Comments form	Q4	Q4	**The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.** Great to have an easy Read version of the consultation, please also produce easy read version of the guideline.	Thank you for your suggestion. The committee will pass this suggestion onto the NICE team who plan implementation support.
CoLab Partnership	Guideline	050 - 052	gene ral	The section on page 50 on training for professionals is very strong, e.g. 1.15.21 "Education, health and social care services should work together to develop joint training " & 1.15.24 "involving parents and carers in training". The same approach is needed for developing training for families: coproduction with families and joint training between different services.	Thank you for your comment. The committee have amended the wording of the recommendation to include co-production.
CoLab Partnership	Guideline	028 - 029	gene ral	It would be helpful to add something on safe working hours for parents and carers, ensuring parents and carers are protected from extreme sleep deprivation. Sleep-deprivation can be especially dangerous when parents are tasked with performing medical procedures	Thank you for your comment. No evidence was identified by the guideline literature searches to support making recommendations about safe working hours for parents and carers.

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				for their children, such as complex medication regimes or managing a child with a tracheostomy or long-term ventilation. Over time it also erodes the mental and physical health of the parent.	
CoLab Partnership	Guideline	029 - 030	general	The training section for parents needs to include a reference to coproduction. Training resources should be co-produced with expert parents and carers. Families will have expertise and lived experience that professionals do not necessarily have that needs to be included in training resources. Families will likely benefit from learning from other families as well as professionals.	Thank you for your comment. The committee have amended the wording of the recommendation to include co-production.
CoLab Partnership	Guideline	029 - 030	general	The comments in the guidelines on accessibility of training are helpful. Online formats, such as pre-recorded videos and training sessions, and interactive group videos calls should be considered as they can help make training more accessible to busy families, save time for professionals and may make it easier for more than one parent/carer to attend. Families can also re-watch training videos as needed in the future	Thank you for your comment. The recommendations on training are not prescriptive about the format that should be used which allows flexibility to use the format that best meets the needs of families and carers.
CoLab Partnership	Guideline	030 - 031	014 onwards	Section 1.7 – this is really great and needs to stay; social participation is hugely important and something that needs addressing. However, my worry is that the burden for ensuring this is carried out will fall firmly on parents and carers, who will try their hardest to make sure that their children are included regardless of the additional work that they have to carry. This is particularly true for children with medical complexity, because they have specific care needs. From my research, I'm aware of families who: have access to	Thank you for your comment. Implementation of the recommendations in this guideline should help prevent this from happening by having more joined-up, co-ordinated person-centred support available.

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				respite care, but who have to spend all the time with their child because the staff aren't trained to manage their medical device; have spent weeks sat in school car-parks supporting teaching staff who felt too scared to have their child in school otherwise; accompany their child to residential events to provide the technical/nursing support for their child. All of this adds to the workload that families experience. In some cases, it actually makes things harder (e.g. going to spend the whole weekend at "respite" means that families can't do all the normal life work – meal prep, shopping, cleaning, laundry – which all builds up).	
CoLab Partnership	Guideline	032 - 033	021 – 002	Transition plans should also be planned with children, young people, and families, not just practitioners.	Thank you for your comment. The committee were aware that services often complete their sections of the transition plan independently and that this can lead to a lack of alignment across sections and a transition plan that is not practical to implement. This was supported by qualitative evidence that transition lacked coordination and was experienced as a period of uncertainty and stress (see evidence report A, sub-themes 4.2 and 11.5; evidence report K, sub-theme 16.2). They therefore focussed the recommendation on practitioners to address this issue.
CoLab Partnership	Guideline	004	019 – 020	The comment here is that should "take the views of parents (or other people with parental responsibility) into account. I'm concerned that this will exclude those people who don't have this formal relationship, but who still play an important role in the child or young person's life and who will have important contributions to make to their care. One example of this would be an older sibling who is heavily involved with care and	Thank you for your comment. The committee have added a recommendation about taking into account the views of those who know the child or young person best.

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				decision-making, but who doesn't have parental responsibility. It's also inconsistent with the rest of this document which is considering up to age 25.	
CoLab Partnership	Guideline	005	005 – 008	Again, this speaks specifically about family members with parental responsibility – but it doesn't take into consideration that there will be other people important to the child or young person who have valid contributions to make. If this is really to get a true picture of what the child or young person wants and what matters to them, then it has to be open to views outside this small group of people. It also puts a huge amount of pressure on parents, who might have their own care needs, and who then can't share that with other family members.	Thank you for your comment. This recommendation covers situations where it may not be appropriate to have a family member present (for example family breakdown). The committee have therefore not included a wider group as you suggest. However the reasons behind this recommendation have been clarified in the related rationale and impact section.
CoLab Partnership	Guideline	006	005 – 007	The phrase "Spirit of partnership" is used here. I'd like to see this taken further and that the expectation is a co-production approach.	Thank you for your comment. This recommendation is about information that would be provided as part of discussions and therefore the committee have not made your suggested change.
CoLab Partnership	Guideline	008	002 – 008	Another support to consider here would be for families to be able to take an advocate with them to the meeting, and that services are supportive in facilitating this, and provide information about where suitable advocates can be found.	Thank you for your comment. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.

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CoLab Partnership	Guideline	009	021	Breaks are good – definitely need to keep this.	Thank you for your comment and support for the recommendations.
CoLab Partnership	Guideline	009	021	Would also consider the physical environment: is the location accessible if there are physical needs? Are there facilities for the child or young person to be able to lie down if needed? Is there enough room so that the child or young person can move around or stim the way they need to? Is there too much stimulation or noise?	Thank you for your comment. The committee have added a new bullet to recommendation 1.1.29 about checking that meetings are physically accessible.
CoLab Partnership	Guideline	017	017 – 024	Provide information on how these plans will be implemented; who has responsibility for implementation; and where/how families can seek support if they are struggling to get this implemented within the time frame.	Thank you for your comment. As specified in the recommendation, Local Authorities would be responsible for implementation. Families can access support via the SEND Information, Advice and Support services which has now been added to the bullets .
CoLab Partnership	Guideline	018	006 – 008	Explain to families that needs may change with time and they can seek re-assessment (this really isn't clear to everyone, and I've seen families struggle on with the same plans they had when the child was a small child and isn't suitable now).	Thank you for your comment. These issues are already covered by the recommendations in the section on review and re-assessment
CoLab Partnership	Guideline	020	021 - 022	What would happen if the child, young person, or somebody they trust wanted to have an assessment, but the family were in disagreement? What's the mechanism, and whose views would be paramount?	Thank you for your comment. Mechanisms for resolving disagreements are included in the SEND Code of Practice and therefore are not covered by this guideline.
CoLab Partnership	Guideline	020	013 – 015	Clarify when the 20 weeks begins please – it wasn't clear to me.	Thank you for your comment. The committee have added this clarification.
CoLab Partnership	Guideline	021	007 – 008	"Take the views of parents and carers into accounts" – should also include the children and young people in these discussions where possible – and explain why they weren't involved if not.	Thank you for your comment. Taking the views of children and young people into account is covered by recommendation 1.4.1.

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CoLab Partnership	Guideline	022	002 – 008	I worry that this statement does not take into account the work that parents and carers have to do to manage the treatment burden (e.g. see May/Montori/Mair, BMJ 2009;339:b2803, on minimally disruptive medicine). The plan as a whole may make sense to the practitioners, but may not fit with the needs of the child in the context of family life. (there's no point arranging physio if it clashes with swimming or the school run for other kids).	Thank you for your comment. The committee have reworded the recommendations to clarify that practitioners should read the advice and information provided by others within the same service, to ensure they can support all the proposed outcomes through their own work with the child or young person. This should already be current practice. The committee have also recommended that Local Authorities share a child/young person's EHC plan outcomes with education, health and social care services so that they can include how they will help to achieve these outcomes when providing their advice and information. Whilst Local authorities may need to change their practice to do this up-front it should result in the advice and information provided by different services being more consistent, less time being needed to resolve inconsistencies and issues and an EHC plan that is practical to implement.
CoLab Partnership	Guideline	022	012 – 015	Similar to above, there has to be room for the family to contribute here – and for it not just to be about what practitioners think. There is a real risk that plans made with good intentions by practitioners are simply not practical and cannot be implemented by the families.	Thank you for your comment. Sections B, C and D of the EHC plan are required to describe the needs of the child or young person, not provision. It is therefore appropriate for these sections to be completed by practitioners without contribution from families.
CoLab Partnership	Guideline	023	003 – 008	What's the timeline for carrying out these plans and ensuring that the support is in place?	Thank you for your comment. Timeframes for producing EHC plans are included in the SEND code of practice so the committee have not repeated this information here. It is not within the remit of this guideline to specify timelines for implementing the required support.

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CoLab Partnership	Guideline	024	013 – 016	It's great that this is in here. What I think would be helpful would be a recommendation to give the families an idea of when they are likely to receive the plan, **and** some way of extending the consultation period if needed. These are medically fragile children who are likely to have lots of procedures, hospital admissions etc (Again, this references the treatment burden and May/Montori's work). Asking families to review a complex document will take time and adds to their workload – they need to be able to plan some time to review it, and to know that they can have additional time if there's a crisis (like an unplanned hospital admission). Would also be helpful to clarify what the anticipated time scale is if parents feel that something needs changing (i.e. does the rest of the plan get put on hold? Do they go through the whole 20 week process again?).	Thank you for your comment. In line with stakeholder feedback the committee have reduced the number of recommendations which repeat content from the SEND code of practice and associated legislation. This is one of the recommendations that has been removed and a cross reference added instead.
CoLab Partnership	Guideline	025	012 – 016	Parents/Carers/children and young people should be able to request a re-assessment if they feel things have changed.	Thank you for your comment. The committee have clarified that this is a professional assessment not an EHC plan re-assessment. Therefore your suggested change has not been made.
CoLab Partnership	Guideline	029	012 - 013	Helpful point here. Training for families' needs to be planned and better co-ordinated across the system – different teams supporting a family need to meet to discuss training provision and be aware of who is responsible for what training and develop some training resources for families together.	Thank you for your comment and support for the recommendation.

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CoLab Partnership	Guideline	033	011 – 014	Children and young people should also be involved in these discussions about how their needs will change, and how parental involvement/decision making will change.	Thank you for your comment. The committee have added a recommendation in line with your suggestion.
CoLab Partnership	Guideline	035	020 – 022	Please review the language here: "let" feels a bit like benevolent paternalism.	Thank you for your comment. The term 'let' was used because NICE recommendations try to use plain English.
CoLab Partnership	Guideline	049	011 – 006	Ensure that this change is communicated to the child, young person, and their family; Assign the new practitioner with child/young person/family input.	Thank you for your comment. The committee have added communicating the change to the recommendation. Getting input from the child or young person on who should be their new key worker is already covered in the first bullet.
CoLab Partnership	Guideline	051 – 052	027 – 02 001 - 003	Good to see the involvement of families in training for healthcare professionals recommended. Practitioners should consider whether experienced parents are involved in training new paid carers assigned to support their child. Parents have a unique insight into child-specific needs which ought to be incorporated into training. Also can help parents trust the new carer.	Thank you for your comment. The committee agree that Agree parents have a unique insight which is why they have recommended parents and carers are involved in developing training. The final bullet is to involve them in delivering the training so would address the point you raise.
CoLab Partnership	Guideline	053 – 054	025 – 021 001 - 005	Good to see a section on delegated clinical tasks to parents and carers. Would be helpful to add a statement on parents having a means to request further training. Also add some additional detail on what routes are available for parents to report problems and concerns (some suggestions or more detail here would be helpful).	Thank you for your comment. The committee have added requesting further training to the recommendation. It is not possible to add detail about what the routes would be to report problems as these will be different in different organisations.
CoLab Partnership	Guideline	058	016 – 018	Ensure that all care needs are met by staff and not reliant on family to provide care (related to my comments on section 1.7).	Thank you for your comment. The guideline does not have a remit to change the statutory requirements for short breaks services.

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CoramBAAF	Guideline	019	013 - 014	1.3.11 A considerable number of children become " looked after children" as a result of complex health needs and disabilities. In these circumstances there are then additional regulations and guidance to consider. It is important that SEND processes and "LAC" processes are aligned so that children and families do not experience duplication of assessments and process. Consideration must always be given to who holds parental responsibility in these situations.	Thank you for your comment. The committee agree on the importance of aligning processes so that children, young people and their families do not experience duplication of assessments and process and have made recommendations on information sharing between services to help with this. Whilst some children and young people will be 'looked after children' as a result of their severe complex needs, not all of the population of this guideline will be 'looked after children'. It is not within the remit of this guideline to specify how SEND process and 'looked after children' processes should be aligned, that is covered by legislation and other guidance.
Council for Disabled Children	Guideline	General	General	The guidance is very long, large parts of it are taken up by descriptions of processes (for example EHCPs) which could be edited out as they are available elsewhere in statutory guidance. For example, in 1.2.1 it suggests that CYP with complex needs may have SEN, however it is fair to assume (as the document does later on) that they will and link to the Code or at least cut this section right down giving a brief overview of assessment and plans, and describe the responsibilities of health and social care.	Thank you for your comment. The committee have reviewed the guideline to ensure any unnecessary repetition is removed. However this guideline covers a complex subject area where there is a lot of variation in practice. As such it has made lots of recommendations to try and address these issues.
Council for Disabled Children	Guideline	General	General	Consent and decisions are referenced throughout but sometimes the two concepts are confused without giving any clarity. For example, a 14-year-old can in some circumstances withdraw consent for an intervention but the decision on whether that intervention is included in their EHCP/or other plan is not theirs to make albeit their voice should be heard.	Thank you for your comment. The committee have checked the recommendations related to decisions and consent for information sharing and think that they are accurate. The committee's view of the example you provide is that if a child or young person refuses an intervention e.g. surgery the EHC plan should not include that intervention (other than to say that the intervention was offered but refused).

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Council for Disabled Children	Guideline	General	General	There are regular references to parents/CYP agreeing to referrals/assessments/plans/information sharing which is fine, however this needs to be underlined with the legal responsibilities on the LA and others. The LA have an absolute duty to assess a child and to produce a plan where it thinks this is necessary and it has a duty to consult and inform parents, but not to get their consent. The same is true of the duty on health to notify the LA.	Thank you for your comment. 'Consent' in this recommendation relates to the need to get consent to share someone's information with a different service, under GDPR legislation.
Council for Disabled Children	Guideline	005	002	**1.1.2** **Some CYP may not want to attend all meetings but still need opportunities to input. Wording could be changed to 'invite young people to attend and include other accessible opportunities for young people to input into all meetings where their views should be represented**' – Simply inviting CYP to meetings may not be enough for those with complex needs to actually input – discussions and opportunities for input need to be accessible. From our experience working with CYP with a range of needs, accessible options may include sending a short 'about me' presentation, sending photo diaries, only attending parts of the meeting. One young person put together a guide with ideas for inputting into EHCPs, including a like/dislike list, collage, vlogs and others: https://councilfordisabledchildren.org.uk/sites/default/files/uploads/files/CYP.4pp.HI-RES.pdf	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may include other accessible options).

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Council for Disabled Children	Guideline	007	001	1.1.15 Add that information should be accessible (as well as up-to-date).It is also important to find out what information families want, rather than give them materials on policies and processes that may be overwhelming	Thank you for your comment. The committee have added 'accessible' to the recommendation as suggested. Only providing the information that families want is a cornerstone of effective communication so the committee do not think it is necessary to specify here.
Council for Disabled Children	Guideline	007	022	1.1.17 Please replace with 'SENDIAS services provide information, advice and support to children, young people and their families and carers to help them understand how systems work, what provision should be available, based on their specific needs and how to access it, this can include advocacy where needed. You can find out more about them in their Minimum Standards https://councilfordisabledchildren.org.uk/resources/all-resources/filter/inclusion-send/minimum-standards-iass which are also available in Easy Read.'	Thank you for your comment. The focus of this recommendation is to ensure that SENDIAS services help children, young people and their families and carers to understand what support is available to them. What those support needs are will be specific to the individuals concerned - they may require advocacy services but they may not. Therefore the committee have not added this to the recommendation.
Council for Disabled Children	Guideline	007	023	1.1.18 This recommendation is confusing and presupposes that services will not be able to meet family's needs. If inviting this conversation from families, clear parameters would need to be set and there should be a focus on getting to the root of what they want and why, exploring alternatives that can meet some of their needs, where it is not possible to meet their expectations within a service.	Thank you for your comment. There was moderate quality evidence that service users did not receive the level of support or input that they had expected from services. In order to understand and potentially meet the expectations of service users, the committee agreed that services would need to be aware of what those expectations might be. The focus of this recommendation is about finding out what people's expectations are, which can be different to their needs. The committee have added exploring alternatives to the recommendation.

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Council for Disabled Children	Guideline	007	024	1.1.19 Add reference to DfE SEND Code of Practice	Thank you for your comment. In light of feedback from other stakeholders the committee have reduced the cross references to the SEND Code of Practice to help make the guideline shorter.
Council for Disabled Children	Guideline	009	005	1.1.23 This section should include other ways children and young people can be involved e.g. submitting a presentation/photo essay/video. It could also explain that children and young people not have to stay for the whole meeting to input into it, and encourage professionals to help young people to think about who they would like to be with them in the meeting. A young person from FLARE but together a guide about how other disabled young people can input into the EHCP process: https://councilfordisabledchildren.org.uk/sites/default/files/uploads/files/CYP.4pp.HI-RES.pdf	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involve attending meetings).
Council for Disabled Children	Guideline	010	013	1.1.29 Do *all* actions/action logs need to be shared with CYP? At a recent meeting on EHCPs, several practitioners raised the tension between transparency and being required to show children write-ups and actions which included potentially upsetting material e.g. around safeguarding needs, family breakdown, foetal alcohol syndrome etc. This balance should be acknowledged.	Thank you for your comment. Practitioners would only actively not share information/actions if there was a specific reason not to do so. This would be a matter for their professional judgement and specific to the circumstances of an individual. Therefore the committee cannot include it in a recommendation.
Council for Disabled Children	Guideline	012	008	1.1.37 Not sure 'unable to formulate a view' is the appropriate wording, perhaps 'unable to verbalise their views,' because behaviour, play etc. *is* a form of	Thank you for your comment. The committee have amended the wording to read 'When a child is unable to respond with intentional communication…' to provide clarity.

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				communication, particularly for nonverbal CYP and those with complex needs.	
Council for Disabled Children	Guideline	015		Add reference to the SENDIAS here and wherever IAS is mentioned	Thank you for your comment. The committee have added this to recommendation 1.2.3 and 1.2.5
Council for Disabled Children	Guideline	017	003	1.3.1 Clarify that any parent/carer and any practitioner working with a child can request an EHC needs assessment	Thank you for your comment. This would be encompassed by the first bullet ('who can request an EHC needs assessment').
Council for Disabled Children	Guideline	017	015	1.3.3. Move, 'or whether they have a diagnosis at all' out of brackets, as lack of diagnosis is a key barrier to accessing EHCPs due to misperception that a diagnosis is needed	Thank you for your comment. The committee have made this change.
Council for Disabled Children	Guideline	017	017	1.3.4 LAs should not explain the 'possible outcomes' to CYP and parent carers when assessing needs – outcomes should be led by the child or young person. The SEN Code of Practice says outcomes should be personal, not led by services. Outcomes and aspirations are not subject to appeal, so they do not need to be limited in this way.	Thank you for your comment. The committee have amended the wording to clarify that this refers to the potential outcomes of the EHC needs assessment process, not outcomes that would be included in an individuals' EHC plan. Paragraph 9.67 of the SEND code of practice states "When agreeing outcomes, it is important to consider both what is important to the child or young person – what they themselves want to be able to achieve – and what is important for them as judged by others with the child or young person's best interests at heart."
Council for Disabled Children	Guideline	018	003	1.3.5 This is unclear – is it services that are available to support them while they wait for a needs assessment? Otherwise, the assessment process should be needs-led rather than starting by limiting discussions to the	Thank you for your comment. The committee have clarified that this is services that are available whilst people wait for a needs assessment.

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				provision already in place in an area and its criteria. This point is captured in 1.3.9 where it is clearer. Is 1.3.5 needed?	
Council for Disabled Children	Guideline	021	003	1.4.1 It's good to see that children and young people should be encouraged to express their life goals – this should apply to *all* CYP. Wording could be changed to 'encourage all children and young people, including those with severe complex needs, to express their life goals and ambitions." Outcomes should be led by the CYP, supported by professionals rather than "decided" by the professionals as this guideline makes it seem.	Thank you for your comment. Whilst The committee agree that all children and young people should be encouraged to express their life goals, the population for this guideline is disabled children and young people with severe complex needs. As such the committee have not expanded this to all children and young people. The committee have also reworded the recommendation to refer to 'agreeing outcomes' as this is a joint process between the child/young person, their parents and carers and the practitioners that support them. Paragraph 9.67 of the SEND code of practice states "When agreeing outcomes, it is important to consider both what is important to the child or young person – what they themselves want to be able to achieve – and what is important for them as judged by others with the child or young person's best interests at heart."
Council for Disabled Children	Guideline	021	009	1.4.3 Outcomes should be developed/established with CYP in initial conversations (in the same way as aspirations) and then made SMART by professionals. This guidance suggests professionals should be deciding the outcomes for the child – which would undermine existing good practice where outcomes are child-led.	Thank you for your comment. The committee have reworded the recommendation to refer to 'the agreed outcomes' as this is a joint process between the child/young person, their parents and carers and the practitioners that support them. Paragraph 9.67 of the SEND code of practice states "When agreeing outcomes, it is important to consider both what is important to the child or young person – what they themselves want to be able to achieve – and what is important for them as judged by others with the child or young person's best interests at heart."

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Council for Disabled Children	Guideline	021	019	**1.4.5** **Aspirations do not need to be 'realistic' and are not subject to appeal. Practitioners should not be encouraged to question and overrule aspirations they feel as unrealistic or too high – if this is talking only about SMART outcomes, that should be clearer in these recommendations. Otherwise, this may undermine existing good practice.**	Thank you for your comment. The committee have reworded the recommendation to be about when practitioners expectations are too low.
Council for Disabled Children	Guideline	021	021	1.4.6 is unclear as outcomes should not be a description of support needs, or based on existing provision. Could change to 'Outcomes should be personalised to each child or young person. Do not assume that all children and young people with a particular diagnosis will have similar outcomes or will need the same support'	Thank you for your comment. The committee have moved this recommendation to the start of the guideline so it is in the 'Principles for working with children, young people and their families' section.
Council for Disabled Children	Guideline	022	011	1.4.9 Why is only therapeutic support for education and medical support mentioned in this section? The SEN code of practice is clear that **EHCPs must consider children's holistic needs, including their social and emotional needs. Can these be added?**	Thank you for your comment. The committee have added practical support to the recommendation.
Council for Disabled Children	Guideline	023	016	1.4.14 Include other ways of young people providing their views in EHCPs which are already being used by areas implementing good practice, such as drawings, photo collages, like/dislike lists etc.	Thank you for your comment. The committee have added these examples to the recommendation.
Council for Disabled Children	Guideline	024	001	1.4.16 CYP should be guiding the development of their outcomes – not just asked to understand them at the end	Thank you for your comment. The committee agree that children and young people should be involved in deciding on outcomes, but think that the other recommendations in this section and the other bullets in this recommendation

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					adequately clarify that. Therefore they have not made any changes to this recommendation.
Council for Disabled Children	Guideline	026	001	1.4.22 Add section covering the final review - EHCP outcomes agreed at the final review before leaving school and moving to college must be fit-for-purpose, age-appropriate, and support the development of an appropriate study programme	Thank you for your comment. Moving on to college is only one potential option after leaving school and so the committee have not added this to the recommendations. Agreeing outcomes is covered by the SEND code of practice and so this has not been repeated.
Council for Disabled Children	Guideline	048	025	1.15.11 Have young people and families been consulted as to what support they want from key workers? Our work with NHSE on keyworking found that families want the role to be informal and family-facing, providing support, advice and signposting for the family (including siblings who may need signposting to sibling support/carer support groups), rather than being professional facing.	Thank you for your comment. Consultation with registered stakeholders on the draft guideline has been undertaken in line with processes set out in Developing NICE guidelines: the manual. In addition there were 3 committee members with lived experience who contributed to the development of these recommendations. The recommendations on key working support were based the experience of the committee and qualitative evidence that: • key workers are seen as important by families and practitioners, for being able to better understand the child or young person's needs, and for being able to coordinate services • having a single person for families to contact would simplify processes and be beneficial to joint working • families are less accepting of key workers who have not had much involvement with the family • children, young people and their families spent a considerable amount of time chasing and coordinating services, conducting administrative work and arranging meetings

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					• more information and support is needed to help children, young people and their families to understand and access services • there is a lack of communication between services. • continuity of key workers is important for consistency (particularly during transition to adult services), and that children and young people felt negatively when key worker support ended prematurely The ethos behind these recommendations is to provide person centred care and the recommendations provide guidance about how this can be implemented in practice. The rationale and impact section describes the committee's reasoning for making these recommendations.
Council for Disabled Children	Guideline	049	009	1.15.12 This section should emphasise the need for smooth and supported transitions between keyworkers to minimise disruptions to young people. This is a message we received very strongly during our work on keyworking.	Thank you for your comment. The committee have amended the recommendation so it now specifies transitions should be supported.
Council for Disabled Children	Guideline	057	003	1.17.6 As well as consulting CYP and families about *needs* to inform commissioning, commissioners must also work with CYP and families to "identify the **outcomes** that matter to children or young people with SEN or disabilities to inform the planning and delivery of services and the monitoring of how well services has secured those outcomes." (SEN Code of Practice 3.31). This recommendation should include a mention	Thank you for your comment. The committee have now combined recommendations 1.17.6 and 1.17.7. By making this change, there is now a bullet about focussing on outcomes and personalised services

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				of commissioning based on strategic outcomes – this is good practice which is increasingly being adopted across the country when commissioning services for complex CYP already. Could the wording be changed to "consult children and young people and their parents and carers, to ensure services meet the needs of the local population and enable them to reach the outcomes that matter to them."	
Council for Disabled Children	Guideline	057	020	1.17.9 Change to "commission services based on the needs and preferences of children and young people, and the outcomes that matter to them"	Thank you for your comment. There is not a requirement for all agencies to commission based on outcomes – only for unmet needs. Outcomes are variable and a well commissioned service will ideally provide for the needs of the child or young person, whilst having the flexibility to deliver outcomes that matter to them. Therefore the committee have not made your suggested change.
Council for Disabled Children	Guideline	060	001	1.18 Joint commissioning frameworks should be outcomes-based: focused on achieving the strategic outcomes they want to achieve for young people with complex needs. This is good practice happening already e.g. Hertfordshire, Leeds, Rochdale – and is recommended in the Code of Practice.	Thank you for your comment. Recommendations 1.17.1 and 1.17.6 highlight the importance of focussing on outcomes when commissioning services.
Department for Education	Guideline	General	General	**Reviewing interactions with the SEND Code of Practice:** The interaction with the Code of Practice needs to be carefully reviewed. At present there is a conflation of elements within the Code (which is statutory guidance) and additional information/interpretation, which is advisory only. We are also concerned that the advisory	Thank you for your comment. The committee have reviewed the content of the guideline and removed any unnecessary repetition of the content of the SEND code of practice. However, the evidence reviewed for this guideline identified many instances where legislation and statutory guidance in the SEND code of practice is not being implemented. In these instances the committee

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				information reflects the views of the Committee, and whilst this is a group of experts, it is necessarily narrower than the wide consensus which was secured in the production of the Code of Practice (with the content of the Code ultimately reflecting the will of Parliament). The guideline also contains a number of inaccurate or misleading interpretations of elements of the Code which could result in unlawful practice. We would request that the whole document is checked by lawyers to ensure no dilution of the intent and accepted interpretation of the Code or SEND legislation. The guideline could usefully be shortened by removing sections which replicate content in the Code of Practice and replacing with a link to the relevant section. Sections which replicate existing established processes (e.g. safeguarding referrals) could also be removed or replaced with a link to the relevant guidance. Examples of where the nuance is lost in material lifted from the SEND Code of Practice: • The statutory deadlines for EHC needs assessment and plan processes are subject to various statutory exceptions, that are not referenced (see for example para 1.3.12 of the guideline?). • Where paragraphs 5.15 and 5.16 of the Code about early intervention are quoted, this is	have highlighted in the recommendations what should be done and provided guidance about how this could be achieved. This has been clarified in the introductory information at the start of the guideline. Developing NICE guidelines: the manual documents the processes that are used to develop NICE guidelines. A committee with relevant expertise is created (via an open application process) to agree the review questions the guideline will investigate, what these review questions should cover and to develop recommendations based on the evidence identified. The views of the wider group of organisations with an interest in the topic of the guideline are obtained by consultation with stakeholders on the draft guideline. The committee have reviewed the content of the recommendations and removed any inaccurate cross references to the SEND code of practice. In relation to the specific examples given in your comment: • Recommendation 1.3.14 (previously 1.3.12) now cites the legislation rather than the SEND code of practice. An introductory sentence has been added to direct readers to paragraphs 9.41 to 9.44 of the SEND code of practice which details the exemptions. • Reference to paragraphs 5.15 and 5.16 of the SEND code of practice have been removed. • The committee have amended the text to refer to the SEND Local Offer in line with your comment.

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				material about children aged 0 to 2. Early intervention has a broader meaning: intervening before the consequence of a condition that impacts on accessing education develops at any age, as is recognised in the text of the guideline. So there is a mismatch between the issue referred to and the source quoted. • The term 'Local Offer' now in law refers to the care leavers local offer as a result of the 2014 Act being amended, so you may wish to consider whether there is scope for misunderstanding this in how the SEND Local Offer is currently referenced. • When making a point about disclosure of information generally, the guideline quotes from the material in Chapter 9 of the SEND Code of Practice. This Chapter is about the disclosure of EHC plans (where there are specific statutory provisions), not the more general information the guideline is referring to.	• The committee have removed reference to the SEND code of practice in relation to disclosure of information.
Department for Education	Guideline	General	General	**Clarifying who the intended audience is for the guideline:** It isn't currently clear how this guideline will be utilised by practitioners outside the health system. We would propose a clearer introduction setting out who this guideline is for, which emphasises that the statutory guidance in the SEND Code of Practice is the primary guidance for the processes around SEND. The	Thank you for your comment. Page 1 of the guideline already sets out the audience for the guideline which includes education, health and social care practitioners; education, health and social care service providers; local authorities and health commissioners and disabled children and young people with severe complex needs, their families and carers.

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				Introduction should state that this guideline aims to set out how health services and practitioners can engage with those processes and may also be useful for LA and education-setting based staff who work with health practitioners and commissioners. It is unclear in some places who particular paragraphs are aimed at; e.g: *1.3.3 Do not exclude children and young people from assessment based solely on whether or not they have a particular diagnosis (or no diagnosis at all).* It is not clear whether this is advice for local authorities (who coordinate the Education, health and Care (EHC) assessment process), or whether it refers to any type of assessment and thus to health, care **and** education practitioners.	The committee have amended the introductory text to clarify that the government's Special educational needs and disability (SEND) code of practice is the primary guidance for processes around SEND and that the recommendations in this guideline provide guidance on how existing legislation and statutory guidance should be put into practice. As such it will be relevant for practitioners in health, social care and education. In reference to recommendation 1.3.3, the committee have clarified that this relates to EHC needs assessment and hence it applies to Local Authorities.
Department for Education	Guideline	General	General	**Clarifying the aims of the guideline:** The introduction should also specify (in addition to the context of the link to the Code of Practice) those particular issues which this guidance aims to address, complementing and supplementing the Code of Practice. This could include a focus, for example, on joint commissioning, or transitions/join up between children's and adults' services (which are aspects of current multi-agency practice that have been highlighted as a concern in Ofsted/CQC Local Area SEND Inspections). If the guideline can be developed	Thank you for your comment. The issues that the guideline has written recommendations on are already summarised by the contents list at the start of the document and the context section, so the committee do not think this needs to be repeated in the introduction. The review questions that the guideline proposed to investigate were subject to input from stakeholders during consultation on the draft scope and after appropriate revisions were published in the final guideline scope. These are the areas that the guideline has investigated and written recommendations about and the committee are not able to change them now.

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				so as to add significant value in this regard, it is likely to get more take up by relevant practitioners.	
Department for Education	Guideline	General	General	**Clarifying interactions with the changes proposed in the Health and Social Care Bill:** The forthcoming changes to the health system as proposed in the Health and Social Care Bill will have implications for the wording throughout the guideline. References to Clinical Commissioning Groups (CCGs) will need ultimately to be replaced with 'health commissioners' or an explanation provided of how Integrated Care Systems will assume the responsibilities for SEND which currently fall to CCGs. This is currently explained in the rationale, but not visible in the text of the guideline itself.	Thank you for your comment. The committee agree that changes to the health system as proposed in the Health and Social Care Bill may have implications for the wording throughout the guideline. The terminology that is currently used in the guideline aligns with what is used in the SEND code of practice, which is the primary guidance for the processes around SEND. The term clinical commissioning groups is only used in the rationale and impact sections, not the recommendations. Therefore the committee think it is sensible to retain this wording at the moment. NICE can update the terminology used in the guideline once reforms to the health system have happened. The committee will pass your comment to the NICE surveillance team which monitors guidelines to ensure that they are up to date.
Department for Education	Guideline	General	General	**Clarifying the status of information (statutory, advisory, etc.)** The SEND Code of Practice describes the law on SEND and exemplifies good practice, it is not itself the source of any statutory duties. The duties are set out in the Children and Families Act 2014 and the associated Regulations (e.g. the SEND Regulations 2014). This is not always clear in the text, when using wording such as 'requirements of the Government's Special Educational Needs and Disability (SEND) Code of Practice'. Conversely, the guideline refers to the content of the SEND Local Offer as being advisory,	Thank you for your comment. The committee have reviewed the content of the guideline and removed any reference to 'requirements of the SEND code of practice'. The committee have also tried to make it clearer which primary legislation and associated regulations the requirements come from. The recommendations made in the guideline about what to include in the SEND Local Offer were based on evidence that certain information that would be useful to children, young people and their families is not currently included. Whilst this information aligns with what the

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				when this is in fact mandatory. This is not an exhaustive list of potential errors - the guideline needs a thorough check to ensure that the status of the information is clear throughout. Direct quotes from the Code of Practice should be indicated (e.g. through formatting), and clearly demarcated from advisory or interpretative text. A consistency check would also be useful – in some places the guideline says 'severe and complex needs', in other places, 'complex needs'.	SEND Regulations 2014 require to be included in the SEND Local Offer, the regulations do not go to this level of detail so the committee have not phrased the recommendation as 'must'. This is reflected in the rationale and impact text that supports these recommendations. The committee have checked that any direct quotes from the SEND code of practice are indicated by quote marks – these instances happen in the rationale and impact text and the text about the committee's interpretation of the evidence in the evidence reports, not the recommendations. The commitee have checked the use of 'severe complex needs' and 'complex needs' in the guideline and made necessary changes.
Department for Education	Guideline	General	General	**Ensuring the guideline comprehensively covers process for children and young people with complex needs:** The guideline should demonstrate where integration of the various processes which may relate to children and young people (CYP) with severe and complex needs may occur. For CYP who are looked after, EHC plan annual reviews should be coordinated with social care reviews. This does not mean that one meeting should cover both the EHC annual review and the Care Plan review, but professionals from all agencies involved with a child or young person should coordinate their planning and align the review periods where it makes sense to do so. Paragraph 9.169 of the Code of Practice provides more detailed guidance on alignment	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all processes that are relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions. The committee have added a recommendation (1.4.19) about aligning review periods for EHC plan annual reviews and social care reviews. The committee have also added introductory text to the sections on 'Decision making' and 'EHC needs assessment' to reference Deprivation of Liberty Safeguards/Liberty Protection

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				between EHC processes and those for Looked After Children. We would propose that the guideline suggest consideration of the same principle for any health-led reviews. The guideline should reference processes including Deprivation of Liberty Safeguards/Liberty Protection Scheme reviews and Care, Education and Treatment Reviews, where relevant. The guideline should make reference to links to mental capacity, and to mental health needs, as both may be relevant to CYP in this cohort. The guideline should also refer to Learning Disability Registers and Dynamic Support Registers for those at risk of poor outcomes. Practitioners in health should proactively seek to ensure children and young people are included in such registers, and practitioners in other agencies should be made aware of how to refer a child or young person to be considered for inclusion on such registers, where appropriate.	Safeguards and Care, Education and Treatment reviews respectively. Mental capacity is already mentioned in recommendation 1.1.50 (along with reference to the Mental capacity Act 2005) and the committee have added a recommendation about awareness of emotional and mental health needs in section 1.2. Recommendations have been added to section 1.18 about Dynamic Support Registers.
Department for Education	Guideline	General	General	The text describing the consultation refers to challenging behaviour, but the guideline is light on matters such as positive behavioural support and says nothing about good practice or the law on restraint or deprivation of liberty. These topics are likely to be relevant to the intended cohort and we would recommend expanding the guideline to link to relevant guidance for health and social care practitioners, in particular.	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all processes and legislation that is relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions.
Department for Education	Guideline	General	General	**Ensuring the guideline links to all the relevant guidance:**	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all

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				The guideline does not include links to all relevant guidance which may be applicable for this group of CYP and useful for practitioners. Around the point of transition, for example, the guidance on post-16 EHC plans and Preparation for Adulthood would be particularly relevant: [16 to 19 study programmes: guidance (2021 to 2022 academic year) - GOV.UK (www.gov.uk)]().	processes and legislation that is relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions.
Department for Education	Guideline	General	General	**Referring to children in care:** There isn't any explicit reference to children in care. This needs to be reflected throughout the guidance. A suggestion could be the use of 'corporate parent' - when a child comes in to care the local authority becomes the corporate parent and will have responsibility for those children that are looked after.	Thank you for your comment. The recommendations in this guideline focus on meeting the needs of disabled children and young people with severe complex needs. They would apply equally to the sub-set of this population who are children in care. However the committee have amended the definition of 'parents and carers' to include corporate parent.
Department for Education	Guideline	039 - 040	001	The section on 'environmental accessibility' appears to have limited coverage. The Committee might wish to seek additional evidence from relevant professionals and families, to help give a fuller picture of the legal requirements and good practice expectations of relevant practitioners. For example, the Committee may wish to consider the implications of the duties on schools and local authorities under Schedule 10 to the Equality Act 2010 to produce accessibility plans and accessibility strategies respectively and the design standards that relate to schools (such as relevant DfE Building Bulletins). We would be happy to advise further on this point and to suggest stakeholders who could help the Committee strengthen this section.	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all legislation that is relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions.

