NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

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

Draft for consultation, August 2021

This guideline covers support for disabled children and young people with severe complex needs, from birth to 25 years. The recommendations are based on the best available evidence, and will help practitioners put this into practice in a way that is consistent with the requirements of the government's Special educational needs and disability (SEND) code of practice. There are also recommendations for local authorities, health commissioners and individual services, to help them work together and provide more coordinated support to children and young people.

Who is it for?

- Education, health and social care practitioners
- Education, health and social care service providers
- Local authorities and health commissioners
- Disabled children and young people with severe complex needs, their families and carers

What does it include?

- the recommendations
- recommendations for research

- rationale and impact sections that explain why the committee made recommendations and how they might affect practice and services
- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

Contents

Recommendations on support for all disabled children and young people with severe complex needs

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

These recommendations cover the support that all disabled children and young people with complex needs should receive. There are also recommendations on:

- specialist support, covering palliative care, communication aids, environmental adaptations and accessibility, travel training and employment
- service organisation, including working culture, training, integrated working, and commissioning.

This guideline is aligned with the Special educational needs and disability (SEND) code of practice. Recommendations that state ‘as specified in the SEND code of practice’ are referring to existing statutory requirements in the code of practice.

1.1 Principles for working with children, young people and their families

1.1.1 Education, health and social care practitioners should always:

- put the views, life goals and ambitions of the disabled child or young person with severe complex needs at the centre of planning and decision making.
- take the views of parents (or other people with parental responsibility) into account.

Involving children and young people and their families

1.1.2 Ensure that all children and young people are involved in discussions and decisions about their education, health and social care support. Include them in all meetings where their views should be represented.

1.1.3 Find out which members of the child or young person's family should be involved, in the context of their current individual family circumstances (for example, when a family member other than a parent has parental responsibility). Review this if their family circumstances change.

1.1.4 Work closely with children, young people and their families and carers to:

- get to know them better, to understand their needs
- draw on the expertise they have from their lived experience and associated needs
- build a positive working relationship with them, to better understand their views, life goals and ambitions.

1.1.5 Encourage and support children and young people to give their views on their care, education and support, and express what they want and need.

1.1.6 Encourage parents and carers to think about how their child can give their own views and be involved in decisions. Ask them what services can do to support their child to communicate their views.

1.1.7 Regularly check that children and young people and their families and carers are satisfied with how they are involved in decisions about their support. If they are not satisfied, look for ways to address their concerns.

1.1.8 Learn about the approaches families and carers use when caring for their child, and continue to use these in the same context if they are beneficial.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on principles for working with children, young people and their families.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review B: involving children and young people
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Communication formats and providing information

1.1.9 Take care to use empathetic, supportive language when communicating with families and carers, because they are often anxious about judgemental attitudes from practitioners.

1.1.10 Provide information in a spirit of partnership with families and carers. Avoid being directive, and take their experience and perspective into account.

1.1.11 Be sensitive to and address the feelings of children, young people and their families and carers when providing information. Help them to understand and reflect on information, and direct them to sources of support if needed.

1.1.12 Enable children and young people to communicate their views in a way that is appropriate for their age, developmental level and communication skills.

1.1.13 Find out what communication formats and media the child or young person prefers (for example, children who are non-verbal might use alternative and augmentative communication technology). Communicate with them using their preferred format.

1.1.14 Establish the most effective way of communicating with families and carers, for example providing information in different languages or involving an interpreter.

1.1.15 Education, health and social care services should give children, young people and their families and carers up-to-date information and advice about:

- the process and purpose of assessment and diagnosis
- the care and support they are receiving
- any delays or changes in the above
- the meetings they will be involved in and how to contribute their views
- the roles of the practitioners and services that are currently supporting them, and any services or practitioners that they have been referred to for future support
- relevant policies and processes.

1.1.16 Education, health and social care services should direct children, young people and their families and carers to sources of support and advice, including:

- SEND Information, Advice and Support Services
- specialist national or local support groups
- local carer support groups
- peer support groups.

1.1.17 SEND Information, Advice and Support services should help children, young people and their families and carers understand what support is available for them, based on their specific needs.

1.1.18 Ask children and young people and their families and carers what they expect from services. If their expectations cannot be met, explain why.

1.1.19 For more guidance on communicating and discussing complex information, and on tailoring information to individuals, see the:

- NICE guideline on babies, children and young people’s experience of healthcare
- NICE guideline on patient experience in adult NHS services (in particular recommendation 1.5.14).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on communication formats and providing information.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review B: involving children and young people
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Planning and running meetings with children and young people

1.1.20 Before discussions and meetings, practitioners should help children and young people prepare by:

- providing them with information (in accessible formats) and support
- encouraging their parents and carers to discuss the meeting with them in advance
- providing support for their parents or carers before the meeting if they need help completing any documents.

1.1.21 Before meetings, the chair should find out:

- what is important to the child or young person
- their age, communication abilities and circumstances (see recommendation 1.1.13).

Use this information when planning the meeting, to ensure that the child or young person can meaningfully participate.

1.1.22 When planning meeting agendas:

- prioritise the child or young person's wishes and goals, in addition to the statutory content **and**
- include any other relevant issues that parents, carers and education, health and social care practitioners need to cover.

1.1.23 As far as possible (based on practitioners' contracted working hours), consider the child or young person's preferences when planning meetings, to help them participate and understand what is happening. For example:

- Ask them when and where they would like to have the meeting:
  - consider scheduling it at a time of day when they are not usually tired **and/or**
  - consider scheduling meetings outside of school time when possible, because they may feel excluded if they are regularly taken out of school **and/or**
  - consider having the meeting in a place where they feel comfortable and do not have to travel too far.
- Consider if they are anxious in groups of people or do not want to discuss a sensitive topic in front of everyone. Arrange a separate meeting so they can get their views across (for example, a one-to-one meeting with a practitioner they trust, or a videoconference).
- Consider providing breaks during long meetings.

1.1.24 Ensure that, at each meeting:

- there will be education, health and social care practitioners who know the child and are involved in their support
- key additional relevant people will be able to attend (for example, a college representative for a review on transition from school to college).

1.1.25 Take account of the child or young person's right to privacy:

- hold meetings in places with as much privacy as possible
- tell them who will be at the meeting, and why

- only invite the key education, health and social care practitioners who are needed at the meeting, to avoid large groups of practitioners that may be intimidating for some children and young people.

1.1.26 Consider using person-centred planning tools (for example, Planning Alternative Tomorrows with Hope [PATH]) to help structure and conduct meetings.

1.1.27 Communicate with the child or young person at meetings using their preferred format, and any basic rules that help them to feel comfortable. The chair should remind everyone at the meeting what the child or young person's preferences are before the meeting starts.

1.1.28 Give children and young people plenty of time to express their views in discussions and meetings. Do not rush them.

1.1.29 Agree clear actions (at meetings, and in other discussions between practitioners and the child or young person and their family and carers). For actions that will directly affect the child or young person:

- record them in an action log, in a format that the child or young person and their family and carers can understand
- share the log with the child or young person and everyone involved in their care
- review the log regularly to ensure the actions are being done.

1.1.30 Consider recording meetings (written, audio or video), so the child or young person and their family and carers can review them again later.

1.1.31 If a key practitioner cannot attend a meeting, think about whether it needs to be rescheduled. Take into account:

- the problems caused by delaying the meeting
- the risk of the meeting not being productive if it goes ahead without all the key practitioners
- the risk of causing discomfort or distress to the child or young person if there are people at the meeting that they do not know

- the consequences for the family and carers (such as parents having to rearrange time off from work).

1.1.32 If a key practitioner cannot attend an interagency team meeting, or any meeting with the child or young person, they should:

- tell the person who arranged the meeting in advance
- send a fully briefed delegate to represent them, or provide a written update or report
- request details of any relevant actions and follow these up
- review the meeting minutes and action log when available.

1.1.33 Ask the child or young person if they would like to involve any siblings or friends in meetings (to share their views on the child or young person's strengths and interests). If they would like to do this:

- tell the child or young person to invite the sibling or friend
- if the sibling or friend agrees to attend the meeting, contact them to explain how they can be involved
- involve the parents and carers of the child or young person and their sibling or friend as necessary at each stage of this process.

1.1.34 Ask children and young people and their families and carers how they would like to be involved in multidisciplinary and interagency team review meetings about them.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on planning and running meetings with children and young people.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review B: involving children and young people
- evidence review K: barriers and facilitators of joined-up care

- evidence review M: views and experiences of service providers.

Using a consistent approach

1.1.35 Education, health and social care services should work together to make the way they interact with each child and young person more consistent.

For a short explanation of why the committee made this recommendation, see the rationale and impact section on using a consistent approach.

Full details of the evidence and the committee's discussion are in evidence review M: views and experiences of service providers.

Decision making

1.1.36 Provide children and young people and their families and carers with information to help them play a part in decision making, in line with the SEND code of practice.

1.1.37 When a child is unable to formulate a view (because they are unable to contextualise), think about whether their preferences could be identified in another way (for example through observation or play).

1.1.38 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.

1.1.39 If disagreements cannot be resolved and the child or young person is under 16:

- take the views of the parents (or other people with parental responsibility) into account
- remember that the child or young person's needs are paramount
- remember that children and young people under 16 can give their own consent if it is clear that they fully understand what is involved.

1.1.40 If disagreements cannot be resolved and the young person is over 16, consider the young person's views first. You must uphold their decision if they have capacity to make it.

1.1.41 If you think a young person aged 16 or over lacks capacity to make a particular decision about their support and education, you must:

- follow the principles of the Mental Capacity Act 2005
- ensure that the young person is as involved as possible in the decisions made on their behalf.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on decision making.

Full details of the evidence and the committee's discussion are in evidence review B: involving children and young people and evidence review K: barriers and facilitators of joined-up care.

Information sharing and privacy

1.1.42 For guidance on information sharing, see paragraphs 9.211 to 9.213 and 9.32 to 9.34 of the Special educational needs and disability (SEND) code of practice.

1.1.43 Ask children and young people and their parents and carers about information sharing as early as possible, to avoid them having to repeat information to different practitioners.

- Ask for and record informed consent to share information when needed with other practitioners and services.
- Ask if there is any information they do not want to be shared.
- Ask who they would prefer to discuss sensitive information with.

1.1.44 Practitioners must follow and stay up to date with their organisation's policy on consent, and with the relevant legislation and statutory guidance.

1.1.45 Once you know the child or young person's preferences, share all agreed information with all services involved in supporting them.

1.1.46 Make sure that all services involved have access to all agreed information about the child or young person.

1.1.47 When specialised care plans (such as behaviour management plans) have been agreed for a child or young person, share these plans with all practitioners working with them.

1.1.48 Check the information sharing preferences of children and young people and their families and carers at least annually (for example, check at each education, health and care plan review).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on information sharing and privacy.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

1.2 Identifying needs and involving other services

When needs are first identified in health services

1.2.1 If you think a child or young person may have complex health needs or disabilities, think about whether they are likely to also have special educational needs and social care needs.

1.2.2 If a child or young person is likely to have complex health needs or disabilities and is also likely to have special educational and social care needs:

- discuss this with them and their parents and carers before notifying the local authority, and if possible, get their agreement on when to do this
- tell them and their parents and carers about any voluntary organisations that can provide advice or assistance, and any educational support that is available before they start or return to school (for more information, see paragraphs 5.15 and 5.16 on early identification in the SEND code of practice)
- after getting consent, find out which education and social care services need to be involved and contact them at the first opportunity (for more information about whose consent is needed, see paragraphs 8.13, 8.17 and 8.19 of the SEND code of practice).

When needs are first identified in education services

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:

- Do they have specific needs that can be addressed with clear actions and solutions, or are they likely to need broader support?
- Could there be an underlying health condition, and do health services need to be involved?
- Could they have unmet social care needs, and do social care services need to be involved?

1.2.4 If a child or young person is likely to have special educational needs and is also likely to have complex health and social care needs:

- discuss this with them and their parents and carers
- tell them and their parents and carers about any support organisations in the Local Offer that can provide advice or assistance, and any educational support that is available before they start or return to school (for more information, see paragraphs 5.15 and 5.16 on early identification in the SEND code of practice)
- after getting consent, find out which health and social care services need to be involved and contact them at the first opportunity (for more

information about whose consent is needed, see paragraphs 8.13, 8.17 and 8.19 of the SEND code of practice).

Referral to social care services

1.2.5 When making a referral for a social care assessment for family support:

- include a detailed description of the reasons for making the referral, including the emerging health and social care needs **and**
- discuss the potential outcomes of the assessment with the child or young person and their family.

1.2.6 Include any barriers to engaging with healthcare services (for example, families on low income who have difficulty attending appointments) in the referral to social care services.

1.2.7 Be aware that parents and carers may be anxious about involving social care services. Find out what they know about social care (particularly family support services), and:

- explain areas they do not understand
- address any misconceptions
- explain the difference between safeguarding, child protection social care, and broader family support services.

1.2.8 If you identify a safeguarding concern, refer in line with local criteria or thresholds.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on identifying needs and involving other services.

Full details of the evidence and the committee's discussion are in evidence review C: combined approaches to identifying, assessing and monitoring needs and evidence review K: barriers and facilitators of joined-up care.

1.3 Education, health and care needs assessment

Requesting a needs assessment

1.3.1 If you think a child or young person may have a special educational need, explain to them and their families and carers:

- who can request an education, health and care (EHC) needs assessment
- how to request an EHC needs assessment
- how to get help with this process (for example, from support groups)
- how to make an appeal, if the local authority does not think an EHC needs assessment or plan is needed.

1.3.2 Local authorities should explain to education, health and care practitioners that EHC needs assessments should be requested based on a child or young person's needs, and not on other factors such as potential availability of funding.

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).

1.3.4 When assessing the needs of a child or young person for an EHC plan, local authorities should explain to them and their families and carers:

- the purpose of the plan, the possible outcomes, and what it can help with
- how they can be involved in the process
- how long it should take to get an EHC plan (no more than 20 weeks after their initial request)
- how and when the plan will be reviewed.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on requesting a needs assessment.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Supporting children, young people and their families during a needs assessment

1.3.5 Explain what services are available and the criteria for accessing them.

1.3.6 Give children, young people and their families and carers clear information about the criteria for funding and support.

1.3.7 Give families and carers help, time and opportunities to express their views and explain what support they think their child needs. Record this information during the assessment process.

1.3.8 Education, health and social care services should start working together before an EHC plan is issued, to ensure that:

- the child or young person gets the interim assessments they need, and interim support as soon as a need is identified
- the transition from interim support to EHC plan is as simple as possible.

1.3.9 While children and young people and their families and carers are waiting for the EHC needs assessment process to finish, provide support based on their identified needs. For example:

- healthcare specialists should work with local teams to identify what interim assessments and support can be provided
- practitioners should explain what support is available as part of the Local Offer (such as short breaks)

- education services should provide special educational provision, based on what is currently understood about the strengths and needs of the child or young person.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on supporting children, young people and their families during a needs assessment.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Carrying out the needs assessment

1.3.10 During the EHC needs assessment process:

- take into account the child or young person's age, level of understanding, communication needs and specific circumstances
- contact practitioners who have relevant knowledge about the needs of the child or young person, but who are not part of the interagency team, to better define the child or young person needs
- identify emerging needs and make referrals as these needs are identified, without waiting for the assessment process to finish.

1.3.11 Use all information available (including information from other practitioners or services) for assessments of children and young people.

Timescales for completing a needs assessment and producing an EHC plan

1.3.12 When conducting EHC needs assessments, local authorities, services and practitioners must work to the timescales specified in paragraphs 9.41 to 9.44 of the SEND code of practice. In particular:

- when an EHC needs assessment is requested, local authorities must decide whether the assessment is needed within 6 weeks
- when a local authority requests information as part of an EHC needs assessment, services and practitioners must respond within 6 weeks
- if the local authority decides that an EHC plan is not needed, they must inform the child or young person and their parents within 16 weeks of the initial assessment request
- if the local authority decides that an EHC plan is needed, they must complete the needs assessment and produce a finalised EHC plan within 20 weeks.

If parents or carers decline any assessments

1.3.13 If parents or carers decline any assessments:

- think about why they are declining and take account of any cultural or communication challenges
- discuss their reasons for declining and address any concerns they have
- explain how they can request an assessment in future, and encourage them to get in touch if they change their minds
- think about whether this may cause a safeguarding issue, and refer if needed.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on carrying out the needs assessment, timescales for the assessment and when parents or carers decline an assessment.

Full details of the evidence and the committee's discussion are in evidence review C: combined approaches to identifying, assessing and monitoring needs and evidence review K: barriers and facilitators of joined-up care.