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Department for Education	Guideline	004	001	The definition of the children and young people (CYP) in scope of this guideline needs to be made more explicit in the introduction. This should reference the fact that this guideline is intended to cover those CYP with an EHC plan, but should also make clear the fact that not all CYP with severe and complex needs will have an EHC plan. The logic of the Special Educational Needs system is that an EHC plan is only issued when it is necessary to do so to secure provision that is additional to or different from that which is available within the setting otherwise for those with SEN. Local commissioning practices and the differences between settings (some of which, for this cohort, will have particular specialisms) will mean that the decision as to whether an EHC plan is required for an individual may vary by context, though the LA must satisfy itself that the child or young person's needs can be met without an EHC plan, if it deems it unnecessary to provide one. The guideline makes no reference to the system for providing support to those with SEN who do not have an EHC plan, nor the key role (for example) of the Special Educational Needs Coordinator if the child is in a mainstream school or Early Years Setting. The guideline does variously reference 'interim support' while a request for a plan is being processed, but again the assumption is that this is a prelude to the issue of a plan, which is not always correct – support without a plan may continue on an ongoing basis. In	Thank you for your comment. The term 'disabled children and young people with severe complex needs' at the start of the guideline is hyperlinked to the 'terms used' section where a definition of the population covered by this guideline is provided. Doing this serves to make it explicit who the guideline covers. The committee have amended the definition to clarify that this is guideline is about those who need co-ordinated education, health and social care support because of their severe and complex needs and therefore are eligible for an EHC plan in line with Children and Families Act 2014. The guideline does not only cover those children and young people who have an EHC plan. The guideline is not trying to address the needs of the four times larger group of children and young people who have special educational needs and who are identified as needing SEN Support. Therefore the committee have not made recommendations in this area. The focus of this guideline is integrated service delivery and organisation across education, health and social care. As such the committee have made recommendations aimed at practitioners rather than any specific roles and hence have not made recommendations about Special Educational Needs Coordinators. Local authorities determine the criteria for eligibility for an EHC plan, not the guideline. Therefore the committee cannot include a recommendation that diagnosis should not be an eligibility criterion.

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				addition, although the guideline makes clear that providing support should not be contingent on a diagnosis, at no point does it say explicitly that a diagnosis is not a criterion for eligibility for an EHC plan.	
Department for Education	Guideline	004	001	The guideline should be clearer on the role of adult social care services for young people aged 18-25. Not all young people with severe and complex needs in this age group will have an EHC plan – if a young person has achieved the outcomes in their EHC plan by age 19, then no further special educational provision should be required after that age. The introduction should make links to other relevant guidelines – e.g. health and social care support for young adults 18-25 who are not in education, as well as the role of adult social care services for those with an EHC plan. Further guidance on provision for young people over the age of 19 with SEND is available in SEND: 19- to 25-year-olds' entitlement to EHC plans - GOV.UK (www.gov.uk)	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all guidelines that are relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions. However the committee have included a link to the 'SEND: 19- to 25-year-olds' entitlement to EHC plans' in section 1.8.
Department for Education	Guideline	005	002 - 004	This could be taken to be saying that the child or young person should be physically involved in relevant meetings in all circumstances, which would not be good practice as is later recognised. We believe that the experience during Covid has demonstrated that virtual attendance at meetings (and indeed for other interactions, including some assessment activities) can be a valuable addition to in-person interactions, and can improve efficiency in the assessment and review processes. We would welcome acknowledgement of	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involve attending meetings). Recommendations about establishing the communication preferences of children and young people and using these

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				the potential benefit of virtual involvement within the guideline. It is also noted further down in the guideline that children and young people's participation may be facilitated by means other than in-person attendance at meetings. The guideline should be consistent in emphasising the need to engage and involve children and young people (noting that young people over the age of 16 have specific rights in relation to the SEND system) in whichever way is most effective for that individual, taking account of any necessary communication aids or approaches required.	are covered in the sections on 'Communication formats and providing information' and 'Planning and running meetings with children and young people'.
Department for Education	Guideline	006	002 - 004	It is our view that professionals should be using this kind of language anyway, regardless of the family's experience (as per the expectations set out in the SEND Code of Practice paras 1.3 – 1.10)	Thank you for your comment. As documented in Evidence report A, the qualitative evidence identified this doesn't always happen and so the committee made recommendations to prompt staff and professionals to be empathetic and supportive when talking to children, young people and their families.
Department for Education	Guideline	008	002	This paragraph doesn't reference the possibility of having third parties present to support the child, this being helpfully explored further down in the guideline. It would be beneficial to reference this here as well.	Thank you for your comment. This recommendation is about practical steps to take to help children and young people prepare for discussions and meetings. As such having third parties attend to provide support would not be relevant here.
Department for Education	Guideline	008	016	This is an example of where reference should be made here to aligning meetings to the EHC process where appropriate – as per section 9.169 of the Code of Practice. (See similar comment above.)	Thank you for your comment. The recommendation you cite is about any meeting agenda, not just those related to the EHC process. Therefore the committee have not made your suggested change.

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Department for Education	Guideline	009	012 - 014	The main reason that a child shouldn't be taken out of school is because they have a right to education the same as everyone else and time out of the classroom impacts on their learning. This is a group with higher than average absence levels. This point should be made explicit in this section.	Thank you for your comment. The committee have amended the recommendation to include consideration of not missing out on lessons.
Department for Education	Guideline	009	022	Here and elsewhere: it would be helpful to underline the importance of the meeting venue being physically accessible and otherwise suitable for all present with disabilities.	Thank you for your comment. The committee have added a new recommendation about holding meetings in physically accessible venues.
Department for Education	Guideline	010	General	It would be helpful to include more on the possibility of professionals delivering advice virtually if they cannot attend in person. The possibility of remote delivery of input to meetings should reduce the number of absences from such meetings.	Thank you for your comment. The recommendations on planning and running meetings are not prescriptive about the format that should be used which allows flexibility to use the format that best meets the needs of families and carers.
Department for Education	Guideline	020 027	017 002	We were surprised to see the content which focuses on when parents might decline an EHC needs assessment or the issuing of an EHC plan. We note that the rationale for including this is on page 84 – but the evidence described does not give any sense of scale. We would welcome further information on the evidence base here. The guideline also talks about parents declining a plan and references as a possible reason for this parents being dissatisfied with the setting named (on page 92 of the rationale). In that circumstance the parent or young person has a right of appeal to the First-tier Tribunal (SEND) and the LA has a duty to advise the	Thank you for your comment. The committee have amended the rationale and impact text to clarify that these recommendations are based on the experience of the committee. In line with feedback from stakeholders the committee have tried to minimise repetition of content in the SEND code of practice. Therefore the committee have not added anything about right of appeal to the First-tier Tribunal. Instead an introductory statement has been added at the start of sections 1.3 and 1.4 to say that the recommendations in this guideline should be read alongside chapter 9 of the SEND code of practice.

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				parent or young person of this right. None of this process is referenced; we propose that if the section relating to declining an EHC assessment or plan is retained, a link should be provided to the relevant parts of the Code of Practice to highlight parental rights of redress should they disagree with LA decisions. We would again welcome further information on the evidence base for this point.	
Department for Education	Guideline	021 022	001 - 022 001 - 018	We consider that this section of the guideline is likely to cause confusion. The responsibility of writing the EHC plan rests with the local authority, working from the advice and information provided by the health, education and social care practitioners involved with the child. This section implies that individual practitioners would draft sections of the plan, which we understand does not reflect practice in most areas. We would propose that this section should change all references to practitioners drafting 'the EHC plan' to refer to 'advice and information'. It should also make clear that the practitioners may be asked to contribute to the processes described but are not responsible for leading them. This section replicates guidance in the Code of Practice but using different wording. We would recommend that paras 1.4.1 – 1.4.3 be deleted and simply replaced with the link to the Code. Para 1.4.9 is particularly concerning as this implies that practitioners will determine which provision is included in sections F, G and H of the plan. In practice and in law this is the role of the local authority. The guidance	Thank you for your comment. The committee have amended the text to clarify that is the Local Authority Officers who write EHC plans, based on information and advice contributed by practitioners from education, health and social care. The wording has also been corrected for recommendation 1.4.9. Whilst the SEND code of practice clarifies how these sections of the EHC plan should be completed, the committee's experience was that this often done poorly (see the rationale and impact section) so they want to highlight what should be done in a recommendation. The committee have retained recommendations 1.4.1 - 1.4.3 because qualitative evidence was found that despite these things being in the SEND code of practice, they were not happening, so the committee agreed it was important to re-iterate them.

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				in the Code of Practice clarifies the issue of therapy provision which educates or trains, and also provides clarity that only health provision necessary to access education and make progress towards the specified outcomes should be recorded in section G – it is not necessary to include routine medical care or interventions to support existing health conditions which are irrelevant to the child's educational progress.	
Department for Education	Guideline	023	001	*1.4.10 Commissioners must use the information in sections F and G of the EHC plan to secure the services the child or young person needs.* We would suggest removing reference to section H here. Local authorities and health commissioning bodies have to secure or arrange what's in the plan, as either Special Educational Provision (F) or Health Provision (G). Inclusion of social care provision (H) within an EHC plan doesn't impose any new duty.	Thank you for your comment. As commissioners have a duty to use the information in section H, the committee think it is important to retain this in the recommendation.
Department for Education	Guideline	023	009	Para 1.4.12 The reference to the Code is inaccurate – the relevant paragraphs are **9.73 – 9.76.** *must follow the guidance in the SEND code of practice (paragraphs 9.62 and 9.69) on detailing the resources needed to provide the child or young person's support.*	Thank you for your comment. In line with stakeholder feedback the committee have reduced the number of recommendations which repeat content from the SEND code of practice and associated legislation. This is one of the recommendations that has been removed.
Department for Education	Guideline	023	012	Para 1.4.13 As above, to reflect practice (which is that local authority teams write the EHC plan, based on the	Thank you for your comment. The committee have made this change.

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				information and advice received), the wording should be changed to: *Local authorities should ensure that EHC plans:* • *are based on up-to-date information* • ***are informed by information and advice provided*** *by practitioners who have the right expertise and knowledge of the child or young person.*	
Department for Education	Guideline	025	005 - 022	These sections (1.4.20-1.42) should make clear what is required as part of the statutory EHC process (i.e. annual review of the EHC plan as a minimum, re-assessment if needs or circumstances change significantly) and what is advised as good practice for practitioners – i.e. more regular review of clinical need if the child's condition warrants this. The purpose of a plan and of the annual review process should be made clear with wording aligned with the Code of Practice (see paragraphs 9.166 – 9.185). This focus on reviewing the purpose of the EHC plan is not emphasised in the guideline. Para 1.4.20 seems to relate to a health review or re-assessment of need which may then inform a formal review of the child's EHC plan, if applicable. This is not clear from the text. Currently the sections from para 1.4.20 to 1.4.22 read as though they relate to formal EHC review processes.	Thank you for your comment. The committee have amended the recommendations to clarify that they relate to professional assessments and reviews, not EHC plan re-assessments. The information from these professional assessments can then be used to determine if an EHC plan re-assessment is needed. The committee have also removed the example about starting school from recommendation 1.4.17 (previously recommendation 1.4.20).

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				The example of a change in circumstances at 1.4.20 should be **removed** – a child starting school does not usually warrant a full re-assessment (and this para, as described above, reads as though it is referring to a statutory EHC re-assessment) unless their needs have significantly changed. There is a significant difference between re-assessment and review. In each case, the local authority must satisfy itself that the information informing the assessment remains current and relevant, and must, by law, conduct a re-assessment if there is evidence that this is necessary. This is based on the individual child's needs and is not a blanket decision at a specific transition point. For a child with an EHC plan in early years provision, typically a transition review (rather than a full re-assessment) would be held in advance of the placement decision, to update the plan as necessary and to determine the primary school placement. If this section is intended only to apply to a re-assessment of health needs this must be made clear. If not, please amend this to provide a different example (such as a bereavement, parental separation or entry to care) – otherwise this would imply that practitioners should be seeking re-assessments for a large number of children that are neither required in law nor likely to result in better support for the child than a review would deliver.	
Department for Education	Guideline	026	001	Para 1.4.22 *Only reduce the level of support provided if the child or young person no longer needs this level of support.*	Thank you for your comment. The committee have reworded the recommendation to clarify that support specified in the EHC plan should not be reduced just because children and young people show improvements

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				This sentence needs to be amended to reflect the fact that provision detailed in an EHC plan **must** be secured, unless the EHC plan is reviewed and the provision reduced. (This is on the assumption that the support which is being described here is that set out in a plan, which is not entirely clear from the text.)	in certain areas or are able to do new things. The guideline identified low-quality qualitative evidence indicating that children and young people and their families and carers were concerned that their support would be reduced if they acknowledged improvements or talked about the child or young persons' strengths in the EHC plan. The committee agreed that this can be a problem in practice and made this recommendation to prevent this from happening.
Department for Education	Guideline	026	009	Para 1.4.23 *Local authority commissioners and their partners must provide sufficient funding to cover all support listed in the EHC plan that they are responsible for, as specified in paragraph 9.102 of the SEND code of practice.* This is inaccurate – paragraph 9.102 in the Code of Practice relates to Personal Budgets. For provision detailed in EHC plans where no Personal Budget is in place, the local authority and the health commissioners must secure or arrange (respectively) the provision specified. Para 1.4.24 *When requests for additional funding are refused:*	Thank you for your comment. The committee have amended recommendation 1.4.21 to remove the incorrect reference to the SEND code of practice and to be clearer about what is being recommended. The committee have amended recommendation 1.4.22 to clarify that this recommendation relates to when requests for additional resources are refused. This would apply regardless of the type of additional resource that is being requested. The committee have also amended the wording of the second bullet point to be about explaining potential courses or action, rather than how to make an appeal.

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				• *the people who make this decision should explain the reasons for not providing this support to the practitioners involved* • *the practitioners should discuss this with the child or young person and their family and carers, and explain how to make an appeal.* We are concerned that this paragraph may conflict with local arrangements. It is not clear from the text whether this relates to special educational provision or to health provision. In each case the routes to request additional funding will differ and there may be specific thresholds or criteria which need to be satisfied. We are particularly concerned about the second bullet point. Practitioners need to work in partnership with commissioners to resolve any disputes and seek resolutions which do not rely on the parents' ability or willingness to pursue an appeal. Appeals to the First-tier Tribunal (SEND) cannot in any case be made on the basis of funding alone – they can only be made based on the description of needs or the provision detailed. If the funding relates to a service commissioned by health the route of redress may be different and this needs to be made clear. We would recommend that this paragraph be removed.	
Department for Education	Guideline	027 028	009 018	**Section 1.5: Personal budgets and direct payments**	Thank you for your comment. The committee have amended the definition to clarify that this is guideline is about those who need co-ordinated education, health and

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				…should inform disabled children and young people with severe complex needs and their families and carers about personal budgets (including personal health budgets) and direct payments, Local authorities … This section is unclear in the definition of personal budgets. It conflates personal health budgets with personal budgets made available to CYP with an EHC plan. There is an issue (as noted above) around the scope of the guideline which excludes in its definition CYP with severe and complex needs who do not have an EHC plan – their entitlement to a personal budget would be different. We recommend that this section provides links to the relevant sections of the Code of Practice and to the NICE guideline on personal health budgets, and that the paragraphs are either removed or re-written to clarify which type of personal budget they refer to. We think that the treatment in the text of Personal Budgets for those in EHC plans generally could be strengthened, perhaps by drawing on good practice material issued by SEND organisations. We can provide contacts if it would be helpful to link NICE to such bodies.	social care support because of their severe and complex needs and therefore are eligible for an EHC plan in line with Children and Families Act 2014. The guideline does not only cover those children and young people who have an EHC plan. The majority of disabled children and young people with severe complex needs would be eligible for Children and young people's continuing care and therefore a personal health budget. This would be the mechanism used to deliver the health component of a personal budget (which people with an EHC plan are allowed to have). Recommendation 1.5.1 is only about providing information on personal budgets because evidence was found that children, young people and families find them confusing. The committee have not recommended who should have a personal budget. As such they think the current text is appropriate and does not need amending.
Department for Education	Guideline	028	019	This section should make reference to the role of Special Educational Needs Information, Advice and	Thank you for your comment. The committee have included SENDIAS services in the recommendation

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				Support Services. See the SEND Code of Practice paragraph 9.29: ***9.29 Local authorities must provide all parents, children and young people with impartial information, advice and support (IAS) in relation to SEN to enable them to take part effectively in the assessment and planning process.***	
Department for Education	Guideline	029	012	This section should make reference to the role of Parent Carer Forums (PCFs) and how they can help with this. There should be references to the principles of co-production. We would recommend that this section be reduced in length with a link to the relevant sections of the Code of Practice. Some best practice on health working with PCFs may be helpful – NICE may wish to consult with the National Network of Parent Carer Forums to request case study information. ***Parent Carer Forum: A Parent Carer Forum is a group of parents and carers of disabled children who work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families.***	Thank you for your comment. Not all local areas have a Parent Carer Forum (PCF) and not all PCF's operate in the same way or have similar levels of capacity. In addition, references to PCFs in the SEND code of practice relate to commissioning not training. Therefore the committee have not included these in the recommendation. The committee have amended recommendation 1.6.5 to include reference to co-production.
Department for Education	Guideline	031	001	The guideline currently includes the statement that the need for social interaction '*may justify a young person in attending school or college, even if they are unlikely to complete their course.'* This statement should be **removed** as there is no funding mechanism available	Thank you for your comment. The committee have amended the final bullet to be about recognising that social participation may justify a young person with progressive or fluctuating illness in participating in school or college, even if their attendance may be interrupted.

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				to support a young person to attend college if there is no expectation of the study programme being completed. Young people who have an EHC plan should be enrolled on a study programme which meets their needs and which provides for accreditation which is achievable for the individual, or accounts for an alternative means of measuring progress such as RARPA (see Chapter 2 of SEND: 19- to 25-year-olds' entitlement to EHC plans - GOV.UK (www.gov.uk) and 16 to 19 study programmes: guide for providers - GOV.UK (www.gov.uk) for details). If a young person has achieved all of the educational outcomes specified in their EHC plan, their EHC plan would be ceased and they would be supported (if applicable) by adult social care provision, rather than a school or college place.	
Department for Education	Guideline	032	004	Para 1.8.1 *Local authorities must ensure that preparing for adulthood is covered at education, health and care (EHC) plan transition reviews from year 9 onwards.* The Code of Practice explains that it may be useful for Preparation for Adulthood to form part of EHC plan reviews from an earlier stage, and this should be reflected in the guideline text.	Thank you for your comment. In line with a previous comment the committee have reduced repetition of the content of the SEND code of practice within the guideline. As such this suggested change has not been made, but have added introductory text which cross-references section 8 of the SEND code of practice.
Department for Education	Guideline	033	026	Units of the Code of Practice are known as **'*Chapters*'** not 'Sections'	Thank you for your comment. The committee have amended our terminology as you suggest. This bullet point has been deleted and replaced with introductory text at the start of the section.

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Department for Education	Guideline	040	012	Para 1.11.11 This paragraph makes reference to 'interagency teams' ensuring that accessibility assessments are inclusive of different environments which a child or young person may need to access, and that these assessments are shared with other providers and organisations which may provide services for the child or young person (e.g. out of school clubs). It is not clear which practitioners are expected to carry out these assessments It is not clear how this would apply to public transport, as highlighted in the bullets. The guideline does not make clear who is expected to conduct such an accessibility assessment for public transport. *Interagency teams should make sure that the results of the accessibility assessments are available for key places that the child or young person needs to access (in line with their EHC plan). For example:* • *after-school clubs (if they are not held at the school)* • *public transport* • *short break services* • *community facilities*	Thank you for your comment. As defined in the 'terms used' section, the interagency team are the existing team of key education, health and social care practitioners who are working together with the family to support the child or young person. It would be practitioners within this team who are responsible for implementing it. The committee have removed reference to public transport from the recommendation as on reflection those responsible for undertaking accessibility assessments in that area are not likely to be within the intended audience of this guideline.
Department for Education	Guideline	041	002	Para 1.12.1 *"to help them get anywhere they need to go"*	Thank you for your comment. Including destinations related to Preparation for Adulthood outcomes could be misinterpreted as meaning that travel training is an EHC plan entitlement, which is not the case. Therefore the committee have not made this change. The

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				This statement should be more specific re destinations to include e.g. employment, local health services, community inclusion. These relate to the Preparation for Adulthood outcomes, which are aspirational for all CYP with SEND. Travel training here seems to refer to public transport, but local authority good practice extends this to include travel training for walking and cycling.	recommendation does not specify that the training is only in relation to public transport. As documented in the rationale and impact section 'The recommendation is not limited to public transport, because in the committee's experience there will be significant benefits to training children and young people in other areas of transport.'
Department for Education	Guideline	041	010	Para 1.12.3 *Public transport providers must provide disability awareness training for their staff.* We presume that this relates to public transport rather than dedicated school transport. It is therefore read as a statement of fact to inform the reader – not as guidance, since this document isn't aimed at transport operators. This should be made clear, and if there is separate guidance for public transport providers, this should be linked here.	Thank you for your comment. As documented in the rationale and impact section 'The study on travel training also included providing disability awareness training for staff as part of the intervention. The committee agreed that disability awareness training was needed for public transport staff to facilitate independent use by disabled children and young people with severe complex needs.' However as providers of public transport have a statutory duty under the Equality Act (2010) to provide disability awareness training to their staff the committee have decided to remove this recommendation.
Department for Education	Guideline	041	012	Para 1.12.4 Travel training should also cover the important phase of working with parents and carers of CYP around shared aspirations, so that the training provided is tailored to the individual's goals. The bullet *"Having someone accompany the child until they are used to the route"* should be extended to	Thank you for your comment. The use of the phrase '…until they are used to the route.' implies that after that point the child or young person does not necessarily need to be accompanied. The committee have not made your suggested change about support tapering off because this would counteract another recommendation in the guideline (1.4.20) which is about not reducing support specified in the EHC plan just because children and young

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				make clear that once a young person can complete a route independently, the support tapers off - and this is a key part of the process of promoting independence.	people show improvements in particular areas or are able to do new things.
Department for Education	Guideline	042	002	Para 1.13.1 *Education providers should ensure that Information, Advice and Guidance on employment is provided using the Gatsby benchmarks, to help disabled young people with severe complex needs think about their employment options.* This paragraph should reference the duty on maintained schools, academies and pupil referral units to secure independent careers advice for CYP with SEND.	Thank you for your comment. The committee have added independent careers advice to the recommendation.
Department for Education	Guideline	042	023	Para 1.13.5 *Education, health and social care practitioners should start discussing employment as a future option from the start of transition planning (in year 9, age 13 or 14)*. We would recommend adding **'at the latest, but preferably earlier than'** to the section in brackets.	Thank you for your comment. The committee have made this change.
Department for Education	Guideline	058	010	Para 1.17.13 As set out above, this paragraph implies that practitioners from outside the local authority may be involved in writing EHC plans. This is incorrect. We would propose amending as follows:	Thank you for your comment. The committee have amended the recommendation along the lines you have suggested to be clear that practitioners do not write EHC plans.

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				Local authorities should provide training on EHC plans for practitioners, covering: • an explanation of the EHC needs assessment process and how an EHC plan is developed • **[for those practitioners in health and care services, and education settings] any specific formatting or digital templates for the provision of advice and information to support the development of the EHC plan** • **[for those practitioners in the LA SEND team]** how to write an EHC plan.	
Department for Education	Guideline	111	General	We note that the section on the rationale for the recommendations relating to travel training is more detailed than the content within the recommendation itself. Specifically, the view of the committee in terms of what constitutes good travel training is more detailed in this section than in the recommendation itself. We would propose considering whether elements of this section should be included in the recommendation at section 1.12, particularly those elements which highlight the benefits of good quality travel training and would encourage wider provision.	Thank you for your comment. This text describes the evidence found about travel training and the committee's deliberations on this when making recommendations. As such it is intentionally more detailed than the recommendations. The intention is for users to read the recommendations alongside this supporting text, so the committee have not added extra detail to the recommendations.
Department for Education	Guideline	111	019 - 029	Lines around age threshold for travel training are not clear. This section does not make it clear that local authorities are **not** required to offer travel training for 16-18 year olds.	Thank you for your comment. The committee have removed the text about age thresholds for travel training. The committee have also clarified that local authorities are not required to offer travel training to 16-18 year olds, although in the committee's experience many of them do.

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					The committee were of the view that there can be significant short and long term benefits in the application of independent travel training for disabled children and young people with severe complex needs. The training can result in savings to transport budgets in the short term, but can also provide long term benefits to the child or young person in terms of developing a 'life skill' that may lead to greater social inclusion and employment prospects.
Department for Education	Guideline	111	030 - 032	It is not clear which statutory guidance is being referred to here. A link is required.	Thank you for your comment. The committee have deleted this text.
Department for Education	Guideline	112	004 - 008	As noted in the comment on para 1.12.4, we are not sure of the purpose of including this, as public transport operators are not the intended audience of this document.	Thank you for your comment. The committee have removed this recommendation and reworded this text to clarify that because providers of public transport have a statutory duty under the Equality Act (2010) to provide disability awareness training to their staff no recommendation was made about this.
Department for Education	Guideline	112	014 - 017	*The recommendation is unlikely to have significant resource implications because the SEND code of practice already requires local authorities to provide enough funding for all the provisions agreed in EHC plans.* **We are concerned by this statement.** Whilst it is the case that local authorities are required to provide funding for provision in EHC plans, where a young person would benefit from travel training but this	Thank you for your comment. As has been clarified in other responses, this is guideline is about those who are eligible for an EHC plan in line with Children and Families Act 2014. Therefore the costs of travel training should be covered and there is unlikely to be a significant resource implication. The committee agree that there would be a resource implication if the guideline was recommending providing travel training to the larger group identified for SEND Support but that is not the population covered by the guideline recommendations.

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				is not specified in their EHC plan, or they do not have a plan, the local authority may choose to fund this through council budgets. This is not mandatory. A minority of local authorities currently fund such schemes. Any expansion of such schemes would therefore have resource implications. Extending travel training beyond what is typically provided, to cover 'using powered wheelchairs, taxis or learning to drive adapted vehicles' as suggested, would have significant resource implications. We would recommend that the committee explores further with local authority stakeholders how travel training is currently delivered before making recommendations.	The text about powered wheelchairs, taxis and learning to drive adapted vehicles is not in the recommendations it is in the rationale and impact section. The recommendations made are about what travel training could cover. If the training covered all of these things it would facilitate children and young people to use the modes of transport cited in the supporting text. However the recommendation does not mandate that local authorities have to cover all of these things in travel training.
Department for Education	Guideline	112	001 - 003	It is not clear whether this relates to staff on public transport, or those conducting travel training.	Thank you for your comment. This evidence is documented in Evidence Report K and relates to practitioners in education, health and care services. The committee have clarified this in the text.
Department for Education	Guideline	132	007	"Equalities Act 2010" should read "Equality Act 2010".	Thank you for your comment. The committee have made this change.
Dravet Syndrome UK	Guideline	General	General	These guidelines provide 'Recommendations on support for all disabled children and young people with severe complex needs', a group defined as 'Disabled children and young people from birth to 25 years who need education, health and social care support and who are eligible for an education, health and care plan' (page 61). Overall, we feel that these guidelines do not sufficiently recognise the diversity of ability within this group. While the guidelines seem appropriate for a	Thank you for your comment. The committee have added a recommendation about taking into account the views of those who know the child or young person best.

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				disabled child/young person with no learning disability or mild/moderate learning disability, there is a significant lack of clarity for working with more severely and profoundly disabled children, with or without mental capacity and the ability to communicate to people they don't know. In this situation, the guidelines lack a recognition that parents are often at the heart of providing care and, in many cases, a voice for their child/young person with severe or profound learning disability. For example, children and young people living with Dravet Syndrome children and adults with Dravet Syndrome need 24/7 care, not just because of the seizures but also learning disability (severe to profound in more than 50% of individuals) and a spectrum of related conditions including autism, ADHD, challenging behaviour, and difficulties with speech/language, mobility, feeding and sleep. Of course, we absolutely support including and listening to young people in decision making and every measure should be in place to enable and safeguard this. But what the guideline seems to lack is a recognition that the parent's voice is also central to meeting the needs of the individual with severe complex needs (e.g. as stated in Department of Health Practice Guidance from 2000: "Recognising the needs of parent carers is a core component in agreeing services which will promote the welfare of the disabled child").	

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				Our concern is that, without recognising this, the guideline may inadvertently add more barriers to getting the right care package in place that will enable children and young people with complex needs and severe or profound learning disability to develop and thrive.	
Dravet Syndrome UK	Guideline	004	019	"take the views of parents (or other people with parental responsibility) into account". We feel this should be clarified in situations where children and young people have severe or profound learning disability to recognise and respect that, in these circumstances, listening to the parent/carer's views may be central to ensuring the welfare of the child or young person and, in many cases, they will be in position to voice and/or advocate for their views, life goals and ambitions, with the exception of cases where safeguarding concerns apply. This clarification should be applied wherever the phrase recurs in the guidelines.	Thank you for your comment. The committee agree on the importance of parent/carer views when children and young people have severe or profound learning disability. However the existing wording about taking the views of parents into account would enable these views to be ascertained and so have not changed the wording.
Dravet Syndrome UK	Guideline	032	003	Transition. We request to include an additional section on parental deputyship. We feel this is a significant gap in the current guidelines, which again to the point that the relationship of the parent as the young person's voice is very important in situations where disabled children and young people have severe/profound learning disability, with or without mental capacity and the ability to communicate to people they don't know. By the time their children are reaching adulthood, parents are - in most cases - best positioned to understand and advocate for their child. Yet parental	Thank you for your comment. The committee have added parental deputyship to recommendation 1.8.2.

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				deputyship - and its benefits for the welfare of the child/young person are not referenced here.	
Dravet Syndrome UK	Guideline	033	011	'When young people are approaching adulthood, explain to parents how their child's rights will change, how their level of parental involvement will change…'. As currently worded, this could be a distressing message for parents/carers to receive and it gives no encouragement to professionals to provide information about solutions that could benefit the welfare of all the family i.e. via parental deputyship (in the appropriate circumstances). We would request additional bullets here to explain that in situations where disabled children and young people have severe/profound learning disability, with or without mental capacity and the ability to communicate to people they don't know, parents/carers can apply for deputyship and be given timely advice on how to do so.	Thank you for your comment. The committee have added a bullet point about how parents can register to act as deputy for their child.
Dravet Syndrome UK	Guideline	045	011 - 019	Training and working culture. We welcome the statement (lines 15-16) to treat everyone involved in the care of the disabled child/young person as equals. We would also recommend adding a statement encouraging professionals to take time to listen and learn from parents/carers of children and young people with rare conditions, such as Dravet Syndrome, and those whose complex needs include severe/profound learning disability. For example, in our experience, the majority of social workers are not familiar with Dravet Syndrome as it is a rare neurological condition (occurring in around 1 in 15,000 live births). Dravet Syndrome is a spectrum	Thank you for your comment and providing information on Dravet Syndrome. Recommendations 1.1.7, 1.1.12 and 1.1.14 already cover listening and learning from parents.

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				condition that has key features in common (seizures, learning disability, and a range of comorbidities), but it affects individuals differently. Dravet Syndrome is also very challenging and impacts every area of life. Listening and learning from parents/carers would help professionals not familiar with Dravet Syndrome to understand how the condition, and its spectrum of symptoms, affect the individual child or young person.	
ESC Management Services Limited	Guideline	001	004 - 007	A minor formatting point. Throughout the Final Scope document (June 2019) the format is '*health, social care and education*.' The title of this draft guideline also uses this format. However, within the actual guideline this is persistently reordered to '*education, health and social care'*. This inconsistency is acknowledged in the Evidence Review document referring to the 'NICE style' of health, social care and education but that the education, health and care (EHC) format has been used to align with EHC plans. It may be beneficial to replicate this Evidence Review explanation in the guideline.	Thank you for your comment. The committee have added text at the start of the guideline to clarify this.
ESC Management Services Limited	Guideline	003	012 - 013	**Contents:** The guideline includes recommendations on specialist support for disabled children and young people with particular needs and lists a range of specific requirements. A notable gap is continuing care.	Thank you for your comment. The committee have referred to continuing care in new introductory text at the start of this section. The committee acknowledge that there are difficulties with continuing care services and different contractual arrangements across organisational boundaries, but the guideline does not have a remit to

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				Whilst section 1.5 covers 'Personal budgets and Direct Payments' this is focused on funding streams. There can be challenges around continuing care services and the different contractual arrangements across organisational/sector boundaries. For example, continuing care health services provided in the education setting via direct payments can result in significant operational issues for schools e.g. safeguarding, governance, accountabilities and insurance. It would be beneficial if recommendations could be made on how continuing care arrangements can be integrated and effectively managed across orgainsational/sector boundaries.	make recommendations about how continuing care is delivered. However the guideline has made recommendations in section 1.18 to facilitate integrated working across all 3 services which hopefully will help.
ESC Management Services Limited	Guideline	009	024	Could the committee consider adding '……*education, health and social care practitioners who know the child or young person and are involved in their support'.*	Thank you for your comment. The committee have made this change.
ESC Management Services Limited	Guideline	022	002 - 006	**Rec 1.4.7** The 'Writing the plan' section advocates that services should co-ordinate and agree the content of the EHC plan together. As there are later recommendations relating to reviews and reassessments, it would seem this relates to the preparation of the initial EHC plan. Joint working and integration are positive and consistent themes of the	Thank you for your comment. The committee have reworded the recommendations to clarify that practitioners should read the advice and information provided by others within the same service, to ensure they can support all the proposed outcomes through their own work with the child or young person. This should already be current practice. The committee have also recommended that Local

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				SEND reforms and whilst there would be definite advantages in this approach, this recommendation could be challenging to implement. Since the SEND reforms, the national picture has been one of difficulties with compliance around the statutory EHC process. Most notably, this has related to timings but problems have also been evident in the quality of assessments/information. Over recent years, national data shows the proportion of EHC plans that were issued within the 20 week statutory time limit has hovered at around 60% and there is significant pressure on local authorities to comply with/improve timescales. Hence, compliance with statutory timescales is a key driver for local authority improvement plans. The implementation challenge will be that the statutory process for assessment and preparation of EHC Plans is limited in terms of facilitating professional co-production. Unlike the annual review, which specifies a meeting between a child's parents/young people and professionals, no such step exists in the statutory process for initial assessment and preparation of the EHC plan. There is a statutory requirement to share the draft plan with a child's parents/young person but there is no equivalent statutory step to share/amend	Authorities share a child/young person's EHC plan outcomes with education, health and social care services so that they can include how they will help to achieve these outcomes when providing their advice and information. Whilst Local authorities may need to change their practice to do this up-front it should result in the advice and information provided by different services being more consistent, less time being needed to resolve inconsistencies and issues and an EHC plan that is practical to implement.

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				the draft plan with professional contributors. Consequently, this recommendation will require steps that are additional to the statutory process and this is likely to significantly impact on timescales. In 2020, only eight local authorities achieved 100% compliance for the 20 week timescale and the national average was 58%. Given this national picture and the priority to achieve statutory compliance, it is difficult to envisage how local areas could adopt what is likely to be a lengthier process and still make progress against the 20 week target. The committee may view this an aspirational recommendation and if this is the case, perhaps it would be helpful to supplement the recommendation with additional practical detail. For example, of the eight local authorities achieving 100% statutory compliance, are there best practice examples of either 'how does' or 'how could' this co-production recommendation work whilst achieving compliant timescales.	
ESC Management Services Limited	Guideline	022	012 - 015	**Rec 1.4.9:** The meaning of this recommendation is a little unclear. Specifically, using healthcare professional information to describe special educational needs and social care needs.	Thank you for your comment. Under the SEND code of practice, therapists may describe both health needs and special educational and social care needs to distinguish between the support needed to stay well and the support needed to educate and train. In light of feedback received

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				The SEND Code of Practice provides guidance on what to include in different sections of the EHC Plan. Using health professional information in section B (SEN) would have relevance when the needs require 'traditional' health services that have been deemed provision that educates or trains. For section D (social care) content, there is no mention of using healthcare information to describe social care needs (SEND Code of Practice pg. 165). Could this recommendation be expanded to provide more detail or include the relevant SEND Code of Practice reference on the use of healthcare professional information in sections B and D.	from stakeholders the committee have removed recommendations which repeat the content of the SEND code of practice so this suggested change has not been made.
ESC Management Services Limited	Guideline	022	016 - 018	**Rec 1.4.9:** Placing the responsibility on practitioners to determine whether therapeutic interventions educate or train is entirely appropriate and reasonable. Decisions about whether health provision educates or trains must be made on an individual basis (SEND Code of Practice para. 9.74, pg. 170). This appears relatively straightforward but the committee may wish to consider the contextual factors that may influence professional decision-making and whether it is necessary to strengthen this recommendation.	Thank you for your comment. Whilst the SEND Code of Practice provides guidance on detailing the resources needed to provide the support specified in a child or young person's EHC plan, the committee's experience was that this guidance is not always followed in practice. In addition, whilst different NHS services need to input in specific sections of the EHC plan so that commissioners can see which services need to be provided from which budget lines, this is often done poorly, with a lack of distinction between what therapeutic support is needed to educate or train the child or young person and what health and medical support they need to stay well. This causes issues with support being provided so they made

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				External influences include local arrangements for NHS therapy services and Tribunal powers, this is illustrated by the Association of Paediatric Chartered Physiotherapists (APCP) guidance on writing advice for EHC plans (2017 current version available via APCP website). This states (text format as presented in guidance); 'Health professionals asked to contribute to the EHCP often find their reports listed in section G of the plan: Any health provision reasonably required by the learning difficulties or disabilities which result in the CYP having SEND. **(See section on legal issues as to why you may want to encourage your advice to be included in section F).**' pg. 11 The 'Legal Issues' section of the guidance contains a description of the SEND Tribunal powers and the impact and implications when physiotherapy services are placed in either section F or G. This details that the local authority is responsible for delivering (including funding) section F services and for this reason, professionals may wish to ensure that the physiotherapy requirements needed for daily life such as postural management are listed in section F. The	recommendations to highlight the need provide this information more clearly when writing EHC plans and for commissioners to use this information when planning what services to provide. The recommendations aim to clarify what content needs to be included in different sections of the EHC plan so that it can be completed correctly. The committee are not able to make this recommendation stronger as 'must' can only be used when there is relevant legislation. The committee would expect that the relevant professional codes of conduct should prevent professional decision making being influenced as you allude to in your comment.

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				guidance goes on to say that this will secure provision regardless of local therapy provider arrangements. Therefore, this appears to suggest that services required for 'daily activities' i.e. not services that are for the specific purpose of educating or training are specified as section F special educational provision. The APCP guidance warns that local authorities should not be using blanket approaches to allocate physiotherapy services as health provision but then appears to '*encourage*' registered professionals to include physiotherapy services in section F as special educational provision. Although specifying provision as special educational rather than health may increase the likelihood of securing services, there are wider implications. These include inappropriate use of local authority special education funding and the impact on standards of care when what should be NHS services sit outside the NHS commissioning and quality statutory framework.	
ESC Management Services Limited	Guideline	022	001	**'Writing the plan' title:** The committee may wish to consider the word 'Writing' in the title and when used in this section. It is the local authority that has the statutory duty to prepare the EHC plan (The SEND Regulations 2014 s.11). The SEND Code of Practice	Thank you for your comment. The committee have amended the text to clarify that is the Local Authority Officers who write EHC plans, based on information and advice contributed by practitioners from education, health and social care.