1.4 Education, health and care plans

Deciding on outcomes for the plan

1.4.1 Encourage disabled children and young people with severe complex needs to express their life goals and ambitions, and explore their strengths, abilities and interests with them. Focus on all of these when deciding on outcomes for the education, health and care (EHC) plan.

1.4.2 Take the views of parents and carers into account throughout the assessment, production and review of EHC plans.

1.4.3 When writing outcomes for EHC plans:

- make them SMART (specific, measurable, attainable, relevant and timely)
- consider using the 'outcome sandwich' (specify the timeframe, the skill to be developed, and what this skill would help the person to do).

For more information, see paragraphs 9.64 to 9.69 of the Special educational needs and disability (SEND) code of practice.

1.4.4 Base your expectations for a child or young person on their own life goals and ambitions, rather than on their condition or needs.

1.4.5 Query with other practitioners if you think their expectations for a child or young person are unrealistic (too high or too low).

1.4.6 Do not assume that all children and young people with a particular diagnosis need the same support.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on deciding on outcomes for the plan.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Writing the plan

1.4.7 Services should coordinate and agree the content of EHC plans together, to make sure the plan works as a whole and makes sense to everyone involved. Each practitioner should read the sections of the plan produced by other practitioners, to ensure they can support all the outcomes through their own work with the child or young person (for example, education practitioners should think how school would be affected by changes made in response to a home assessment).

1.4.8 Record the views of children and young people in EHC plans. Make it clear which parts of the plan contain their contributions.

1.4.9 When writing EHC plans:

- practitioners should use the information provided by healthcare professionals to describe the special educational, therapy, medical, health and social care needs of children and young people in sections B, C and D of the plan
- practitioners should distinguish 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.

1.4.10 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.

1.4.11 When writing EHC plans, practitioners should specify the special education, health and social care support that will help children and young people to achieve the outcomes in the plan, including:

- the type of support they need
- the level of expertise required to deliver the support
- who is responsible for providing the support.

1.4.12 Local authorities 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.

1.4.13 Local authorities should ensure that EHC plans:

- are based on up-to-date information
- are written by practitioners who have the right expertise and knowledge of the child or young person.

1.4.14 Preserve the child or young person's voice when recording their views:

- use their preferred communication format
- use their own words, or the equivalent in a different format if they do not communicate verbally (for example, symbols or other alternative or augmentative communication technology formats)
- do not rewrite what they have said.

1.4.15 Write the outcomes and support provision sections of the plan in language that is understandable to the child or young person. For guidance on providing information in different formats, see:

- the section on providing information in the NICE guideline on babies, children and young people's experience of healthcare
- recommendation 1.5.13 in the NICE guideline on patient experience in adult NHS services.

1.4.16 During the planning process, check with the child or young person and their family and carers and:

- make sure that they understand the plan outcomes, and what these will mean in practice
- make sure that the plan makes sense to them and they agree with it
- check if they have any concerns.

If they have a concern that cannot be addressed as part of the EHC planning process, explain and record the reasons why. It may be difficult to do this for some children and young people. However, you should still involve them as far as possible.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on writing the plan.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review B: involving children and young people
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Checking the draft plan with children, young people and their families

1.4.17 When the draft plan is ready, local authorities must:

- send it to the child's parent or the young person
- give them at least 15 days to propose changes to the plan
- make its officers available to meet with them.

For more information, see paragraph 9.77 of the SEND code of practice.

For a short explanation of why the committee made this recommendation, see the rationale and impact section on checking the draft plan with children, young people and their families.

Full details of the evidence and the committee's discussion are in evidence review B: involving children and young people.

Implementing the plan

1.4.18 Start implementing the EHC plan when plans for provision are in place, without waiting for the results of other assessments or for a final draft to be agreed.

Review and re-assessment

1.4.19 Education, health and social care practitioners should review the child or young person's progress and needs at regular intervals (according to statutory requirements, or more often if needed), to:

- check if their needs or circumstances have changed
- ensure that outcomes remain realistic and focused on helping them reach their full potential.

1.4.20 Conduct a re-assessment if:

- the child or young person's needs change significantly (for example, if they develop new health problems) **or**
- their circumstances change significantly (for example, when they start school).

1.4.21 Share the results of the re-assessment with the local authority so that they can decide whether:

- the EHC plan is still fit for purpose **or**
- any provisions in the existing EHC plan should be changed (without a full EHC plan review or re-assessment) **or**
- to conduct a re-assessment of the EHC plan.

1.4.22 Only reduce the level of support provided if the child or young person no longer needs this level of support. Do not reduce support just because they show improvements in particular areas or are able to do new things, because they may rely on the support they get to do this (for example, they may start travelling to school independently after having travel training, but still need help with travel in other cases, such as when attending specialist after-school clubs).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on implementing the plan, review and re-assessment.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Funding

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.

1.4.24 When requests for additional funding are refused:

- 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.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on funding.

Full details of the evidence and the committee's discussion are in evidence review K: barriers and facilitators of joined-up care.

If children, young people and their families decline an EHC plan

1.4.25 If parents or carers decline an EHC plan:

- discuss their reasons for this and address any concerns they have
- explain how they can request an EHC needs assessment in future, and encourage them to get in touch if they change their minds
- agree what ongoing support will continue to be provided
- think about whether this may cause a safeguarding issue, and refer if needed.

For a short explanation of why the committee made this recommendation, see the rationale and impact section on if children, young people and their families decline an EHC plan.

Full details of the evidence and the committee's discussion are in evidence review M: views and experiences of service providers.

1.5 Personal budgets and direct payments

1.5.1 Local authorities 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, covering:

- if they are eligible, and if so how to apply
- what they can use the money for
- how much money they would receive, and whether or not this is equivalent to their current funding (that is, whether they could afford all of their current support with direct payments)

- how this will affect their access to services outside of their personal budget.

1.5.2 Local authorities and health commissioners should continue to ensure services coordinate even if they have been commissioned using direct payments. For example, if the family commission health and care support for a child or young person, the local authority should ensure that those providers still have access to health and care advice directly from statutory providers.

1.5.3 Be aware that personal budgets are mandatory for people aged 18 and over who have a care and support plan (although the person can decide whether or not to receive their budget as a direct payment).

1.5.4 For children, young people and families and carers who are receiving direct payments, local authorities should assess the full cost of providing the services proposed in the needs assessment (for example, include transport costs).

1.5.5 For more guidance on personal budgets and direct payments for young people aged 18 and over, see the NICE guideline on people's experience in adult social care services.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on personal budgets and direct payments.

Full details of the evidence and the committee's discussion are in evidence review A: views and experiences of service users and evidence review K: barriers and facilitators of joined-up care.

1.6 Supporting parents and carers

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).

1.6.2 Consider using a person-centred planning approach, to help include parents and carers in care planning.

1.6.3 Ask families and carers how much they want to be involved in making decisions about care planning, because different families will want different levels of involvement.

1.6.4 The interagency team should consider providing information about the support options available to help parents plan for what will happen when they cannot care for their child (for example if they are too unwell, or after their death). Support options could include voluntary and community support, advocacy, or seeking independent legal advice.

Training for parents and carers

1.6.5 Education, health and social care services should consider jointly developing training for parents and carers.

1.6.6 In training for parents and carers, consider covering:

- helping them to understand and meet their child's needs
- helping them effectively support their child's preferred method of communication
- how the different services work and what support they can provide
- how to advocate for their child.

1.6.7 Tailor the level of training to the needs of each family. Ensure that the practitioners leading the training have the appropriate knowledge and skills (for example, a consultant might not be needed if the training is not going into detail on medical needs).

1.6.8 Consider using different teaching styles as needed, so the training is useful for all parents and carers.

1.6.9 Consider providing opportunities for parents and carers to discuss their experiences with each other during the training (for example with group activities or by setting time aside for free discussion), because this will help them to learn from each other and develop support networks.

1.6.10 Do not restrict training to a single point in time (for example at diagnosis). Let parents and carers take up training when they are ready for it, at different points in the child or young person's life. Regularly ask parents if they want to take up training (for example, at review meetings).

1.6.11 Consider making training sessions more accessible to parents and carers by:

- providing flexibility on training session times, locations, and formats
- scheduling training at times when the child or young person has pre-arranged care (for example, when they are at school).

1.6.12 Evaluate training (for example, by asking for feedback from parents and carers), to ensure it meets its objectives.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on supporting parents and carers, and training.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review D: supporting families and carers
- evidence review K: barriers and facilitators of joined-up care.

1.7 Social participation

1.7.1 Be aware that social participation:

- is as important as care and education for maintaining and improving the quality of life of disabled children and young people with severe complex needs
- is more difficult for children and young people who are not in education or work

- may justify a young person in attending school or college, even if they are unlikely to complete their course.

1.7.2 Local authorities should consider developing and funding group activities (for example sports or theatre) as part of their short break services. When developing these activities, they should work with other organisations (including voluntary and community organisations).

1.7.3 When local authorities are planning group social activities as part of short break services, they should:

- ensure there is a range of options to accommodate different cultural backgrounds and family circumstances
- think about access for those living in rural areas.

For statutory requirements on short breaks, see the guidance on short breaks: safeguarding the welfare of disabled children.

1.7.4 Education, health and social care services should adapt activities, communication formats, the physical environment and participation methods as needed to meet the needs of the children and young people who are attending.

1.7.5 Interagency teams should plan support to help children and young people to participate in social activities. This could involve:

- helping them make friends and access local community facilities
- helping them use the internet and social media to maintain their friendships and meet new people safely
- helping them to volunteer in the community.

1.7.6 Use short breaks for the benefit of the child or young person (for example, by running group social activities), as well as a break for families.

1.7.7 Health services should work with education and social care services to address children and young people's health needs flexibly, so they can join in with education and social activities alongside other children and young people.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on social participation.

Full details of the evidence and the committee's discussion are in evidence review F: supporting participation in education and social activities and evidence review K: barriers and facilitators of joined-up care.

1.8 Transition

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 for all disabled young people with severe complex needs, as specified in paragraph 8.9 of the Special educational needs and disability (SEND) code of practice.

1.8.2 When working with young people, interagency teams should:

- focus on the young person's goals for adulthood, instead of just treating health problems or providing short-term support
- help the young person to prepare for adult life and maximise their independence.

1.8.3 Do not assume that young people will have a clear plan for adulthood at the start of transition planning. Help them to understand the different options, and give them and their families enough information to make informed decisions.

1.8.4 Education, health and social care services should work with the young person to coordinate the age at which they transfer to adults' services, to ensure a consistent approach across sectors.

1.8.5 Interagency teams should work together to plan the transition between children's and adults' services for each young person. Each practitioner should read the sections of the plan produced by other practitioners, to make sure the plan works as a whole.

1.8.6 In transition reviews, make short-term goals (such as staying away from home overnight) as well as long-term goals (such as living independently).

1.8.7 Do not assume that all young people will go on to further education.

1.8.8 Plan well in advance of the transition to adults’ services to prepare young people for alternatives to education (for example, look at supported internships and community adult social care support).

1.8.9 For young people who are not continuing in education after age 18, see paragraphs 8.75 to 8.78 and 9.151 to 9.152 of the SEND code of practice.

1.8.10 When young people are approaching adulthood, explain to parents:

- how their child’s rights will change
- how their level of parental involvement and decision making may change.

1.8.11 When a young person is transferring from children’s to adults’ services, the named worker should:

- oversee and coordinate transition
- hand over their responsibilities as named worker to someone in adults' services.

1.8.12 During transition, give young people and their families and carers information about:

- the purpose and potential outcomes of the adult needs assessment
- the timing of appointments and when decisions will be made.
- which services will be involved in their care during and after transition.

1.8.13 For more guidance on transition, see:

- section 8 of the SEND code of practice (in particular paragraph 8.10)

- the NICE guideline on transition from children's to adults' services for young people using health or social care services, in particular the sections on:
  - person-centred approaches (recommendation 1.1.4)
  - named workers
  - involving young people in their transition planning
  - involving parents and carers in transition planning
  - support from the named worker before transition
  - planning and developing transition services
  - involving young people and their carers in service design (recommendation 1.1.1)
  - nominating senior executives and managers to develop and implement transition strategies (recommendation 1.5.1).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on transition.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review G: promoting inclusion, independence and wellbeing
- evidence review J: planning and managing transition from children's to adults' services
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

Recommendations on specialist support for disabled children and young people with particular needs

These recommendations cover specialist support on palliative care, communication aids, environmental adaptations and accessibility, travel training and employment. There are also recommendations on:

- general support for all disabled children and young people with severe complex needs
- service organisation, including working culture, training, integrated working and commissioning.

1.9 Palliative care

1.9.1 When making a palliative or end of life care plan for a disabled child or young person with severe complex needs, healthcare professionals should:

- tell the education and social care practitioners who are supporting the child or young person
- request a review of the education, health and care (EHC) plan (if they have one).

1.9.2 The interagency team should find out what further support family and carers need at each stage of the palliative and end of life care pathway.

1.9.3 Let the child or young person choose which support and activities to continue with. Keep providing these alongside the palliative care plan and end of life support.

1.9.4 When reviewing the EHC plan and other support the child or young person receives, focus on:

- maintaining things that the child or young person views as important, such as social activities and contact with friends (this includes seeing friends at school or college)

- addressing new problems or needs that have developed since palliative or end of life care started (for example, new health problems).

1.9.5 When a child or young person's needs change and new support is agreed, implement this as soon as possible, without waiting for the EHC plan to be finalised.

1.9.6 Education and social care practitioners should continue to be involved. They should adjust the support they provide in line with the palliative or end of life care plan.

1.9.7 Interagency teams should arrange regular joint reviews of the palliative or end of life care plan, because the child or young person's situation can change frequently.

1.9.8 Health services should consider providing training for education and social care practitioners, to help them understand how palliative and end of life care and parallel planning work. This training should be delivered by healthcare professionals with experience in providing palliative and end of life care for children and young people.

1.9.9 For more guidance on end of life care, see the NICE guideline on end of life care for infants, children and young people with life-limiting conditions. In particular, see the sections on:

- general principles and decision making
- care of the child or young person who is approaching the end of life
- preferred place of death.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on palliative care.

Full details of the evidence and the committee's discussion are in evidence review E: palliative and end of life care.

1.10 Communication aids

1.10.1 When conducting assessments for communication aids:

- think about how these would work across multiple settings (for example, if the child or young person can use the communication aid at school and at home)
- if possible, provide equipment to the child or young person rather than to a service they use (such as their school).

1.10.2 When a child or young person has been provided with a communication aid, education, health and social care services should:

- provide information to staff, and train them to support the child or young person and to make best use of the communication aid (the augmentative and alternative communication service can provide this training)
- ensure that staff know how to get support if the device is damaged or no longer fit for purpose
- agree who is responsible for maintaining, servicing and insuring the communication aid
- provide support during transition (for example, when the child or young person finishes education), so that they can continue using the communication aid in new environments and with new staff.

1.10.3 Education, health and social care services should train families and carers to use any communication aids their child is provided with.

1.10.4 Education, health and social care practitioners should tell children and young people who use augmentative and alternative communication technologies and their families and carers about any support and mentoring groups that could help them with communication and social interaction.

1.10.5 Education, health and social care services should tell their staff about local augmentative and alternative communication services, so that staff know to refer children and young people that meet the eligibility criteria.

1.10.6 Education, health and social care practitioners should refer disabled children and young people with severe complex needs to local specialised augmentative and alternative communication services if they meet the eligibility criteria.

1.10.7 Education, health and social care services should follow the referral process and eligibility criteria specified in the NHS England service specifications for augmentative and alternative communication services. Do not add requirements for referrals to be made by specific practitioners (such as occupational therapists), because this will cause delays.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on communication aids.

Full details of the evidence and the committee's discussion are in evidence review I: suitability and accessibility of environments.

1.11 Environmental adaptations

1.11.1 When an environmental adaptation has been made for a child or young person, education, health and social care services should:

- provide information and train staff on how to use the adaptation
- agree who is responsible for maintaining, servicing and insuring the adaptation.

1.11.2 Education, health and social care services should train families and carers to use any environmental adaptations their child is provided with, and check that they are competent to do so.

1.11.3 Education, health and social care practitioners should tell children and young people who use environmental adaptations and their families and carers about any support and mentoring groups that could help them with environmental accessibility and social interaction.

1.11.4 Education, health and social care services should tell their staff about environmental control services, so that staff know to refer children and young people that meet the eligibility criteria.

1.11.5 Education, health and social care practitioners should refer disabled children and young people with severe complex needs to local specialised environmental control services if they meet the eligibility criteria.

1.11.6 Education, health and social care services should follow the referral process and eligibility criteria specified in the NHS England service specifications for environmental control services. Do not add requirements for referrals to be made by specific practitioners (such as occupational therapists), because this will cause delays.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on environmental adaptations.