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				has a section with the title 'Writing the plan' which starts with the statement '*The following principles and requirements apply to local authorities and those contributing to the preparation of an EHC plan* (para 9.61, pg.160/161). This makes the distinction between local authority and professional responsibilities and recognises that the statutory duty on practitioners is to contribute advice and information. Although it may be considered subtle, there is a difference between practitioners 'contributing' advice and information for plans and practitioners 'writing' plans. The current use of the word 'writing' could inadvertently over-extend the responsibilities placed on health, education and social care professionals which go beyond their statutory duties. This may result in EHC plan administrative tasks being inappropriately shifted from local authorities to these professionals. The committee may wish to consider being more explicit in the distinction between the duties on local authority and professionals. Perhaps '*Preparing the plan'* may be a more appropriate title and when referring to practitioner contributions, rather than 'writing' plans, this should align to statutory duties e.g. practitioners *'contributing advice and information'.*	

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ESC Management Services Limited	Guideline	023	012 - 015	**Rec 1.4.13:** *Local authorities should ensure* that EHC plans are *written* by practitioners who have the right expertise and knowledge of the child or young person. a) This recommendation implies that local authorities should ensure all practitioners including health practitioners contributing to the EHC plan have the right knowledge and expertise. In terms of the health input, this might be considered unreasonable, impractical and outside the scope of local authorities. NHS commissioning bodies have a legal duty to identify the appropriate health professional to provide health information and advice (SEND Regulations 2014, regulation (6)(1)(c)). The Committee may wish to draw on this health statutory duty in this recommendation i.e. '*Local authorities and health commissioners should ensure that EHC Plans….'* b) As noted in comment 4, the statutory requirement and process for professionals contributing to EHC plans is to provide advice and information to local authorities either directly or via schools in a school-led annual review. Local authorities have the statutory duty to prepare the plan taking into account professional advice and information and considering how best to achieve the outcomes	Thank you for your comment. The committee have made changes to the recommendation that align with your suggestions.

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				sought (SEND Regulations 2014 s.11). As noted previously, a more appropriate phrase could be *'practitioners contributing advice and information' have the right expertise and knowledge of the child or young person.'*	
ESC Management Services Limited	Guideline	023	001 - 002	**Rec 1.4.10:** Although not explicitly stated in the recommendation, the assumption is that local authorities would commission services specified in section F and H and that the relevant NHS commissioner would commission the services specified in section G. This would be aligned to the legal framework. This distinction between the local authority and health commissioning functions is critical because it determines the statutory scheme for service provision. NHS commissioning initiates the NHS pathway to ensure compliance with the NHS statutory quality duty and adherence to the NHS constitution. A consideration for the committee is that a significant proportion of section G health services delivered within the education sector sits outside NHS commissioning. The current service delivery model for section G health provision is largely reliant on the education workforce providing health services via delegation. This	Thank you for your comment. The committee were aware that different NHS services need to input in specific sections of the EHC plan so that commissioners can see which services need to be provided from which budget lines. In the committee's experience this is often done poorly, with a lack of distinction between what therapeutic support is needed to educate or train the child or young person and what health and medical support they need to stay well. This causes issues with support being provided so they made recommendations to highlight the need to provide this information more clearly when writing EHC plans and for commissioners to use this information when planning what services to provide. Whilst the committee are aware of the issues around health services that are delivered within the education sector sitting outside NHS commissioning, this guideline does not have a remit to specify what the commissioning arrangements should be for delegated clinical activity. However, the committee have attempted to clarify the guidance around delegated clinical tasks in section 1.15.

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				delegated activity is often not associated with a CCG commissioning arrangement. This lack of formal NHS commissioning for what should be NHS activity has serious implications in terms of clinical governance, accountabilities and funding. There is no national metric/data that quantifies or monitors delegated health services within education and this contributes to the 'hidden' nature of this activity. Although this model applies to all schools, this is particularly relevant for specialist schools which due to the needs of pupils can represent unique clinical environments led and managed by education professionals. Within the specialist school sector, the national picture is that these arrangements are subject to highly variable levels of NHS input and oversight. So in effect, for children and young people with severe complex health needs there is a two-tier standard of healthcare; an NHS service underpinned by the NHS statutory duty for quality and an education healthcare service functioning outside the NHS statutory and operational framework. This two-tier system along with the postcode lottery of approaches, variability of NHS support and the hidden nature of delegated activity, paint a picture which is of significant concern.	

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				Since the Francis Inquiry into Mid-Staffordshire NHS Foundation Trust and the Cavendish Review, much has been done to improve the quality of services delivered by unregistered workers in the health and care sectors but this has not extended to healthcare delivered in the education sector. Over recent years, education leaders report that NHS services and support in school have actually decreased, this is despite increasing numbers and complexity of health needs. Unsurprisingly, school leaders persistently raise concerns and warning about the gaps in clinical governance, accountability, funding and inspectorate/regulatory oversight. There are discussions taking place in the specialist school sector about the legal aspects of the current service delivery model. Firstly, taking the view that NHS commissioning responsibilities remain even when care can be delegated to unregistered support workers (see case law Haringey 2005; Nascot Law 2018). This suggests that where there is an NHS commissioning responsibility for health services, if the healthcare is delegated then the delegated activity should be NHS commissioned. However, if a CCG did commission a school to provide NHS funded health services,	

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				questions then arise including, do schools have the statutory power to function as an NHS service provider? and how can a school provide NHS 'quality' services when it sits outside the NHS 'quality' statutory framework? Currently, a special school could provide NHS care plan services to 250+ children and young people with EHC plans but there is no requirement for the school to be registered with the CQC as a provider of NHS services. It may be beneficial for the committee to be aware of these discussions in relation to this recommendation.	
ESC Management Services Limited	Guideline	028	005 - 008	**Rec 1.5.2:** The example of a family commissioning health and care support using direct payments states that the local authority should ensure that those providers still have access to health and care advice directly from statutory providers. Again, it might be considered unreasonable and impractical to allocate the task of ensuring health providers receive appropriate health advice to local authorities. Particularly, when CCGs have statutory duties under the NHS (Direct Payment) Regulations 2013 to ensure care planning and support from a care	Thank you for your comment. The committee have made this change.

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				coordinator (Regulation 8) and access to information, advice and other support (Regulation 9). The committee may wish to reflect these statutory duties in this example and add *'the local authority and health commissioner should ensure…...'*	
ESC Management Services Limited	Guideline	052	016 - 019	**Rec 1.15.27:** This list appears to focus on nursing e.g. NMC and RCN references. However, as noted, delegated activity encompasses a range of 'health' interventions such as therapy and dietetic provision. So it may be helpful to also include the HCPC as a statutory regulatory body governing professional standards. There is also the potential that professional bodies may have different interpretations of standards for delegation (see comment 15). This could result in confusion. Therefore, it may be beneficial to limit this list to NMC, HCPC and CQC. As an aside, the RCN guidance 'Meeting health needs in educational and other community setting' 2018 was due to be reviewed in January 2021. If the RCN is retained on this list, it may be helpful for the committee to request a status update on this guidance.	Thank you for your comment. The committee have added the HCPC to the recommendation and removed direct reference to the RCN as suggested.
ESC Management	Guideline	052	015	**Title 'Competency in delegated clinical tasks'**	Thank you for your comment. The committee have amended the section heading as suggested. In line with

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Services Limited				a) This set of recommendations cover a number of aspects of delegation; training, supervision, insurance and incident management. Delegation of healthcare tasks encompasses far more than competency as the recommendations illustrate. Therefore, the committee may wish to consider removing '*Competency in*'. b) The title specifies 'clinical' tasks and coupled with the focus on nursing (i.e. references to Nursing and Midwifery Council (NMC) and Royal College of Nursing (RCN) pg. 52 line 17/18) there could be an impression that this recommendation is limited to nursing activity. If the intention is to focus on 'health' provision then this would incorporate therapy services specified in an EHC plan section G e.g. postural support and dysphagia management that are also delegated to unregistered, non-health support workers. Therefore, this would draw in the professional standards for delegation stipulated by the Health and Care Professions Council (HCPC) i.e. Standard 4 - to delegate appropriately. Perhaps the committee may wish to consider whether 'clinical' implies a limited scope of	stakeholder feedback the committee have added the HCPC to the recommendation and removed direct reference to the RCN so there is no longer the potential for a 'nursing focus' to interpreted from the recommendation. However the committee have kept the term 'clinical tasks' to align with terminology used in other NICE guidance.

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				delegated health tasks and whether a better option may be *'Delegated health tasks'*.	
ESC Management Services Limited	Guideline	052	016	**Rec 1.15.27:** a) The beginning of this sentence is a little confusing 'For staff, services….'. It has been difficult to decipher with certainty if this is intended for the staff that are delegating the activity or the organisations employing the delegator and/or the delegatee. On balance, the consensus is that this recommendation probably relates to registered healthcare professionals/NHS organisations but it would be helpful if this could be clarified. b) This recommendation states '*services must follow guidance on training and competency.*' The NMC and HCPC set the professional standards for delegation, which for both NMC and HCPC includes the requirement for supervision. NMC guidance also emphasises the importance of risk assessment (NMC Delegation and Accountability 2018). The phrase 'training and competency' is used by the CQC in guidance for medicines optimisation in adult social care and by NICE in the guideline 'Managing medicines for adults receiving social	Thank you for your comment. The committee have amended the recommendation to clarify that it relates to registered health professionals, when training support workers to undertake delegated clinical tasks. With this clarification in place, the committee consider that the phrase 'training and competency' is accurate.

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				care in the community' [NG67]. However, in both these, medicines support tasks do not appear to be specifically related to delegated activity. If this recommendation is intended to reinforce professional delegation standards in their entirety, rather than limiting to 'training and competency', ideally this recommendation would read *'services must follow guidance on delegation'* to capture all the professional requirements for delegating activity.	
ESC Management Services Limited	Guideline	053	001	**Rec 1.15.27:** *'only train support workers….'* There is a widely held view that health professionals provide training for the specialist education workforce but they do not delegate. The absence of NHS commissioning for delegated activity and a belief that a school providing health services for pupils with complex needs is simply a scaled up version of mum at home providing care for her child are possibly contributory factors. The terms 'train' and 'delegate' are often used as though they are interchangeable. Whilst training is an important component of delegation, they are not one in the same. As noted, delegation comprises of a wider set of activities and standards such as risk	Thank you for your comment. The committee agree that training is a component of delegation and think that the revised wording of this recommendation reflects that distinction.

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				assessment, competency assessment and supervision. To ensure the recommendations reflect the requirements for delegation, the committee may wish to consider the distinction and use of these two different terms. For example, should this bullet point read *'tasks should only be delegated to support workers if these support workers are employed…..'*	
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	General	General	I have reviewed this guideline from the viewpoint of Special Care Dentistry where young people with severe complex needs often access dental treatment. I think that overall, this guideline is extremely comprehensive and helpful and looks at the child/young person holistically rather than dealing with different issues that they may face individually. It endeavours to explore and respect the views of the young person/ child and seeks to support them in decision making processes.	Thank you for your comment and your support of the guideline
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	054 - 060		Sections 1.16-1.18 are all excellent ideas which I hope can be implemented.	Thank you for your comment and your support of the guideline.
Faculty of Dental Surgery of	Guideline	004		I think that section 1.1 is crucial as it sets out the Principles for working with children, young people and their families at the outset and puts their views, life	Thank you for your comment and your support of the guideline

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the Royal College of Surgeons of England				goals and ambitions at the forefront yet also takes in to account the views of parents/family members.	
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	008		Section 1.1.20 is very helpful regarding the planning and running of meetings and serves as a useful reminder that the young people may require information in accessible forms and may require support prior to the meeting. In Special Care Dentistry, we use many aids to communication including sign language, picture symbols and high and low fidelity aids which make communication and consent processes much easier and ultimately lead to greater patient satisfaction and understanding. General Dental Practitioners may struggle with providing accessible information and then should consider a referral to Specialist Service providers.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health. The recommendations in the guideline would not stop General Dental Practitioners referring to specialist service providers if they are unable to provide accessible information.
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	014		Section 1. 2.1 is very useful in alerting clinicians to patient's special educational needs and social care needs which may impact on their dental care and the need to liaise with local authorities when planning care. This is often forgotten. Referrals to Social Care may be beyond the beyond the remit of dental practitioners if they do not see the patient on a regular basis and know them well.	Thank you for your comment and support for the recommendations.
Faculty of Dental Surgery of the Royal	Guideline	016		Section 1.2.5 is vitally important when consideration is given to making a referral for social care assessment/ family support, however, it may have been better to tie	Thank you for your comment. This recommendation is about social care assessment for family support to ensure children, young people and their families are able to access support to continue caring. Recommendation 1.2.8

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College of Surgeons of England				this section in with section 1.2.8 which mentions safeguarding concerns.	is about what to do if you identify safeguarding concern. As such they are separate issues and the committee have not combined the recommendations.
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	021		In Section 1.4, it would be helpful to mention oral health in health care plans as oral health is often overlooked with the demands of other medical/ social appointments.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health.
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	028		Section 1.6 seems crucial so that parents and carers are involved in care planning and understand how that they can be conduits in meeting their child's needs. Prevention of preventable oral health problems such as caries and periodontal disease has not been mentioned in this document and from an oral health point of view, prevention is crucial for the prevention of dental pain and infection and the parents/carers have a vital part to play in this.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health.
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	032		1.8 has great relevance for dentistry as patients move from paediatric to adult dental services. It is important that dental providers make provision for transition to occur smoothly at an appropriate age for each individual taking in to account their level of maturity and understanding so that the patient's dental care is not neglected. Information, in an appropriate format must be provided to the young person as to how the process will occur and what may be expected of the new provider; Social Stories are very useful to explain the process in many cases.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health.

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Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	035		1.9: Palliative Care: Dental Practitioners must be fully involved in end of life care planning and provide domicilary services and preventative advice as necessary to ensure that the child/young person is kept as healthy as possible from a dental viewpoint.	Thank you for your comment. The focus of this guideline is making recommendations on integrated service delivery and organisation across education, health and social care. As such the committee have not looked at evidence or made recommendations for specific services within health.
Faculty of Dental Surgery of the Royal College of Surgeons of England	Guideline	046		Section 1.15.2 is great and should be put in to practice more. A good example of this working Is the Rainbow Centre in Ashford in Kent, a multi agency Specialist Hub.	Thank you for your comment and support for the recommendation.
Independent Provider of Special Education Advice	Guideline	015	025 - 027	Rec 1.2.4 – This recommendation should include telling young people and their parents/carers about national organisations that can provide information, support and advice, not just those organisations that are part of the Local Offer.	Thank you for your comment. The committee have added a bullet point about signposting to SENDIAS services. These services would be able to provide information on national support organisations.
Independent Provider of Special Education Advice	Guideline	016	012 - 018	Rec 1.2.7 – The explanation for parents/carers about social care and family support services should include a clear explanation that a disabled child is automatically a 'child in need' under section 17 of the Children Act 1989 and as such is entitled to an assessment of their social care needs.	Thank you for your comment. The committee have added introductory text to this section to clarify that all disabled children are defined as in need under section 17 of the Children Act 1989 and are entitled to an assessment of need. However some social care support for families may be available without an assessment
Independent Provider of Special Education Advice	Guideline	017	002 - 010	Rec 1.3.1 – We suggest adding a bullet point to this list on the criteria set out in law for when a local authority should carry out an EHC needs assessment, namely if a child has or may have special educational needs and if they may need special educational provision to be	Thank you for your comment. The committee have added the criteria for when a local authority should carry out an EHC needs assessment to the list of bullets.

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				made through an EHC plan (section 36(8) of the Children and Families Act 2014).	
Independent Provider of Special Education Advice	Guideline	017	019 - 024	Rec 1.3.4 – This recommendation should include a requirement to explain to young people and their families/carers what their legal rights are and the statutory timeframe for each step of the process of finalising an EHC plan, as set out in SEND Regs 2014.	Thank you for your comment. The timescales for completing a needs assessment and finalising the EHC plan are included in recommendation 1.3.14. Legal rights in relation to EHC plans are covered in the SEND code of practice so the committee have not repeated them here.
Independent Provider of Special Education Advice	Guideline	017	015 - 016	Rec 1.3.3 – We recommend strengthening this recommendation to say that it is unlawful to refuse to carry out an EHC needs assessment on the grounds that a child does not have a specific diagnosis. The fact that a child has, or may have, special educational needs is enough. (See section 36(8) of the Children and Families Act 2014.)	Thank you for your comment. As documented in the rationale and impact section, there was low and moderate-quality qualitative evidence that access to services sometimes depends on the child or young person receiving a particular diagnosis. This excludes some disabled children and young people from support, because they can have severe complex needs but not have a specific, diagnosable health problem. The committee made this recommendation to highlight this issue and think it is important to retain it, even in light of the legal requirements.
Independent Provider of Special Education Advice	Guideline	019	005 - 012	Rec 1.3.10 – This recommendation should explicitly acknowledge the legal requirements for the EHC needs assessment process as set out in SEND Regs 2014. The point is, this recommendation is not simply advice based on good practice: it is the law.	Thank you for your comment. This recommendation is based on the committee's experience and qualitative evidence reviewed by the guideline. This is documented in the rationale and impact section and the committee's interpretation of the evidence section in evidence report C. As such it is advice and not the law, although it does align with the legal requirements.
Independent Provider of Special Education Advice	Guideline	020	003 - 005	Rec 1.3.12 – This recommendation refers to the SEND Code of Practice, which is statutory guidance. However, the timescales set out here are required by law – specifically the Children and Families Act 2014 and SEND Regs 2014 – and the recommendation	Thank you for your comment. The committee have amended the recommendations to refer to the legislation as you suggest.

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				should refer to the legislation rather than the Code of Practice.	
Independent Provider of Special Education Advice	Guideline	023	003 - 008	Rec 1.4.11 – This recommendation should state clearly that provision in EHC plans should be detailed, specific and quantified. A child's EHC plan should state not only who is responsible for providing support but also when it has to happen and how often it should be reviewed. (EC v North East Lincolnshire LA [2015] UKUT 0648 (AAC))	Thank you for your comment. This recommendation is intended to supplement what the SEND code of practice says about production of EHC plans. As such the committee have not repeated this information. Who is responsible for providing support is included in the fourth bullet of this recommendation. Recommendations about review are already covered in the section on 'Review and reassessment'.
Independent Provider of Special Education Advice	Guideline	029	014 - 019	Rec 1.6.6 – We recommend that training for parents/carers includes training in the SEND legal framework, to enable them to understand children and young people's entitlement to educational support that meets their individual needs.	Thank you for your comment. The committee do not think training in the SEND legal framework would be helpful. Instead they have included extra items in what the training could cover so that it encompasses entitlements and what support they can expect for their child.
Independent Provider of Special Education Advice	Guideline	032	007 - 008	Rec 1.8.1 – This recommendation refers to the SEND Code of Practice, which is statutory guidance. However, the requirement that preparation for adulthood is covered at EHC plan reviews from Year 9 onwards is set out in Regulation 20(6) and Regulation 21(6) of SEND Regs 2014. The recommendation should refer to regulations rather than the Code of Practice.	Thank you for your comment. The committee have amended the recommendation to refer to the regulations as you suggest.
Institute of Health Visiting	Guideline	5	17-19	We are concerned about this statement. It assumes that parents know how to make the child communicate their views and the right services they need to enable their child to communicate effectively perhaps practitioners should work with parents and help them to understand what services are available and how they can help their child to communicate and together	Thank you for your comment. In the committee's experience parents often report feeling like services are telling them what to do. The purpose of this recommendation is to find out what the parent knows so that services can be put in place to support them.

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				find something that helps the child to express themselves so they can contribute to the discussions.	
Institute of Health Visiting	Guideline	5	20-21	We are concerned that the statement assumes that the relationship between the practitioner and the family is amiable and that parents can freely express their opinion about the level of involvement in decision making or quality of support without the fear that this may affect future access to support. Perhaps this can be rephrased to parents are given information about where they can express concerns about the quality of their involvement in decision making and or support and that they have the understanding that the person/body informed will be able to address their concerns with the practitioner. This would be more empowering to parents and ensures accountability on the part of the practitioner.	Thank you for your comment. The committee hope that if this recommendation, alongside the other recommendations made by this guideline are implemented, this will result in more amicable relationships between practitioners and families. Therefore the committee have not made the change you have suggested.
Institute of Health Visiting	Guideline	6	1.1.9	Replace the word "often" with "may" be anxious about judgemental attitudes – by suggesting often this is potentially a judgement.	Thank you for your comment. The committee have made this change.
Institute of Health Visiting	Guideline	6		We think it is a good idea for professionals to use evidenced based frameworks when they deliver difficult or unexpected news. Our research has taught us that information about the condition needs to remain balanced and not overly negative. It would be crucial to ensure that professionals have the time and space when they give this information to allows parents and the young person to ask questions. The professional also needs to be knowledgeable about the condition and about appropriate sources of local and national support. The professional may need to have an open	Thank you for your comment. The recommendations made in this section are specific to children and young people with severe complex needs and their parents and carers. The changes you have suggested would be more relevant to generic guidance on how to communicate effectively and the committee have therefore not made them here.

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				discussion with the parents and young person about how much information needs to be shared to avoid information overload and to enable the family to process what they have been told at their own pace.	
Institute of Health Visiting	Guideline	6	19	Professionals may also need to make information accessible due to variation in literacy levels and or parents/carers having learning difficulties, learning disabilities or any other form of disability which may impact on their ability to understand the standard format in which information may be provided.	Thank you for your comment. The committee have added a recommendation on the additional communication needs of parents and carers.
Institute of Health Visiting	Guideline	7	22-23	This is an important point but also assumes that parents know what to expect but this may well be a new experience for them, and they are not sure what to expect so maybe here or in the point made earlier 1.1.15 it would be important to educate parents about what to expect from services so that they can in turn be able to communicate their expectations when they get to the services.	Thank you for your comment. The committee have added 'what to expect from services' to the list of bullet points.
Institute of Health Visiting	Guideline	7	11	We feel it is important that information is provided on how to raise a concern about their care – this needs to be specified on its own in a separate statement bullet point of this section. Evidence shows parents and carers don't know where to go when the care is not as expected and are afraid to raise concerns in case this impacts on their support.	Thank you for your comment. The committee have added 'how to raise a concern about their care' to the list of bullet points
Institute of Health Visiting	Guideline	7	12	We need to avoid the use of "direct" the research clearly shows that we need to work collaboratively with parents as partners in care, we suggest that this word is changed to "share with .."	Thank you for your comment. In the context of this recommendation the use of the word 'direct' is intended to mean point people in the direction of sources of support and advice. As such the committee think it is appropriate.

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Institute of Health Visiting	Guideline	7	22	We feel it is not enough to just leave an individual with unmet needs even if the reason for not meeting them is explained, we suggest this should be expanded to advice the professional to explore alternatives or agree a future plan within expectations and include a clear review of the needs.	Thank you for your comment. The committee have added exploring alternatives to the recommendation.
Institute of Health Visiting	Guideline	8	16	Please consider an additional point to be able to support parents/ carers of pre-school children and babies to allow them to fully participate in meetings for example provision of child care, consideration of time and place of meetings in baby friendly environments.	Thank you for your comment. The committee have added a bullet about taking family circumstances into account when arranging meetings, which would include those with pre-school children and babies.
Institute of Health Visiting	Guideline	11	1	Parents/carers are included here but in the earlier discussions the parents were not included. We think it's important for the parents/carers to be involved at all times.	Thank you for your comment. The committee agree that involvement of parents and carers is important, but are unsure which recommendation you think needs to be changed.
Institute of Health Visiting	Guideline	12	4	This section involves parents/those with parental responsibility as well as the child/young person. It would be good if this is also done for the Planning and Running Meetings section on page 11.	Thank you for your comment. The committee have added to the terms used section to clarify that when the guideline uses the term 'parents' this also includes those with parental responsibility.
Institute of Health Visiting	Guideline	11	13	Replace word tell with ask (this is less directive) which was clear from the evidence review needs to be the approach taken in working in partnership.	Thank you for your comment. The committee have made this change.
Institute of Health Visiting	Guideline	15	1	This discussion is critical and needs to be handled sensitively to ensure that the young person/child and their family for do not experience significant distress. Evidence from research in this area indicates that this is a defining moment for the emotional and mental wellbeing of the family. It also determines how well families continue to engage with services. We think it's important to spell out here that the	Thank you for your comment. The committee have made recommendations about sensitive communication in section 1.1 and so have not repeated them here. The review questions investigated by the guideline did not look at the most effective method to deliver information and so the committee are not able to make recommendations on this.

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				professional/practitioner needs to use evidenced based guidelines on how, when, where to inform parents about this news as it may be unexpected and different from what they had hoped to experience. This section would need to emphasise that this discussion is a pivotal moment for the child/young person and their family.	
Institute of Health Visiting	Guideline	15	3 & 25	Use the word "advice" rather than "tell" this is less directive, research suggests that conversations need to be in partnership, and we need avoid this directional approach with parents/carers.	Thank you for your comment. The committee have made this change.
Institute of Health Visiting	Guideline	15	24	The comment we made above also applies here as the discussion needs to be sensitive.	Thank you for your comment. The committee have made recommendations about sensitive communication in section 1.1 and so have not repeated them here. The review questions investigated by the guideline did not look at the most effective method to deliver information and so the committee are not able to make recommendations on this.
Institute of Health Visiting	Guideline	16	4 and 16	It is best practice to involve the whole family in referrals for support even when this involves safeguarding, we suggest it is important for the practitioner to engage the child/young person and their family into the process so that this does not feel like something being done to them but actually that they are active agents in the decision to engage social care services. In this discussion, it would be important to discuss concerns with the family, find out what their concerns are and how social care may be able to help. This should be a joint decision. These discussions will also help to identify any misconceptions and ensure	Thank you for your comment. Discussion of the potential outcomes of the referral with the family are already covered by the last bullet point of recommendation 1.2.6. The first bullet point has been amended to reflect that the reasons for making the referral should be discussed with the family.

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				that families are better prepared to engage and work with social care.	
Institute of Health Visiting	Guideline	17	15-16	It is essential that support is offered regardless of a formal diagnosis from our insights with families they reported feeling abandoned with no support until the diagnosis was made which can take many years especially in the pre-school years. This point needs to be strengthened in the guideline to make more explicit for early years.	Thank you for your comment. Whilst the committee agree that formal diagnosis can be more difficult during the pre-school years, the recommendation as currently worded applies to all ages (including early years).
Institute of Health Visiting	Guideline	17	37	This discussion is also critical and needs to be handled sensitively to ensure that the young person/child and their family for do not experience significant distress. Please see comment number 14.	Thank you for your comment. The guideline makes recommendations about sensitive handling of discussions in the section on 'Principles for working with children, young people and their families'. These principles are intended to apply throughout the guideline and so have not been repeated here.
Institute of Health Visiting	Guideline	21	17	It is important to actively involve parents/ carers of preschool children in the development of the EHC plan ensuring their views on goals for their child are taken into account. This was a key finding from our insights work with parents/ carers of autistic children who felt professional had given up hope for their children to achieve anything.	Thank you for your comment. Taking the views of parents and carers into account is already covered in recommendation 1.4.2, which would include parents and carers of preschool children.
Institute of Health Visiting	Guideline	22	9	Where appropriate record the views of parents/ cares in the EHC plan, along with the views of the child/young person.	Thank you for your comment. Although recording the views of children and young people in EHC plans is mandatory, moderate-quality qualitative evidence indicated that this is not always done accurately or in enough detail. Practitioners often paraphrase the words of children and young people, and this can lead to inaccuracies. The committee want to highlight this issue in

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					the recommendation and therefore have not broadened it to include parents and carers.
Institute of Health Visiting	Guideline	General	General	The guideline is aimed at children and young people from birth to 25. The section on terms used in the guideline is located on page 61 we feel it is essential that the detail in this section appears at the start of the guidelines rather than half way through the documents as when reading the focus appears to be on school age and young people.	Thank you for your comment. Wherever a term is used that requires a definition, there will be a hyperlink to that definition so that users can jump to that section of the guideline.
Institute of Health Visiting	Guideline	General	General	A greater emphasis is needed throughout on the preschool years and the importance of early intervention and support to reduce the trauma and burden on families of unmet need which we are aware of from our research and insights with families.	Thank you for your comment. The recommendations in the guideline apply equally to all disabled children and young people with severe complex needs including those in preschool years. The committee do not think that there needs to be greater emphasis place on any particular group.
Institute of Health Visiting	Guideline	General	General	The need for robust transition at key stages including school entry as well as leaving school need to be considered further, these are challenging periods and the guidelines do not include any references to transfer into school settings for preschool children	Thank you for your comment. The review question on transition only looked at transition between children's and adult's services. As such the guideline is not able to make recommendations for other transitions.
Institute of Health Visiting	Question			Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why? The need to a have a lead practitioner is essential and we support this proposal, the challenge will be health and social care agreeing this and maintaining continuity of worker with significant cuts and staff shortage	Thank you for your response. It is encouraging that you agree with the key working approach. A key working approach should already be happening across services as these recommendations are only reiterating what is said in the SEND Code of Practice. As such, the committee would expect services to have frameworks in place to agree on who will be taking this role. However, the committee understand that it may be challenging agreeing on this, and they made some recommendations to facilitate this, e.g. key working should be undertaken by a

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					healthcare professional if children and young people with disabilities and severe complex needs mainly have healthcare needs. The committee have passed your comment onto the NICE team, which plan implementation support.
Institute of Health Visiting	Question			Would implementation of any of the draft recommendations have significant cost implications? The provision of appropriate personal support will come at a cost although we would argue that without this support as early as possible the longer-term burden on health and social care should not be underestimated	Thank you for your response. The committee are unclear which recommendation you are referring to. However, throughout the guideline, the recommendations do make reference to personalised care and support and services. The committee acknowledge that support needs are individual to each child or young person, and not everyone with the same diagnosis will need the same support. The committee also refer to personal budgets and the flexibility it gives to families. The committee agree that there may be some cost implications where this is not happening. However, as you state, providing support that is tailored to individual needs and considers family circumstances have the potential to reduce the long-term burden on health, social care and education services., e.g. it will ensure that children and young people and their families get the support they need, result in better care and outcomes and may prevent family breakdown and long-distance placements.
Kent Community Health NHS Foundation Trust	Guidance	017	Section 1.3	We are concerned that emphasising the statutory assessment route only (i.e. formal request for an education, health and care needs assessment) leads families to think this is the only route to accessing support, More emphasise should be placed on identifying need and accessing support at the local universal, targeted and if required specialist levels.	Thank you for your comment. The population of this guideline is disabled children and young people with severe complex needs, which is a subset of the population with special educational needs. The routes for support that you describe would be appropriate for the population with special educational needs. However, the population of this guideline will require integrated support from

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				Focusing only on EHC assessment process provides parents/carers with a misunderstanding about what support could be accessed more easily and also places considerable burdens on health services as resources are being directed towards EHCPs and not on the needs of all children with significant or complex health needs.	education, health and social care. As such they will be eligible for an EHC needs assessment and plan and this will be the most effective route for them to get support based on their needs. Therefore the guideline has focussed on this route. This focus also reflects feedback received from stakeholders during consultation on the guideline scope.
Kent Community Health NHS Foundation Trust	Guidance	027	002 – 004	We are concerned that this recommendation may be difficult to implement as health practitioners do not have sight of draft EHC plans	Thank you for your comment. There should be existing process in place for Local Authorities to inform health services if an EHC plan is declined.
Kent Community Health NHS Foundation Trust	Guidance	033	Section 1.8	There is no reference to supporting young people and their families to accessing Annual Health Checks (AHC) for those with learning disabilities and/or autism. We suggest that including this as part the Year 9 review would be very beneficial and ensure young people are aware of and start to access annual health checks. We also suggest that having a section in the annual review paperwork / process to discuss annual health checks would be beneficial and increase access / uptake to this vital health assessment.	Thank you for your comment. This section of the guideline makes recommendations about transition between children's and adult services. The committee have amended the section title to make this clearer. The focus of this review question was about the impact of including education with combined health and social care support models and frameworks on transition from children's to adults' services. As such the committee have not made any recommendations about Annual Health Checks for those with learning disabilities and/or autism.
Local Government Association	Guideline	General	General	The biggest impact on practice & the biggest challenge is for the key agencies of health, education & social care to work collaboratively together, accepting that different organisations have different drivers but putting these aside to focus on the children & young people with severe complex needs ensuring they are at the centre of discussions & decisions about their aspirations, needs & support.	Thank you for your comment. The committee agree that this will be challenge in some areas but hope that the recommendations made in the guideline will facilitate joint working across services.

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Local Government Association	Guideline	General	General	There is a financial & logistical challenge for health & local authorities in developing & supporting a range of personalised/individualised support options, tailored for each child or young person & available at the appropriate time.	Thank you for your comment. Where possible, the committee have acknowledged the change in practice and potential resource implications resulting from recommendations. NICE will note your comment concerning funding and logistical challenges, but NICE is not involved in funding decisions or monitoring infrastructure and support.
Local Government Association	Guideline	General	General	The pandemic has impacted on the mental health & emotional wellbeing of many people including children & young people & this has not been mentioned within the guidance.	Thank you for your comment. The committee have added a recommendation about recognition of emotional and mental health needs at the start of section 1.2
Local Government Association	Guideline	056	003	Suggest a further bullet point is added 'Work together with the market to develop services to meet the needs of children and young people to avoid long-distance placements'.	Thank you for your comment. The principle behind this recommendation is that children once placed should be maintained in stable effective provision and not moved arbitrarily. As such the committee have not mad your suggested change.
Local Government Association	Guideline	060	004	Consider adding a link to Integrated Commissioning for Better Outcomes Integrated Commissioning for Better Outcomes: a commissioning framework | Local Government Association. Although this was developed for adult commissioning it could be useful for children and young people under 18 years too.	Thank you for your comment. The committee did not identify any evidence to support recommending a particular tool to use when commissioning services and therefore have not made this change to the recommendation.
Mencap	Evidence	021	001	1.4 - Mencap has produced guidance on helping to set outcomes in EHC plans: https://www.mencap.org.uk/sites/default/files/2016-08/Setting_outcomes_guide%20%281%29.pdf	Thank you for your comment. The committee will pass this information to the NICE resource endorsement team.
Mencap	General	General	General	Effective joined up care across education, health and care is crucial for CYP with a learning disability and behaviour that challenges. NICE has specific guidance	Thank you for your comment. Under the section 'Finding more information and committee details' there is a link to related NICE guidance. This includes NG11 (Challenging behaviour and learning disabilities)

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				on challenging behaviour and learning disability and it would be helpful to cross-reference that guidance.	
Mencap	Guideline	General	General	The guideline is for children and young people with severe complex needs. This is defined at the end of the document as 'Disabled children and young people from birth to 25 years who need education, 15 health and social care support and who are eligible for an education, health and care 16 plan.' We believe it would be helpful to give this definition sooner. We would like to see the guideline include a specific focus on CYP with a learning disability. Currently there is no specific mention of learning disability within the guideline. We think it is important the needs of CYP with a learning disability are recognised, understood and met. We also believe it would be beneficial to include a particular focus on CYP with a learning disability who have the most complex needs: those with '**profound and multiple learning disabilities (PMLD**)'. Children and adults with PMLD have more than one disability, the most significant of which is a profound intellectual disability. These individuals all have great difficulty communicating, often requiring those who know them well to interpret their responses and intent. They frequently have other, additional, conditions which may include for example:	Thank you for your comment. Where the term 'disabled children and young people with severe complex needs' is used in the guideline, it will be hyperlinked to this definition to make it easy to access. The recommendations in this guideline focus on providing support to meet the needs of all disabled children and young people with severe complex needs, which would include those with a learning disability. However the committee have added recommendations with a specific focus on those who are not able to actively participate in planning or decision making (recommendation 1.1.2) and young people who lack capacity to plan for adulthood (recommendation 1.8.4). The committee have also included parental deputyship in recommendations 1.8.2 and 1.8.11.

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				• physical disabilities – that limit them in undertaking everyday tasks and often restrict mobility; risk to body shape •sensory impairments •sensory processing difficulties •complex health needs (eg. epilepsy, respiratory problems, dysphagia and eating and drinking problems) •'coping behaviours' (to their communication or other difficulties for example) which may present as challenging •mental health difficulties' (Supporting people with profound and multiple learning disabilities: core and essential service standards, Doukas, Fergusson, Fullerton & Grace, 2017) Note: For more information about the needs of people with PMLD – please see final comment below. On first reading the title of this guideline we thought that children with PMLD were the focus for the guideline. We do think that if there is a focus on how to get joined up care for those with the most complex needs then this should improve joined up care for all disabled children. We would like to see the needs of both children and adults with PMLD covered by NICE guidelines.	
Mencap	Guideline	General	General	Due to the broad nature of this guideline, we felt that a more holistic introduction would be helpful to set out	Thank you for your comment. The purpose of the 'context' section is to provide information about the reason the

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				what 'good' looks like overall for children and young people, touching on the various areas in which the document goes into more detail later on. We would like this introduction to reference CYP with PMLD and for there to be a more detailed section on CYP with PMLD.	guideline was developed. As such the committee have not made your suggested change. The recommendations in this guideline focus on providing support to meet the needs of all disabled children and young people with severe complex needs, which would include those with a learning disability
Mencap	Guideline	General	General	Palliative care is very important for children and young people who need it. Palliative care is not only indicated in situations where death is expected very soon, and we know that many children and young people can benefit from this service. However, at several points in this document, palliative care is first in lists/sections etc, and we feel this may influence commissioners/practitioners/families thinking to assume that the child or young person's life may be limited in some way. A holistic introduction to what 'good' looks like, and what outcomes we expect for a child or young person with complex needs (along with a definition of what is meant by 'complex needs' (see earlier comment), would help to ensure that the rest of the guideline is in context and meaningful.	Thank you for your comment. The committee have added a definition of palliative care to the terms used section so it is clear what is meant when this term is used in the guideline. The guideline includes a definition of the population of the guideline which clarifies that it relates to Disabled children and young people from birth to 25 years who need co-ordinated education, health and social care support because of their severe and complex needs and therefore are eligible for an education, health and care plan in line with the Children and Families Act 2014." As such, complex needs is defined as having needs in education, health and social care. The format of NICE guidelines does not enable us to include an introduction about what 'good' looks like and the expected outcomes, but since these would be different for each individual it would not be appropriate to include them in an introduction.
Mencap	Guideline	General	General	Understanding profound and multiple learning disabilities (PMLD) – from PMLD Network long definition Learning needs. Like all of us, people with profound learning disability will continue to learn throughout their lives if offered appropriate opportunities. Such	Thank you for your comment and providing this information about people with profound and multiple learning disabilities. The guideline recommendations have focussed on principles of integrating care rather than addressing specific health conditions or disabilities.