Full details of the evidence and the committee's discussion are in evidence review I: suitability and accessibility of environments.

Environmental accessibility

1.11.7 Be aware that there is existing best practice and statutory guidance on environmental accessibility (for example, the Royal College of Occupational Therapists guide to planning and delivering home adaptations, and UK building regulations on access to and use of buildings). Examples of environmental accessibility adaptations include:

- disabled access for children and young people who use mobility aids and devices
- space to use and to store environmental control equipment
- suitable toilets
- lighting and acoustic adaptations, to avoid distractions or distress.

1.11.8 Education, health and social care providers should conduct regular accessibility assessments (at least annually) of their services, looking at the physical environment (including sensory aspects and whether the environment is child or young person friendly) and staff knowledge of disability and accessibility. Charities and support organisations can provide advice on what changes are needed (for example, see the National Autistic Society accreditation scheme).

1.11.9 Education services should make the results of these accessibility assessments publicly available.

1.11.10 Health and social care services should consider making the results of these accessibility assessments publicly available.

1.11.11 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.

1.11.12 When conducting assessments for environmental adaptations:

- think about how these would work across multiple settings (for example, whether the child or young person can use a switch at school and at home)
- if possible, provide equipment to the child or young person rather than to a service they use (such as their school).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on environmental accessibility.

Full details of the evidence and the committee's discussion are in evidence review I: suitability and accessibility of environments.

1.12 Travel training

1.12.1 Local authorities should help all disabled children and young people with severe complex needs use transport (to help them get anywhere they need to go, not just to school). They should consider providing a training framework to achieve this. Local authorities could develop their own training programmes as part of this framework, or use existing ones (such as ASDAN's Using transport).

1.12.2 Local authorities should ensure that services implement the training framework.

1.12.3 Public transport providers must provide disability awareness training for their staff.

1.12.4 Travel training could cover:

- assessing the child or young person's mobility skills and identifying problems they will have with using public transport
- assessing and managing risks
- route planning
- mobility and traffic awareness
- having someone accompany the child or young person until they are used to the route
- travelling with parents and carers, for children and young people who will not be able to travel on their own
- how communication aids can help, if the child or young person uses them
- how to safely ask for help when something goes wrong.

1.12.5 Local authorities should provide parents, carers and relevant professionals (such as teachers) with information to help them better support children and young people who are using public transport (for example, independent travel training, availability of concessionary fares).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on travel training.

Full details of the evidence and the committee's discussion are in evidence review I: suitability and accessibility of environments.

1.13 Employment

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. For more information on the Gatsby benchmarks, see the Department for Education's statutory guidance on careers guidance and advice.

1.13.2 Local authorities and commissioners should ensure that supported internship programmes are available in their local area for young people, to help them develop job searching and employability skills and support them into employment.

1.13.3 When commissioning employment support services for young people, local authorities should include a requirement in the service specification to provide a lead employment practitioner (for example a job coach) for each young person who is going to undertake a supported internship. This practitioner should have the authority to coordinate work and direct the interagency team on issues related to employment.

1.13.4 When commissioning employment support services for young people, local authorities should consider including a requirement in the service specification to provide a lead employment practitioner (for example a job coach) for each young person who has employment as an outcome in their EHC plan.

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). Follow this up with more specific discussions, and direct the young person and their family and carers to relevant sources of information.

1.13.6 Education, health and social care practitioners should consider making a vocational profile with young people who are considering employment by the time they are ready to move into post-16 education, to identify their skills and what they want to do in the future.

1.13.7 Education, health and social care practitioners should work together when planning employment support and consider that young people may need to be involved in:

- travel training, to help young people prepare for a work commute
- developing communication passports or communication plans to support the young person at work
- planning for the young person's personal care needs at work
- planning for how they can help young people with anxiety about starting work
- training for employers, to help them communicate with and support the young person at work.

1.13.8 Supported internship providers should help disabled young people to find work by:

- creating links with local employers, so they can identify job opportunities, address employer misconceptions about disabled young people, and explain what on-the-job support the interagency team can provide
- contacting relevant support groups.

1.13.9 Following a supported internship, and before ceasing the EHC plan, the current provider should work with the prospective employer to plan next steps for the young person after the internship ends:

- agree what changes will happen, and when
- agree who the young person can go to for help

- look for ways the young person can use their experience from the internship in their job.

1.13.10 Local authorities should include information about support workers and job coaches in their Local Offer, so that young people, their families and prospective employers know what help and resources are available. Funding for support workers and job coaches is available through the Department for Work and Pensions' Access to work scheme.

1.13.11 Encourage employers to train and appoint workplace buddies for disabled young people who are not their line manager.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on employment.

Full details of the evidence and the committee's discussion are in evidence review H: preparation for employment.

Recommendations on working culture, training, service organisation, integration and commissioning

These recommendations cover service organisation, including working culture, training, integrated working and commissioning. There are also recommendations on:

- general support for all disabled children and young people with severe complex needs
- specialist support, covering palliative care, communication aids, environmental adaptations and accessibility, travel training, and employment.

1.14 All education, health and social care practitioners

Working culture

1.14.1 Education, health and social care practitioners should collaborate to develop a positive working culture and:

- take time to develop positive relationships with each other
- treat everyone involved in the care of the disabled child or young person with severe complex needs as equals
- encourage open discussion
- be sensitive and constructive when challenging someone else's professional opinion.

Organising handovers

1.14.2 If the key practitioners involved need to change, organise a handover to avoid disruptions in care. Update any new practitioners on the child or young person's history, and tell the child or young person and their family about the change.

Learning about other practitioners and services

1.14.3 Practitioners should learn about the responsibilities of other people and services involved in the education, health and care (EHC) needs assessment, review and re-assessment processes. They should use this knowledge to provide more wide-ranging and coordinated support and advice (outside their own specialty) to children and young people and their families and carers, and to reduce the number of different people the family have to contact.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on all education, health and social care practitioners.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers.

1.15 Education, health and social care services

These recommendations also apply to local authorities when they provide services.

Working culture

1.15.1 Education, health and social care services and managers should ensure that practitioners have dedicated time for team and relationship building.

Organising interagency teams

1.15.2 Education, health and social care services should:

- organise all the practitioners working with the child or young person into an interagency team
- ensure that interagency teams include practitioners with the skills and experience to address all of the child or young person's needs (from birth to 25 years).

1.15.3 Education, health and social care services should develop policies for resolving disagreements that arise within interagency teams.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on education, health and social care services.

Full details of the evidence and the committee's discussion are in evidence review G: promoting inclusion, independence and wellbeing and evidence review K: barriers and facilitators of joined-up care.

Key working support

1.15.4 Local authorities should adopt a key working approach, as specified in paragraph 2.21 of the Special educational needs and disability (SEND) code of practice. The code specifies that the main functions of key working support should include some or all of the following:

- emotional and practical support as part of a trusting relationship
- enabling and empowering for decision making and the use of personal budgets
- coordinating practitioners and services around the child or young person and their family and carers
- facilitating multi-agency meetings
- being a single point of regular and consistent contact
- supporting and facilitating a single planning and joint assessment process
- identifying strengths and needs of family members
- providing information and signposting
- advocating on behalf of the child or young person and their family and carers
- facilitating the seamless integration of clinical and social care services with specialist and universal services.

1.15.5 The level of key working support for disabled children and young people with severe complex needs should:

- be flexible
- be tailored to individual needs (some children and young people will need more of the support detailed in recommendation 1.15.4, and some will need less)
- take account of their family circumstances.

1.15.6 Senior managers in education, health and social care services should work together to ensure that:

- each disabled child and young person with severe complex needs has a practitioner providing them with key working support
- these practitioners have the training, time and resources needed to provide this support, taking into account their other commitments.

1.15.7 Managers should ensure that interagency team members understand what key working support involves.

1.15.8 The practitioner who is assigned to provide key working support should:

- become part of the interagency team
- be someone the child or young person is comfortable with
- get to know the child or young person well and understand their needs
- be identified based on the child or young person's individual needs and preferences (for example, if they mainly have healthcare needs then a healthcare practitioner would be best).

1.15.9 Provide children and young people and their families with contact details for the practitioner providing them with key working support.

1.15.10 Interagency teams should work with managers to assign a practitioner to provide key working support for each child and young person.

1.15.11 Practitioners providing key working support should:

- coordinate meetings, timings and records between the different services involved, and with the child or young person and their family

  and carers (this should not be left to parents or carers to arrange themselves)
- keep other practitioners updated with changes in the child or young person's care (for example, by sharing hospital letters with their school)
- help the child or young person and their family and carers to navigate services
- be available for discussions between reviews and meetings if the child or young person has questions or needs more support.

1.15.12 If the practitioner who provides key working support needs to change, managers should:

- work with the interagency team to assign a new practitioner (chosen based on the child or young person's needs and preferences, and not just because they do the same job as the old practitioner)
- organise a handover
- ensure the new practitioner is updated on the child or young person's history, preferences, goals and ambitions.

1.15.13 Practitioners who provide key working support should support families when they move area (in particular, to help families who move area regularly), by:

- identifying practitioners in their new area to share relevant information with, to ensure continuity of care and support
- giving a copy of this information to the child or young person and their family and carers.

1.15.14 Managers should have a contingency plan for how to maintain consistency if the practitioner providing key working support leaves.

1.15.15 Education, health and social care services should have governance and information sharing arrangements in place to ensure that practitioners providing key working support can work effectively with all the different organisations involved.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on key working support.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers
- evidence review N: commissioning, practice and service delivery models.

Making processes easier to understand

1.15.16 Education, health and social care services should consider looking for ways to make what they do and how they work together more transparent to children and young people.

For a short explanation of why the committee made this recommendation, see the rationale and impact section on making processes easier to understand.

Full details of the evidence and the committee's discussion are in evidence review K: barriers and facilitators of joined-up care.

Training

1.15.17 Education, health and social care services should consider training practitioners to understand the roles of other people and services involved in the care of children and young people.

1.15.18 Education, health and social care services should work with local authorities to provide training for education practitioners on how to include and support disabled children and young people with severe complex needs in mainstream education.

1.15.19 Education, health and social care services should provide training for practitioners to help them recognise:

- social, emotional and mental health needs

- internalising symptoms (such as anxiety and depression).

1.15.20 Education, health and social care services should work together to develop joint training for all practitioners on:

- working with disabled children and young people with severe complex needs
- taking their views into account, and supporting them to achieve their life goals
- how to adapt communication for children and young people with communication difficulties
- use of communication aids.

1.15.21 Education, health and social care services should consider running training workshops for practitioners from all 3 sectors, covering needs that are present in all settings (for example, safe eating and drinking, personal care and language development).

1.15.22 Education, health and social care services should provide practitioners with opportunities to observe practitioners from different sectors working with the child or young person.

1.15.23 Education, health and social care services should work together to ensure that staff understand:

- how their contributions affect education, health and care (EHC) needs assessments
- how the contributions of individual staff fit together to show what support the child or young person needs
- how their contributions will affect the EHC plan outcomes that will be agreed for the child or young person.

Involving parents and carers in developing training

1.15.24 When developing awareness training programmes, involve parents and carers in:

- deciding what to cover in the training
- deciding how to structure and evaluate it
- delivering the training.

Cross-sector placements

1.15.25 Education, health and social care services should consider providing short-term placements for practitioners from other sectors (as part of induction and then annually). Design these placements to help practitioners learn about children and young people's needs in different contexts, and to understand how other services work to meet those needs.

1.15.26 Services that provide short-term placements should ensure that interagency teams have a process for providing these short-term placements (for example, they have identified work for practitioners on placement).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on training.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review D: supporting families and carers
- evidence review K: barriers and facilitators of joined-up care
- evidence review L: enabling professionals to meet needs of children and young people
- evidence review M: views and experiences of service providers.

Competency in delegated clinical tasks

1.15.27 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. In particular, services must:

- only train support workers to carry out clinical tasks if these workers are employed and insured for these tasks, and accountable for their professional conduct
- after delivering training, actively assess the competency of support workers to carry out delegated clinical tasks at the required standard
- ensure that ongoing clinical supervision arrangements are in place for support workers.

1.15.28 For support workers who have been delegated clinical tasks by healthcare practitioners, employers 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. In particular, employers must:

- ensure support workers are competent to carry out these tasks
- ensure the type of delegated work they are expected to carry out is specified in their job descriptions
- put indemnity insurance in place for delegated healthcare tasks
- ensure that training providers or other suitable organisations will provide ongoing supervision of support workers when a clinical competency must be assured to be at a required standard
- agree a joint incident investigation policy with relevant education, health and social care partner organisations, covering:
  - reporting of incidents
  - who will lead investigations
  - when a collaborative investigation is needed.

1.15.29 For parents and family members who have been delegated clinical tasks, healthcare practitioners must follow guidance from the Care Quality Commission, the Nursing and Midwifery Council, the Royal College of Nursing, and other professional governance organisations allied to medicine. In particular, practitioners must:

- train parents to undertake delegated clinical tasks and use any equipment needed to undertake these tasks

- after training, actively assess the competence of parents to carry out delegated clinical tasks at the required standard
- provide parents with ongoing clinical support from an agreed named contact
- set up a process for parents to report problems.

Feedback

1.15.30 Education, health and social care services should jointly request feedback from children and young people and their families and carers on how well they have worked together with the other services involved in their care and support.

1.15.31 Services should jointly request feedback from children and young people and their families and carers on how well they worked together with them.

1.15.32 Services should have processes in place for addressing the feedback of young people and their families and carers, if they are not satisfied with the support they have received.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on competency in delegated clinical tasks and feedback.

Full details of the evidence and the committee’s discussion are in evidence review A: views and experiences of service users and evidence review K: barriers and facilitators of joined-up care.

1.16 Interagency teams

Meeting needs in all settings

1.16.1 Interagency teams should ensure that the child or young person’s needs are met in all settings (for example, if they have communication difficulties, make sure they have support at home and in school).

Sharing knowledge within the team

1.16.2 Interagency team members should share their experiences of supporting the disabled child or young person within the team, so they can learn from each other and gain a broader understanding of the needs of the child or young person.

1.16.3 In interagency team meetings, members should share specialist knowledge and sources of support with practitioners outside of their speciality. This could include:

- changes in clinical practice, legislation or statutory guidance
- particular caring techniques
- professional networks
- other organisations that can provide support (such as patient organisations).

Resolving disagreements within the team

1.16.4 Interagency teams should follow the processes for resolving disagreements between different practitioners on the team (see recommendation 1.15.3).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on interagency teams.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review G: promoting inclusion, independence and wellbeing
- evidence review K: barriers and facilitators of joined-up care
- evidence review L: enabling professionals to meet needs of children and young people.

1.17 Local authorities and health commissioners

1.17.1 When commissioning education, health and social care services for disabled children and young people with severe complex needs:

- focus on early multi-agency involvement to identify, assess and address needs
- only make long-distance placements if all options to provide care and support close to home and within their community are exhausted
- specify outcomes in contracts, and avoid contracts that only describe what services should be provided
- think about how each service will fit in and work with other services, and how commissioning changes in one service may affect other services and the ability to provide integrated education, health and social care support.

1.17.2 Local authorities and health commissioners should plan how funding and services will be organised across education, health and social care for young people once they turn 18, to ensure continuity of support.

1.17.3 Do not restrict access to services based solely on:

- what support people have previously received
- whether or not they have a particular diagnosis, or no diagnosis at all (unless there is a medical reason for these restrictions).

1.17.4 Do not reprioritise children and young people who are having an education, health and care (EHC) needs assessment solely to meet organisational targets or statutory deadlines.

Making referral and joint working easier

1.17.5 Commissioners, local authorities and service providers should make referral and joint working easier by:

- establishing clear processes for referring children and young people between services
- making information about these processes easily available, so practitioners know how and when to make a referral.

Involving children, young people, parents and carers in planning services

1.17.6 When commissioning education, health and social care services, commissioners must:

- consult children and young people and their parents and carers, to ensure services meet the needs of the local population (as specified in paragraph 1.11 of the Special educational needs and disability (SEND) code of practice)
- involve disabled children and young people and their parents and carers in planning services (as specified in paragraph 3.18 of the SEND code of practice).

1.17.7 Commissioners should also:

- work with children, young people and their parents and carers to ensure their participation is effective and their role in planning is clear (as specified in paragraph 1.12 of the SEND code of practice)
- focus on outcomes and personalised services.

1.17.8 Involve disabled children and young people in the review of existing services, by asking for their feedback on how services are working.

Commissioning based on the needs of children and young people

1.17.9 For guidance on identifying the needs of children and young people, and on joint strategic needs assessments, see paragraphs 3.20 to 3.24 of the SEND code of practice.