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				opportunities must take account of the fact that most people are likely to be learning skills that generally appear at a very early stage of development. For example, cause and effect, such as pressing a switch to make something happen, or turn-taking, such as rolling a ball between two people. Learning is also likely to take place very slowly. For example, some people may have a very small short-term memory and so will need the opportunity to encounter events many times before they become familiar. Constant repetition and a great deal of support will be needed to generalise learning into new situations. Supporting the learning needs of a child or adult with profound and multiple learning disabilities also needs to take account of any additional needs, such as sensory needs (see sensory needs section), so that the best approach to learning can be established. Communication needs. Many people with profound and multiple learning disabilities rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a small range of formal communication, such as speech, symbols or signs. However, some people with profound and multiple learning disabilities may not have reached the stage of using intentional communication, and they may rely on others to interpret their reactions to events and people. Most people are also likely to find it difficult to understand the verbal communication of others. Some people will	

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				rely heavily on the context in which the communication takes place, such as the clues given by a routine event. It is important that those who support people with profound and multiple learning disabilities spend time getting to know their means of communication and finding effective ways to interact with them. Physical needs. Some people described as having profound and multiple learning disabilities are fully mobile. Many may use a wheelchair. Others have difficulty with movement and are unable to control or vary their posture efficiently. These individuals will need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. It is vital that people with physical needs have access to physiotherapy, occupational therapy and hydrotherapy, and that their carers receive training to enable them to manage their physical needs confidently on a day-to-day basis. Complex health needs. There is a wide range of conditions that children and adults with profound and multiple learning disabilities may have, such as complex epilepsy. An increasing number of people are described as being 'technology dependent', which may mean they need oxygen, tube feeding or suctioning equipment. Some people have conditions that are described as 'life-limiting'. Others have fragile health and may be susceptible to conditions like chest	

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				infections and gastro-intestinal conditions. Skilled support may be needed for feeding and swallowing, as good nutrition is a vital part of achieving good health. Many people may experience a combination of medical needs and need access to specialised health support to ensure the holistic management of these conditions. People with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is about how these conditions are identified in people who may not be able to communicate their symptoms easily. For example, it is very important to develop effective ways to recognise and manage pain. It is crucial that a proactive approach is taken to ensure that each person is able to achieve the best possible health they can, for example, by arranging annual health checks and support to access general health care. Sensory needs. Special attention needs to be given to the sensory needs of people with profound and multiple learning disabilities. Many people have some degree of visual and or hearing disability or a combination of both. Some people's sense of taste or smell may be affected by the drugs they are prescribed. Other people may be hypersensitive to touch. It is essential to know as much as possible about a person's vision, hearing and other senses in	

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				order to develop the most effective way to approach their learning and communication needs. Understanding behaviour. Some behaviour that is seen as challenging may arise because little attention has been given to other needs. It should never be assumed that certain behaviours are just part and parcel of having profound and multiple learning disabilities. For example, a behaviour that services may see as challenging, such as pushing people, may be an attempt to communicate a need. Other changes in behaviour may be due to undetected health needs, such as scratching the face because of a toothache. However, some behaviour will be because people are simply doing things that they enjoy, for example putting a hand under the tap to enjoy the feeling of running water. The important thing is to understand what the behaviour may mean and to respond accordingly, such as checking out any possible health causes or making changes in the environment. Mental health needs. The mental health needs of individuals with profound and multiple learning disabilities are often not considered. For example, someone who becomes very quiet and passive may be seen as having improved their behaviour when in fact they are depressed. Research suggests that people with profound and multiple learning disabilities may be more susceptible to mental health conditions than the rest of the population. It is important that careful	

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				attention is given to these needs and that the right treatment and support is found to meet them. Profound and multiple learning disabilities and other syndromes or conditions. There are many other conditions and syndromes used to describe people, some of whom could also be described as having profound and multiple learning disabilities. Conditions and syndromes that are more usually associated with profound and multiple learning disabilities include Rett syndrome, Tuberous Sclerosis, Batten's Disease and some other rare disorders. However, some people who are described as having autism and Down's syndrome may also have the combination of profound learning disability and one or more of the needs we have discussed – therefore, they could equally be described as having profound and multiple learning disabilities. Support needs. All children and adults with profound and multiple learning disabilities will need high levels of support from families, carers and paid supporters. This will include help with all aspects of personal care, such as washing, dressing and eating, as well as ensuring that each individual has access to high quality and meaningful activity throughout their lives. Those who offer this support will need access to good quality and appropriate training, especially around particular skills. For example, on particular feeding needs and communication approaches. Good support is person-	

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				centred, flexible and creative to enable the person with profound and multiple learning disabilities to learn and to achieve their full potential.	
Mencap	Guideline	008 - 011		It is also important to think about times that work for families, not just professionals. It is important there is as much notice as possible of meetings. There is the opportunity, particularly with all the learning during the pandemic, to carefully consider use of digital technology if that would be appropriate in certain circumstances for example if a key professional is unable to attend in person and it would help avoid a delay which is likely to impact negatively on the child.	Thank you for your comment. The committee have added consideration of family circumstances to the list of bullets. The committee was aware that some people might not be able to afford the equipment needed to attend appointments remotely and so have only included this as an option.
Mencap	Guideline	012 - 013		It is important that children and families understand their rights and routes of challenge, where they disagree with professionals.	Thank you for your comment. There are established processes included in the SEND code of practice to be used when children, young people and their families disagree with professionals. In line with feedback from stakeholders the committee have removed repetition of the content of the SEND code of practice and therefore have not made a change based on your comment.
Mencap	Guideline	012 - 013		We think it would be helpful to include the principles of the MCA in full in this guideline, as the MCA is going to be very relevant when working with CYP aged 16 and over who may lack capacity. This could be a significant proportion of those with severe and complex needs.	Thank you for your comment. It is not NICE style to replicate the content of legislation in its recommendations, but to include a cross reference to where this information is available.
Mencap	Guideline	004		To reflect the needs of those children with PMLD it may be helpful to also include that people's wishes and preferences should be at the centre of decision-making. Recognition of the key role that families and others who know the person well, and understand their way of	Thank you for your comment. The committee have added preferences to the recommendation. The committee have also added a new recommendation about taking into account the views of those who know the child or young person well. Valuing the expertise of parents is already covered by recommendation 1.1.12.

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				communicating, especially where the child does not use formal communication such as words and signs. Value the lived experience of children and young people and their parents and their expertise.	
Mencap	Guideline	005		Ensure involvement is meaningful. Support the person to be at the 'centre' of decision-making. Need to consider how will it be made meaningful for individuals. For example, some people may not want to attend a long meeting and they may get distressed with lots of people. It is important there is a personalised approach. Not one size fits all. Creative approaches may be needed, for example enabling the person and their family to share film showing the person's experiences and preferences. At the heart of involving is supporting communication needs. For more about meaningfully involving people with PMLD in decision- making see resources from Mencap and BILD's Involve Me project: https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me and information about CBF and the Tizard Centre's Seldom Heard project: https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/valuing-individuals-and-their-families/seldom-heard/ It is important professionals have had appropriate training around the needs of people with a learning disability and autism, including those with profound and multiple learning disabilities, and understand the	Thank you for your comment and providing information about how to involve people with PMLD in decision making. The committee agree that the approached used to support the child or young person to be at the centre of decision making needs to be tailored to the individual. The committee have amended the recommendation to clarify that input needs to be obtained in the way that is most effective for the individual. Recommendations are also made in the section on 'Communication formats and providing information' about establishing the best format for communication and using this.

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				different ways people may communicate/ communication needs.	
Mencap	Guideline	006		Families may be anxious and worried that their family member's needs will not be understood or met. They may have had difficult experiences with professionals and experienced judgemental attitudes in the past. It is important that work with individuals and families is trauma-informed.	Thank you for your comment. The committee hope that implementation of the recommendations in this guideline will help to address the issues you describe.
Mencap	Guideline	009	017	1.1.23 - This is good but should also be mindful that sensitive topics may not just be 'embarrassing' or personal to the child. A reminder in this section that children may also be sensitive to the feelings of parents, or other practitioners, and many may not feel able to give an honest appraisal of their current support arrangements/unmet needs etc in a setting with their supporters.	Thank you for your comment. The issue you describe is already covered by the bullet about not wanting to discuss sensitive topics in front of everyone and so the committee have not made a change.
Mencap	Guideline	012		Re: 'When a child can express a view, but their view does not align with the views of their parents (or other people with parental responsibility), work impartially and separately with them and with their parents.' – It may be helpful to encourage professionals in the first instance, and where appropriate, to try to support/ facilitate the parent and child to understand each other's perspective and views and to get a positive outcome that way, rather than working with them separately.	Thank you for your comment. The committee have added this to the recommendation.
Mencap	Guideline	013		It would be helpful to include 'relevant legislation and statutory guidance around information sharing' in addition to consent. Too often we see families being excluded and not having information shared with them	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all legislation that is relevant to disabled children and young people with severe complex needs. The guideline

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				eg. after complaining or challenging, so anything the guideline can do to stop this happening would be helpful. It would also be helpful to be clear that where someone is over 16 and is found to lack capacity around a decision about information sharing, then a decision should be made in line with the MCA. It may be helpful to include something about 'information' and 'record keeping' in the guideline. We hear from families the serious consequences of inaccurate records and notes – eg. where a description has been put in the notes about the child or young person, by a professional who didn't know them and understand their needs, and this has stayed in their notes and influenced how they have been viewed and treated by other professionals. It is important that children and their families are listened to and inaccurate information is addressed.	focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions. Recommendation 1.1.51 already covers the Mental Capacity Act
Mencap	Guideline	014	011	1.2 - It would be good to include explicit reference to the need to intervene early in this section. The principle of early help is embedded in both the Children Act 1989 and the Children and Families act 2014.	Thank you for your comment. The concept of intervening early is already covered by the final bullets of recommendations 1.2.3 and 1.2.5 which refer to involving other services at the first opportunity. The principle of early help is guidance by not a legal requirement.
Mencap	Guideline	016	004	1.2.5 - This section would also benefit from reference to the fact that s.17 of the Children Act 1989 gives a specific right for all disabled children to have an assessment of their social care needs	Thank you for your comment. The committee have added introductory text to this section to clarify that all disabled children are defined as in need under section 17 of the Children Act 1989 and are entitled to an assessment of need. However some social care support for families may be available without an assessment

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Mencap	Guideline	018	005	1.3.6 - Information should be available through their Information Advice and Support Service so this should be mentioned. In addition to this, this section is missing information that some people may be eligible for help from an Independent Supporter	Thank you for your comment. The committee have added signposting to SENDIAS services to the recommendation. Independent Supporters are no longer a nationally recognised programme and so we have not mentioned them in the recommendation.
Mencap	Guideline	027		It is important that CYP with severe/profound learning disabilities and complex needs are able to get support that truly meets their needs and that their choice, autonomy, independence is maximised. In his Raising our Sights report (2010), Prof Jim Mansell said 'the major obstacles to wider implementation of policy for adults with profound intellectual and multiple disabilities are prejudice, discrimination and low expectations.' It is important professionals are aware of this.	Thank you for your comment and providing this information.
Mencap	Guideline	032	003	1.8 Transition – This section must include a statement around transition in healthcare services, including several key items: 1. Ensure that children with a learning disability are known to their GP and on the GP learning disability register. Young people aged 14+ should be offered a learning disability annual health check. 2. Ensure that families are aware of how to access support with accessing healthcare, including the local learning disability community team's health liaison function, the	Thank you for your comment. The committee have added a recommendation that should make practice more effective when transitioning between children's and adults' health services. The evidence did not support making recommendations at the level of detail you request in your comment.

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				learning disability nurse or lead in the local hospital trust and any learning disability nurses working with the local primary care hub. Children and young people with complex health needs are likely to be frequent users of health services, including hospital inpatient settings. They must be supported to build relationships with adult services, for example, hospital wards. Any practical considerations, for example ensuring wards are able to access any particular equipment the person may need, must be planned for.	
Mencap	Guideline	041	001	1.12 Travel Training – This is a positive addition, however, only seems focused on those children or young people who may be able to use public transport – and who may be expected to use public transport independently at some point. We would like to see extra focus on families, and children and young people for whom public transport may not be suitable – including transport provision from the local authorities, benefits and support, including support to access Motability vehicles.	Thank you for your comment. This guideline does not have a remit to make recommendations about transport provision, benefits or access to Motability vehicles.
Mencap	Guideline	058		It is important that short breaks services can meet the complex communication and complex health needs that children with severe or profound learning disabilities may have. Families won't want to use services that aren't equipped to meet the child's need and this puts them at risk of breaking point. It may be helpful to bring the section on short breaks forward in the guideline and ensure there is a strong focus on	Thank you for your comment. Further recommendations on short breaks have been made in section 1.7 which address the points you raise. The focus of the guideline is delivering person-centred care, which should prevent crisis situations.

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				early intervention and preventing crisis situations throughout the guideline.	
Mencap	Guideline	060		See the Raising our sights commissioning how-to guide – which focuses on commissioning effective support and services for people with PMLD.	Thank you for your comment and providing this information.
National Network of Parent Carer Forums	Guideline	014	016	Rec 1.2.2 – Professionals should signpost families to the SEND Local Offer for their area.	Thank you for your comment. The committee have made this change.
National Network of Parent Carer Forums	Guideline	015	003	Rec 1.2.2 – Parent Carer Forums can be a good place to start	Thank you for your comment. Not all local areas have Parent Carer Forums so the committee have not included these in the recommendations. However this would not prevent families from accessing them should they exist.
National Network of Parent Carer Forums	Guideline	015	025	Rec 1.2.4 – Information, Advice and Support services can support families across Education, Health and Social Care.	Thank you for your comment. The committee have added a bullet point about signposting to SENDIAS services.
National Network of Parent Carer Forums	Guideline	017	011	Rec 1.3.2 – Threshold for accessing an EHC Needs Assessment is low in law. Whether a LA will agree to issue an EHC Plan following the assessment will depend on local thresholds and what funding is ordinarily available to meet the cyp's assessed needs.	Thank you for your comment and providing this information.
National Network of Parent Carer Forums	Guideline	018	004	Rec 1.3.6 – see 1.3.2	Thank you for your comment. The committee think you are requesting a cross reference to recommendation 1.3.2 is added to recommendation 1.3.6 (although it is not clear in the comment). The committee have not made this change as the focus of recommendation 1.3.2 is informing practitioners that EHC needs assessment should be based on needs.

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National Network of Parent Carer Forums	Guideline	046	008	Rec 1.5.1 – Include coproduction as a core value. https://contact.org.uk/help-for-families/parent-carer-participation/what-is-parent-carer-participation/	Thank you for your comment. As documented in the rationale and impact section 'There was moderate-quality qualitative evidence that joint working improved when practitioners had shared values and priorities. From their experience, the committee agreed there is difficulty in practitioners from different services building effective teams and relationships with each other without having dedicated time for this and support from managers.' As the evidence was about practitioners the committee have not made your suggested change. However co-production is recommended elsewhere in the guideline.
National Network of Parent Carer Forums	Guideline	057	003 & 012	Rec 1.17.6 & 1.17.7 – The SEND Code of Practice recommends working the local Parent Carer Forum to do this.	Thank you for your comment. Parent carer forums would be one way to engage and consult but the committee considered that it was still important to engage with those parents/carers who have chosen not to join a forum. The committee have therefore kept the text as is.
Newlife the Charity for Disabled Children	Guideline	004	006	We are concerned that the reference to communication aids is too limited and recommend that it includes the need for all specialist equipment.	Thank you for your comment. The text you cite lists the names of other sections in the guideline and as such it would not be appropriate to make the change you suggest.
Newlife the Charity for Disabled Children	Guideline	005	004	We recommend that there is reference to professional advocacy services that can help facilitate consultative conversations.	Thank you for your comment. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included

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					it. Parents and families normally act informally as advocates to ensure their child's views are heard.
Newlife the Charity for Disabled Children	Guideline	005	015	The term 'support' is limited in the way that support is implemented, ie. the communication aids that may be required or the translation services needed to help a child to express themselves.	Thank you for your comment. Recommendations about establishing the communication preferences of children and young people and using these are covered in the sections on 'Communication formats and providing information' and 'Planning and running meetings with children and young people'.
Newlife the Charity for Disabled Children	Guideline	005	016	Question 1: How can a child express their wants and needs if they aren't told what support is available to them?	Thank you for your comment. The committee felt is was very important to delivering person-centred care, that children and young people are encouraged and facilitated to express what they want and need, rather than this being determined by the support currently available.
Newlife the Charity for Disabled Children	Guideline	005	020	We recommend stating the frequency rather than using the term 'regularly'	Thank you for your comment. As stated in the rationale and impact section, the committee were not able to specify a time frame for doing this because it would depend on the services and support being received.
Newlife the Charity for Disabled Children	Guideline	005	023	We agree that it is important to know what works for the individual child, but it is equally important to know what hasn't worked in the past so that lessons can learned and distress avoided.	Thank you for your comment. The committee have amended the recommendation to include avoiding things that have not worked well previously.
Newlife the Charity for Disabled Children	Guideline	006	002	Rec 1.1.9 – We don't feel as though there is enough reference to barriers affecting a parent's ability to communicate, and as such recommend that an extra line is added explaining that anxieties often stem from the parent's own mental health needs and/or cognitive or communication disabilities.	Thank you for your comment. The committee have added another recommendation about being aware that parents or carers may have communication preferences and needs of their own that may affect their ability to take part in discussions and understand information that is provided to them.
Newlife the Charity for	Guideline	006	006	The term 'avoid being directive' could be replaced with 'tailor the extent to which direction is given' as many families prefer a paternalistic approach to delivering	Thank you for your comment. The committee have changed the text to "Avoid being directive (unless the family and carers prefer this),..."

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Disabled Children				care as opposed to professionals who actively avoid giving guidance in fear of litigation.6	
Newlife the Charity for Disabled Children	Guideline	006	011	We recommend stating 'sources of statutory and charitable support if needed.'	Thank you for your comment. The committee have changed the text to "statutory and independent support" as this could be wider than just charities.
Newlife the Charity for Disabled Children	Guideline	006	013	We recommend replacing 'communication skills' with 'ability to communicate' in recognition that there may be specialist methods of communication required, eg. makaton.	Thank you for your comment. The committee have changed this to 'communication abilities'.
Newlife the Charity for Disabled Children	Guideline	006	018	In our experience, children with disabilities don't always have access to the communication aids they need to express themselves in all locations, ie. they may have access at school but not at home because of the insurance held by the school. Is this going to change? At what cost should the professional communicate in their preferred format?	Thank you for your comment. The committee hope that if the recommendations in this guideline are implemented it will mean children and young people with severe complex needs do have access to the communication aids they need.
Newlife the Charity for Disabled Children	Guideline	007	001	Rec 1.1.15 – We recognise that this is fundamental, but would welcome changes that also encourage information about entitlements and care/support options that could be accessed being provided so that children and families can make informed decisions.	Thank you for your comment. The committee have added entitlements within the education, health and social care system to the list of information that should be provided.
Newlife the Charity for Disabled Children	Guideline	007	023	We agree that it is important to manage expectations, but if expectations cannot be met by a service then information about alternative services (eg. charitable services) could be provided. Also, if a service cannot meet user's expectations then they should be given the opportunity to know how they can escalate a conversation to encourage service development and/or complain.	Thank you for your comment. The committee have added exploring alternatives to the recommendation. The committee have also added to recommendation 1.1.23 that information should be provided on how to raise a concern about care and how to feedback to encourage service development.

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Newlife the Charity for Disabled Children	Guideline	008	002	Rec 1.1.20 – In our experience it is very difficult to coordinate all necessary professionals to attend a meeting, yet alone schedule preparatory meetings. We are supportive of this principle, but this needs more practical guidance.	Thank you for your comment. This recommendation is about practical steps to take to help children and young people prepare for discussions and meetings. The committee did not envisage that additional preparatory meetings would be needed in order to implement this recommendation.
Newlife the Charity for Disabled Children	Guideline	009	001	We recommend that the term aspirations is added so that it reads 'prioritise the child or young person's wishes, aspirations and goals' and could refer to short and long-term goals.	Thank you for your comment. The committee have added 'aspirations' to the recommendation.
Newlife the Charity for Disabled Children	Guideline	009	004	This bulletpoint could be an opening statement for a list of practical considerations, eg. poverty indicators, safeguarding, historical experience of parental engagement with services, etc.	Thank you for your comment. The bullets in this list are based on concepts identified by the qualitative evidence reviews. The items included in your comment, were not identified by the evidence and so the committee have not made this change.
Newlife the Charity for Disabled Children	Guideline	009	023	We agree that it is important for representation from health, social care and education, but also feel that many families and their children would find it daunting to talk to a room of professionals and therefore in preparation it should be noted if a family advocate or keyworker would be beneficial.	Thank you for your comment. The bullets in this recommendation were based on qualitative evidence that practitioners are not taking adequate responsibility. Therefore The committee have not made this change as it would mix the message.
Newlife the Charity for Disabled Children	Guideline	010	020	It would be preferred if the term 'regularly' was explained so that there was a frequency.	Thank you for your comment. The frequency of review would depend on the specific actions so it is not possible to include this in a recommendation.
Newlife the Charity for Disabled Children	Guideline	010	023	Rec 1.1.31 – In our experience meetings are often held despite key practitioners being unable to attend.	Thank you for your comment and reflecting your experience. The committee hope that implementation of the recommendations in this guideline will mean this doesn't happen frequently in future

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Newlife the Charity for Disabled Children	Guideline	011	018	Rec 1.1.34 – It is important to provide options for engagement before the child and family/carers express how they would like to be involved in meetings about them.	Thank you for your comment. There was qualitative evidence that parents and carers had differing views about involving children and young people in decisions about their care. Some parents and carers felt that participation was inappropriate for their child because of their age, or the nature of their special educational need or disability. Other parents and carers thought it was important to fully involve their child. The SEND code of practice requires that children and young people are involved in discussions and decisions about their support. As some of these decisions would take place during practitioner led review meetings, the committee felt strongly that children and young people should be present at these meetings. However, given the concerns of parents and carers and the qualitative evidence that meetings can be intimidating for children and young people, they agreed it would be better to ask them how they would like to be involved rather than imposing options for engagement.
Newlife the Charity for Disabled Children	Guideline	012	002	Rec 1.1.35 – In our experience there is too much silo working that acts as a barrier to creating a consistent approach. This often leads to multiple meetings and assessments being undertaken because services are reluctant to accept outcomes that come at a financial cost.	Thank you for your comment. The committee hope that the recommendations made throughout this guideline will address the issues that you have described.
Newlife the Charity for Disabled Children	Guideline	014	006	We recommend an addition that says 'share these plans, and any associated updates to them, with all practitioners working with them.'	Thank you for your comment. The committee have added this to the recommendation.

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Newlife the Charity for Disabled Children	Guideline	015	003	We suggest adding 'tell them and their parents and carers about statutory entitlements and any voluntary organisations…'	Thank you for your comment. The committee have added signposting to the SEND Local Offer to the recommendation which would encompass providing information about statutory entitlements and voluntary organisations.
Newlife the Charity for Disabled Children	Guideline	015	013	Rec 1.2.3 – In our experience, the service to which a referral needs to be made may unnecessarily restrict who can refer the child. This is not only going to cause unnecessary delays but also potentially cause families to disengage.	Thank you for your comment. The committee have added to the existing recommendation to clarify that processes should be established for referral between different services. It will be up to local implementation to decide what these processes should be and so the committee cannot specify them in the recommendation.
Newlife the Charity for Disabled Children	Guideline	017	022	In our experience the assessment and implementation of an EHC is greater than 20 weeks. How is this to be measured and monitored to hold the local authority to account?	Thank you for your comment. OFSTED and the CQC undertake local area SEND inspections which would monitor this. The output from such inspections are written statements of action on things that need to be addressed by Local Authorities. If the implementation of EHC plans was not being done to the required timeframe it would be addressed via this route.
Newlife the Charity for Disabled Children	Guideline	018	003	In our experience, this is crucial. There is a high likelihood that focus will be on educational needs and associated therapeutic services rather than support in the home and the role that equipment can play in bridging the gap between the two. For instance, if a child has interrupted sleep because their care needs aren't met overnight by providing an appropriate bed then they will be limited to how much information they can retain at school. Or, the number of hours for additional assistance may be specified but not that a wheelchair is needed to get from A to B. Also, in our experience the insurance of equipment can be a	Thank you for your comment and support of the recommendation. Insurance of communication aids and environmental adaptations is covered in recommendations 1.10.2 and 1.11.3 respectively.

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				barrier to supporting education at home because communication aids and other types of equipment are only provided for use in school.	
Newlife the Charity for Disabled Children	Guideline	022	016	We recommend adding the term 'practical and therapeutic support' because in our experience it is the practical considerations of how to safely transport and mobilise around the school and on field trips that are overlooked in favour of prescribing therapeutic support.	Thank you for your comment. The committee have made this change.
Newlife the Charity for Disabled Children	Guideline	023	006	This would benefit from having type of support and frequency of delivering the support added.	Thank you for your comment. Type of support is already covered by the first bullet point. The committee have added another bullet about frequency of support.
Newlife the Charity for Disabled Children	Guideline	023	023	The language used should also be understandable to the child's parents taking into account any known disabilities.	Thank you for your comment. The committee have added families and carers to the recommendation.
Newlife the Charity for Disabled Children	Guideline	024	015	It should be stated that there may be extenuating circumstances associated with meeting the child's care needs which means that a longer period is required and therefore should be readily considered.	Thank you for your comment. In line with stakeholder feedback the committee have reduced the number of recommendations which repeat content from the SEND code of practice and associated legislation. This is one of the recommendations that has been removed and a cross reference added instead.
Newlife the Charity for Disabled Children	Guideline	026	001	Rec 1.4.22 – Any reduction in the level of support provided should be in consultation and agreed by the child's parent/carer.	Thank you for your comment. The committee have reworded the recommendation to clarify that support specified in the EHC plan should not be reduced just because children and young people show improvements in certain areas or are able to do new things.
Newlife the Charity for	Guideline	027	014	Rec. 1.6.6 should have reference within a separate bulletpoint to the training that parent/carers need to	Thank you for your comment. Training in order to use equipment safely and appropriately is covered in section 1.11.

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Disabled Children				appropriately and safely use equipment to meet their child's needs – not just a focus on communication.	
Newlife the Charity for Disabled Children	Guideline	031	003	Rec. 1.7.3 should have reference with a separate bulletpoint that the equipment needed to facilitate social participation is all too often a barrier to accessing supportive services and as such equipment should be provided to allow use of such services, eg. the equipment to allow participation should be provided through a grant or loan arrangement.	Thank you for your comment. The committee have added a bullet to think about what equipment will be needed to make the activity accessible.
Newlife the Charity for Disabled Children	Guideline	032	013	Please continue this so it recognises that 'where independence is not possible, that appropriate care plans and equipment are provided.	Thank you for your comment. This consideration is covered by the wording "maximise their independence", which does not suggest that full independence is always achieved.
Newlife the Charity for Disabled Children	Guideline	033	018	Rec. 1.8.4 – while we welcome the intent of personalising care, it should be recognised that there is clear legislation regarding the statutory entitlements at specific ages which could lead to confusion.	Thank you for your comment. The committee have amended the recommendation to clarify that it relates to non-statutory transition points.
Newlife the Charity for Disabled Children	Guideline	033	020	Rec 1.8.12 – an observation of working with families is that there is frustration about access to equipment that they can use in adulthood but need during childhood and the funding arrangements to provide this equipment during transition. This should be clarified/rectified within this guidance.	Thank you for your comment. It is not within the remit of this guideline to rectify issues with funding arrangement for equipment during transition.
Newlife the Charity for Disabled Children	Guideline	035	018	Rec. 1.9.2 – It should be noted that the parent/carer may not understand that services they can access when there is a change of prognosis and therefore options of services should be given rather than there being an expectation that these are known.	Thank you for your comment. The committee have added explaining what support options are available to the recommendation.

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Newlife the Charity for Disabled Children	Guideline	036	002	Please expand the example given to read (for example. Address new health problems with the provision of additional aids and equipment)	Thank you for your comment. The committee have not made your suggested change as addressing new health problems will not necessarily require provision of additional aids and equipment.
Newlife the Charity for Disabled Children	Guideline	036	006	Rec 1.9.6 – In our experience education services tend to take a back seat when children develop palliative needs and local authority funded social care tends to be deemed unnecessary when hospice support service are accessed relying too heavily on charitable funds.	Thank you for your comment. The committee hope that implementation of this recommendation will help to resolve these issues.
Newlife the Charity for Disabled Children	Guideline	036	009	Rec. 1.9.7 – the use of the terms regular and frequent are non-prescriptive and could benefit from clarity, even if this is just to say that the frequency should reflect the extent to which the child's needs are changing.	Thank you for your comment. The committee cannot give specific timeframes but have linked the frequency of review to the extent to which the child or young person's needs are changing, as you suggest.
Newlife the Charity for Disabled Children	Guideline	036	012	Rec. 1.9.8 – this should be revised to read 'Heath services must provide training for education and social care practitioners…..' as this is a fundamental to ensuring appropriate cross-sector care for the most vulnerable of children.	Thank you for your comment. NICE recommendations can only use the word 'must' when there is a legal requirement. As such the committee are not able to make the change you suggest.
Newlife the Charity for Disabled Children	Guideline	037	002	Rec. 1.10.1 – It is our experience that children have access to communication aids in a specific setting because of the funding arrangements and/or the service that has insured the equipment. Children should have access in all settings but these barriers need to be addressed within the guidance.	Thank you for your comment. It was the committee's view that under equitable provision what you describe should no longer be happening. However the committee have added to the recommendation about the equipment being used in all settings.
Newlife the Charity for Disabled Children	Guideline	037	020	Please consider adding that the child should be able to access a similar level of service from adult-funded care to that available to children with communication needs.	Thank you for your comment. The committee were not aware of difficulties with referral and access to communication aids between children's and adults services and therefore have not changed the recommendations.

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Newlife the Charity for Disabled Children	Guideline	038	001	Rec 1.10.5, 1.10.6 and 1.10.7 – the ways these points are separated into different recommendations seems lengthy and only serves to overcomplicate this matter. Please consider merging them into one recommendation.	Thank you for your comment. The committee have merged 2 of the recommendations to avoid repetition.
Newlife the Charity for Disabled Children	Guideline	038	013	Rec. 1.11 – It is our experience that families need support to gain the necessary assessments and reassessments to ensure that environmental adaptations are wholly appropriate rather than equipment, and remain appropriate for the child and their family. We recommend adding more information about supporting access to assessments and follow ups after an adaptation has been made rather than jumping straight to training parents and carers/staff and maintaining the adaptation.	Thank you for your comment. The committee have added a recommendation to cover the points you have raised.
Newlife the Charity for Disabled Children	Guideline	039	014	It is not clear whether this information relates solely to public spaces being accessed by a disabled child, or should include accessibility in the home. We recommend clarity is given within the subtitle or within the rec 1.11.11.	Thank you for your comment. The committee have clarified this relates to public spaces.
Newlife the Charity for Disabled Children	Guideline	040	023	Rec. 1.11.12 – We feel that it is extremely important to ensure equipment is provided to the individual child rather than to the service or for multiple users in the same environment. Please strengthen this bullet point to say that this should be preferential rather than 'if possible..'	Thank you for your comment. This recommendation has been moved earlier in the guideline (now 1.11.2) and the committee have added to it about the equipment being used in all settings. The committee are not able to make the wording stronger than 'if possible' due to the quality of the evidence supporting this recommendation.
Newlife the Charity for Disabled Children	Guideline	041	010	Rec. 1.12.3 – How are public transport providers held accountable to providing training, regular updates, and ensuring implementation of the information and skills	Thank you for your comment. On reflection, the committee have decided to remove this recommendation because providers of public transport have a statutory duty under

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				provided within the training? Is there cross-department working with Dept for Transport anticipated?	the Equality Act (2010) to provide disability awareness training to their staff.
Newlife the Charity for Disabled Children	Guideline	042	017	Rec 1.13.3 – We welcome the introduction of a specific practitioner role, but feel the recommendation falls short of specifically stating that the practitioner should have expertise related to employment of young people with disabilities.	Thank you for your comment. The committee have added this to the recommendation.
Newlife the Charity for Disabled Children	Guideline	043	002	We would like to see this expanded so that discussions don't just signpost to information but give access to required aids and equipment that will enable development of vocational skills and improve employment opportunities.	Thank you for your comment. The focus of this recommendation is to introduce discussions about employment as a future option early so that the child can consider this. It would therefore not be appropriate to make the change you have suggested.
Newlife the Charity for Disabled Children	Guideline	043	007	Rec. 1.13.7 – we recommend the addition of a further bulletpoint that recognises that workplaces often need to adapt environments or provide additional equipment to ensure young people have the opportunity to perform in the same way as their peers.	Thank you for your comment. The committee have added a bullet point about identifying necessary adaptations.
Newlife the Charity for Disabled Children	Guideline	043	011	There is an omission regarding the provision of communication equipment and adaptable communication software that we recommend is rectified.	Thank you for your comment. Recommendations about providing communication aids, including that these should be provided to the individual where possible are made in section 1.10. The committee have therefore not repeated them here.
Newlife the Charity for Disabled Children	Guideline	043	016	Please expand this bulletpoint to ensure that it reads 'training for employers to understand the full extent of the young person's needs as documented in the EHC Plan, them communicate with and support the young person at work.'	Thank you for your comment. It would not be appropriate to share the EHC plan with an employer because the employer has no duties to provide the support documented in that plan. The committee have amended the bullet to clarify that it relates to supporting the young person with their work, as that is all the employer should be doing.

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Newlife the Charity for Disabled Children	Guideline	046	006	It isn't clear why the recommendations in 1.15 also apply to local authorities when social care and education are funded by the local authority and therefore the points above in Rec. 1.14 should apply to local authorities too.	Thank you for your comment. Section 1.15 makes recommendations aimed at education, health and social care services. As some local authorities also provide services directly the committee have included this statement. The recommendations in section 1.14 are aimed at education, health and social care providers and as such it would not be appropriate to include the same statement there too.
Newlife the Charity for Disabled Children	Guideline	048	010	Rec 1.15.6 – It is felt that the senior managers should be also accountable for ensuring that funding is available for prescribed equipment and therefore would ask that an example is added so that it reads '… time and resources, eg. provision of essential equipment, needed to provide this support….'	Thank you for your comment. This bullet point relates to the time and resources needed by the practitioner to provide key working support. As such it would not be appropriate to make your suggested change.
Newlife the Charity for Disabled Children	Guideline	048	025	Rec 1.12.11 – It is recommended that an additional bullet point is added in order to reduce the amount of bureaucracy and red tape when it comes to who can refer into specific services. Please add a point that says 'be able to refer across sectors into necessary services, e.g. access wheelchair services even if the practitioner is employed by education or social care.	Thank you for your comment. The need to establish clear processes and criteria for referring children and young people both within services and between different services is already covered in recommendation 1.17.5. It will be a local decision as to what the processes will be so the committee are not able to make your suggested change.
Newlife the Charity for Disabled Children	Guideline	049	017	Rec. 1.15.13 – Please add an additional bulletpoint that says the practitioner should 'lead on ensuring aids and equipment needed in the new area move with the child, or facilitate discussions and assessments by service providers in the new area.'	Thank you for your comment. The committee have added a recommendation in section 1.11 to improve access to aids and equipment when families move area.
Newlife the Charity for Disabled Children	Guideline	050	002	Rec. 1.15.16 – Please change so that this reads 'Education, health and social care services must ensure that they make what they do and how they	Thank you for your comment. Recommendations are only able to use the word 'must' when there is a legal requirement. Therefore the committee are not able to make your suggested change.

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				work together more transparent to children, young people and their families.'	
Newlife the Charity for Disabled Children	Guideline	051	002	Rec. 1.15.20 – please consider adding line 20 into the point above and including a separate bulletpoint that ensures training is given on 'how to adapt environments and provide necessary equipment to support children and young people with physical and cognitive/behavioural/sensory disabilities.'	Thank you for your comment. The areas for training covered in this recommendation were identified by the reviews of the qualitative evidence (see evidence reports A, K and M). The areas you cite in your comment were not identified by the evidence and so the committee have not made this change.
Newlife the Charity for Disabled Children	Guideline	054	007	Rec. 1.15.30 – please update this recommendation to read, 'education, health and social care services should periodically request joint feedback from….' because while we welcome the idea of joint feedback we feel it lacks reference to the fact this should be reoccurring.	Thank you for your comment. The committee have made this change.
Newlife the Charity for Disabled Children	Guideline	056	011	Rec. 1.17.2 – this is very specific to supporting transition between childrens and adult services, and as such we recommend that it is broadened out to read '…. organised across education, health and social care, including when young people turn 18 to ensure continuity of support.'	Thank you for your comment. The review question investigated the guideline was about transition from children's to adult services so the recommendation needs to stay focused on that group. In recognition that not all transfers to adult services happen at 18 (some are earlier) the recommendation has been amended for clarification.
Newlife the Charity for Disabled Children	Guideline	056	016	In our opinion access to services are all too often restricted because a diagnosis hasn't been made which we agree is completely inappropriate. We strongly welcome the addition of this content.	Thank you for your comment and support of the recommendation.
Newlife the Charity for Disabled Children	Guideline	056	022	Rec. 1.17.5 – please add a bulletpoint that recognises that any health, education or social care professional should be able to refer into services provided by another organisation, ie. education and social care professionals can refer children into services commissioned by health.	Thank you for your comment. The committee have added to the existing recommendation to clarify that processes should be established for referral between different services. It will be up to local implementation to decide what these processes should be and so the committee cannot specify them in the recommendation.

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Newlife the Charity for Disabled Children	Guideline	058	001	Rec 1.17.11 – It isn't clear why this section doesn't stipulate that service users should be consulted on changes to services. We recommend that this is specified in order to avoid legal challenges.	Thank you for your comment. As documented in rationale and impact section (and the committee's discussion of the evidence section in Evidence report K) 'there was high-quality qualitative evidence that the paperwork and processes of EHC plans are revised without service providers being given any notice or consultation. The committee agreed that this is a source of inefficiency and frustration, and made recommendations to involve services and commissioners more closely in the process.' As these processes are about internal paperwork the committee did not think that children, young people and their families need to be involved in discussions. The committee have removed the term 'consult' from recommendation 1.17.10 to avoid this being confused with the duty to engage and consult with children, young people and their families and carers.
Newlife the Charity for Disabled Children	Guideline	059	003	Please change to read 'a comprehensive explanation….'	Thank you for your comment. The committee have made this change.
Newlife the Charity for Disabled Children	Guideline	059	004	Please expand this point to say 'any thresholds or eligibility criteria including why these are in place and what alternative arrangements are available in terms of service provision when children fall outside of these.'	Thank you for your comment. . The bullets in this list were based on things that are supposed to already be included in the SEND Local Offer (if available) but evidence indicated that this wasn't the case. The committee have not expanded the recommendation as you suggest because there is no requirement for the SEND Local Offer to include a justification for eligibility criteria. Alternative arrangements for service provision if children do not meet eligibility criteria should be covered by the existing needs

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					assessment process so this information would be made available anyway.
Newlife the Charity for Disabled Children	Guideline	059	008	Please consider changing this content to read 'details of what services are available, and the roles of the different services and practitioners including what to expect from them in terms of help available to access charitable and other non-commissioned supportive services.'	Thank you for your comment. It is not possible for a guideline to be prescriptive about what help specific practitioners and services can provide. Different areas will have different responses on who should provide the help and what it should cover. Therefore the committee have not made your suggested change.
Newlife the Charity for Disabled Children	Guideline	059	011	Please expand to reference aids/equipment and assistive technologies, as the current terminology is somewhat limited.	Thank you for your comment. The bullets in this list were based on things that are supposed to already be included in the SEND Local Offer (if available) but evidence indicated that this wasn't the case. The evidence only related to assistive technologies and therefore the committee have not expanded the bullet as suggested.
Newlife the Charity for Disabled Children	Guideline	060	003	Rec. 1.18.1 – we welcome the guidance on developing integrated care systems as this should mean that OT assessments in health do not need to be duplicated in social care, although it would be great if this were explicit as an example.	Thank you for your comment and support for the recommendation. The committee have not included your suggested example as there are a wide range of services that would be covered by this recommendation and only citing one could be misinterpreted.
Newlife the Charity for Disabled Children	Guideline	052 & 053		Rec. 1.15.27 and 1.15.28 – please reference Royal College of Occupational Therapists alongside the RCN. It is felt that this is important because of the professional standards associated with assessing the equipment needs of children with disabilities.	Thank you for your comment. The committee have revised the wording of the recommendation so that specific Royal Colleges are no longer named.
NHS England & NHS Improvement	Guideline	038 - 040	General for this section	1.11 We feel that this section should state more explicitly that environmental adaptations should not be restrictive or isolating.	Thank you for your comment. The review question investigated by the guideline aimed to find out what were the most effective practices to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education. The review

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				We further feel that environmental audits should include staff (including reception/security/first contact staff) and their behaviours. Staff should pro-actively offer support, quiet waiting areas, etc rather than waiting to be asked. Environmental audits should be co-produced with autistic/disabled adults.	questions investigated by the guideline did not look at experience of specific services or interventions. Therefore the evidence about restrictive or isolating uses of environmental adaptations has not been appraised and the committee have not made any recommendations in this area. Recommendation 1.11.12 already specifies that staff should be part of accessibility assessments and he committee have added staff behaviour in response to your comment. The committee do not have evidence to suggest how audits should be undertaken, but the recommendations do not prevent them being co-produced if that is what providers want to do.
NHS England & NHS Improvement	Guideline	037 - 038	001	1.10 (general for this section) We feel that this section would benefit from clearly asking teams to demonstrate best practice in alternative communication methods, such as being Makaton-friendly. No communication method should be in any way restrictive for the children and young people	Thank you for your comment. No evidence was found to support recommending that practitioners have to demonstrate best practice in alternative communication methods.
NHS England & NHS Improvement	Guideline	027 - 028	009	1.5 (general for this section) We recommend that the guidance includes the provision of accessible support for families with managing a direct payment and associated financial procedures, recruitment, contracting, employment issues and financial returns. We further suggest that the use of independent support brokerage should be made available to families and funded appropriately.	As documented in the rationale and impact section and evidence reports A and K, moderate quality qualitative evidence was identified that service users felt uncertainty around the entitlement to, or effectiveness of personal budgets or direct payments. They were unsure what the funds could be used to purchase, whether they improved the child' or young person's access to services, and whether either would be applicable to their individual circumstances. The evidence also indicated that personal budgets and direct payments can increase flexibility and give families greater choice about what services they use,

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					but that it also created additional responsibility for the family. Further, some parents reported they were not sure if they were able, or wanted, to take on the responsibility and questioned whether they had sufficient knowledge to make care decisions and if the receipt of personal budgets and direct payments would impact ongoing professional involvement. The committee therefore recommended that disabled children and young people with severe complex needs and their families and carers should be given information about personal budgets and direct payments. No evidence was identified to support recommending provision of accessible support for families with managing a direct payment and associated financial procedures, recruitment, contracting, employment issues and financial returns or the use of independent support brokerage. Therefore the committee cannot add this to the recommendation. However, other recommendations in the guideline (such as those about key working support) should ensure that families receive more support to navigate services.
NHS England & NHS Improvement	Guideline	029 - 030	011	1.6 (general for this subsection) We recommend including peer-support training. We further believe that training should be based on up to date, evidenced research, so that ABA-type (Applied Behaviour Analysis) approaches are explicitly not recommended. It must be made clear to parents/carers that techniques that encourage masking/camouflaging are shown to lead to serious	Thank you for your comment. No evidence was identified by the guideline literature searches to support recommending peer-support training. The review questions investigated by the guideline focussed on integrated service delivery and organisation across education, health and social care. As such evidence about Applied Behaviour Analysis was not looked at and the

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				mental health issues, including suicidality, for autistic people.	committee have not made any recommendations in this area.
NHS England & NHS Improvement	Guideline	028 - 029	019	1.6 (General for this subsection) In section 1.6, could social prescription link workers be explicitly mentioned as a potential source of support for parents, families and carers?	Thank you for your comment. The focus of the guideline is making recommendation on integrated service delivery and organisation across education, health and social care. No evidence was identified by the guideline literature searches to support recommending specific interventions and therefore the committee are not able to make recommendations on social prescription link workers.
NHS England & NHS Improvement	Guideline	006	008	1.1.11 In addition, it is important to be sensitive to cultural diversities within communities. Often some communities may believe it is their duty or responsibility to look after a loved one and believing that they should not ask for much or be a burden to the system. Therefore, when giving information it would be imperative to let families aware of their entitlements within the health and social care system.	Thank you for your comment. The committee have added this to recommendation 1.1.23.
NHS England & NHS Improvement	Guideline	008	002	1.1.20 (general for this section) In addition to who can be invited to these meetings are those playing the advocacy role which is independent and not part of family or friends. Being independent means, they are there to represent wishes of the child or young person without giving their personal opinion and without representing anyone else's views.	Thank you for your comment. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.

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NHS England & NHS Improvement	Guideline	015	031	1.2.4 The phrase "contact them at first opportunity" is open to interpretation. Should this be a stipulated expected time frame?	Thank you for your comment. It is not possible to include a timeframe in the recommendation as in complex cases it may take some time to find the right referral pathway. The committee thought it was better to ensure the referral is directed appropriately rather than fit into a specific timeframe.
NHS England & NHS Improvement	Guideline	016	004	1.2.5 (general for this section) Add any "reasonable adjustments" which need to be made in the referral details.	Thank you for your comment. The committee have added introductory text to this section to clarify that these recommendations should be read alongside duties on reasonable adjustments set out in the Equality Act 2010.
NHS England & NHS Improvement	Guideline	018	001	1.3.1(general for this section) It would be helpful to have hyper links to the National EHC process such as https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help that give specific info on EHC process.	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all processes that are relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions.
NHS England & NHS Improvement	Guideline	021	012	1.4.3 "*outcome sandwich*" Not sure that this is language universally understood and it would be helpful to have a definition making clear its links to person centred care and plan development	Thank you for your comment. The components of the 'outcome sandwich' are already included in brackets in the recommendation and so a definition is not needed.
NHS England & NHS Improvement	Guideline	025	012	1.4.20 (general for this section) "*the child or young person's needs change significantly (for example, if they develop new health problems)*" Could we include or a change in pre-existing conditions as there may be the need for reviews due to a change in current conditions and the wording is suggestive its only for new conditions	Thank you for your comment. The committee have made this change.

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NHS England & NHS Improvement	Guideline	027	002	1.4.25 (general for this section) Whilst the section makes reference to the fact that should the family or child decline the EHCP a possible safeguarding should be considered I think that it would be of benefit to have a section or risk analysis between health and social care. Also, this section should refer to mental capacity and competency as should a young person or parents decline an intervention then there maybe the need to consider capacity Furthermore it would be important to link into other statutory obligation for example if we where to look at Speech and Language Therapy and named as an intervention in a plan means that there is a legal requirement to provide the level of therapy and a plan being declined would not mean that therapy was not required. There needs to be clarity that rejection of a plan or someone declining a plan is not to say that they are rejecting everything offered in the plan.	Thank you for your comment. The committee have amended the last bullet point to be about following local safeguarding policies if a safeguarding issue exists. Local policy will determine what form of risk analysis is needed. The committee have also added a bullet about discussing the potential implications of deciding not to have an EHC plan. However they have not recommended an assessment of capacity as disagreeing with an EHC plan does not necessarily mean there is a capacity issue. The recommendation already includes a bullet point about agreeing what support will continue to be provided.
NHS England & NHS Improvement	Guideline	027	010	1.5.1 This should not be limited to 'Local Authorities' – For example, if a child is CHC funded, it could be made clearer that Education (as part of the local authority) will lead on informing CYP/carers. Regarding Personal **Health** Budgets, are Local Authorities solely responsible for giving out this information?	Thank you for your comment. The committee have added health services to the recommendation as they would also have a role in providing this information.
NHS England & NHS Improvement	Guideline	027	017	1.5.1 We have questions/concerns over the legality of the wording '… whether they could afford all of their current support with direct payments'. Our	Thank you for your comment. The third and fourth bullet points have been removed from the recommendation as at the point this information is provided it would be too early to say anything about either of these items. Also

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				understanding is that a direct payment must be sufficient to cover the person's assessed need and to buy an equivalent service to those provided by the relevant statutory sector organisation (council, etc).	they are covered by relevant legislation and so do not need to be repeated here.
NHS England & NHS Improvement	Guideline	028	003 - 005	1.6.3 We recommend guidance adding that families can change their minds about the level of involvement and should be able to do so without prejudicing the outcomes. Where families need extra time or support to be involved, this should be provided without prejudice.	Thank you for your comment. The committee have added to the recommendation that families may change their minds about their level of involvement.
NHS England & NHS Improvement	Guideline	029	001 - 002	1.6.2 We are concerned that the language is not strong enough here. The word 'consider' should be strengthened, to ensure that a personalised approach is used at all times.	Thank you for your comment. NICE uses 'consider' to reflect a recommendation for which the evidence of benefit is less certain. As the evidence on person-centred planning was very low to low quality the committee have used the term 'consider' in the recommendation.
NHS England & NHS Improvement	Guideline	029	013	1.6.5 We recommend adding '… that is in line with the content and value-base of the mandatory Oliver McGowan training framework' in terms of learning disability and autism.	Thank you for your comment. The committee did not find any evidence to recommend a particular framework for developing training and so have not made your suggested change.
NHS England & NHS Improvement	Guideline	035	General to this section	1.9 Before an end of life care plan is drawn up (1.9.1) there needs to be first context around establishing whether the child or young person has their wishes written somewhere within care records. People with a learning disability and/or autism often have hospital passports that detail medical information as well as their wishes in urgent care. Some people utilise the GP Summary Care Records to make their wishes known.	Thank you for your comment. The committee have added a new recommendation about establishing if the child or young person has previously documented their wishes, for example in an advanced care plan, before making a palliative or end of life care plan.

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				Therefore before drawing up an end of life care plan it is important to establish whether there has not been any other discussions before relating to advance care planning and to involve the child or young person and their families well before anything is drafted to share with other practitioners. Children and young people must always be at the centre of their care, including advance care planning and DNACPR (Do Not Attempt Cardio-pulmonary Resuscitation) decisions. During the Covid-19 pandemic recurring concerns around application of DNACPR orders were more exposed in different patient groups including those with a learning disability and/or autism. DNACPR decisions need to be recognised as part of wider conversations about advance care planning and end of life care, and these decisions need to be made in a safe way that protects people's human rights. Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions, that supports their human rights. Clinicians, professionals, and workers must have the knowledge, skills, and confidence to speak with people about, and support them in, making DNACPR decisions. It would be beneficial if this section refers to the LeDeR Programme where deaths of people aged 4+ with a learning disability are notified. This is a service improvement programme where the learning from death reviews informs local prioritisation of services for	

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				people with a learning disability. This programme will also soon include people with autism.	
NHS England & NHS Improvement	Guideline	037	002	1.10.1 (general for this subsection) We recommend that the guidance states that assessors/dispensers/approvers are up-to-date and trained on current accessible technology, such as tablets (e.g. Proloquo2Go)	Thank you for your comment. The committee did not find any evidence to support including this level of detail in a recommendation. However recommendation 1.10.2 does cover staff training.
NHS England & NHS Improvement	Guideline	038	004	1.10.6 (general for this subsection) We have a question over whether best practice may be to allow families to make these referrals themselves.	Thank you for your comment. It is not within the remit of the guideline to specify who can make referrals to specialised AAC services. The recommendation includes a hyperlink to the referral criteria.
NHS England & NHS Improvement	Guideline	038	014	1.11.1 We recommend that 1.11.2 should come before 1.11.1, placing the emphasis on training children and young people and families over and above staff first, on using the equipment.	Thank you for your comment. The recommendation about training staff comes first because the staff will be the ones who train the children, young people and their families.
NHS England & NHS Improvement	Guideline	042	008	1.13.2 We believe that 'Local Authorities 'should read 'Local Authorities and the NHS', as responsibility sits across various agencies	Thank you for your comment. Although many NHS Trusts are involved as providers of supported internships, the committee did not think that the NHS had a role in commissioning supported internship programmes and therefore have not made your suggested change.
NHS England & NHS Improvement	Guideline	045	012	1.14.1 (general to this section) Add "explain their role in detail to the young person and their parents/carers	Thank you for your comment. Recommendation 1.14.1 is about how practitioners interact with each other. Recommendations about how practitioners interact with service users are covered in section 1.1. Your specific point is included in recommendation 1.1.23.
NHS England & NHS Improvement	Guideline	055	015	1.16.4 (general to this section) Would this be a service level agreement between all agencies? It is not clear in link (1.15.3 page 47)	Thank you for your comment. The committee did not have evidence to recommend the specific mechanism by which these should be resolved.

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NHS England & NHS Improvement	Guideline	056	004	1.17.1 Definition of "Exhausted" is open to interpretation. This should be more explicit with evidence to support that all options have been exhausted?	Thank you for your comment. The committee have amended the recommendation to be about options close to home not being suitable to meet the needs and outcomes of the child or young person
NHS England & NHS Improvement	Guideline 1.1.15	007	001	1.1.15 (general for this section) We recommend identification of specific roles/individuals who play a coordinator role or act as a point of contact for families. This is vital when families are concerned about a process or the changing needs of their loved one.	Thank you for your comment. The existing bullet on the roles of the practitioners and services that are currently supporting them would encompass what you have requested.
NHS England & NHS Improvement	Guideline 1.3.8	018	011 and 012	*'the child or young person gets the interim assessments they need, and interim support as soon as a need is identified'.* Not sure this is clear - is it interim support? Not clear on interim assessment	Thank you for your comment. Interim assessments are assessments undertaken within specific disciplines that are required to contribute to the EHC needs assessment. Interim support is the support identified by these interim assessments.
NHS England & NHS Improvement	Guideline	9	15, 28	It would be useful to include the offer of a virtual remote meeting using online or smartphone technology.	Thank you for your comment. The committee have added the option for virtual appointments.
NHS England & NHS Improvement	Guideline	18	17	The use of the word "specialist" in "healthcare specialist" may be misinterpreted as secondary care services excluding primary care.	Thank you for your comment. The committee have changed this to 'healthcare professionals'.
NHS England & NHS Improvement	Guideline	21	Oct-22	It would be useful to include the information about responsible practitioners/services who would help achieve/facilitate achievement of the outcomes for EHC plans.	Thank you for your comment. This is already covered by the 4th bullet of recommendation 1.4.11.
NHS England &	Guidelines	32	28	It would be useful to highlight health needs of carers and provision of support for their healthcare needs.	Thank you for your comment. This is outside the scope of this guideline.

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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NHS England & NHS Improvement	Guidelines	42-44		The guidance needs to consider provision of occupational health and medical reports for physical abilities and clearer recommendations for required standards.	Thank you for your comment. The review question investigated by the guideline aimed to find out what were the most effective models of health, social care and education services working together to prepare disabled children and young people with severe complex needs for employment. As such, making recommendations about occupational health and medical reports are outside of this review question.
NHS England & NHS Improvement	Guidelines	General	General	It could be improved with inclusion of considerations about equality and diversity of clients/patients and considerations for the team to make when working with families who are living in challenging circumstances.	Thank you for your comment. Consideration of equality and diversity has been included in a variety of recommendations in the guideline. There is also an equalities impact assessment that supports the guideline which describes how the potential equalities issues identified during scoping have been addressed by the guideline. In addition the committee have included taking into account the cultural background of the child, young person and their families into recommendation 1.1.1.
NHS England & NHS Improvement	Guidelines	General	General	Importance of shared information, continuity of care and support for families in general needs to be highlighted further particularly its impact on the ability of primary care teams who are more likely to be looking after carers and providing supportive role. Facilitation of appointments, consideration of key clinical needs such as coordination of preventive care and attendance at primary care settings.	Thank you for your comment. The guideline already includes recommendations on information sharing, support for families and providing person-centred, co-ordinated care. The focus of the guideline is providing integrated service delivery and organisation across education, health and social care so the committee have not focussed on specific parts of the health service.
Oakdale School - Greater	Guideline	003	012	We agree with the list of particular needs listed, and would also like "Continuing Health Care" package to be included in this list and considered in the guidance due	Thank you for your comment. The text you cite is the contents page, which reflects the review questions investigated by the guideline and the recommendations

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Manchester SEND Group				to the impact on education currently due to continuing care health services being provided in education settings via direct payments which can result in significant operational issues for a school e.g. safeguarding, governance, data protection, insurance and confidentiality.	made as a result. It is not a list of needs and therefore the committee have not added Continuing health care to it. However the committee have cross referenced continuing health care processes at the start of section 1.5.
Oakdale School - Greater Manchester SEND Group	Guideline	006	016	Rec 1.1.13- The recommendation will be a challenge for the most complex needs pupils. It can prove very difficult for them to communicate their views. However, the addition in the guidance with acknowledge observations and annotations of work/responses and their communications we are then able to identify what a child likes or dislike. It is a good idea to include records of observations and annotation of works as a preferred method of communication. Could the committee consider that it may be beneficial to be some examples of good practice for gaining pupil views of most complex needs pupils or signposting to further guidance.	Thank you for your comment. The committee did not have any evidence on which to recommend specific methods for getting children or young peoples' views.
Oakdale School - Greater Manchester SEND Group	Guideline	022	001 - 006	Rec 1.4.7 - The approach is that professionals contribute, LA complete and then draft EHCP only shared with parents/carer. The recommendation will be a challenge for all to read all other practitioners suggestions returning to LA to meet compliance of a 20wk turn round for the creation of an EHC plan. The current National Average to complete the 20wk turn around is 58%, with only 8 LA meeting the 20wk expectation. Could the committee consider some signposting and sharing of good practice for meeting these expectations, plus consideration for the	Thank you for your comment and drawing our attention to this error. The committee have reworded the recommendations to clarify that practitioners should read the advice and information provided by others within the same service, to ensure they can support all the proposed outcomes through their own work with the child or young person. The committee have also recommended that Local Authorities share a child/young person's EHC plan outcomes with education, health and social care services so that they can include how they will help to achieve

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				additional time that will be needed for sharing of information for the plan.	these outcomes when providing their advice and information.
Oakdale School - Greater Manchester SEND Group	Guideline	022	016 - 018	Rec 1.4.9 - It is highly important to ensure the provision that children need is recorded correctly in each part of the EHCP. There needs to be clear guidance of health care provision/services in the EHCP to avoid inappropriate use of LA high needs funding.	Thank you for your comment. The committee hope that this recommendation will address the issue that you have described.
Oakdale School - Greater Manchester SEND Group	Guideline	022	001	Writing the plan – this implies that it is education, health care and social care write their section of the EHC plans where it is the LA that write the plans and education, health and social care services contribute to writing the plan. Could the committee consider changing the title of this section?	Thank you for your comment. The committee have amended the text to clarify that is the Local Authority Officers who write EHC plans, based on information and advice contributed by practitioners from education, health and social care.
Oakdale School - Greater Manchester SEND Group	Guideline	023	001 - 002	This states that Commissioners use sections, F, G & H of the EHC plan to commission the services of the child or young person needs. However, the LA uses sections F & H and Healthcare services use section G to ensure child's needs are met. Who provides these services, majority of health services delivered in education are not commissioned by CCG. It may be beneficial for the committee to be aware that the GM SEND group are in discussions regarding the legality of the current service delivery model for healthcare provision. We have created a workstream action plan and information gathering and liaison with NHS commissioning. Our collective concerns and investigations currently are;	Thank you for your comment. The committee were aware that different NHS services need to input in specific sections of the EHC plan so that commissioners can see which services need to be provided from which budget lines. In the committee's experience this is often done poorly, with a lack of distinction between what therapeutic support is needed to educate or train the child or young person and what health and medical support they need to stay well. This causes issues with support being provided so they made recommendations to highlight the need to provide this information more clearly when writing EHC plans and for commissioners to use this information when planning what services to provide. Whilst the committee are aware of the issues around health services that are delivered within the education sector sitting outside NHS commissioning, this guideline

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				-that NHS commissioning responsibilities remain even when care can be delegated to unregistered non-health support workers (see case law Haringey 2005; Nascot Law 2018). This suggests that the current model of service provision which sees healthcare services that are an NHS commissioning responsibility provided by the education workforce but outside any NHS commissioning arrangement is statutory non-compliant. - if a CCG does commission a school to provide these services, questions then arise, do schools have either the legal obligation or power to be a provider of NHS funded services? How could a school provide NHS 'quality care' when it sits outside the NHS quality statutory framework e.g. CQC registration?	does not have a remit to specify what the commissioning arrangements should be for delegated clinical activity. However, the committee have attempted to clarify the guidance around delegated clinical tasks in section 1.15.
Oakdale School - Greater Manchester SEND Group	Guideline	028	003 - 008	1.5.2 We consider this to be unreasonable / impractical to stipulate the local authority to provide appropriate health advice. We would like the wording to be changed to read "For example, if the family commission health and care support for a child or young person, the local authority ***and health commissioners*** should ensure that those providers still have access to health and care advice directly from statutory providers.	Thank you for your comment. The committee have made this change.
Oakdale School - Greater	Guideline	029	012	Rec 1.6.5 – Training for parents and carers, unless there is something specific requiring medical training, predominantly other training opportunities are provided by Education sometimes with support of other	Thank you for your comment. Who would need to lead the joint development of training would depend on what the training covered. It is not possible to specify this in a recommendation.

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Manchester SEND Group				professionals e.g. "Riding the Rapids" training, led by education but with social care or healthcare services in attendance. It would be beneficial if it could be clarified e.g. a multi agency training be led by relevant professionals, not left for education to organise and/or pass onto parents as a training/information sharing opportunity.	
Oakdale School - Greater Manchester SEND Group	Guideline	038	019	Rec 1.11.2 – Environmental adaptations. Would a brief/effective sentence be beneficial at the beginning of this section to clarify what constitutes environmental adaptations, rather than at the end via a link.	Thank you for your comment. The committee have added a definition of environmental adaptations to the terms used section.
Oakdale School - Greater Manchester SEND Group	Guideline	045	026	Rec 1.14.3 – This recommendation will be challenging as practitioners change, change location, change role etc so it would be beneficial if practitioners would share with each other a flow chart, contact booklet of who is who, location, contact details etc. Could this be an expectation to share on local offer?	Thank you for your comment. It would be very difficult to implement your suggestion because, as you point out, the workforce across education, health and social is dynamic and therefore this information at an individual level would be out-of-date quickly. This is why have focussed the recommendation on learning about roles.
Oakdale School - Greater Manchester SEND Group	Guideline	052	015	We recommend removing Competency from "Competency in delegated clinical tasks" title and changing from delegated clinical tasks to "Delegated Healthcare Tasks"	Thank you for your comment. The committee have removed 'Competency in' from the section heading as suggested. However they have kept the term 'clinical tasks' to align with terminology used in other NICE guidance.
Oakdale School - Greater Manchester SEND Group	Guideline	052 & 053	016 – 019 and 001 - 007	Rec 1.15.27 – It states "For staff, services must follow guidance on training and competency from the Care Quality Commission, the Nursing and Midwifery Council, the Royal College of Nursing, and other professional governance organisations allied to medicine." This needs to be changed from "For staff" to "**For healthcare staff**".	Thank you for your comment. The committee have amended the recommendation to clarify that it relates to registered health professionals, when training support workers to undertake delegated clinical tasks

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Oakdale School - Greater Manchester SEND Group	Guideline	053	008 - 024	The definition of "Support Worker" includes education teaching assistants, who are employed for educational activities and to follow guidance / activities from healthcare provider i.e. supporting feeding plans of children with a "peg" or to undertake daily physio activities provided by physiotherapist. It currently reads that this includes Teaching assistants. We want to advise that we are currently reviewing the legal aspects of the current service delivery model for our staff and settings and that this section implies that education must follow all DFE expectations and meeting teaching standards, as well as then to include the competency bodies from lines 10-11 on page 53. How reasonable is this? What measures could NICE put in place to support, possible making reference to the delegating of clinical tasks and safeguarding measures?	Thank you for your comment. It would be up to employers to decide if teaching assistants should undertake delegated clinical tasks, not the guideline. The purpose of this recommendation is to help delegated clinical tasks to be done safely if it is decided that a support worker should do them.
Oakdale School - Greater Manchester SEND Group	Guideline	063	001 - 003	Support workers – this definition includes, Teachers, Teaching Assistants. We recommend that the title is changed from Support worker as this could tie schools in knots / legality of education staff being delegated clinical tasks. See above related previous comments.	Thank you for your comment. It would be up to employers to decide if teaching assistants should undertake delegated clinical tasks, not the guideline. The purpose of this recommendation is to help delegated clinical tasks to be done safely if it is decided that a support worker should do them.
Royal Borough of Windsor and Maidenhead Council	Guideline	021	005 - 022	It is not clear whether this section refers to the statutory EHC Re-assessment process or to other unspecified re-assessments. The guideline suggests that an EHC Re-assessment is required for any change in circumstances whereas this would generally be covered by an amendment to the	Thank you for your comment. The committee have amended the recommendations to clarify that they relate to professional assessments and reviews, not EHC plan re-assessments. The information from these professional assessments can then be used to determine if an EHC plan re-assessment is needed.

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				EHC Plan following an Annual Review or at School Phase Transfer. For example, LAs certainly wouldn't generally carry out an EHC re-assessment just because the child has started school. SEN CoP 9.186 onwards refers: *The review process will enable changes to be made to an EHC plan so it remains relevant to the needs of the child or young person and the desired outcomes. There may be occasions when a re-assessment becomes appropriate, particularly when a child or young person's needs change significantly.* 9.193: *EHC plans are not expected to be amended on a very frequent basis. However, an EHC plan may need to be amended at other times where, for example, there are changes in health or social care provision resulting from minor or specific changes in the child or young person's circumstances, but where a full review or re-assessment is not necessary.*	
Royal Borough of Windsor and Maidenhead Council	Guideline	026	008 - 017	LAs have a duty to deliver the support set out in an EHCP. However, funding is usually an internal matter between the LA and the party delivering the support (e.g. the school) so it is unlikely that this would be the subject of a Tribunal Appeal – appeals should be concerned with the SEN provision and placement set out in the EHCP. I think this section of the guideline is mixing up provision with funding and is therefore confusing for users.	Thank you for your comment and pointing out this error. The committee have now re-worded the recommendation and amended the rationale and impact text to clarify that under section 42 of the Children and Families Act 2014 local authorities and health commissioners have a duty to secure or arrange (respectively) the provision specified in EHC plans. So the committee recommending that sufficient funding should be provided to enable the support in EHC plans to be provided.

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				If however this section refers specifically to Personal Budgets then this needs to be made much clearer.	
Royal Borough of Windsor and Maidenhead Council	Guideline	027	001 - 008	It's not clear what 'If parents or carers decline an EHC plan' refers to. There is no reference to such an occurrence in the SEN Code of Practice and I'm not aware that parents can 'decline an EHCP'. What does this section mean?	Thank you for your comment. The text refers to when parents decide that they do not want their child to have an EHC plan. The committee were aware, based on their experience that this can happen.
Royal College of Nursing	Guideline	General	General	The Royal College of Nursing (RCN) welcome the proposal to develop NICE guidance for Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education guideline. The RCN invited members who work with people in these settings and care for people with this condition to review and comment on the draft guidelines on our behalf. The comments below, reflect the views of our reviewers.	Thank you for your comments. The committee have responded to your comments individually.
Royal College of Nursing	Guideline	General	General	This guideline provides welcomed guidance for ensuring young people are involved as much as possible, that they are not underestimated in what their contribution can be, and that their families' views are listened to.	Thank you for your comment and your support of the guideline
Royal College of Nursing	Guideline	General	General	The guidelines may benefit from considering sensory processing disorders and how this is an important consideration when presenting a decision to young people with complex needs. Ignoring sensory	Thank you for your comment. The recommendations in section 1.1 of the guideline aim to ensure that children and young people are involved in decisions about their care and support to the fullest extent possible. These

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				processing needs may inadvertently limit a young persons ability to make decisions.	recommendations would apply to all children and young people with severe complex needs, including those with sensory processing disorders.
Royal College of Nursing	Guideline	General	General	The guideline may also benefit from considering behaviours that challenge us as a form of communication. Challenging behaviours can sometimes lead to people being less involved in their decisions. These behaviours are often an indication that the persons needs and wishes are not being appropriately listened to, so a counter-intuitive approach of involving young people more when their behaviours are challenging us may be likely to reduce this presentation.	Thank you for your comment. The recommendations in section 1.1 of the guideline aim to ensure that children and young people are involved in decisions about their care and support to the fullest extent possible. These recommendations would apply to all children and young people with severe complex needs, including those with behaviour that challenges.
Royal College of Nursing	Guideline	012 013	014 004	There will be a small number of young people, particularly young people with Profound and Multiple Learning Disabilities, who will be unable to contribute to their support planning. They may not fully understand the decisions that are being made and their short and long term implications. They may be unable to understand what is communicated to them, and they may be unable to express their thoughts and wishes. For some young people, anxiety in the situation and the present moment may override what their long term wishes are and lead to behaviours indicating refusal. Whilst it is appreciated the support this guideline offers to supporting inclusion, it would benefit from further advice on when people are unable to participate. The advice related to this are limited to points 1.1.39 (p12, row 14) to 1.1.41 (p13 row 4).	Thank you for your comment. Those who are 16 or over and cannot contribute to their support planning are covered by recommendation 1.1.50. The committee have added a recommendation about taking into account the views of those who know the child or young person best in the section on 'Principles for working with children, young people and their families' to cover those who are under 16 and cannot contribute to their support planning.

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Royal College of Paediatrics and Child Health	Guideline	Section 1.1	004 onwards	This is a given, but corners are sometimes cut in clinic consultations, due to time constraints, child having communication +/or cognitive difficulties. Therefore, often resort to default of talking mainly with parents/ carers who bring child to an appointment.	Thank you for your comment. Implementation of the recommendations in this guideline should help prevent this ineffective practice from happening.
Royal College of Paediatrics and Child Health	Guideline	004	General	1.1.1 There needs an additional bullet point here: For children and young people with the most complex needs who are not able to actively participate in planning or decision-making, the views of those who know them best should also be taken into account, to ensure that the perspective of the child or young person is fully represented.	Thank you for your comment. The committee have added a recommendation about taking into account the views of those who know the child or young person best.
Royal College of Paediatrics and Child Health	Guideline	005	General	1.1.2 Again, there needs to be a caveat to ensure that those with the most complex needs who cannot actively participate in discussions and decision-making have their views considered in a holistic way. Being present in a meeting may not be appropriate for all young people, who may find being in such a meeting distressing. This needs to be adequately acknowledged.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involve attending meetings).
Royal College of Paediatrics and Child Health	Guideline	005	General	1.1.3 Whilst of course family members should be consulted and involved in decision-making, for children and young people with the most complex needs, the views of those who know the child or young person best should also be taken into account, i.e., a wider group than those with parental responsibility.	Thank you for your comment. This recommendation covers situations where it may not be appropriate to have a family member present (for example family breakdown). The committee have therefore not included a wider group as you suggest. However the reasons behind this recommendation have been clarified in the related rationale and impact section.

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Royal College of Paediatrics and Child Health	Guideline	005	General	1.1.5 This is great for those who can be involved in expressing their views, but not all children can. This should be acknowledged, and a statement should be included to ensure that for the group of children and young people who are not able to express their views, the views of those in the health and care team who know them best should be sought, along with the views of parent carers and those with parental responsibility, to ensure a full perspective is presented i.e. what the child or young person would have expressed for themselves, had they been able to do so.	Thank you for your comment. The committee have added a recommendation about taking into account the views of those who know the child or young person best.
Royal College of Paediatrics and Child Health	Guideline	006	019	1.1.14 Determine if the child uses lip-reading. This may be compromised if speakers are wearing masks or other PPE.	Thank you for your comment. The committee did not have any evidence to make recommendations about the detail of specific communication formats.
Royal College of Paediatrics and Child Health	Guideline	006	015 and 019	1.1.13 and 1.1.14 Consider sign language and appropriate interpreter (cost). Ensure hearing aids/cochlear implants if prescribed are worn and functioning.	Thank you for your comment. The committee did not have any evidence to make recommendations about the detail of specific communication formats.
Royal College of Paediatrics and Child Health	Guideline	008	General	1.1.20 This section should include a statement about the importance of assessing the appropriateness (or not) of the child or young person being present during meetings about them. Would being present cause them distress? Would being present lead to more meaningful ascertainment of their views (or not)? The current wording in the guideline assumes that the child	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involved attending meetings).

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				or young person being present is always the right thing, but in reality, for those with the most complex physical and/or emotional and/or sensory needs, this may not be the case. It is very important for this to be carefully considered ahead of any meetings, not just wheeling in the young person as a way of ticking a box about inclusion, as the child or young person may not be being included in reality and may find the experience negative and distressing.	
Royal College of Paediatrics and Child Health	Guideline	009	General	1.1.23 All of this is great, but not very practical for those who need to plan meetings for multiple children and young people, e.g., in special school settings. The way this is written, practice will 'fall short' more than it will reach the stated standard, as it will be impossible to arrange all meetings in the place of the child's choosing and out of school time. This recommendation needs to be reconsidered and written in a way that is more practical to deliver.	Thank you for your comment. This recommendation is to consider the preferences of the child or young person as far as possible. It may well be the case that it is not possible to deliver their preferences because of practical reasons, but consideration should at least be given to seeing if it possible. There are also other recommendations in this section which cover what to do if practitioners cannot attend.
Royal College of Paediatrics and Child Health	Guideline	015	General	1.2.3 If you think a child or young person may have a special educational need, think more broadly about their circumstances and decide whether they need to be referred to other services. For example: could there be an underlying health condition, and do health services need to be involved? On this point, the reviewer would argue that it will only be known if the child or young person has health needs (or not) if a health assessment is completed by a health practitioner. It is not reasonable to expect education practitioners to	Thank you for your comment. The staff in question are not being asked to diagnose but to refer to the appropriate service for assessment. Educators are quite often the first professionals to pick up traits that turn out to have medical or health causes and they already identify possible health issues and make referrals.

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				assess as to whether a child may have health needs (or not). All children and young people who are suspected to have special educational needs should have access to a health assessment, e.g., with a paediatrician with expertise in SEND.	
Royal College of Paediatrics and Child Health	Guideline	017	003	1.3.1 In the reviewer's area, the process of notifying LA of EHC Assessment need is not currently clear. There is no clear referral form or Pathway for paediatricians to use, therefore they rely on child's educationalists (nursery, school, specialist Advisory teachers) to initiate this.	Thank you for your comment. Each Local Authority has a responsibility to have a system for EHC needs assessment. As such, this is not something the committee have covered in the guideline recommendations.
Royal College of Paediatrics and Child Health	Guideline	017	015	1.3.3 In practice, some schools still tell parents that they cannot initiate a EHC needs assessment, until their child has a diagnosis. There needs to be better over-arching guidance shared with Education and monitoring/ reporting of schools where this practice continues.	Thank you for your comment. This recommendation aims to help address the issue that you describe. It is not within the remit of this guideline to make recommendations about monitoring/reporting schools.
Royal College of Paediatrics and Child Health	Guideline	021	General	1.4.1 In this section, for children and young people with the most complex needs who cannot express their own views or engage actively in discussions and decision-making, there should be consultation and engagement with all those who know the child or young person best, to ensure that their holistic needs are fully represented, not just those with parental responsibility.	Thank you for your comment. The committee have added a recommendation in the general principle section about taking into account the views of those who know the child or young person best when they are not able to actively participate in planning or decision making.
Royal College of Paediatrics	Guideline	023		1.4.14 Consider those reliant on BSL (British Sign Language) and provide a BSL interpreter (cost).	Thank you for your comment. This recommendation was based on moderate quality qualitative evidence that children and young people's views are not always

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and Child Health					captured accurately and that it was important to make sure views are not rewritten in a way that changes the meaning. The evidence did not identify any particular communication formats and therefore the committee have not specified them in the recommendation.
Royal College of Paediatrics and Child Health	Guideline	023	General	1.4.15 Whilst this is appropriate for children and young people who have the mental capacity to understand, the statement needs to be more inclusive of children and young people who do not have such capacity, for example, by acknowledging that not all children and young people will have the capacity to understand the outcomes in their EHC plan.	Thank you for your comment. The final sentence of recommendation 1.4.15 already acknowledges that some children and young people may have difficulties in understanding the EHC plan content. However the committee thought it was still important to involve them as far as possible.
Royal College of Paediatrics and Child Health	Guideline	032	General	1.8 Transition There should be more emphasis on appropriate commissioning in this section so that the excellent transition principles are deliverable for all young people.	Thank you for your comment. Evidence report J looked at different ways of delivering transition services, which included commissioning. However the evidence identified was not useful for informing recommendations as too many factors differed between services and so it was not possible to isolate the impact of any one factor. Therefore the committee were not able to make recommendations about commissioning in relation to transition between children's and adults' services. However the recommendations made about commissioning in other sections of the guideline would apply here too.
Royal College of Paediatrics and Child Health	Guideline	032	General	1.8.3 This statement needs to be more inclusive of those young people who lack capacity to plan for adulthood, emphasising the importance of engaging with those who know the young person best, including but not restricted to, their parent carers, in the spirit of the best	Thank you for your comment. The committee have added another recommendation about those who lack capacity.

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				interests decision-making framework of the Mental Capacity Act.	
Royal College of Paediatrics and Child Health	Guideline	032	003	1.8 - Transition This section doesn't really allude to medical transition, it seems to be about Education and social care. But there is a real gap in Health transition, apart from a few pockets of good practice (e.g., for Epilepsy; Enhanced GP reviews for YP/ adults with LD). Barriers to strong transition in health from Community paediatrics (who often hold many of these CYP on their caseload): - No one in adult healthcare to run a transition clinic with – need to identify relevant adult physicians – Palliative care or neurorehabilitation neurologists are developing this role in some areas of UK, but not in the reviewer's local area. CYP with ASD might also benefit from GP Enhanced health reviews, but currently these check are only highlighted for CYP with documented LD. (In NE England, GP commissioners have apparently agreed to flag records for ASD as well as LD, so would be helpful to encourage this to be rolled-out nationally).	Thank you for your comment. The committee have added a recommendation that should make practice more effective when transitioning between children's and adults' health services. The evidence did not support making recommendations at the level of detail you request in your comment.
Royal College of Paediatrics and Child Health	Guideline	035	General	1.9 Palliative care The reviewer noted that they now have access to draft EOL plans/ parallel care plans on Coordinate My Care platform. But they are not sure all clinicians have received training/access codes to use this platform as yet.	Thank you for your comment and providing this information. The committee did not have evidence to support recommending the use of the Coordinate My Care platform.
Royal College of	Guideline	037	General	1.10 Communication Aids	Thank you for your comment and providing this information about existing pathways in your area.