1.17.10 Commission services based on the needs of children and young people, rather than expecting them to just use the services that already exist.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on local authorities and health commissioners.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users
- evidence review C: combined approaches to identifying, assessing and monitoring needs
- evidence review K: barriers and facilitators of joined-up care
- evidence review M: views and experiences of service providers
- evidence review N: commissioning, practice and service delivery models.

Coordinating EHC plan process changes with local services

1.17.11 Local authorities should consider notifying services before making changes to their processes for producing EHC plans (for example, changes in the plan format or the information they require from practitioners).

1.17.12 Local authorities should consider consulting services on these changes, if they can do this without delaying support or assessments for children and young people.

Training

1.17.13 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
- how to write an EHC plan.

Short breaks

1.17.14 Local authorities must provide a range of short break options for disabled children and young people with severe complex needs, as specified by paragraphs 4.44 to 4.45 of the SEND code of practice.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on coordinating EHC plan process changes with local services, training and short breaks.

Full details of the evidence and the committee's discussion are in evidence review D: supporting families and carers and evidence review K: barriers and facilitators of joined-up care.

What to include in the Local Offer

1.17.15 Local authorities should include the following in their Local Offer:

- an explanation of their EHC needs assessment process, including:
  - any thresholds or eligibility criteria
  - making it clear that EHC needs assessments should be requested based on a child or young person's needs, and not on other factors such as potential availability of funding
- details of what services are available, and the roles of the different services and practitioners
- a list of support groups for disabled children and young people who use assistive technologies
- details of the leisure activities (including social activities) and related support available to disabled children and young people
- details of the employment support they offer disabled young people.

1.17.16 Tell children, young people and their families that they can give feedback on the Local Offer (for more information, see paragraphs 4.8 to 4.13 of the SEND code of practice).

For a short explanation of why the committee made these recommendations, see the rationale and impact section on what to include in the Local Offer.

Full details of the evidence and the committee's discussion are in the evidence reviews:

- evidence review A: views and experiences of service users

- evidence review F: supporting participation in education and social activities
- evidence review H: preparation for employment
- evidence review I: suitability and accessibility of environments
- evidence review K: barriers and facilitators of joined-up care.

1.18 Improving how local authorities, commissioners and services work together

1.18.1 Integrated care systems and local authorities should develop a joint commissioning framework to use when commissioning services across education, health and social care.

1.18.2 Commissioners should specify in their contract requirements that education, health and social care services should work together in an integrated way to support disabled children and young people with severe complex needs.

1.18.3 Senior managers in education, health and social care services should have formal processes in place to support interagency team working (see the recommendations on decision making and information sharing and privacy).

1.18.4 Education, health and social care providers should make arrangements or agreements setting out how they will work together in an integrated way to support disabled children and young people with severe complex needs.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on improving how local authorities, commissioners and services work together.

Full details of the evidence and the committee's discussion are in evidence review G: promoting inclusion, independence and wellbeing and evidence review N: commissioning, practice and service delivery models.

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions, see the NICE glossary and the Think Local, Act Personal Care and Support Jargon Buster.

Augmentative and alternative communication (AAC) services

Services that help people with significant communication impairment. For more information, including eligibility criteria, see the NHS England service specification for specialised AAC services.

Awareness training programmes

Any training programme that is:

- for parents and carers **or**
- for practitioners, but is focused on helping them work more effectively with the child, young person and their family or carers.

Disabled children and young people with severe complex needs

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.

Some recommendations in this guideline may be difficult or impossible to implement for babies or very young children. However, it is also difficult to give useful age cut-offs for particular recommendations. Children develop at different rates, and their development rate will be affected by their specific disabilities and health conditions. Any age cut-offs risk mistakenly excluding and disadvantaging some children. If a particular recommendation is not appropriate for a baby or young child, it is still important to involve them as far as possible in discussions and decisions about their care and support. For more information, see:

- recommendation 1.1.37
- NICE's guideline on babies, children and young people's experience of healthcare.

Environmental control services

Services that help people with complex physical disabilities to make modifications to their environment. For more information, see the NHS England service specification for environmental control services.

Interagency team

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.

Local authorities

This includes individual and combined local authorities.

Named worker

This refers to the named worker as defined in the NICE guideline on transition from children's to adults' services.

Parallel planning

Planning for end of life care while taking account of the often unpredictable course of life-limiting conditions. It involves making multiple plans for care, and using the one that best fits the child or young person's circumstances at the time.

Supported internships

A study programme designed for young people who are aged 16 to 24 and who have an education, health and care plan. It provides them with the extra support they need to find employment. The internship includes support from a job coach.

Supported internships are primarily based with an employer, and are normally designed to lead to a job when they finish. Because of this, a supported internship is usually the final year of education for a young person.

For more information, see the guidance on supported internships from the Department for Education.

Support workers

Anyone other than a family member who has been delegated clinical tasks (including teachers, teaching assistants and other staff in education or care settings).

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Assistive technology

How effective is assistive technology in enabling disabled children and young people with severe complex needs to express their views to education, health, and social care services?

For a short explanation of why the committee made this recommendation, see the rationale section on communication aids.

Full details of the evidence and the committee's discussion are in evidence review G: promoting and maintaining inclusion, independence and wellbeing.

2 Environmental adaptations

What are the most effective environmental adaptations to ensure the suitability and accessibility of the settings where disabled children and young people with severe complex needs receive education, health and social care support?

For a short explanation of why the committee made this recommendation, see the rationale section on environmental accessibility.

Full details of the evidence and the committee's discussion are in evidence review I: suitability and accessibility of environments.

3 Dedicated key workers

What is the effectiveness of dedicated key workers for delivering joined-up services to meet the education, health and social care needs of disabled children and young people with severe complex needs?

For a short explanation of why the committee made this recommendation, see the rationale section on key working support.

Full details of the evidence and the committee's discussion are in evidence review N: commissioning, practice and service delivery models.

4 Care close to home

What are the most effective commissioning, practice and service delivery models to deliver joined-up services to meet the education, health and social care needs of disabled children and young people with severe complex needs while enabling them to stay close to home?

For a short explanation of why the committee made this recommendation, see the rationale section on local authorities and health commissioners.

Full details of the evidence and the committee's discussion are in evidence review N: commissioning, practice and service delivery models.

5 Short break services

What components of short break services are most effective for disabled children and young people with severe complex needs and their families and carers?

For a short explanation of why the committee made this recommendation, see the rationale section on short break services.

Full details of the evidence and the committee's discussion are in evidence review D: supporting families and carers.

Other recommendations for research

Telehealth and virtual platforms

What is the effectiveness of telehealth and virtual platforms for communicating with disabled children and young people with severe complex needs and providing education, health and social care interventions?

For a short explanation of why the committee made this recommendation, see the rationale section on involving children and young people and their families.

Full details of the evidence and the committee's discussion are in evidence review B: involving children and young people.

Joint commissioning arrangements

What are the most effective joint commissioning arrangements for disabled children and young people with severe complex needs?

For a short explanation of why the committee made this recommendation, see the rationale section on local authorities and health commissioners.

Full details of the evidence and the committee's discussion are in evidence review N: commissioning, practice and service delivery models.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice and services.

Recommendations on support for all disabled children and young people with severe complex needs

Principles for working with children, young people and their families

Recommendations 1.1.1 to 1.1.8

Why the committee made the recommendations

There was moderate-quality qualitative evidence that:

- service providers do not always use a person-centred approach, and do not adequately capture the child or young person's perspective
- the potential of children and young people may be underestimated, while good education, health and care (EHC) plans should recognise their aspirations and think about long-term options.

The SEND code of practice also highlights the importance of supporting children and young people to achieve their ambitions.

There was moderate and high-quality evidence that parents and carers felt positive when given the chance to provide their views, and that they felt negative when their views were ignored.

There was moderate-quality qualitative evidence that disabled children and young people and their families and carers value a person-centred approach. Despite this, in the committee's experience, children and young people are often not invited to meetings and are not actively included if they do attend. The qualitative evidence highlighted multiple benefits from involving children and young people in their care and support:

- there was low-quality evidence that this made them feel more positive
- there was moderate-quality evidence that it made them show more confidence
- there was moderate-quality evidence that their involvement gives practitioners a more accurate understanding of their needs, goals and ambitions.

In the committee's experience, it is important to find out which family members need to be involved (for example, when a family member other than a parent has parental responsibility). They made a recommendation to cover this, so that practitioners do not make assumptions about family roles and structure.