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Paediatrics and Child Health				There are good existing pathways for the reviewer's patients including low-tech strategies and local SLT services. Higher tech strategies include either the SLT regional communication hub (previously with CLCH) or via GOSH AAC pathways (via referral from paediatrician).	
Royal College of Paediatrics and Child Health	Guideline	038	General	1.11 Environmental Adaptations The reviewer was not sure who, if anyone is making referrals for EC equipment for CYP in their local area. Perhaps this is a remit for local OTs, but there is a severe scarcity of OTs locally (and nationally), there was concern that very few CYP receive this consideration. The UK needs to urgently address OT shortages, there is a fundamental grassroots problem with training programmes in OT, training in paediatrics OT is not given high enough priority/trainees receive little if any exposure; it's often just a post-grad training opportunity, when most UK OTs have already settled for Adult OT posts. Hence most of the community paediatrics OTs come from overseas (SA, Aus, NZ), where they have more robust training programmes.	Thank you for your comment and providing information on practice in your local area. The guideline has not looked at the evidence on which roles should undertake specific tasks and therefore is not able to make recommendations about this or about how to address shortages in certain specialisms.
Royal College of Paediatrics and Child Health	Guideline	039	General	1.11.7 Environmental accessibility Again, shortage in OTs affects waiting times for these assessments. The reviewer noted the recommendation for there to be annual reviews of children's needs. This is not happening in their local area. Once a Social Care OT has assessed a home and made a plan or recommendations for adaptations, then the case is closed with no ongoing review plans.	Thank you for your comment. The committee have not investigated staff levels within this guideline and so are not able to make recommendations in this area. As documented in the rationale and impact section 'annual assessments of accessibility at a service level represent a change in practice for health and social care services. However, health and social care practitioners do already conduct accessibility assessments for individuals, to comply with legislation on access for disabled people.

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					Overall this recommendation should not be a substantial change in practice. There may be some additional resources associated with setting accessibility assessments up and coordinating at a service level.'
Royal College of Paediatrics and Child Health	Guideline	039		1.11.7 Consider the needs of the child/YP who uses lip-reading i.e., seating position, lighting etc, face masks (consider transparent alternatives and cost).	Thank you for your comment. The list in recommendation 1.11.11 are only examples of environmental adaptations, not recommendations on what should be supplied. This is not intended to be an exhaustive list and so the committee have not added your suggestion to it.
Royal College of Paediatrics and Child Health	Guideline	039		1.11.7 Consider child/YP with dual sensory impairment i.e., hearing and vision who may need further environmental adaptation.	Thank you for your comment. The list in recommendation 1.11.11 are only examples of environmental adaptations, not recommendations on what should be supplied. This is not intended to be an exhaustive list and so the committee have not added your suggestion to it.
Royal College of Paediatrics and Child Health	Guideline	039	015	1.11.7 Within environmental adaptations consider the use of soundfield systems, FM systems or loop systems if these are usually used by the child in their own setting.	Thank you for your comment. The list in recommendation 1.11.11 are only examples of environmental adaptations, not recommendations on what should be supplied.
Royal College of Paediatrics and Child Health	Guideline	041	General	1.12 Travel training The reviewer had previously been informed that this was available in their local area, but could find no up to date information about this scheme on their Local Offer Website, so this needs to be clarified and better advertised if available.	Thank you for your comment. The committee agree that if travel training is available it should be included on the SEND Local Offer website. However this is a matter for local implementation.
Royal College of Paediatrics and Child Health	Guideline	042	General	1.13 Employment There is an officer in the local authority who sits on the Joint LA/CCG Transitions Focus group, who has the remit to develop better links to employment and training for YP/Adults with LD and complex disabilities.	Thank you for your comment and providing this information.

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Royal College of Paediatrics and Child Health	Guideline	047	General	1.15.4 KW support Not all CYP with complex disabilities have an allocated KW who performs the roles described in this section. Some children may have a helpful colleague who undertakes this role, but the reviewer was not aware of this being rolled out as a basic provision to all eligible CYP. This is probably due to a short fall in local funding. They are aware that TAC coordinator role in the LA was previously cut.	Thank you for your comment. The variable provision of key working support is documented in the rationale and impact section.
Royal College of Paediatrics and Child Health	Guideline	056	General	1.17.5 Making referrals and joint working easier The reviewer's local area has devised a Multi-agency referral form for access to a range of health and educational services which are part of the Child Development Service. Only one form needs to be completed which can then be disseminated at the single point triage meeting to all relevant services. Actual joint working is hindered by having too many providers. E.g., community paediatrics employed by one Trust, therapists by another, community nurses by another. The reviewer tries to run some MDT and multi-agency clinics but operationally this is complicated.	Thank you for your comment and providing this information.
Royal College of Speech and Language Therapists	Guideline	005	015	Disabled children and young people with severe complex needs may require specialist support from speech and language therapists in order to be able to give their views and express what they want and need. We suggest an additional recommendation is included as follows: **Individuals with communication needs might need support from a specialist (such as a speech and**	Thank you for your comment. The committee have added a recommendation about the potential need for specialist support.

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				language therapist) in order to participate in discussions and decisions and express their views.	
Royal College of Speech and Language Therapists	Guideline	006	008 - 018	It is important to recognise that these young people may need support with understanding the discussion as well as with expressing themselves and that their preferred communication formats may vary for different purposes. For example, a child who uses a communication aid to express their own views may have good understanding of spoken language or they may require different strategies such as short, simple language supported by visuals, to help them understand. This section could be clarified to make it clearer that professionals may need to a) use different strategies and forms of communication in order to help a young person understands information and b) allow additional time and resources to enable young people to communicate their own views in their own preferred format.	Thank you for your comment. The committee have added a recommendation about being aware that a child or young persons preferred communication format may vary for different purposes. There is already a recommendation in the 'Planning and running meetings with children and young people' section about giving them plenty of time to express their views in discussions and meetings.
Royal College of Speech and Language Therapists	Guideline	006	015	As referenced on p43, line 11 of the Guideline, some children and young people may already have a communication passport which details their most effective means of communication. (A communication passport is specifically about a child's communication preferences and is different from a healthcare passport. For more information on communication passports see:	Thank you for your comment and providing this information on communication passports. The committee have added a recommendation about asking if children and young people have an up-to-date communication passport.

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				https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/communication-passports/) We suggest adding an additional recommendation here as follows: - **Some children and young people may have a communication passport which sets out their communication needs and preferences. Ask children and young people and their families and carers if they have a communication passport, to prevent them having to repeat information they have already provided.**	
Royal College of Speech and Language Therapists	Guideline	006	019	As well as speaking English as an additional language, parents/carers may have their own communication needs. We suggest adding an additional recommendation here are follows: **Be aware that parents or carers may have communication preferences and needs of their own that may affect their ability to take part in discussions and understand information that is provided to them.**	Thank you for your comment. The committee have added a recommendation on the additional communication needs of parents and carers.
Royal College of Speech and Language Therapists	Guideline	010	007 - 022	Although 1.1.27 relates to preferred communication formats and 1.1.28 recommends giving time for children and young people time to express their views there is not a specific recommendation about ensuring they have understood the discussion or agreed actions. Children and young people's preferred communication formats may vary for different purposes. For example, a child who uses a	Thank you for your comment. The committee have added a recommendation about allowing time to absorb/ reflect on information and checking this information has been understood

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				communication aid to express their own views may have good understanding of spoken language or they may require different strategies such as short, simple language supported by visuals, to help them understand. We suggest expanding recommendation 1.1.27 to include the following: • **Give children and young people plenty of time to absorb and reflect on information they are given. Check they have understood it, and how it applies to them, as is appropriate for their age and developmental level** • **Additional resources may be required (for example, foreign language or sign language interpreters, picture boards, computer-based systems)** • **Identification of a 'yes' or 'no' response (which might be non-verbal) can allow a direct conversation between a child or young person and a healthcare professional** • **Individuals with additional communication needs might need more time and specialist support for alternative forms of communication (for example, speech and language therapist support for augmentative and alternative communication).**	

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				- **Some children and young people may have a communication passport which sets out their communication needs and preferences. Ask children and young people and their families and carers if they have a communication passport, to prevent them having to repeat information they have already provided.** (A communication passport is specifically about a child's communication preferences and is different from a healthcare passport. For more information on communication passports see: https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/communication-passports/)	
Royal College of Speech and Language Therapists	Guideline	010	011	We suggest expanding recommendation 1.1.28 about children expressing their views as follows (this wording is adapted from the recently updated Babies, children and young people's experience of healthcare NICE guideline [NG204] Recommendation 1.2.6) **Take into account that:** - **English may not be their first language** - **communication may be non-verbal (for example, sign language, Makaton)** - **identification of a 'yes' or 'no' response (which might be non-verbal) can allow a direct conversation between a child or young person and a healthcare professional**	Thank you for your comment. A cross reference to the Babies, children and young people's experience of healthcare guideline is already included in recommendation 1.1.27. The committee have added identifying preferred communication formats to the stem of this recommendation. However, in line with NICE style, the committee have not repeated the content here.

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				- **additional resources may be required (for example, foreign language or sign language interpreters, picture boards, computer-based systems)** - **individuals with additional communication needs might need more time and specialist support for alternative forms of communication (for example, speech and language therapist support for augmentative and alternative communication).** - **Some children and young people may have a communication passport which sets out their communication needs and preferences. Ask children and young people and their families and carers if they have a communication passport, to prevent them having to repeat information they have already provided.** (A communication passport is specifically about a child's communication preferences and is different from a healthcare passport. For more information on communication passports see: https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/communication-passports/)	
Royal College of Speech and	Guideline	015	013	It might be helpful to include the definition of special educational need from the SEND Code of Practice here: "**A pupil has SEN where their learning difficulty or disability calls for special**	Thank you for your comment. The committee have added this definition to the terms used section.

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Language Therapists				**educational provision, namely provision different from or additional to that normally available to pupils of the same age." (SEND Code of Practice, p. 94)**	
Royal College of Speech and Language Therapists	Guideline	017	003	We are concerned that this recommendation may imply that all children and young people with a special educational need should apply for an EHC needs assessment. This is not what the SEND Code of Practice states, so may give inaccurate information to children and families. Suggest amending as follows: "If you think a child or young person may have a special educational need **which cannot be met by the provision in their early years or education setti**ng, explain to them and their families and carers:"	Thank you for your comment. The population of this guideline is disabled children and young people with severe complex needs. As such they will need education, health and care support. The committee have not made your suggested change as it is about those with only a special educational need - who are not the population covered by this guideline.
Royal College of Speech and Language Therapists	Guideline	037	002	The guideline does not acknowledge the specific role of the speech and language therapist in assessing a child's communication skills and potential need for a communication support, which may not always be a high-tech aid. We suggest adding the following points to 1.10.1 • **Consider a referral to your local Speech and Language Therapy service.** • **Ask your local Speech and Language Therapy service to support with assessing whether a communication aid is suitable (this could be electronic or non-electronic).**	Thank you for your comment. The review question investigated by the guideline was 'What are the most effective practices (for example, environmental assessments and use of equipment such as assistive technology across different contexts) to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education?'. The committee did not look at the evidence for who should undertake specific aspects of care and are therefore are not able to recommend specific roles who should undertake assessments.
Royal College of	Guideline	037	002	There needs to be clear recognition of the views of families, carers and support networks when assessing	Thank you for your comment. The committee have added to the recommendation that the child or young person and

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Speech and Language Therapists				communication aids, as these can differ from those of professionals: Murray J, Lynch Y, Goldbart J, Moulam L, Judge S, Webb E, et al. The decision-making process in recommending electronic communication aids for children and young people who are non-speaking: the I-ASC mixed-methods study. Health Serv Deliv Res 2020;8(45) https://doi.org/10.3310/hsdr08450 Recommendation 1.10.1 should include a point that families and carers should be involved in the decision-making process.	their families and carers should be involved in the assessment process.
Royal College of Speech and Language Therapists	Guideline	037	012	The specialised AAC service may only provide bespoke training for a communication aid they have provided, so this recommendation should be amended to reflect the fact that in some cases training and support may be provided by local health services (e.g. speech and language therapy may support with promoting language development, or occupational therapy or a technician may support with access options).	Thank you for your comment. The committee have amended the wording of the recommendation to clarify that the local AAC service can provide training in collaboration with the specialist hub where needed.
Royal College of Speech and Language Therapists	Guideline	037	020	Recommendation 1.10.2 should have an additional point about the importance of ongoing specialist input for use of communication aids • **Education, health and social care services should liaise closely with specialist services, to ensure that children's communication environment at home, at school and in leisure contexts supports the use of communication aids**.	Thank you for your comment. The committee have added this recommendation to the guideline.

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Royal College of Speech and Language Therapists	Guideline	037	021	1.10.2 and 1.10.3 should be amended to make it clear that the recommendations about providing information, training and knowledge about if a device is damaged etc should apply equally to staff AND families, carers and support networks.	Thank you for your comment. The committee have reflected the need for this in the recommendations.
Royal College of Speech and Language Therapists	Guideline	038	001	RCSLT welcomes the importance placed on telling staff about augmentative and alternative communication services, but the recommendations are unclear. AAC services are provided on a "hub and spoke" model, with a specialist hub providing services for a minority (For the 0.05% of population with the most complex needs) and supporting local, generic SLT services who provide for the majority (0.5% of population) who may not need highest tech AAC. To access a specialised AAC service a child would have : • severe or complex communication difficulty typically with a range of other difficulties. • clear discrepancy between their level of understanding and their ability to speak. • the ability to understand the purpose of a communication aid • developed beyond cause and effect understanding, • may have experience of using low-tech AAC which is insufficient to enable them to realise their communicative potential. Exclusion criteria are: not having achieved cause and effect understanding	Thank you for your comment. The committee have reviewed the wording of the recommendations to be clearer on the distinction between local AAC services and NHSE specialised AAC services. The committee have not made your suggested change as the revised recommendations are now clear.

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				preverbal communication skills RCSLT asks that recommendation 1.10.5 is clarified using bold text below: 1.10.5 Education, health and social care services should tell their staff about local augmentative and alternative communication services **(e.g. local speech and language therapy service),** so that staff know to refer children and young people that **do not meet the eligibility criteria for specialised augmentative and alternative communication services, but would benefit from specialist support for their communication.**	
Sense	Guideline	General	General	General comment in relation to section 1.3 Education, Health and Care Needs Assessment: Many parents we support find themselves driving forward the process of the EHC Needs Assessment. The Children and Families Act 2014 intended to remove the burden from parents, and this is also highlighted in the SEND Code of Practice. We recommend that emphasis is added in this section on ensuring professionals supporting a family through this process are not placing the burden of driving this process forward on families.	Thank you for your comment. The committee have added a recommendation about this to section 1.3.
Sense	Guideline	004	013	We agree with the principles listed here. These are often referred to as co-production. We believe co-production should be explicitly mentioned here as a standard that should be met. This is also reflected in the SEND Code of Practice.	Thank you for your comment. The committee agree on the importance of co-production and have referenced this in other recommendations, particularly those about training. The focus of recommendation 1.1.1 is ensuring that practitioners deliver person-centred care.

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Sense	Guideline	006	015	Section 1.1.13- We welcome the recognition that many children and young people with complex needs will likely communicate in a range of different ways. We recommend that this section 1.1.13 should be broadened. It should cover the following: 1. Finding out the individuals preferred method of communication- for example, email, phone. 2. Finding out hat format the individual wishes to receive information in- for example, large print, braille. 3. Putting in place communication support required for appointments or meetings- for example, British Sign Language Interpreter Not only should this cover the child, but should also cover family members involved, for example parents. We would recommend this should replicate the Accessible Information Standard.	Thank you for your comment. This recommendation is about communication with individuals, rather than organisational communication. As such the committee have not replicated or cross referenced the Accessible Information Standard in the recommendations, but it will be cited on the NICE website
Sense	Guideline	007	012	This section could specifically mention charitable organisations providing information and support, such as Sense.	Thank you for your comment. The committee are not able to cite specific organisations in recommendations but relevant support organisations will be listed on the 'Information for the public' tab of the NICE website when the guideline is published.
Sense	Guideline	012	001	This section should also include ensuring that a child or young person only has to explain their needs once- information should be shared as far as possible between education, health and social care to the benefit of the child or young person and meets the standards set out in the information and privacy section.	Thank you for your comment. The recommendations in the section on 'Information sharing' aim to prevent children and young people and their families from having to repeat information multiple times.

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Sense	Guideline	017	002	There should be a focus throughout this section on ensuring families have the information they need to go through this process. Many families tell us that they do not have sufficient information from local authorities and services about the services that are available and often have to do their own research, so providing more information to families both at the start of the process and throughout could improve families experiences navigating the system.	Thank you for your comment. Explaining what services are available (and might be appropriate) and the criteria for accessing them is covered in recommendation 1.3.7.
Sense	Guideline	019	008	We believe this should read 'contact practitioners who have relevant and/or specialist knowledge about the needs of the child or young person'.	Thank you for your comment. The committee have made this change.
Sense	Guideline	020	015	We believe it's important to state here that this should be completed within 20 weeks of the initial assessment request, as per page 20 line 12.	Thank you for your comment. The committee have made this correction.
Sense	Guideline	030	General	Comment in relation to section 1.7 on Social Participation. Local Authorities should also give due regard to ensuring disabled children and young people have the opportunity to socialise with their non-disabled peers. This can help break down barriers, raise awareness and reduce levels of loneliness and social isolation amongst disabled children and young people.	Thank you for your comment. The focus of the review question and the resulting recommendations was about making social opportunities for those children and young people who are unable to access any social opportunities due to their severe complex needs. The committee have added introductory text to section 1.7 to clarify this. As such your suggested change has not been made.
Sense	Guideline	033	020	Young people and their families should also be provided with information about what happens if their education health and care plan ceases.	Thank you for your comment. The committee have added this to the recommendation.
Sense	Guideline	045	026	We welcome this recommendation. We think this recommendation should go further, and encourage professionals to also learn about the other services that children, young people and their families might be	Thank you for your comment. The committee have reworded the recommendation so it is no longer focussed just on EHC plan processes.

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				reliant on outside of the EHC needs assessment, review, and reassessment process. Children with complex disabilities rely on a multitude of different services, and having knowledge of the other services families use can help join up the experience for families, and encourage better joint working.	
Sense	Guideline	051	009	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. The committee have used the term 'communicate differently' in line with your suggestion.
Sense	Guideline	054	019	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. The committee have reworded the text to 'communicate differently'.
Sense	Guideline	057	023	Sense strongly supports this recommendation.	Thank you for your comment and support for the recommendations.
Sense	Guideline	058	010	We recommend that not only practitioners receive this training, but also any additional staff within the local authority who are responsible for administering the process.	Thank you for your comment. The use of the term 'practitioners' in this guideline encompasses staff who work for education, health and social care services. As such it would cover staff in the local authority who administer the process. However the committee have amended the third bullet to make this more explicit.
Sense	Guideline	058	016	We recommend this sentence is expanded to include a requirement that short breaks services provided by local authorities meet the needs of the local population.	Thank you for your comment. The guideline does not have a remit to change the statutory requirements for short breaks services.

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Sense	Guideline	064	001	It would also be relevant to understand how a dedicated key worker can improve the experience of families navigating the system more broadly, and whether it provides a smoother, more informed journey to accessing support, aside from just delivering joined up services.	Thank you for your comment. Service user satisfaction is one of the outcomes already suggested for this research.
Sense	Guideline	068	017	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. The committee have changed the text to 'communicate differently'.
Sense	Guideline	068	023	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. We have changed the text to 'disabilities or difficulties' as this relates to communication challenges experienced by parents.
Sense	Guideline	071	029	Change 'condition' to 'disability'.	Thank you for your comment. The committee have not made this change as they mean 'condition'.
Sense	Guideline	072	011	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. The committee have changed the text to 'communicate differently'.
Sense	Guideline	083	028	There is also quantitative Department for Education produced statistics showing that only 58% of all EHC plans are issued within the 20 week timescale. For more information see: https://explore-education-	Thank you for your comment and providing this information.

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				statistics.service.gov.uk/find-statistics/education-health-and-care-plans	
Sense	Guideline	089	021	Replace 'have other difficulties' with 'face other barriers to' – this shifts the burden away from the individual.	Thank you for your comment. The committee have made this change.
Sense	Guideline	101	001	The evidence on this is clear. Education continues until 25 whereas the transition to adult social care services happens at 18. This creates a clear tension between social care support in an EHC Plan.	Thank you for your comment. This text is describing the evidence was found about transition from children's to adult's services and the committee's deliberations on this when making recommendations.
Sense	Guideline	123	005	Replace 'communication difficulties' with 'children who face barriers to communicating' or 'children who communicate differently'. This is so that we don't frame the challenges communicating as the child's; it's important to think about how we can understand and support them to communicate better.	Thank you for your comment. This text describes the evidence and the wording used reflects that used by the evidence. Therefore the committee have not made your suggested change.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	049	024	I agree that there should be consistency and an allocated worker but if that worker was to leave, then surly the whole MDT would be also part of the contingency plan for the YP/Family/carer to contact. Don't always think having one direct person from one team works due to the pressure of sickness, annual leave anyway and puts significant pressure on that manager to fulfil their place	Thank you for your comment. The recommendation is that there needs to be a contingency plan to maintain consistency. However it is not prescriptive about what this contingency plan should be as the committee did not have any evidence about the most effective way to do this. The recommendation would not prevent the process you describe being used.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	053	001 - 006	With regards to training, is this talking about mandatory training? We struggle as a trust to engage staff with transition training due to not being mandatory or JSET (as an example)	Thank you for your comment. The guideline cannot specify what would be mandatory training as this would be different for each organisation.

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Somerset System	Guideline	General		The NICE guidelines will require commitment from all commissioners in education health and social care. They will require a huge injection of finances for all 3 parties in order to boost resources such as staff numbers, staff quality, staff training/investment and equipment to meet the needs of these children and young people.	Thank you for your comment. Where possible, the committee have acknowledged the change in practice and potential resource implications resulting from recommendations. It has to be noted that most of the recommendations reinforce current practice as outlined in the Children and Family Act 2014 and the SEND Code of Practice and should not represent practice changes and require substantial additional resources to implement. NICE will note your comment concerning the need for additional funding, but NICE does not have a remit to affect funding decisions.
Somerset System	Guideline	General		Good use of pictures to interpret the language. Friendly. Flow well through individuals experience.	Thank you for your comment and your support of the guideline
Somerset System	Guideline	003 - 005	General	Concise	Thank you for your comment.
Somerset System	Guideline	045 - 046	016	Working Culture – organising professionals from all 3 agencies into interagency teams potentially working with a geographically focused group of children with complex needs – could this be a virtual team now? How would this be funded and how would historic boundaries between the 3 agencies be removed? P.46 line 16 – noted this is birth-25 years – how does this work with paediatric health professionals who are only registered to provide health input up to 18 years?	For disabled children and young people with severe complex needs, most services already have an 'informal' interagency team around that individual. The focus of the recommendations in this section is improving relationships between team members to ensure a 'wrap round' service for children and young people that is capable of delivering person-centred care. The evidence identified did not enable the committee to make recommendations on funding arrangements and as the legislation only requires services to work together, without any mechanism to require it to happen, the guideline cannot be more specific.

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					The recommendation does not specify a particular format for interagency teams to work together, so virtual working could be a potential option.
Somerset System	Guideline	001	All	How does this guideline link in with the SEND inspection format?	Thank you for your comment. Local area SEND inspections are controlled by Government. There is no formal link to this guideline.
Somerset System	Guideline	002	General	Well structured.	Thank you for your comment.
Somerset System	Guideline	004	019	This needs to be rephrased to emphasise the weight of parental voice changes with age of child and competency e.g a parent would have more say when child is 5 than 16.	Thank you for your comment. Taking the views of parents into account is a general principle for working with children, young people and their families which applies throughout the guideline. Taking their views into account would apply even after legal responsibility ends (although it may ultimately be decided no action is taken based on these views) and so this change has not been made.
Somerset System	Guideline	005	015	1.1.5 The children and Families act 2014 states Local authority functions: supporting and involving children and young people In exercising a function under this Part in the case of a child or young person, a local authority in England must have regard to the following matters in particular— (a)the views, wishes and feelings of the child and his or her parent, or the young person; (b)the importance of the child and his or her parent, or the young person, participating as fully as possible in	Thank you for your comment. Whilst the committee agree that families may also require support they thought it was important to focus on the views of the children or young person, because these can differ from the views of their parents.

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				decisions relating to the exercise of the function concerned; (c)the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions; (d)the need to support the **child and his or her parent**, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes. This requires more than just encouragement and staff need to facilitate this. This is not adequality reflected within the guidance as it only refers to support and encouragement for children and there is no inclusion of families.	
Somerset System	Guideline	006	002	Could we include abbreviations too? Also add record this to provide consistency and tell it once approach.	Thank you for your comment. The committee are unclear of the relevance of abbreviations to the recommendation about using empathetic, supportive language when communicating with families. The committee have added a recommendation about recording and sharing the communication preferences of children and young people.
Somerset System	Guideline	006	015	If professionals are going to support children and young people to communicate their views in a way that uses AACT then this equipment will need to be provided to the individual so it can accompany the YP in all settings. Commissioners of SLT will need to be	Thank you for your comment and for highlighting this error. The committee have removed the word 'technology' from the recommendation - we meant alternative and augmentative communication. The majority of alternative and augmentative communication (AAC) for children and

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				mindful of the cost implications and ensure funding is not an issue when providing this communication technology.	young people with complex needs is already being handled by local SLT teams and the committee do not think significant investment in these services will be required to implement this recommendation.
Somerset System	Guideline	006	015	Needs to include parent and carers as practitioners need to understand how they prefer to communicate.	Thank you for your comment. Establishing the communication preferences of parents and carers is covered by different recommendations in the same section.
Somerset System	Guideline	007	General	Easy to follow links	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	007	015	Reference each area's 'Local offer' webpage as part of this bullet point.	Thank you for your comment. The committee have added the SEND Local Offer to the list of bullets
Somerset System	Guideline	007	018	Add in Parent carer forum, Healthwatch and the Local Offer to list of information that should be provided	Thank you for your comment. The committee have added the SEND Local Offer to the list of bullets. Parent/carer forums would be encompassed within the existing bullets so the committee have not named them specifically. Healthwatch would be covered by the SEND Local Offer.
Somerset System	Guideline	008 onwards		All patient centred.	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	008	009 - 025	Whilst this is good practice, if YP /families choose to have meetings outside school hours this may have an impact on the practitioners' own availability to join the meetings. May be difficult to co-ordinate representative from education, health, social care and key relevant people to these meetings.	Thank you for your comment. This recommendation is to consider the preferences of the child or young person as far as possible. It may well be the case that it is not possible to deliver their preferences because of practical reasons, but consideration should at least be given to seeing if it possible. There are also other recommendations in this section which cover what to do if practitioners cannot attend.
Somerset System	Guideline	008	009	This line assume that the chair will be a professional, in many cases the child or young person may be the best to be the chair.	Thank you for your comment. The chair needs to be someone who is experienced in the processes in order for the meeting to serve the needs of the child or young

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					person. Therefore it is most likely to be a professional undertaking this role.
Somerset System	Guideline	009	005 - 021	Really like this.	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	012	011	Really like this.	Thank you for your comment and your support.
Somerset System	Guideline	015	012	Does this need to start with the Statutory guidance from the children and families act, Section 23 notifications?	Thank you for your comment. The committee have added introductory text to this section to make this reference.
Somerset System	Guideline	016	003	Clear and concise.	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	016	012	Referral to Social Care- who would be providing this information to the family not everyone will be aware of the differences in the services provided by SC. This also links with interagency cross over training.	Thank you for your comment. Practitioners will be providing this information. The recommendations about cross-over training should ensure that practitioners are better informed about the difference between safeguarding, child protection social care, and broader family support services.
Somerset System	Guideline	017	001	Good summary	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	020	011	Should this read 6 weeks, not 16?	Thank you for your comment. No, the timeline is 16 weeks.
Somerset System	Guideline	023	001	Writing an EHCP- Section C health needs should not just be a list of diagnosis but the "needs" arising form this and how these impacts on the YP. This should be covered in any training provision.	Thank you for your comment. The committee agree that section C should be used to document needs. This is specified in the SEND code of practice and also in recommendation 1.4.9. Training on EHC plans is already covered by recommendation 1.17.11.
Somerset System	Guideline	023	003	I think this reads as though a professional in one area can make recommendations from another service, could the wording be reflective of within each professionals own scope of practice.	Thank you for your comment. The committee have made this change.

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Somerset System	Guideline	023	021	Excellent	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	030	007	Training for schools too?	Thank you for your comment. This review question focused on identifying what interventions were effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs. Training for families and carers was identified as an effective intervention. Making recommendations for training for schools would be outside the protocol for this review question.
Somerset System	Guideline	032	004	LA's are responsible for ensuring transition is on the agenda at the year 9 EHCP review – this does not happen in practice or lip service is paid to this. Often it is health professionals that ask for it to be on the agenda. How do we ensure that more than lip service is paid to transition with clear action points for all team around the YP from this point on? How do we hold each other accountable? Should a key worker/named worker be identified at this point to lead on this for each YP? There needs to be an interagency transition plan held in a portal so that all agencies can contribute to it, read each other's contributions and update it as a live document. Parents and YP should be able to access this too.	Thank you for your comment. The committee hope that the recommendations made in section 1.8, if implemented, will improve the preparation for adulthood and the process of transition. Recommendation 1.8.12 is about the role of the named worker and there are additional recommendations in the NICE guideline on transition from children's to adults' services for young people using health or social care services. The committee do not have evidence to recommend a portal to hold the interagency transition plan.
Somerset System	Guideline	032	013	New bullet point 'Provide advice and guidance should the young person be eligible for Annual Health Checks from their primary care setting'	Thank you for your comment. The review question investigated by the guideline was 'What is the impact of including education with combined health and social care support models and frameworks on transition from children's to adults' services for disabled children and young people with severe complex needs?'. Making

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					recommendations about Annual Health Checks would be outside the protocol for this review question.
Somerset System	Guideline	033	011	This needs to be as early as possible not just when they are approaching adulthood as too late. This discussion needs to start early and align with the rest of the guidance which highlights the weight of the child's voice increases over time it's not just a switch from parent to child at 16.	Thank you for your comment. The committee have added to the recommendation that this should happen as early as possible.
Somerset System	Guideline	035	011	Palliative Care-the terminology needs to be clear here that an end of life plan that has been developed means that the end of life is near. Sometimes an advanced care plan or Family wishes plan is devised many years ahead of the end of life for a child with a palliative condition – to ensure the views of the YP and family are heard in any sudden deterioration of the condition. This would not be the same as an active end of life plan which would override the need for waiting for an EHCP to be finalised etc in order to ensure the best support gets to the child immediately.	Thank you for your comment. The committee have added definitions of end of life care and palliative care to the terms used section.
Somerset System	Guideline	042		Travel training is very needed by YP with complex needs – this is a huge gap that could be filled with adequate resources to implement a travel training framework – this would improve independence and build confidence in YP and in their parents.	Thank you for your comment and support for the recommendation. As documented in the rationale and impact section 'Travel training is not consistently available in all areas, so there will be a change in practice for local authorities that do not have a training framework. However, most EHC plans will already specify a need for travel training, either because independent travel is listed as an outcome in its own right or because it is a means to achieve another outcome (for example employment).' As such there should not be a significant resource impact from this recommendation.

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Somerset System	Guideline	045	011	Clear and positive	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	047	004	'LA should adopt a key working approach' – does this imply that the keyworker should be a LA employed worker? What if the most appropriate keyworker is an NHS worker?	Thank you for your comment. In line with stakeholder feedback the committee have reduced repetition of the content of the SEND code of practice within the guideline. As such this recommendation has been deleted.
Somerset System	Guideline	048		Positive and maintains child centred approach.	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	048	010 - 011	'These practitioners have the training, time and resources needed to provide this support, taking into account their other commitments.' Historically 'key working' a case has been on top of all other commitment and usually the keyworker is assumed. How is this to be funded as key working effectively takes a lot of time for that one worker, albeit potentially saving time for the rest of the team around the YP?	Thank you for your comment. As documented in the rationale and impact section '...the recommendations on key working support are in line with the committee's understanding of what the SEND code of practice says about a key working approach, there should not be a significant resource impact.' The committee do acknowledge that services will need to make changes to enable key working approaches and that they will need to ensure caseloads are manageable and practitioners have dedicated resources to deliver effective key working.'
Somerset System	Guideline	049 onwards		Really clear positive guideline.	Thank you for your comment and support for the recommendations.
Somerset System	Guideline	051	008 - 010	Joint training from SLT re communication aids/methods with children/YP is vital if we are all to elicit their views and aspirations.	Thank you for your comment. Training in the use of communication aids for both staff, children and young people and their families is also covered in the recommendations in section 1.10. The review questions investigated by the guideline did not look at who should provide training and so the committee are not able to include this in the recommendations.
Somerset System	Guideline	051	002	Joint training across agencies to ensure all team understand about complex needs etc is the way forward. This should include mental capacity	Thank you for your comment. The areas for training covered in this recommendation were identified by the reviews of the qualitative evidence (see evidence reports

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				assessment, Community DoLs, deputyship issues for 16-17 year olds.	A, K and M). The areas you cite in your comment were not identified by the evidence and so the committee have not made this change.
Somerset System	Guideline	052	005 - 011	Cross sector placements – short term placements for practitioners to understand roles of other sectors is a really good idea but commissioners may need to consider the practical arrangements if the teams are small and impact on moving experience team members alongside the training required for new interagency team members placed on short term placements to carry out the roles. There may also have implications on targets for the agencies.	Thank you for your comment. The circumstance you describe would need to be considered and addressed by services implementing the recommendation if this circumstance applied to them. It is not possible to make recommendations for all possible eventualities.
Somerset System	Guideline	053	001 - 003	It is suggested that support workers cannot be accountable for their professional conduct as they are not professionals nor generally sit in a registration body. However the HCPs that are training those workers are accountable for delivering the evidence-based training to a high standard and are accountable in ensuring that these workers demonstrate competence during a training session. But at this point the accountability for these HCPs ends until they are back to deliver an update or review competence at a minimum of yearly intervals. The support workers are responsible for requesting extra or earlier reviews or updates in training (but are not accountable).	Thank you for your comment. In the committee's view support workers are accountable for their professional conduct to their employer, who will hold a duty of care for the child or young person. However they are not accountable as a registered healthcare professional. This is an important distinction that needs to be made as in this way they are different from parents and family members, who do not have this accountability. The committee are aware that Ofsted and the CQC are currently reviewing where the accountability sits for education staff undertaking delegated tasks.
Somerset System	Guideline	053	006 - 007	Clinical supervision for support workers is a really good point but who is going to commission and be responsible for providing ongoing 'clinical supervision'	Thank you for your comment. The guideline is not able to determine who will be responsible for providing ongoing clinical supervision for school employed workers

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				for school employed workers who are delivering health tasks – the school (as the employer)?	delivering health tasks. This will need to be determined by national policy.
Somerset System	Guideline	064	001	Research n.3 Dedicated key workers – this is a vital piece of research and should be prioritised.	Thank you for your comment. The committee agree this research is important and have therefore made it one of their 5 research priorities.
Somerset System	Guideline	065	006	Research n.6 – this should also be prioritised as research – effectiveness of joint commissioning arrangements. If there is to be such a massive shift in the way we work together to be able to meet these NICE guidelines, the commissioning arrangements will need to change first to enable the resource and culture shift	Thank you for your comment. Whilst the committee agree on the importance of commissioning arrangements enabling implementation of the guideline, they agreed that other research recommendations were higher priority.
Surrey County Council	Guideline	General	General	The document describes a welcome collective aspiration to provide better services and improve cooperation across health, education and social care, thereby securing better outcomes for children and young people with severe complex needs. The guidance reflects best practice and gives a helpful framework for services to review their current offer and make changes where appropriate, however there are subsequent resource implications.	Thank you for your comment. The committee have documented the potential resource implications of the recommendations made in the rationale and impact sections of the guideline.
Surrey County Council	Guideline	General	General	The guidelines rightly build upon the SEND code of practice and have the intention of supporting more collaborative working, however the document needs to be more explicit in understanding and addressing the different duties/responsibilities and knowledge base across the sectors to inform this collaboration and reduce differences and/or challenges by being explicit as to which sector is responsible to lead on each area of the guidance. It is important that a sense of equity	Thank you for your comment. The importance of education, health and social care services working together (for example by having joint commissioning arrangements) to ensure disabled children and young people with severe complex needs get the right support is covered in the SEND code of practice and supporting legislation. The committee understand stakeholders desire for the recommendations to be more specific about exactly which service should take the lead on

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				between health, education and social care is evident within the document to ensure any additional workload generated through this guidance is manageable and can be effectively resourced. Furthermore, where appropriate, this will need to be underpinned by joint policies and procedures, without clarity it will be challenging for these to be formulated.	implementing each recommendation. However, as the legislation and statutory guidance are not prescriptive on this, it is not possible for the guideline to be specific. However, the guideline has made recommendations in section 1.18 that aim to facilitate joint working across services.
Surrey County Council	Guideline	General	General	The lessons learnt from the COVID-19 pandemic need to be reflected in the guidance, we know that those with the most complex needs have been heavily impacted by the pandemic, in particular with increased pressures at home, and subsequently we need to maintain the positive practice that has been generated. In some cases, the use of virtual meetings has been effective in bringing the multi-agency network together and has also been better suited for families. The response to COVID also saw key agencies working together well in terms of risk assessing every child and ensuring that there was a clear safety plan in place. Subsequently, it needs to be highlighted that there are many ways to approach practice and that good practice can still be achieved using alternative methods if this meets the needs of the family and still aligns with the guidance principles. Furthermore, it is important to consider how access to support services and education could be managed should a similar situation arise and what responsibilities health, education and social care would have in these circumstances, the document must reflect key learning points to inform future practice.	Thank you for your comment. Most of the recommendations in the guideline do not specify a particular method that should be used in order to implement them. As such services have the flexibility use the method that best meets the needs of the child or young person and their families and carers. Virtual meetings have been included in the guideline recommendations, but the committee was aware that some people might not be able to afford the equipment needed to attend appointments remotely and so have only included this as an option. The guideline did not have a review question on the most effective way to access services in a pandemic and therefore the committee are not able to make recommendations in this area.

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Surrey County Council	Guideline	General	General	The guidelines do not refer to decision making extensively enough, there needs to be further clarity about involvement of parents, carers and young people within the decision-making process. Clarity is needed about circumstances where complete transparency is appropriate and when services can make decisions internally based on their discretion – this is a current tension.	Thank you for your comment. Recommendation 1.1.4 clarifies that all children and young people should be involved in discussions and decisions about their education, health and social care support. Section 1.1. includes extensive recommendations about how to achieve this in practice. The circumstances when complete transparency is appropriate or when services can make decisions internally based on their discretion will be different for different individuals. As such it is not possible to cover this in a recommendation.
Surrey County Council	Guideline	General	General	Where the document refers to inclusion of children and young people and ensuring their rights to access support, services and education are met, stronger wording is needed to emphasise that this needs to happen in all cases.	Thank you for your comment. Recommendations are only able to use the word must when there is a legal requirement so the committee are not able to make the wording stronger than it currently is.
Surrey County Council	Guideline	004	015	Guidance is required regarding keeping an appropriate balance between being child centred, but also recognising parental views and wishes for their child. Specific guidance is needed for when the views of the child or young person are directly in conflict with that of their parent/carer and how this should be approached by practitioners.	Thank you for your comment. Recommendations on what to do when the views of the child or young person differ to those of their parent/carer are included in the section on 'Decision making'.
Surrey County Council	Guideline	004	015	Additional guidance would be helpful on what process should be followed when there are disagreements between the parent/carer and partner agencies and how to approach resolution. Is there a possible role for advocacy here?	Thank you for your comment. There is a legal requirement for services to tell service users what the process is for raising complaints when there are disagreements between parent/carers and partner agencies. Therefore the committee have not included this in the recommendations.
Surrey County Council	Guideline	005	009	We agree that working closely with children and families is important and much of the practice is already undertaken in our local authority already,	Thank you for your comment. The committee have acknowledged the change in practice and potential resource implications resulting from these

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				however, the extent of engagement recommended in this guidance has resource implications for local authorities.	recommendations. Mainly that practitioners will need more time, for example for discussions with children and young people and their families and carers to get their views. However, if practitioners spend more time getting these views, families are likely to have fewer queries, complaints and problems, resulting in time savings later on, which may offset any additional practitioner time costs required to provide the recommended engagement. Also, such engagement will ultimately result in better choices, care and outcomes for disabled children and young people with severe complex needs.
Surrey County Council	Guideline	007	011	Consider adding 'expected outcomes and the impact of these outcomes'.	Thank you for your comment. The list of bullet points is based on qualitative evidence and the committee's experience about areas that children and young people and their families and carers commonly wanted more information to make more informed decisions. The committee are unsure of the relevance to outcomes in this context
Surrey County Council	Guideline	007	017	Consider adding 'local early help services as required'.	Thank you for your comment. The committee have added the SEND Local Offer to the list of bullets. Local early help services would be covered by the SEND Local Offer.
Surrey County Council	Guideline	007	022	Consider adding 'through their school or local support services'.	Thank you for your comment. The committee have not made your suggested change as they want this recommendation to be relevant to all services.
Surrey County Council	Guideline	008	004	Consider adding 'to help the young person and family to fully take part in the meeting'.	Thank you for your comment. The committee have made this change.
Surrey County Council	Guideline	008	009	A pre-meeting to arrange how to approach a meeting is good practice, however this does add an additional	Thank you for your comment. This recommendation is about practical steps to take to help children and young people participate in discussions and decisions about their

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				layer of resources requirements both in respect of time and cost.	care. The committee did not envisage that additional preparatory meetings would be needed in order to implement this recommendation.
Surrey County Council	Guideline	008	011	Consider adding 'including learning levels'.	Thank you for your comment. There are no set of learning levels that are widely accepted and so the committee have not made this change.
Surrey County Council	Guideline	009	021	Consider adding 'where a young person is unable to attend, the chair should make sure that alternative methods of communication are available e.g. a presentation prepared by the young person, a talking mat, a video or voice recording'.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which includes other accessible opportunities).
Surrey County Council	Guideline	017	011 - 014	Should this read - local authorities, health, education and care practitioners should have joint training around the need for an EHCP NA'.	Thank you for your comment. This is already covered by recommendation 1.15.20
Surrey County Council	Guideline	021	001	Reducing variability and raising the quality and effectiveness of the EHCPs is an ongoing challenge for local authorities . Consideration is needed as to whether there is a role for quality assurance regarding outcomes being identified/secured and how partner agencies co-ordinate and agree the content of an EHCP to ensure it meets need and is deliverable.	Thank you for your comment. OFSTED and the CQC undertake local area SEND inspections which would look at the quality of the EHC plans being produced by a Local Authority (including the outcomes they include). The SEND code of practice describes the need for integrated working across partner agencies. This guideline has made recommendations that should facilitate integrated working during the EHC needs assessment and plan processes. However the committee are not able to recommend either a specific mechanism for how to undertake integrated working or how this could be quality assured.

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Surrey County Council	Guideline	025	003 - 004	Is the wording here representative of the code? What if this conflicts with the child's/parents/carers wishes?	Thank you for your comment. The committee have deleted this recommendation as it is already covered by recommendation 1.3.10.
Surrey County Council	Guideline	026	001 - 003	Consider the level of support should match the needs of the child (or YP) at the time the plan is written.	Thank you for your comment. The committee have reworded the recommendation to clarify that support specified in the EHC plan should not be reduced just because children and young people show improvements in certain areas or are able to do new things. The guideline identified low-quality qualitative evidence indicating that children and young people and their families and carers were concerned that their support would be reduced if they acknowledged improvements or talked about the child or young persons' strengths in the EHC plan. The committee agreed that this can be a problem in practice and made this recommendation to prevent this from happening.
Surrey County Council	Guideline	029	012	Please provide an indication of roles and responsibilities in relation to the proposed training, it needs to be clear who this sits with.	The importance of education, health and social care services working together (for example by having joint commissioning arrangements) to ensure disabled children and young people with severe complex needs get the right support is covered in the SEND code of practice and supporting legislation. The committee understand stakeholders desire for the recommendations to be more specific about exactly which service should take the lead on implementing each recommendation. However, as the legislation and statutory guidance are not prescriptive on this, it is not possible for the guideline to be specific.
Surrey County Council	Guideline	029	020	There needs to be greater clarity about the level of training that is being suggested, in agreement that this needs to be tailored but more guidance is needed to	Thank you for your comment. The committee have amended the text to be about ensuring the training is appropriate to the needs of families, in recognition of the

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				ensure that the offer is fair and consistent across the board.	fact that some people will want more in-depth training straight away, whilst others will not. This has also been clarified in the text of the rationale and impact section.
Surrey County Council	Guideline	037	021	Agree with the principle of training being delivered to staff, families and carers. However, there needs to be clearer guidance about responsibility for delivery of such training to ensure that it is deliverable in practice. Appropriate investment and resourcing will be required to ensure appropriate joint training offers and to fill any gaps in the current offer.	Thank you for your comment. The importance of education, health and social care services working together (for example by having joint commissioning arrangements) to ensure disabled children and young people with severe complex needs get the right support is covered in the SEND code of practice and supporting legislation. The committee understand stakeholders desire for the recommendations to be more specific about exactly which service should take the lead on implementing each recommendation. However, as the legislation and statutory guidance are not prescriptive on this, it is not possible for the guideline to be specific. As documented in the rationale and impact section, providing training on communication aids might represent a change in practice for some services and practitioners may need to spend more time showing children and young people and their families and carers how to use communication aids. However training practitioners properly will ensure that the often costly equipment that has been assessed and prescribed will be used, and used correctly. It will improve outcomes, such as independence. It will also mitigate against the risk that only 1 practitioner knows how to use the equipment, so if they stop working with the child or young person, the equipment stops being used, potentially resulting in a deterioration of the child or young person's health and wellbeing. Therefore the

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					committee did not consider there would be a significant resource impact from making this recommendation. This guideline does not have a remit to make recommendations about investment in or resourcing of services.
Surrey County Council	Guideline	038	013	This needs to link closely with the National Disability Strategy.	Thank you for your comment. It is not the purpose of this guideline to be a comprehensive repository of all Government guidance that is relevant to disabled children and young people with severe complex needs. The guideline focusses on making recommendations based on the review questions that were investigated (see evidence reports for details) and the evidence identified by these review questions. As such the committee have not made your suggested change.
Surrey County Council	Guideline	040	008 - 011	Perhaps consider combining these are the responsibilities of education, health and social care rather than separate bullet points.	Thank you for your comment. There is a requirement for Education services to fulfil this recommendation and hence the recommendation can be worded more strongly. The same requirement does not exist for health and social care services.
Surrey County Council	Guideline	049	020 - 021	Should this be considered in line with express consent?	Thank you for your comment. The committee believe your comment relates to the need to obtain consent to share information before sharing it with the new area. Consent for information sharing is already covered by recommendations in section 1.1 so it has not been repeated here.
Surrey County Council	Practice Implication	061	009	It will be a challenge to ensure that all staff have the same or similar awareness and understanding of the needs of children and young people with complex needs, there will significant resourcing needs to deliver	Thank you for your comment. The text you cite is a definition for what the guideline means when it uses the term 'awareness training programmes'. The guideline makes recommendations about training for practitioners

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				this, both with cost and time, particularly in roles that are not frontline.	and also documents the potential change in practice and resource implications of making these recommendations.
Surrey County Council	Practice Implication	133	025	There will need to be a close working relationship with commissioning services to ensure that these guidelines can be effectively delivered, to ensure that there are sufficient resources and choices available in order to meet the needs of the child or young person e.g. short breaks, PAs, community resources. This relationship should be referred to with more strength in the document.	Thank you for your comment. The guideline does not have a remit to make recommendations about provision of resources or what specific services should be available. Therefore the committee have not made the change you suggest.
Surrey County Council	Practice Implication	134	030	A possible barrier to ensuring that needs are effectively met for children and young people with complex needs is creating pathways that limit potential of children and young people not receiving support to meet their needs, this will require combining and, in some instances, reviewing eligibility criteria to ensure that services can be accessed appropriately.	Thank you for your comment. This will be a matter for implementation of the guideline.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	General	General	The Rational and Impact section of the guideline acknowledges that not all children/young people will have a diagnosis, and that this should not be a barrier to care. Where diagnosis is mentioned in the recommendations, it would be helpful to reinforce that care should be planned around needs rather than diagnosis.	Thank you for your comment. Recommendation 1.17.3 clarifies that access to services should not be restricted based solely on whether or not someone has a diagnosis.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	General	General	We would suggest including some guidance to support children and young people with special educational needs who are not currently in education but wish to return. With no school involved the family may have difficulty finding someone to advocate for them.	Thank you for your comment. If a child who holds an EHC plan is no longer in education, then unless their plan is ceased by the local authority it has a duty to ensure that it is fulfilled. If a child who is not in school appears to have special educational needs, under the SEND Code of Practice the parent is entitled to request an assessment

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					from the local authority, who must follow statutory processes when deciding whether or not such an assessment is required. If the child is not on the roll of a school, and a school is not named on the EHC plan, then school staff will not be able to advocate for that child, but in both circumstances the parent is eligible to independently access the SENDIAS services commissioned by the local authority. Therefore the committee have not included this in the recommendations.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	005	005 - 014	We suggest adding that staff should check that it is in the child or young person's best interests to work with identified family members.	Thank you for your comment. This is already encompassed by the current wording of the recommendation so the committee have not made a change.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	005	015 - 022	In addition to encouraging children, young people and their families to share their views and regularly checking they are satisfied, we suggest measuring satisfaction and making arrangements for this information to be fed back for quality assurance.	Thank you for your comment. The recommendation about regularly checking about satisfaction implies that this information will be fed back. Therefore it can be used for quality assurance. However the committee do not think this needs to be specified in a recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	006	002 - 021	We suggest adding further detail on ensuring any information provided is accessible for family members/carers who might need support with language or understanding.	Thank you for a comment. The committee have added a recommendation on this issue.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	007	019 - 025	We suggest adding recommendations to signpost children/young people, and parents/carers with learning difficulties, to advocacy services. Note that service users/carers who require advocacy services	Thank you for your comment. The focus of this recommendation is to ensure that SENDIAS services help children, young people and their families and carers to understand what support is available to them. What those support needs are will be specific to the individuals

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				often have to meet a set of criteria before they can be referred; change is needed to reduce barriers.	concerned - they may require advocacy services but they may not. Therefore the committee have not added this to the recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	007	002	We suggest clarifying what constitutes 'up-to-date' information by adding timescales.	Thank you for your comment. It is not possible to include timescales as these would vary depending on the specific information being cited.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	007	019	We suggest adding a recommendation to consider mental capacity assessment.	Thank you for your comment. The focus of this recommendation is to ensure that SENDIAS services help children, young people and their families and carers to understand what support is available to them. What those support needs are will be specific to the individuals concerned - they may require mental capacity assessment but they may not. Therefore the committee have not added this to the recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	007	023	We note that the term 'expectations' instead of 'needs' may suggest the two don't go hand in hand. We suggest using the latter term.	Thank you for your comment. The focus of this recommendation is about finding out what people's expectations are, which can be different to their needs. Therefore the committee have not made your suggested change.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	008	002 - 015	We suggest adding a recommendation to ensure meetings are physically and financially accessible to the family.	Thank you for your comment. The committee have made this change.
Tees, Esk and Wear Valleys NHS	Guideline	009	005 - 016	We suggest adding a recommendation to hold a pre-planning meeting with the child/young person to give them an opportunity to see the meeting room and decide where they would like to sit (including their	Thank you for your comment. The committee have added consideration of giving children and young people an opportunity to see the meeting room and decide where they would like to sit.

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Foundation Trust				position in relation to other attendees, particularly for children and young people who may struggle with direct eye contact when placed opposite someone at a conference table).	
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	009	005 - 016	We suggest allowing the child to be the first person to enter the room at the meeting with other participants joining them, rather than the child/young person having them join a room full of people.	Thank you for your comment. The committee have added consideration of making adjustments to the meeting format and schedule, which would encompass the issue you mention.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	009	005 - 016	We note it is best practice to support the child/young person to attend the meeting but also suggest emphasising the child's choice to go to the meeting or not. Staff should ascertain the child/young person's views about attending and consider the possibility of an advocate attending on their behalf.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involve attending meetings).
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	010	013 - 020	We suggest adding timescales to actions.	Thank you for your comment. The committee would expect that timescales for completion would form part of a standard action log and therefore does not need to be specified here.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	010	004 - 006	We suggest adding reference to WRAP (Wellness and Recovery Action Plan).	Thank you for your comment. The committee were not aware of the tool that you cite and so have not included it in the recommendation.
Tees, Esk and Wear Valleys NHS	Guideline	011	003 - 009	We suggest recording in the minutes why a meeting has gone ahead without a key practitioner.	Thank you for your comment. The recommendations cover what to do if a relevant practitioner cannot attend a meeting. This includes sending a briefed delegate or a

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Foundation Trust					written update which should mitigate the risk of the meeting going ahead without that person attending. Decisions can be made locally about whether or not the reasons for a meeting going ahead should be recorded but the committee do not think this needs to be specified in the recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	012	011 - 013	Where the child/young person and their family hold different views, it may be appropriate to appoint two professionals: one to work with the child/young person and one to work with their parents.	Thank you for your comment. The committee are not able to be prescriptive about how this should be done, but the approach you describe could be one option.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	013	004 - 008	We suggest adding further detail to direct readers to best interest processes and the need to identify an Independent Mental Capacity Advocate (IMCA).	Thank you for your comment. This information would be covered by the Mental Capacity Act (2005) which is cross referenced in the recommendation. The committee therefore do not think it is necessary to include this detail here.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	014	008 - 010	We suggest reducing the review period from annually to 6 monthly because a great deal can change in a child/young person's life in a year. Consent is valid for one issue at one time and may need to be reviewed at different intervals for different issues. It may be appropriate to review at transition points and significant life events.	Thank you for your comment. The committee think that annual review is the most practical to implement but the wording 'at least annually' allows flexibility for this to happen more frequently if needed (for example at transition points and significant life events). Reviewing consent at different intervals for different issues would not be prevented by this recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	014	016 - 018	We suggest adding that, in the majority of cases, professionals will gain the child or young person's permission before undertaking a child in need assessment but there are exceptions where permission is not required.	Thank you for your comment. The third bullet of this recommendation refers to getting consent before involving other services.

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Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	014	008	We suggest considering risk and safeguarding issues as part of the review of information sharing preferences.	Thank you for your comment. This recommendation was based on qualitative evidence that services do not always share information with each other, and when they do share it is not always done well because they do not understand what other services need to know. The evidence also showed that children and young people and their families and carers have to repeat the same information to different services, and find this exhausting and difficult (particularly when repeating sensitive or distressing information). Therefore the recommendations focus on how to improve information sharing and so the committee have not made the change you suggest.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	015	013 - 021	We suggest including consent.	Thank you for your comment. Getting consent is already covered in recommendation 1.2.5
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	015	018 - 019	We suggest making reference to both mental health and physical health services. Education staff may need further support/guidance on where to refer. For example, they may be unsure whether to refer a child with a neurodevelopmental problem to Paediatrics or CAMHS (Child and Adolescent Mental Health Services).	Thank you for your comment. 'Health' includes both physical and mental health so the committee think that the current wording is appropriate. If Education staff are unsure where to refer they would approach the child or young person's GP.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	018	004 - 005	We suggest adding that information should be provided in an accessible format.	Thank you for your comment. The committee have amended this recommendation so it is now about signposting people to SENDIAS services for information on the criteria for funding and support. Therefore it would no longer be appropriate to make the change you have suggested.

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	021	002 - 013	We suggest adapting recommendations on outcomes to take account of children and young people whose condition is terminal. Setting targets in this context is difficult for parents and more flexibility, compassion and sensitivity is needed.	Thank you for your comment. The committee have added 'flexibility' to recommendation 1.9.5 which already indicates that priorities might need to be different (for everyone not just those who are terminal).
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	025	012 - 016	We suggest adding that a re-assessment should be provided if the child/young person or family request it.	Thank you for your comment. The committee have clarified that this is a professional assessment not an EHC plan re-assessment. Therefore your suggested change has not been made.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	029	012 - 013	We agree that collaboration between education, health and social care services would be ideal. Working collaborative with other services to provide training is likely to be challenging; it would be helpful to clarify who should coordinate the work (possibly a lead from the Local Authority).	Thank you for your comment. Who would need to lead the joint development of training would depend on what the training covered. It is not possible to specify this in a recommendation.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	045	011 - 019	We would suggest adding that education, health and social care practitioners need to understand each other's individual and unique roles and organisations.	Thank you for your comment. The committee have reworded the recommendation so it is no longer focussed just on EHC plan processes.
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	046	010 - 016	We fully support interagency working to wrap around the child/young person and wonder if we need to share budgets to facilitate this.	Thank you for your comment. For disabled children and young people with severe complex needs, most services already have an 'informal' interagency team around that individual. The focus of the recommendations in this section is improving relationships between team members to ensure a 'wrap round' service for children and young people that is capable of delivering person-centred care. The evidence identified did not enable the committee to

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					make recommendations on funding arrangements and as the legislation only requires services to work together, without any mechanism to require it to happen, the guideline cannot be more specific.
The Challenging Behaviour Foundation	Guideline	General	General	**Understanding challenging behaviour**. Currently the guidance makes no reference to understanding behaviour as communication of an unmet need or the importance of this in providing appropriate care and support for disabled children. Children and young people with severe learning disabilities might display behaviour that can be described as challenging in order to get their needs met. Without the appropriate support including preventative approaches and positive behaviour support, children and young people whose behaviour challenges are at increased risk of restrictive interventions, reaching crisis and inappropriate admission to inpatient services. At the end of June 2021, NHS digital data shows that 210 under 18s were detained in inpatient hospitals. Children and young people with learning disabilities whose behaviour is described as challenging often receive (or are in need of) services from across health, education and social care. The Lenehan Review (2017) of the experiences and outcomes of children and young people in residential	Thank you for your comment and providing this information about understanding challenging behaviour. The recommendations in this guideline focus on providing support to meet the needs of all disabled children and young people with severe complex needs, which would include those with behaviour that challenges. Under the section 'Finding more information and committee details' there is a link to related NICE guidance. This includes NG11 (Challenging behaviour and learning disabilities)

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				special schools and colleges found that there are around 6,000 children and young people educated in 334 residential special schools and colleges at an estimated cost of £500m per annum. The review concluded that "Many of the children and young people currently in residential special schools and colleges could be educated in their local communities if better support was available." Further information can be found here: These are our children: a review by Dame Christine Lenehan (publishing.service.gov.uk). In the least, this guidance must reference relevant NICE challenging behaviour guidance throughout in order that integrated service delivery is promoted to better meet the needs of children and young people with learning disabilities whose behaviour challenges: Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE	
The Challenging Behaviour Foundation	Guideline	General	General	Throughout the guidance there is reference to tasks and procedures education, health and social care practitioners should follow. We fully support joint working across sectors, but greater specificity is needed to avoid each party thinking 'someone else will do it'. If practitioners from education, health and social	Thank you for your comment. The importance of education, health and social care services working together (for example by having joint commissioning arrangements) to ensure disabled children and young people with severe complex needs get the right support is covered in the SEND code of practice and supporting

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				care all need to carry out a task, this should be strengthened in the guidance e.g. 'must' rather than 'should'. Our recent report 'Broken: the psychological trauma suffered by children and adults with a learning disability and/ or autism and the support required' Broken CBF final report (challengingbehaviour.org.uk) highlights how the failure of education, social care and health services to meet the needs of children with learning disabilities and autism leaves family carers traumatised.	legislation. The committee understand stakeholders desire for the recommendations to be more specific about exactly which service should take the lead on implementing each recommendation. However, as the legislation and statutory guidance are not prescriptive on this, it is not possible for the guideline to be specific. In addition, recommendations are only able to use the word must when there is a legal requirement so the committee have not made this suggested change.
The Challenging Behaviour Foundation	Guideline	005	002	Individuals who can't participate in discussions or attend meetings must still have their views and experiences taken into account. See the Challenging Behaviour Foundation website for more information about seeking the views of children and young people with learning disabilities and complex communication needs: Seldom Heard - Challenging Behaviour Foundation	Thank you for your comment and providing a link to your website. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual. Recommendations about establishing the communication preferences of children and young people and using these are covered in the sections on 'Communication formats and providing information' and 'Planning and running meetings with children and young people'. The committee have also added a new recommendation about taking into account the views of those who know the child or young person well in the section on 'Principles for working with children and young people and their families'
The Challenging	Guideline	005	017	See the Challenging Behaviour Foundation website for more information about seeking the views of children	Thank you for your comment and providing this information.

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Behaviour Foundation				and young people with learning disabilities and complex communication needs: Seldom Heard - Challenging Behaviour Foundation	
The Challenging Behaviour Foundation	Guideline	006	015	Education, health and social care practitioners/ professionals must work with families as well as directly with children and young people to understand their views and experiences.	Thank you for your comment. Establishing the communication preferences of parents and carers is covered by different recommendations in the same section.
The Challenging Behaviour Foundation	Guideline	007	005	Add to this list the support and services they have a right to receive including what the options are (not just what is available/ cheapest in the local area)	Thank you for your comment. The committee have added entitlements within the education, health and social care system to the list of information that should be provided.
The Challenging Behaviour Foundation	Guideline	007	022	If expectations cannot be met, explain why this is currently and consider options for ways they could be met going forward in the future.	Thank you for your comment. The committee have added exploring alternatives to the recommendations if expectations cannot be met.
The Challenging Behaviour Foundation	Guideline	007	024	Add reference to the NICE challenging behaviour guidance and emphasise importance of understanding behaviour as a form of communication. Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE	Thank you for your comment. Under the section 'Finding more information and committee details' there is a link to related NICE guidance. This includes NG11 (Challenging behaviour and learning disabilities).
The Challenging Behaviour Foundation	Guideline	009	017	One to one meetings / interactions might also be valuable if the child or young person is non-verbal or has complex communication needs.	Thank you for your comment. This is just one example of when a one-to-one meeting might be useful. It is not intended to be an exhaustive list.

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The Challenging Behaviour Foundation	Guideline	009	021	If family carers are required to attend, ensure care costs are covered	Thank you for your comment. It is not within our remit to make recommendations about what costs are covered or not covered.
The Challenging Behaviour Foundation	Guideline	011	018	The guidance needs to emphasise that if it is not possible for the individual to attend a meeting (as is the case for many children with severe learning disabilities whose behaviour challenges) they should not be excluded from discussions and decisions and reasonable adjustments must be made to include their views in other ways.	Thank you for your comment. The committee have amended the recommendations in the section on 'Involving children and young people and their families' to clarify that children and young people should be involved in discussions and decisions about their education, health and social care support and that their input needs to be obtained in the way that is most effective for the individual (which may or may not involve attending meetings).
The Challenging Behaviour Foundation	Guideline	012	011	Add and Mental Capacity Act 2005 for young people aged 16 years and over.	Thank you for your comment. The committee have cross referenced the Mental Capacity Act in recommendation 1.1.50 (where the young person may lack capacity). It would not be appropriate to include it in this recommendation because there is not a capacity issue.
The Challenging Behaviour Foundation	Guideline	012	011	Parents/ family carers can be valuable communication partners and key to gathering the views and experiences of children and young people who are non-verbal or have limited verbal communication. Excluding family members might not always be productive and therefore this should be carefully considered and context dependent.	Thank you for your comment. The committee have added to the recommendation to support the child and parent to understand each other's perspective and attempt to get a positive outcome.
The Challenging Behaviour Foundation	Guideline	014	003	Add ensure family carers have access to all agreed information. Where appropriate ensure information is shared with Deputies and Lasting Power of Attorneys as required by the Mental Capacity Act 2005	Thank you for your comment. Recommendation 1.1.52 covers asking parents what information they want to share. The onus would be on parents to share the information that they want to with family carers. Legal duties to ensure information is shared with Deputies and Lasting Power of Attorneys would be covered by local

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					policies and do not need to be included in these recommendations.
The Challenging Behaviour Foundation	Guideline	015	003	In addition to voluntary services, professionals must explain what statutory services the family and child or young person can expect.	Thank you for your comment. The committee have added signposting to the SEND Local Offer to the recommendation which would encompass providing information about statutory entitlements and voluntary organisations.
The Challenging Behaviour Foundation	Guideline	016	017	This is very important. Families of individuals with severe learning disabilities and challenging behaviour have often had negative prior experiences of social care support. Our survey of over 200 family carers with relatives with learning disabilities and autism found that the failure of education, health and social care systems and professional bodies to meet the needs of children and adults with learning disabilities and autism is traumatising family carers. See the full report 'Broken: the psychological trauma suffered by children and adults with a learning disability and/ or autism and the support required' Broken CBF final report (challengingbehaviour.org.uk)	Thank you for your comment and providing this information.
The Challenging Behaviour Foundation	Guideline	017	007	Add to this list what the EHC assessment involves and what the outcomes might be	Thank you for your comment. The committee have added what the EHC needs assessment involves to the bullet points. Potential outcomes of the needs assessment have been added to recommendation 1.3.5.
The Challenging Behaviour Foundation	Guideline	017	017	Add to this list how the child or young person's preferences or views will be incorporated, and what the process for challenge is if the child or young person or their family is not happy with the outcome.	Thank you for your comment. The committee have added how the child or young person's views will be incorporated to the bullets. They have also added what will happen if an EHC plan is not issued to the list of things that should be explained - this would encompass the process for challenge.

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The Challenging Behaviour Foundation	Guideline	028	020	We support this, but in addition professionals should ask families and carers what support they would find beneficial, and consider how to provide this if not already available.	Thank you for your comment. Whilst some families may be well informed about available support options and able to tell practitioners what they would find beneficial, this will not be the case for everyone. Therefore the committee have not made your suggested change, but the current wording of the recommendation would not prevent this from happening.
The Challenging Behaviour Foundation	Guideline	029	006	This information needs to cover both emotional and practical support.	Thank you for your comment. The committee have made this change.
The Challenging Behaviour Foundation	Guideline	029	014	Add understanding challenging behaviour and positive behaviour support to this list.	Thank you for your comment. This would be encompassed by the first bullet ('help them to understand and meet their child's needs').
The Challenging Behaviour Foundation	Guideline	030	012	At the same time as evaluating training, it is important to provide a follow up opportunity for families to ask questions and review progress since the initial training.	Thank you for your comment. The committee have added these concepts to the recommendation.
The Challenging Behaviour Foundation	Guideline	031	007	We support these points, but it should be emphasised that transport/ access issues must not be a barrier to accessing short breaks services.	Thank you for your comment. There are existing policies in place about support for transport - this is not something the guideline has a remit to make recommendations on.
The Challenging Behaviour Foundation	Guideline	032	018	Education, health and social care services should work with the young person **and their family.**	Thank you for your comment. The committee have added family and carers to the recommendation.
The Challenging	Guideline	033	011	This should specify when young people are approaching 16 years of age to reflect the age at which the legal framework around decision for making for	Thank you for your comment. The committee have added a bullet point about how parents can register to act as deputy for their child.

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Behaviour Foundation				those children and young people who lack capacity to make specific decisions is introduced. This list should be expanded to include explaining to parents how they can remain involved in their child's care if they wish to do so (e.g. inputting to best interests' decision making and deputyship), and how their child's rights will continue to be upheld (e.g. access to advocacy) when the level of parental involvement or decision making changes.	
The Challenging Behaviour Foundation	Guideline	033	015	In addition, the named worker must make sure that the individual and their family know who the new named person in adult services is, and ensure they have all the necessary contact details.	Thank you for your comment. The committee have added this to the recommendation.
The Challenging Behaviour Foundation	Guideline	037	021	If the communication aid is being used at home (or even if not) family carers should have access to the same level of training/ information as professionals	Thank you for your comment. The committee have reflected the need for this in the recommendations.
The Challenging Behaviour Foundation	Guideline	045	021	This paragraph needs to be strengthened to emphasise that family carers must be involved in handovers between key practitioners, rather than just informed of the change after it has happened. Involvement might include helping to share key information about the child or young person's history.	Thank you for your comment. The committee have amended the recommendation to include updating any new practitioners on the child or young person's history, which would encompass carers. NICE recommendations are only able to use the word 'must' if there is a legal requirement.
The Challenging Behaviour Foundation	Guideline	048	005	Peer support for family carers should be added to this list. This could be delivered alongside keyworker support or as a step down after keyworker input.	Thank you for your comment. This recommendation is about things to consider when deciding what level of key working support is needed. As such it would not be appropriate to recommend peer support for family carers.
The Challenging	Guideline	054	016	Further detail is needed about interagency teams. This should include leadership of the teams e.g. is it one	Thank you for your comment. For disabled children and young people with severe complex needs, most services

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Behaviour Foundation				person from one of the education, health or social care? Or are they jointly led? What funding and resources do they have access to? Interagency teams would also benefit from a family carer perspective, alongside education, health and social care.	already have an 'informal' interagency team around that individual. The focus of the recommendations in section 1.16 is improving relationships between team members to ensure a 'wrap round' service for children and young people that is capable of delivering person-centred care. The evidence identified did not enable the committee to make recommendations on who should have lead responsibility or the format and structure of teams and as the legislation only requires services to work together, without any mechanism to require it to happen, the guideline cannot be more specific. As the recommendations about interagency teams are formalising existing informal arrangements there should not be any additional funding required.
The Challenging Behaviour Foundation	Guideline	056	003	If existing local options are exhausted, then long distance placement should only be short term while services/ support close to home is developed. See Building The Right Support (2015) [ld-nat-imp-plan-oct15.pdf (england.nhs.uk)](ld-nat-imp-plan-oct15.pdf)	Thank you for your comment. The committee do not have evidence to support making the suggested change. In the committee's experience, it is not always in the child or young persons best interests to bring them home from long-distance placements as these placements may be able to provide the most effective support. Further research in this area has been recommended to inform future updates of the guideline.
The Challenging Behaviour Foundation	Guideline	057	005	Consulting children and young people who are non-verbal or have limited verbal communication may require using alternative methods of communication e.g. Talking Mats or Makaton signing. See the Seldom Heard page on the CBF website to find out more about hearing the views of children and young people with	Thank you for your comment. The committee agree that getting the views of children and young people who communicate differently may require using alternative communication methods and may take time. Recommendations on this are made in section 1.1. of the guideline. However the committee still considered it important to engage and consult with them.

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				complex communication challenges: Seldom Heard - Challenging Behaviour Foundation	
The Challenging Behaviour Foundation	Guideline	059	001	The Local Offer must be well advertised, and families must know it exists. It needs to continually be kept up to date and services/ support on the offer need to be accessible/ available.	Thank you for your comment. The issues you raise are covered by the content of the SEND code of practice. In line with stakeholder feedback the committee have removed duplication of the code of practice from the recommendations. So the committee have not made your suggested change.
The Challenging Behaviour Foundation	Guideline	059	015	It is essential to make sure the opportunity to give feedback includes children and young people with severe learning disabilities with limited verbal communication	Thank you for your comment. The committee have amended the recommendation to state '...all children…' in recognition of your point.
The Challenging Behaviour Foundation	Rationale and Impact	077	006	Access to good quality behaviour support plans is very important for a significant number of children and young people in this group, in particular those with severe learning disabilities whose behaviour challenges. Understanding behaviour as communication of an unmet need is essential to providing appropriate support to children and young people. Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE	Thank you for your comment and providing this information
The Children's Trust	Comments form	Q1	Q1	Recommendations on working culture, training, service organisation, integration and commissioning. Defining the training and knowledge translation about different	Thank you for your comment. The committee agree that currently practice is variable in the outlined areas and this is acknowledged in the guideline. The committee have

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				team member's roles, outside of role specialities. Benefits from children and families, however cultural shift required to consider role boundaries in order to reduce the number of professionals for families. Providing the time and commitment for interagency team building and conflict resolution.	passed your comment onto the NICE team, which plan implementation support.
The Children's Trust	Comments form	Q2	Q2	Key worker support, if this was a defined role outside of the interagency team	Thank you for your comment. The guideline is recommending a key working approach that is carried out by existing practitioners as part of their core duties, rather than a defined role. However, the committee have acknowledged that services may need to make changes to enable key working approaches, e.g. to ensure caseloads are manageable and practitioners have dedicated resources to deliver effective key working. The committee have passed your comment onto the NICE team, which plan implementation support.
The Children's Trust	Comments form	Q3	Q3	Defined training packages, examples of good practice, to avoid local duplication and time enable time efficiency	Thank you for your views and for providing the committee with some ideas. It is encouraging to see that the guideline makes a number of recommendations on training, e.g. packages aimed at practitioners, and parents and carers. A number of the committee's recommendations aim to remove duplication, e.g. collaborative approach to parent and carer training, interagency training for practitioners in other services on their roles and responsibilities, training on EHC needs assessment. Also, efficiency gains are inherent to joined-up and coordinated working, which underpins this guideline.

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The Children's Trust	Comments form	Q4	Q4	Increased waiting list times for NHS services e.g. advice and provision from AAC hubs, specialist centres and access to community therapies	Thank you for sharing your views with us. Your identified issues may impact the implementation of the guidance. As a result, the committee have passed your comment onto the NICE team, which plan implementation support.
The Children's Trust	General	General	General	Assistive Technology is mentioned under *communication aids* but not under any other heading, although is implicit under *environmental adaptations*. Assistive Technology is very often used in this population to support their access to education, leisure and activities of daily living; and is a vital part of their daily participation and inclusion.	Thank you for your comment. The recommendations on assistive technology were placed in the section on Communication Aids because the committee thought this is where readers of the guideline would go to to find this information. Placing them in this section was not intended to mean that they are not relevant to other aspects of the child or young person's daily life.
The Children's Trust	General	General	General	Some of the things we are recommending in the DCP report published today are that a whole family approach should be taken to assessments, including siblings and the provision of short breaks. Support for families should include education, health (including mental health) therapies and equipment. Also that children's needs are reassessed in the light of missed support during the pandemic.	Thank you for your comment. Information related to family dynamics would not be relevant to EHC needs assessment for all children and young people. In those instances where family dynamics would have an impact on care, this would be covered by the interim assessments that feed into the EHC needs assessment. Therefore the committee have not recommended a whole family approach to assessment. Support needs would depend on individual circumstances and therefore the guideline is not able to specify what support needs are in a recommendation. The guideline contains recommendations about re-assessing in light of changing needs or circumstances. These would apply to those who have missed support during the pandemic.
The Children's Trust	Guideline	005	016	Agree with giving views, would also like to add views on 'health'	Thank you for your comment. The committee have made this change.

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The Children's Trust	Guideline	007	024	There is national accreditation for communication accessible UK (CAUK) which would be beneficial for services to complete free training resources (individual or organisation)	Thank you for your comment. The committee are not able to endorse any specific training courses in the recommendations.
The Children's Trust	Guideline	007	024	Education, health and social care services need to ensure that a young person's communication system captures equity, diversity and inclusion information relevant to young person	Thank you for your comment. The committee have changed recommendation 1.1.17 to reflect this.
The Children's Trust	Guideline	010	001	Would it be useful to include the role of a lead professional or coordinator to support preparation for the meeting and identified chair?	Thank you for your comment. Lead professional/co-ordinator roles do not exist in all areas. The committee do not have enough evidence of effectiveness and cost-effectiveness to support recommending this role is developed.
The Children's Trust	Guideline	011	018	Should there be a hyperlink definition to multidisciplinary to distinguish the different with interagency?	Thank you for your comment. The committee have removed reference to multidisciplinary and interagency teams and changed this to 'practitioner led' review meetings - as that is the intended focus of this recommendation.
The Children's Trust	Guideline	012	005	Include 'shared' decisions	Thank you for your comment. The committee have made this change.
The Children's Trust	Guideline	019	008	Some practitioners offering advice may be part of the existing interagency team	Thank you for your comment. It would be expected that practitioners in the interagency team would have the opportunity to input their knowledge of the child or young person's needs into the EHC needs assessment process. This recommendation is aimed at ensuring that those practitioners who are not part of the interagency team, but still have information about the child or young person's needs, are able to contribute this.

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The Children's Trust	Guideline	021	004	Include 'aspirations'	Thank you for your comment. The committee have made this change.
The Children's Trust	Guideline	037	002	Families and the individual should be involved in the AAC assessment process	Thank you for your comment. The committee have added to the recommendation that the child or young person and their families and carers should be involved in the assessment process.
The Children's Trust	Guideline	037	002	AAC solutions should provide space for the child's language to grow and develop and for the possibility of spontaneous novel utterance generation	Thank you for your comment. The review question investigated by the guideline was 'What are the most effective practices (for example, environmental assessments and use of equipment such as assistive technology across different contexts) to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education?'. As such the committee have not looked at evidence for what outcomes AAC solutions should achieve and are not able to make recommendations on this.
The Children's Trust	Guideline	037	006	If a child or young person is using primarily a powered system, they should be provided a paper-based system for situations where the high-tech version is not appropriate, or when the technology breaks down	Thank you for your comment. The committee have added this to recommendation 1.10.2.
The Children's Trust	Guideline	037	009	Education, health and social care services need to ensure that a young person's communication aid is reviewed regularly to meet their changing language, physical and environmental needs	Thank you for your comment. The committee have added another bullet about reviewing the communication aid to ensure it continues to meet the changing needs of the child or young person.
The Children's Trust	Guideline	037	012	Many children and young people do not meet criteria for NHS England hubs. This is covered by some local NHS community speech & language therapy services, but not all, depending on CCG priorities.	Thank you for your comment. There is existing guidance for commissioning AAC services and equipment which identifies the need for local NHS areas to commission local AAC services. The guideline does not have a remit

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					to specify what the priorities should be for individual CCGs.
The Children's Trust	Guideline	038	010	Signposting is required to voluntary sector or other routes for assessment as many children and young people do not meet criteria for NHS England hubs. This is covered by some local NHS community speech & language therapy services, but not all, depending on CCG priorities.	Thank you for your comment. Commissioners have a responsibility to commission services that meet the needs of their population. If that population have communication needs then they should commission these services. These services might not be always be called 'local AAC services', for example they could be being provided by community SLT services. However in the committee's view the services are being provided.
The Children's Trust	Guideline	038	017	Repairing	Thank you for your comment. The committee have added this to the recommendation.
The Children's Trust	Guideline	039	005	There is a large amount of smart home technologies that are available from mainstream shopping sources and are increasingly being used in advance of an ECS referral. These are valid and functional approaches that can overcome many barriers but may still require support, or at least a mention.	Thank you for your comment. The committee did not find any evidence to support making a recommendation about smart home technologies.
The Children's Trust	Guideline	051	011	Could include hyperlink to training suggestions, otherwise this is non-specific, for example CAUK training link	Thank you for your comment. The guideline has not critically appraised any specific training courses and so it is not possible to hyperlink to them.
The Children's Trust	Guideline	052	011	Include Health Care Professional Council	Thank you for your comment. The committee were unclear of the relevance of the HCPC to this recommendation. The intention of the recommendation is to observe not participate so practitioners would not be asked to work outside their professional responsibilities. The committee have amended the text to make the observational nature of this placement clear.

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The Children's Trust	Guideline	052	018	Include Health Care Professional Council	Thank you for your comment. The committee have made this change.
The Children's Trust	Guideline	052	019	Correct title is 'allied health professionals' not 'allied to medicine'	Thank you for your comment. The committee have reworded this recommendation such that the text you cite no longer exists.
The Children's Trust	Guideline	053	012	Allied health professionals	Thank you for your comment. This text has been removed during rewording of the recommendation.
The Children's Trust	Guideline	053	029	Allied health professionals	Thank you for your comment. This text has been removed during rewording of the recommendation.
The Children's Trust	Guideline	104	023	The rationale given for the committee's recommendations is based on study described here as "assistive technology" rather than specific to AAC, which includes paper-based alternatives that do not usually fall under the assistive technology banner. There are plenty of studies that have explored the benefits of AAC (including paper-based AAC) which we would not describe as "very-low-quality", although do understand that NICE may have different requirements for inclusion.	Thank you for your comment. The guideline searched for evidence about any practices to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education . This was not restricted to high-tech assistive technology and any relevant studies of paper-based alternative augmentative communication (AAC) would have been included if they were in our population of interest and used comparative study designs. One of the included studies (Desideri 2016) evaluated an assistive technology assessment which included various approaches including: information communication technology (ICT) devices and toys, educational software and AAC aids.
The Down's Syndrome Association	Guideline	General	General	Overall, the principles included in the guidance are those that we would fully support i.e. those around consultation, accessibility, partnership, decision	Thank you for your comment and support for the guideline. The recommendations in the guideline are intended to apply to disabled children and young people with severe complex needs across all the age range

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				making and information sharing. We would expect these to be embedded in everyday practice. The definition that is being used of severe complex needs is wide in terms of who it encompasses, including the age range, but it may have been sensible to order information according to age categories, as well as complexity of need. We especially welcome the guidance extending to age 25, however, it is our experience that families often experience a significant transition at age 18 (sometime beginning at 16+), as children's services move into adulthood. Many families describe this as "falling off the end of cliff", where the coordination role of a paediatrician ceases and they are transferred to adult speciality teams and the coordination role is transferred to their GP, who is sometimes ill prepared to meet the needs of someone who has a learning disability. As is widely acknowledged, there is frequently an artificial divide between what is a health need and what is a social-care need. We need a joined-up National Health and Social Care Service, where both seamlessly work together. We are hopeful that the long-awaited reform of social care will address some of these enduring problems, but would comment that without this, much of the ambitions of this guidance will be unobtainable.	encompassed by the scope, unless specified otherwise (for example those considering employment, those where palliative or end of life care is needed). As such it was not possible to structure the guideline according to age categories. The committee were aware of the issues around transition between children's and adult services and therefore the guideline looked at this. Section 1.8 makes recommendations which the committee hope will make the process more streamlined and co-ordinated. The committee note your comments about a reform of social care being needed in order to implement the recommendations in this guideline. NICE guidelines are not able to influence such reforms. However the committee have made recommendations that encourage integrated working between education, health and social care and give guidance on how this could happen. The importance of education, health and social care services working together (for example by having joint commissioning arrangements) to ensure disabled children and young people with severe complex needs get the right support is covered in the SEND code of practice and supporting legislation. The committee understand stakeholders desire for the recommendations to be more specific about exactly which service should take the lead on implementing each recommendation. However, as the legislation and statutory guidance are not prescriptive on

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				In some parts of the guidance, it is unclear as to who takes responsibility for implementing parts of the guidelines. It would benefit if this was expressed with greater clarity (see further comments in this response). The aims and scope of the document is very ambitious in places (e.g. availability of training, resources and professionals). We are concerned that this may be impractical / unrealistic to implement, when considering the pressures many services are under. We feel the order of the document should be changed with the definition of severe complex needs placed at the beginning along with reversing the order of sections 1.1 and 1.2. We would suggest that some of the key points that are relevant across disciplines should be selected and placed at the beginning of the document, thereby reducing the need to repeat the same ideas and information to different professionals throughout. This would make the guidance shorter and more accessible.	this, it is not possible for the guideline to be specific. The definition of severe complex needs will be hyperlinked to, wherever this term is used in the guideline to make it easy to access the definition. The committee have also moved some of the more cross-cutting recommendations to the start of the guideline as you suggest. It should be noted that the recommendations in the section 1.1 on 'Principles for working with children, young people and their families' are intended to apply throughout the guideline and hence the committee have not made your suggested change of reversing sections 1.1 and 1.2.
The Down's Syndrome Association	Guideline	004	013	In addition, we feel that some mention should be made of the proposed Mandatory Learning Disability Awareness Training for all health and social care staff. All services should have a basic level of awareness and skills in appropriate communication and knowledge of need to make reasonable adjustments.	Thank you for your comment. As this training is only proposed at the moment it is not something the committee can recommend is used.

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				The level of training should increase in intensity and focus, depending on the role of the individual professional, along the lines of the proposed tier system, outlined in the proposed training rollout plan. We note the frustration of many that this has been delayed, due to COVID-19 pressures.	
The Down's Syndrome Association	Guideline	004	015	It is the experience of many families that some health professionals lack the capacity to meaningfully contribute to reviews of their child's EHCP. Sometimes relevant health professionals do not attend, or paperwork they submit is incomplete or outdated and families are required chase this, to ensure that EHCP reviews have information about health conditions/ therapies that is current.	Thank you for your comment. The committee hope that the recommendations made throughout this guideline will address the issues that you have described.
The Down's Syndrome Association	Guideline	005	009	Some family carers feel overwhelmed by the coordinating role they necessarily take on in relation to their child's care. We would mention the usefulness of pilot programmes, which developed key-working model across the country – initially as part of the Early Support Programme. Much of these were successful, but not continued or expanded to included additional areas of England.	Thank you for your comment and providing this information.
The Down's Syndrome Association	Guideline	006	019	As we move to a greater level of online communication (especially post-COVID19), it is important to note issues of digital exclusion and not assume that all families have access to laptops, iPads or a reliable internet connection (or feel confident in using these).	Thank you for your comment. The committee agree that digital exclusion can be an issue for some families. This recommendation is about establishing the most effective communication method for families which should take into account those for whom digital communication is a problem.

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The Down's Syndrome Association	Guideline	007	016	As a support organisation, we welcome referrals from all agencies, but find this is variable across England. Many families find their own way to us, sometimes after a long period of feeling isolated. It would be good if there were a streamlined way for professionals to be aware of the support available from national support organisations like The Down's Syndrome Association. Family Information Services tend to differ in the way in which they operate and the penetration they have within the communities who would benefit from knowing that information.	Thank you for your information. This guideline does not have a remit to make recommendations to standardise how Family Information Services operate.
The Down's Syndrome Association	Guideline	008	006	Where these exist, awareness of independent advocate organisations that might support families at meetings.	Thank you for your comment. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
The Down's Syndrome Association	Guideline	009	013	We would concur that many children and young people miss significant amounts of school because meetings are always scheduled during the school day. An offer of alternative times may be very welcome and mitigate against this.	Thank you for your comment and support of the recommendation.

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The Down's Syndrome Association	Guideline	009	023	Due to significant staff turnover, it is so often the case that families experience a professional that attends a meeting to discuss their child having not actually met the family previously. Relationships begin, only to cease, as a professional moves on into another role. Consistency of professional involvement is very much valued by families.	Thank you for your comment and support for the ethos of this recommendation.
The Down's Syndrome Association	Guideline	010	021	Having a record of a meeting (audio or video recording) may be welcomed by some families (with their prior consent). In practice, when this has been suggested by families it has met with suspicion or opposition. Some clarity on the usefulness and appropriateness of this would be helpful.	Thank you for your comment. The committee have amended this recommendation to clarify that it relates to practitioners recording meetings and needs to be done in accordance with local policies on information governance and consent.
The Down's Syndrome Association	Guideline	011	005	The inability to attend a meeting is frequently announced on the day, so a family only becomes aware of someone not being able to be present when they do not attend. We understand that professionals juggle busy workloads and clinical work often has to take priority, however, In practice, we note that this advance notice rarely happens and can cause a high degree of frustration.	Thank you for your comment. The committee hope that the recommendations made throughout this guideline will address the issues that you have described.
The Down's Syndrome Association	Guideline	012	011	In these instances, the involvement of an independent advocate can be invaluable.	Thank you for your comment. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to

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					recommending this and so the guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard.
The Down's Syndrome Association	Guideline	013	006	This highlights a training need – not all professionals are consistent in their knowledge or application of the MCA and often families are given misinformation or the Act is interpreted incorrectly.	Thank you for your comment. The focus of this guideline is about providing integrated care. It is therefore not within the scope of this guideline to recommend training in the application of the MCA.
The Down's Syndrome Association	Guideline	017	015	Sometimes a diagnosis seems to be required in order for a process to begin. This is often the case for families of children who have Down's syndrome and it is suspected that they may have a dual diagnosis of autistic spectrum condition – this may be an emerging diagnosis, involving a number of key professionals, with assessments carried out over time. Sometimes families feel they are held in "limbo" until a diagnosis is made and there is a gate-keeping approach to providing support, until the diagnosis comes through, if that ever happens.	Thank you for your comment. This recommendation aims to help address the issue that you describe.
The Down's Syndrome Association	Guideline	018	009	Sometimes services or settings (especially schools) delay in putting in place support or do not agree to child joining their setting in the absence of an EHCP. Similarly, the provision of therapy may very unlikely start until a final EHCP has been issued and agreed. This can sometimes involve a significant delay and works against the process of early intervention.	Thank you for your comment. The committee hope that the recommendations made throughout this guideline will address the issues that you have described.
The Down's Syndrome Association	Guideline	023	014	It is our experience that some families encounter professionals who do not seem confident or skilled in assessing their child's needs. When families have sought more specialist advice or commissioned reports from a specialist who has a particular expertise in	Thank you for your comment. The purpose of this recommendation is to ensure that EHC plans are informed by practitioners who have the right expertise and knowledge of the child or young person's needs. Implementation of the recommendations in this guideline

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				supporting children and young people who have Down 's syndrome e.g. a speech and language assessment, these are often disregarded out of hand by the panel involved in developing the EHCP.	should mean that the situation you describe no longer happens.
The Down's Syndrome Association	Guideline	025	002	Please see point 18 above – rarely happens in our experience.	Thank you for your comment. The committee have deleted this recommendation as it is already covered by recommendation 1.3.10.
The Down's Syndrome Association	Guideline	026	009	Sadly, as we suspect many stakeholders will testify, lack of funding is presented as a huge obstacle to provision and in so many cases, provision is not needs led, but determined by available funding. It is our feeling that this situation has worsened over recent years, with some families even being told that if provision was provided at the level being requested this "would take away from other children". This is obviously inappropriate and an unacceptable position to put families into.	Thank you for your comment. The committee hope that the implementation of the recommendations in this guideline should help to address the issues you have described.
The Down's Syndrome Association	Guideline	027	016	There are significant training / information sharing needs relating to advice around personal budgets. Professionals often seem unclear about what the position in or are reluctant to share this information with families. Families' awareness level around this possibility is generally very low and so families are unlikely to ask about these opportunities, unless specifically advised it is a possibility.	Thank you for your comment. The third and fourth bullet points have been removed from the recommendation as at the point this information is provided it would be too early to say anything about either of these items. Also they are covered by relevant legislation and so do not need to be repeated here. The purpose of this recommendation is to provide families with information about personal budgets and direct payments so that they can make an informed choice.
The Down's Syndrome Association	Guideline	029	026	We have a very successful online training offer for families of children and young people who have complex needs. There are two strands of online support – our Complex Needs webinars and our	Thank you for your comment. The committee will pass this information to the NICE resource endorsement team.

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				"Wellbeing Wednesdays" for parents. Both of these take open referrals from professionals and we would welcome the opportunity to publicise these (free events) Well-being Wednesday for Parent /Carers | Downs Syndrome Association (downs-syndrome.org.uk)	
The Down's Syndrome Association	Guideline	031	007	Many families have suffered significant impact of COVID-19 relating to the availability of social opportunities – as so many of these have been paused. In recognition of this, we launched a series of free online activities, which take place daily and cover a wide range of arts, sports, crafts, discussion groups and music activities - DSEngage | Downs Syndrome Association (downs-syndrome.org.uk) These have specifically designed to cater for individuals of all abilities and include participation by young people with more complex needs.	Thank you for your comment. The committee will pass this information to the NICE resource endorsement team
The Down's Syndrome Association	Guideline	032	003	It is our experience that when these transition reviews take place they do not adequately focus on two particular areas of importance, namely transition into independent living (supported living, for example) or employment. These two aspects of adult life take a great deal of planning and coordination and need to start at this early transition stage. Often these discussions are neglected or not explored in sufficient detail.	Thank you for your comment. Maximising independence is covered in recommendation 1.8.2 and section 1.13 makes recommendations on employment. The committee hope that these recommendations should help ensure that transition reviews are more effective in future.
The Down's Syndrome Association	Guideline	033	025	We would include here the need for information for families around the change in their roles and responsibilities in terms of making decisions on behalf of their child, as they become a young adult and	Thank you for your comment. This is covered by recommendation 1.8.11.

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				should be supported to make their own decisions as much as is possible. Families need good quality advice and training resources around deputyships, Power Of Attorney (financial and welfare) and The Mental Capacity Act.	
The Down's Syndrome Association	Guideline	041	001	We would contest that support around travel is provided by a local authority (to help them get anywhere they need to go, not just to school) as in many cases transport to school is a major stumbling-block for families of children who have chosen a school which is not their closest. This is often because of the specialist needs of the child or young person, yet many families are seen as making an elective choice and therefore responsibility for getting their child to schools falls upon them. A significant proportion of calls to our helpline relate to difficulty in accessing transport to school or college.	Thank you for your comment. The recommendations in this section are about providing travel training (under-pinned by disability discrimination law and guidance) and a training framework to achieve this. They are not about providing transport.
The Down's Syndrome Association	Guideline	041	025	Particular regard should be paid to families living in rural areas, where there is no workable public transport system. This is an increasing problem for families, as cuts to public transport have affected them and their communities.	Thank you for your comment. It is not within the remit of this guideline to make changes to public transport provision in rural areas.
The Down's Syndrome Association	Guideline	042	012	We would highlight that not all supported employment need focus upon a job-coaching model, which is often expensive and unsustainable – especially when a job coach needs to phase out. We have a successful employment project for young people and adults who have Down's syndrome called WorkFit, where we provide training for host employers, who provide an in work buddy to give support. This has had significant	Thank you for your comment. The recommendation is for service specifications to include a requirement to provide a lead employment practitioner for every young person who is going to undertake a supported internship. Job coach is cited as an example of such a lead employment practitioner but this does not mean it always has to be a job coach. This is already documented in the rational and impact section.

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				and lasting positive outcomes for young people, including those with more complex needs. See Workfit | Downs Syndrome Association (downs-syndrome.org.uk)	
The Down's Syndrome Association	Guideline	045	020	We would cite the transition from specialist paediatric health support to generic primary care / specialist adult health care as being often very problematic – families often describe this as "falling off the edge of a cliff".	Thank you for your comment. The committee have added a recommendation that should make practice more effective when transitioning between children's and adults' health services.
The Down's Syndrome Association	Guideline	047	003	Fully support this notion. It rarely occurs in practice. Many localised pilot projects, which developed principles of key working, which were developed as part of the Early Support programme around 15 years ago now, do not continue.	Thank you for your comment and support for this recommendation. The rationale and impact section documents that implementation of key working support has been variable.
The Down's Syndrome Association	Guideline	053	008	There is often a lack of training or ability and agreement to train-up non-clinical staff working in schools – especially mainstream schools and this jeopardises a child or young person's placement. These interventions could be low-level e.g. around managing continence, administering medication or eating and drinking support. Sometimes families are inappropriately relied upon to provide this support in school or have been asked to allow children in for only part of the school day or taking children home at lunchtime for these tasks to be performed at home. This is a huge, inappropriate and ongoing burden on parents, often preventing them from taking up employment.	Thank you for your comment. The purpose of this recommendation is to help delegated clinical tasks to be done safely if it is decided that a support worker should do them.
Together for Short Lives	Comments form	Q3	Q3	**What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)**	Thank you for suggesting the Together for Short Lives Family Support Hub. The committee have not linked directly to the hub from the guideline but have included

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				We think that it would be helpful for the guideline to refer to support for children with life-limiting conditions. Specifically, it would be helpful to direct children, families and professionals to Together for Short Lives' Family Support Hub which offers emotional support and practical advice, connections for families, and helping families access free legal advice if they need it.	some recommendations around sources of support and advice which includes support groups. The committee would expect that a SEND Local Offer would include any information about quality-assured sources of support and advice, and any forums for families. Also, in order to make the guideline future-proof the committee have not made specific references to sources of support and advice.
Together for Short Lives	Comments form	Q4	Q4	**The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.** During the pandemic, most families caring for a child with a life-limiting condition have felt even more isolated and alone than normal. The pandemic has had a massive impact on communication, with parents unable to be present in healthcare settings, the use of PPE frightening to some children and the lack of therapeutic touch. Published in June 2020, Together for Short Lives' SHARE study, in collaboration with Martin House Research Centre and the University of Southampton, revealed that:	Thank you for your comment about the additional issues relating to COVID and its impact on the isolation levels and mental health of disabled children and young people and their families. Throughout the guideline, the committee have made specific recommendations on approaches to support parents and carers, improve social participation, and communication. The committee also made recommendations on practitioner training to help recognise social, emotional and mental health needs and internalising symptoms (such as anxiety and depression). To make the guideline future-proof, the committee have not made specific recommendations relating to this in a pandemic but would expect that implementation of the recommendations will support children and young people and their families to deal with the issues you have raised, and also support practitioners to identify such problems and refer to appropriate services for support and care.

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				- 93% of families felt isolated during the pandemic - 57% said isolation has brought up negative memories - 95% are fearful that their child will catch the virus from their parent - 93% fear their child's treatment will be cancelled or delayed. - Families missed out on vital care and support for their child while many services were suspended In addition, in March 2021 the Disabled Children's Partnership published findings from it's latest survey to parents of disabled children. The survey revealed that disabled children and their families are at risk of developing serious mental health issues as a result of the COVID-19 pandemic. The levels of anxiety, isolation and poor mental wellbeing reported are higher compared to the rest of the population.	

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				The survey also found that: - Over 90% of disabled children are socially isolated, with 49% of disabled children not seeing a friend in the last month either online or in person. This sadly isn't limited to children, with three in five parents also socially isolated. - This isolation has had a painful impact on the development of life skills in disabled children. Around half of parents highlighted a negative impact on skills, such as being out and about, communicating with others and interacting with strangers. - As a result, both parents and children are continuing to experience poor emotional wellbeing. On average six out of ten parents are observing symptoms associated with anxiety. 72% of parents report that their child is often unhappy, downhearted, or tearful. Their siblings are also affected with a high proportion of parents reporting that their other children are having negative issues regarding sleep and anxiety.	

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				We believe that it is important that this guideline reflect this context of the COVID-19 pandemic.	
Together for Short Lives	Evidence Review E			We are concerned that the evidence review for palliative and end of life care is too narrow. We believe that the guideline should be informed from the views of a broad range of children's palliative care professionals, however, from the scope of the evidence review, it is unclear whether this approach was taken.	Thank you for your comment. The population covered by this guideline is disabled children and young people with severe complex needs and therefore the review question about palliative and end of life care also focusses on this population. There is existing NICE guidance [NG61] on end of life care for infants, children and young people with life-limiting conditions which has been cross referenced in the recommendations.
Together for Short Lives	Guideline	035	020	1.9.3 The language used here should be consistent with 1.9.8 and reference parallel planning.	Thank you for your comment. The committee have changed the text to 'Keep providing these in parallel with the palliative care plan and end of life support.'
Together for Short Lives	Guideline	036	009	1.9.7 This point should add more clarity on what a 'joint annual review' is. We believe that these reviews should be conducted at least annually and should be done in conjunction with the child and their family.	Thank you for your comment. The text specifies joint reviews of the palliative or end of life care plan. The committee have not specified a frequency for this review as this would be dependent on individual circumstances. This is distinct from annual reviews of the EHC plan.
Together for Short Lives	Guideline	036	012	1.9.8 It would be useful for this point to state that all children and families with severe complex needs should be given the choice of whether they would want to develop an Advanced Care Plan (ACP), in conjunction with an Education, Health and Care (EHC) Plan. This would recognise that many children with complex medical needs and disabilities will have palliative care needs. The guideline should also state in 1.9.8 that a ACP should be introduced to the family by a health	Thank you for your comment. Advanced Care Plans are already covered by the NICE guideline on end of life care for infants, children and young people with life-limiting conditions which has already been cross referenced in recommendation 1.9.10. The committee have added advanced care plans to the list of bullets in recommendation 1.9.10.

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				care professional with knowledge and skills in palliative acre and who are known to the family.	
University of Exeter	Guideline	General	General	**It is of particular concern that any emotional and mental health needs of the child/young person are not considered at an early stage of the process**. This is reflected in them being **first mentioned on page 50 (line 15) of the guideline and only three times thereafter** (under 'social, emotional and mental health needs'). Please consider identifying this aspect earlier in the guideline, so its importance is not buried away and due reference is made nearer the outset to considering emotional and mental health, i.e., alongside other aspects highlighted in the '**Principles for working with children, young people and their families'.**	Thank you for your comment. The committee have added a recommendation about recognition of emotional and mental health needs at the start of section 1.2
University of Exeter	Guideline	006	021	While there may be language issues that need to be mediated, ethnic minority cultural differences might implicate the need to mediate families' cultural understanding of health, social care and education processes any information provided. Please consider revising "involving an interpreter" to "involving an interpreter or appropriate advocate".	Thank you for your comment. This recommendation was based on moderate-quality qualitative evidence that language barriers made it difficult for parents to find out about available services. The committee did not identify any evidence relevant to involving advocates. Section 1.10 of the SEND code of practice states that 'Local authorities should consider whether some young people may require support in expressing their views, including whether they may need support from an advocate (who could be a family member or a professional).' However, for the majority of disabled children and young people with severe complex needs, there is no duty to provide independent advocacy. There would be significant resource implications to recommending this and so the

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					guideline has not included it. Parents and families normally act informally as advocates to ensure their child's views are heard. However the committee have added entitlements within the education, health and social care system to the list of information that should be provided.
University of Exeter	Guideline	012	003	One of the most frustrating and confusing inconsistencies for children and families is how the same terminology can mean different things when used by different services. Please consider revising "the way they interact with each child and young person more consistent" to "the way they interact with each child and young person more consistent (including how terminology is used by different services)".	Thank you for your comment. There are many ways in which services can be inconsistent in their interactions with children and young people. The committee therefore have not included a specific example in case this gives undue prominence to one issue.
University of Sunderland / Association of Paediatric Chartered Physiotherapists	Guideline	012	002	1.1.35 - "Consistent approach introduces the idea of multi agency working. I wonder if we can add a link as this is discussed in further breadth and depth 1.4.7, (1.41.1, 1.15.1 in the context of EHCP's).	Thank you for your comment. Integrated working across education, health and social care is the basis for many of the recommendations in this guideline. As such the committee do not think cross referencing to specific recommendations will help with readability of the guideline.
University of Sunderland / Association of Paediatric Chartered Physiotherapists	Guideline	013	013	1.1.43 - Information families and CYP do not wish to share. I feel that further clarity may be needed in this section. I am concerned that families choose to retain certain pieces of information which could be pertinent to another member of the interprofessional team. There is potential that a less experienced member of the team may not recognise the importance of this. In practice	Thank you for your comment. The committee have added to the recommendation that the implications of not sharing information are discussed with the child or young person and their parents and carers. This should help mitigate the risk of families not sharing information that would be pertinent for the professionals to know. Withholding information that families do not want to be shared (except

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				this may cause issues within the team with reduced openness and perceived honesty. I appreciate that if there were safeguarding concerns, we would not withhold information. Given that many services continue to use "paper" notes or the electronic notes are not congruous with different teams there may be difficulties with information sharing as you outline in your reasoning. I have concerns that it would be difficult to withhold information which the family do not want to share if you are, for example, copying practitioners into a report. It is not appropriate to omit information either from the report or clinical notes, which again could be accessed by others. I feel this may need clarity to avoid issues in practice. I absolutely agree that we should check information sharing policies with parents and CYP although we may need guidelines on this whilst optimising co-ordinated care.	in safeguarding cases) would be in line with legislation and as such needs to happen.
Virgin Care	guideline	general	general	As paediatricians we already work in many of the positive ways this document describes. Our children attending special schools and specialist units mostly access excellent support from education. We do however see gaps in mainstream schools trying to support children with EHCP. We would welcome clearer guidance and better access to both voluntary and LA services for these children. Our LA is already financially stretched and we are concerned about the implementation of this guidance as much of it seems	Thank you for your comment. The committee have acknowledged the change in practice and potential resource implications resulting from these recommendations. Inadequate resourcing may impact the implementation of this guidance. As a result, the committee have passed your comment onto the NICE team, which plan implementation support. Recommendations made by NICE guidelines are optional unless there is a legal requirement for them to be implemented.

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				optional. Social groups, respite and parent training are all lacking. Access to social care is also difficult with many children assessed and refused support despite high level ongoing need. This again reflects their lack of funding. Our service is receiving more referrals for assessment for ADHD, ASD, learning difficulties and a delay in diagnosis does seem to impact on successful EHCP application. Again limited funding and increased demand is driving this.	
Virgin Care	Guideline	015	008	Social care is not currently involved in the assessment process for EHCP, they may be nominally mentioned but do not usually complete an assessment routinely. It would be desirable to offer support through social care at this early stage but this would be a considerable amount of extra work, in our local area even children with significant needs are often refused support through the disability social care team.	Thank you for your comment. This recommendation is not about assessment for an EHC plan or about what support will be provided it is about the principle of early identification of needs.
Virgin Care	Guideline	017	015	Although children without a diagnosis are not excluded from assessment they have a much poorer chance of success meaning schools will often delay access EHCP until a diagnosis is confirmed. Expanding this point to encourage more needs based assessment would be helpful.	Thank you for your comment. This issue is covered by recommendation 1.17.3.
Virgin Care	Guideline	028	012	The local authority should assess the full cost including transport. This can be challenging if a child goes to school out of area by parent choice. Further clarification of funding for transport would be helpful.	Thank you for your comment. The guideline does not have a remit to clarify funding for transport. The committee have therefore removed the example as it was not helpful.
Virgin Care	Guideline	030	003 - 007	Parent training is incredibly important at all stages of a childs development. More access to a range of training	Thank you for your comment and support for this recommendation. The committee do not have a remit to

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				would be widely welcomed. Currently there is limited training available and it is often limited to those with a diagnosis. Access to behavioural support is under enormous pressure as is the local LD CAMHS team. More funding in these areas to support the guidelines goals is important.	determine allocation of funding and so are not able to make any recommendations on this.
Virgin Care	Guideline	031	003	Parents constantly ask where their child can socialise with other young people. Asking the LA to incorporate this into the local offer would be great. However consideration must be given to the wide range of presentation eg- mobility, learning/understanding,communication and behaviour. One group is unlikely to meet all these needs and parents may therefore choose not to access the service. There is also cost implications.	Thank you for your comment. The committee have added mobility, learning and communication needs and behaviour to recommendation 1.7.3. As documented in the rationale and impact section, Local authorities have a duty to provide short break services, and the recommended group activities would fall under this category of service. Because local authorities already have to fund these services, there should be no resource impact. However, the type of short break services provided may change.
Virgin Care	Guideline	041	001	Parents would love the opportunity for their children to work on independence outside the home with someone other than them. Access to support for public transport beyond the school bus would be wonderful but again currently there is not service like this so funding would be needed.	Thank you for your comment. As documented in the rationale and impact section 'Travel training is not consistently available in all areas, so there will be a change in practice for local authorities that do not have a training framework. However, most EHC plans will already specify a need for travel training, either because independent travel is listed as an outcome in its own right or because it is a means to achieve another outcome (for example employment).' As such there should not be a significant resource impact from this recommendation.

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

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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In January 2023, NICE became aware that, due to a clerical error, 10 comments submitted by registered stakeholders as part of the consultation on this guideline had been missed. These are shown below with post-publication responses. NICE apologises for this error.

Stakeholder	Document	Page No	Line No	Comment	Post-publication Response
ESC Management Ltd	Guideline	53	6-7	**Rec 1.15.27:** '*ensure that ongoing clinical supervision arrangements are in place for support workers*.' It would be helpful if the recommendation could provide clarity around delegation and requirements for supervision. This appears to be a perennially thorny issue. For example, the Royal College of Speech and Language Therapists (RCSLT) has guidance available on its website (only accessible to members but can be requested) which relates to delegation. This guidance refers to registered Speech and Language Therapists (SLT) being unable to formally delegate tasks to the wider workforce, unless the SLT has managerial or supervisory responsibilities for their actions. When the wider workforce is involved, this RCSLT guidance signposts registrants to another RCSLT guidance document 'Upskilling the wider workforce.' This states *'the term delegation is often used loosely to explain, for example, the process between an SLT and a teaching assistant asked to undertake carry-over therapy activities.'* Within this guidance there are	Thank you for your comment. Please accept our apologies that it was missed. The purpose of this section is to signpost readers of guideline to guidance from other organisations. Providing the additional detail you describe would have been beyond the scope of the work and the available evidence would not have enabled the committee to provide it in any case.

				numerous references to the wider workforce covering education staff. Upskilling is presented as a different activity to delegation. For example, the upskilling guidance has no reference to assessing competence. There is an urgent need for greater clarity on the 'training' v's 'delegation' distinction. There is a potential risk that standards for delegated activity are being side stepped because cross-organisational delegation arrangements have not been pinned down. For example, when an EHC plan section G specifies delegated dysphagia interventions potentially, this NHS activity could be associated with support worker 'upskilling' and training but with no requirements for supervision or competency assessment. This not only has implications for children and young people receiving care but also for the support workers/organisations providing the services i.e. those accepting responsibility and liability for the activity. The CQC 'Scope of Registration' guidance covers supervision and delegation (pg. 29/30). This states a health care professional employed by one provider will not be responsible for the supervision of staff of another provider. The CQC guidance then signposts to the NMC Code of Practice standards for delegation which obviously includes the requirement for supervision.	

				There is an opportunity for this NICE guideline to not only reinforce the NMC and HCPC delegation professional standards but also provide greater clarity on the supervision component. The ever increasing levels of NHS activity delegated across organisational/sector boundaries to non-health, unregistered support workers means it is more important than ever to ensure consistent standards of NHS care regardless of who is providing the care and where the care is delivered.	
ESC Management Ltd	Guideline	53	8-12	**Rec 1.15.28:** This recommendation is for delegatees and their employing organisations and as the definition of support worker refers to education staff presumably, this is aimed at not only health and social care but also education. This is likely to pose challenges for the education sector. In effect, what this recommendation means is that schools employing teaching assistants who have been delegated clinical tasks must follow guidance from; • Care Quality Commission • Nursing and Midwifery Council • Royal College of Nursing • Professional governance organisations allied to medicine This recommendation is indicative of how normalised it has become for schools to provide delegated NHS	Thank you for your comment. Please accept our apologies that it was missed. This recommendation has been amended to make it clear that it is not addressed to education employers since we do not believe the guidance referred to is directly applicable to education employers.

				health services. In that, a school must follow guidance from the health sector regulatory/inspectorate body and professional governance organisations which have no reach into a school functioning within the education statutory framework. For example, CQC requirements for training and competency are to ensure registered providers comply with the statutory obligations in the Health and Social Care (HSC) Act 2008 (Regulated Activities) Regulations 2014. Schools are not CQC registered and are not subject to the HSC Act 2008 Regulations 2014. Therefore, is it reasonable and practical to expect a school leader to know, understand and implement CQC standards and guidance. Put another way, if NHS providers were informed that when therapists provide EHC plan section F provision that educates or trains, they must follow the guidance and standards set by the DfE Teachers' Standards and the Teaching and Regulatory Agency, this would probably be considered unreasonable and impractical. It is likely, that this suggestion would be dismissed fairly abruptly. Whilst it is understandable that there is an aim to improve standards of clinical activity within the education sector, this recommendation illustrates the fundamental flaw with the current service delivery	

				model and the system attempts to 'square the circle'. Schools are expected to operate as fully functioning NHS healthcare providers but the foundations for high quality, safe NHS provision do not exist in the education sector.	
ESC Management Ltd	Guideline	53	8-12	**Rec 1.15.28:** These recommendations in conjunction with the definition of 'support worker' (pg. 63) indicate that NICE is endorsing the current custom and practice of schools providing NHS care plan services via delegation which sits outside the NHS statutory commissioning/provision framework. It is noted that the committee list (2019) refers to a lawyer as a co-opted member. Assuming that this post has now been filled, the committee may wish to take legal advice on this recommendation in light of the ongoing discussions in the specialist education sector (referred to in comment 8). Of particular importance would be potential organisational risks to NICE. A legal view may advise that mitigation and future proofing steps may be prudent. For example, at some point within this set of recommendations, making reference to delegating health tasks *'where legally compliant'* may mitigate NICE organisational risk and future proof the guidelines against developments in this area.	Thank you for your comment. Please accept our apologies that it was missed. This recommendation has been amended to make it clear that it is not addressed to education employers since we do not believe the guidance referred to is directly applicable to education employers. These recommendations on delegated clinical tasks should not be taken as an endorsement of any service model. Nor did the NICE committee consider or take a position on who funds such activity. The recommendations are a pragmatic response to the reality that delegated clinical activity happens and simply attempt to draw attention to relevant standards. The word 'must' has been replaced with 'should' throughout the three recommendations in this section as this was an incorrect use of the word 'must' in a NICE guideline.

ESC Management Ltd	Guideline	53	12-13	**Rec 1.15.28:** *'In particular, employers must: ensure support workers are competent to carry out these tasks'* Again, this could prove challenging for schools, could the committee clarify what is meant by this element of the recommendation. School leaders/staff are education professionals. Generally, they are not clinically trained and have no experience of working in the NHS. Recommending that schools ensure their workforces are competent in carrying out NHS care plan health procedures, does not seem feasible. NHS commissioners/providers have a duty of care to ensure NHS services including delegation are appropriately commissioned/provided. Registered health professionals also have professional obligations to ensure competency when they delegate tasks. To ensure this recommendation can be applied to the school setting, would a more appropriate phrase be employers must: '*have arrangements in place to ensure support workers are competent to carry out these tasks'*. Schools/NHS partners should have jointly agreed robust governance policies for delegation but it is the health organisation/professional that must be responsible and accountable for ensuring standards and competency for this activity.	Thank you for your comment. Please accept our apologies that it was missed. This recommendation has been amended to make it clear that it is not addressed to education employers since we do not believe the guidance referred to is directly applicable to education employers.

ESC Management Ltd	Guideline	53	17-19	**Rec 1.15.28**: *'ensure that training providers or other suitable organisations will provide ongoing supervision of support workers when a clinical competency must be assured to a required standard'.* In the context of delegation of health interventions and tasks, this recommendation is unclear. As noted in comment 12, the CQC has guidance on training and competence for medicines optimisation in adult social care. This guidance appears to make a distinction between medicines support tasks in which accredited training providers and external assessors are recommended and medicine administration that requires registered nurse delegation. The linked CQC guidance on delegating medicines administration focuses on the responsibilities of both the registered nurse delegating the task and the support worker accepting the task. For example, registered nurses must make sure that everyone they delegate tasks to is adequately supervised and supported. Additionally, both the registered nurse and care worker should understand accountability, liability and responsibility and they should make a record of their understanding. The title of this set of recommendations suggest that they relate specifically to the delegation of health interventions. So presumably, these interventions would be specified in a child or young person's NHS	Thank you for your comment. Please accept our apologies that it was missed. This recommendation has been amended to make it clear that it is not addressed to education employers since we do not believe the guidance referred to is directly applicable to education employers.

				care plan, and require registered NHS professional delegation in line with professional standards for risk assessment, training, competency assessment and supervision. As noted previously, there is a lot of confusion about ‘delegation’ v’s ‘training’. Could the committee clarify within the context of delegation and an NHS pathway i.e. NHS commissioning responsibility, NHS care planning and NHS registered professional delegation, what is meant by a ‘training provider’ and ‘other suitable organisation.’ Do these terms refer to NHS provider Trusts/registered professionals delegating the activity?	
ESC Management Ltd	Guideline	53	24	**Rec 1.15.28:** Following the statement *‘when a collaborative investigation is needed’*, the committee may wish to consider adding a statement about a mechanism to capture and disseminate learning to improve practice.	Thank you for your comment. Please accept our apologies that it was missed. This recommendation has been amended to make it clear that it is not addressed to education employers since we do not believe the guidance referred to is directly applicable to education employers. We believe the substance of your comment was addressed before publication by including a reference to the use the framework set out in the NHS Quality Board Position Statement on Quality in Integrated Care Systems.

ESC Management Ltd	Guideline	53	25-29	**Rec 1.15.29:** Previous point applies re. including HCPC as a statutory regulatory body with specific professional standards for delegation.	Thank you for your comment. Please accept our apologies that it was missed. We believe the substance of your comment was addressed before publication by including HCPC in the list of organisations.
ESC Management Ltd	Guideline	56	5-6	**Rec 1.17.1:** This recommendation states that outcomes should be specified in contracts and the rationale given for this is services will be better equipped to meet needs (Evidence Reviews pg. 29, lines 25-28). This is a positive. However, as noted, a significant proportion of EHC plan health provision in the education sector is delivered by the education workforce outside NHS commissioning. Consequently, there is neither funding nor contractual arrangements for this activity. The committee may wish to consider this recommendation in light of the fact that schools providing EHC plan health provision do so outside any contractual arrangement.	Thank you for your comment. Please accept our apologies that it was missed. This recommendation relates to commissioning of services, so it does not apply to informal arrangements of the type you describe.
ESC Management Ltd	Guideline	63	1-3	**'Support Worker' definition** a) Support workers for disabled children and young people with severe complex needs carry out a vast array of tasks across the education, health and social care sectors. Whilst the guideline focuses on support workers involved in delegated health tasks it does also include reference to support workers providing assistance in seeking employment (rec 1.13.10 pg. 44 lines 3-7). This	Thank you for your comment. Please accept our apologies that it was missed. We agree that the link from recommendation 1.13.10 to the glossary entry on support workers is currently confusing. The term 'support worker' is used in a different sense in this section from that in which it is used in section 1.15.

				latter support worker activity does not appear to fit with the guideline definition of support worker. b) The support worker definition includes '……*(including teachers, teaching assistants and other staff in education or care settings).'* Given the discussions that are taking place in the specialist school sector, the committee may wish to consider future proofing the guideline i.e. removing explicit references to the education workforce and replacing with '*non-health, unregistered employees'*.	So we added a new glossary entry to explain the sense in which the term is used in section 1.13 and have linked to that instead from recommendation 1.13.10. It is not ideal to use the same term in two different senses in a NICE guideline but, in this case, we are reflecting current usage, so we think the above is the best approach to take. Regarding the wording of the definition of the term as used in section 1.15, thank you for your suggestion but we think the current definition captures accurately what the committee had in mind, so we do not propose changing it at this stage.
Kent Community Health NHS Foundation Trust	Guideline	General	General	Useful good practice guidance for supporting children with complex needs which brings together in one place a number of sections from different guidance documents/ best practice etc	Thank you for your comment. Please accept our apologies that it was missed.