There was moderate-quality qualitative evidence that drawing on the experience and expertise of families and carers would improve knowledge of the child or young person's needs. This is important, because there was also qualitative evidence of negative consequences when the child or young person's needs are not well understood.

Moderate-quality qualitative evidence showed that it is important to focus on the views of the children or young person, because these can differ from the views of their parents. In the committee's experience, parents and carers need to be encouraged and supported to help their child express their own views.

In the committee's experience, and in light of the moderate-quality qualitative evidence previously discussed, it is important to regularly ask children and young people and their families and carers if they are satisfied with how they have been involved in decisions about their support, so that involvement is beneficial and not just tokenistic. And when children and young people are not satisfied with their involvement it is equally important to find ways to address their concerns. The committee were not able to specify a time frame for doing this because it would depend on the services and support being received.

There was moderate-quality qualitative evidence that children and young people wanted practitioners to use the same practices that their families and carers had been using to care for them at home. The committee agreed that this consistency was important if the practices used have been beneficial.

There was no evidence on the effectiveness of telehealth or virtual platforms for supporting disabled children and young people with severe complex needs. Therefore, the committee made a recommendation for research in this area.

How the recommendations might affect practice

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.

Return to recommendations

Communication formats and providing information

Recommendations 1.1.9 to 1.1.19

Why the committee made the recommendations

There was low-quality qualitative evidence that children and young people and their families and carers appreciated when practitioners adapted their communication styles to suit the topic of conversation, and moderate-quality qualitative evidence that non-judgemental and non-directive communication was valued. Based on their experience, the committee agreed that practitioners do not always deal with sensitive conversations effectively and that it was important to prompt practitioners to be empathetic and supportive. This style of communication will help to address the family's feelings and help them to process the information they receive.

Low-quality qualitative evidence also showed that a flexible approach to communication was important, taking into account the child or young person's age, developmental level and communication skills. Although this evidence was low quality, the committee were confident that having a flexible approach was necessary to enabling children and young people to express their views, which is one of the key principles underpinning the SEND code of practice. In the committee's experience, finding the child or young person's preferred communication format is particularly important, because this group is more likely to have communication difficulties and to use communication aids.

There was moderate-quality qualitative evidence that language barriers made it difficult for parents to find out about available services, and that more support was needed to help them understand and access support that was available. In the committee's experience parents and carers may also have disabilities or communication difficulties that make it more difficult for them to communicate with practitioners and understand information.

There was qualitative evidence on communication formats and providing information:

- there was low-quality evidence that children and young people and their families and carers needed more information and advice
- there was moderate-quality evidence that the advice they received was limited
- there was high-quality evidence that the advice they received was often based on outdated information.

The committee agreed that it is important to provide enough up-to-date information, support and advice to allow people to make more informed decisions. Based on the qualitative evidence and their experience, they highlighted areas where children and young people and their families and carers commonly wanted more information.

The recommendation on directing children and young people and their families and carers to sources of support and advice is based on:

- the SEND code of practice, which:
  - requires local authorities to provide information on special educational needs, and mentions Send Information, Advice and Support Services as an option for providing this information
  - specifies that the Local Offer must include information about forums for parents and carers and support groups
- moderate-quality qualitative evidence that children and young people benefited from speaking to peers who had experience with the education, health and care system.

In the committee's experience, practitioners providing information on peer support groups would have a professional duty of care to make sure that any sources of support they provide are quality-assured.

Moderate-quality qualitative evidence indicated that children and young people did not receive the level of support or involvement that they had expected from services. The committee agreed that practitioners needed to find out what expectations people had, in order to provide the support they wanted (if possible) and help them to understand what services can do. When it is not possible to meet people's expectations, it is also important to explain the reasons for this.

How the recommendations might affect practice

Practitioners might need more time to communicate with children and young people (depending on their preferred communication format) and their families and carers, and to find out about their expectations. This could mean that some more time is required for preparation, and consultation times are longer, which could create a resource impact for services. However, if practitioners spend more time helping children and young people to communicate and understand what services can do, they are likely to have fewer queries, complaints and problems, resulting in time savings later on from practitioners not having to address these. Training may be needed if the preferred communication method requires specialist knowledge.

Services across education, health and social care will have to establish processes to share information and to allow more coordinated and joined-up working. Interagency training may also be needed, to ensure that practitioners understand relevant policies and processes and the role of other practitioners and services.

Return to recommendations

Planning and running meetings with children and young people

Recommendations 1.1.20 to 1.1.34

Why the committee made the recommendations

Low-quality qualitative evidence showed that children and young people are better able to communicate their views if they are given help to understand their options and prepare for meetings. In the committee's experience, if parents and carers discuss meetings with their child in advance, they can prepare in a more relaxed home environment. This also allows parents and carers to better understand their child's views in advance of the meeting.

These recommendations align with the SEND code of practice, which specifies that 'local authorities must ensure that children, young people and parents are provided with the information, advice and support necessary to enable them to participate in discussions and decisions about their support… including time to prepare for discussions and meetings'.

The committee also recommended helping parents and carers to complete documents before meetings because in their experience this can be difficult and confusing, and meetings may be dominated by completing paperwork if this has not been done in advance.

In the committee's experience, children or young people are more likely to be motivated to participate in meetings if the issues being discussed are ones that are important to them. Therefore it is important to get this information ahead of meetings. It is also crucially important that children and young people are able to meaningfully participate in decisions about their care and support, and this is one way to achieve this.

Qualitative evidence showed that children and young people had various levels of ability that affected their level of involvement and understanding. The committee agreed it was important to establish the age, communication ability and circumstances of the child or young person in advance of meetings, to ensure that they can meaningfully participate.

There was moderate-quality qualitative evidence that:

- children and young people want practitioners to make more effort to respect their privacy
- children and young people may be able to better communicate their views in smaller meetings or one-on-one
- attending meetings can be intimidating for children and young people.

Based on this evidence, and their own experience, the committee highlighted ways that the structure and content of meetings could be improved (for example, having meetings in a place where the child or young person feels comfortable). The committee were confident that these recommendations would enable children and young people to participate more effectively in meetings and understand what is happening – both of which are key to their involvement in making informed decisions.

In response to moderate-quality qualitative evidence that practitioners do not always take a person-centred approach to meetings, the committee recommended considering the use of person-centred planning tools. In their experience, these tools help ensure that planning is based on information from the child or young person about their needs, wishes and what is important to them. This stops practitioners from making generic assumptions and taking prejudiced attitudes towards the child or young person as a result of their condition. These tools also focus on developing a plan to deliver the outcomes desired by the child or young person. Using a person-centred approach is specified in the SEND code of practice as a way to ensure that children, young people and parents are involved in all aspects of planning and decision making.

In the committee's experience, disabled children and young people with severe complex needs may need more time to process information and communicate their views. They may also give very brief answers to questions, and may need encouragement and additional time to expand on these. The committee were confident that giving them adequate time to express their views was necessary to ensure their meaningful involvement in meetings. Children and young people also need to be supported to communicate using their preferred method. Identifying their preferred communication method is particularly important, because this group is more likely to have communication difficulties and to use communication aids. In the committee's experience, children, young people and their families and carers benefit if meetings are recorded, because this gives them more time to process information.

There was moderate-quality qualitative evidence highlighting the importance of respecting children and young people's rights to privacy and that attending meetings with large numbers of professionals can be intimidating. Therefore, the committee made recommendations to reflect this.

There was moderate-quality qualitative evidence that agreeing actions in front of other practitioners and parents improved accountability and made it more likely that practitioners would follow through on agreed actions.

There is an emphasis in the SEND code of practice on integrated working, but moderate-quality qualitative evidence showed that practitioners are often not collaborating effectively and either do not attend interagency meetings or do not prepare for meetings in advance. In the committee's experience, it is crucial that practitioners who know the child or young person and are involved in their support make all reasonable efforts to attend meetings. These practitioners need to come from all services involved, in order for the support provided to be fully integrated. However, the committee acknowledged that this may not always be possible. They used their experience to highlight:

- factors to consider when deciding whether to go ahead with a meeting if a key practitioner cannot attend

- ways to reduce the impact if the meeting does go ahead without a key practitioner.

The committee believe that siblings and friends have a different perspective to the practitioners caring for a disabled child or young person with severe complex needs. This different perspective can improve the practitioners' understanding of the child or young person, and can demonstrate strengths and interests that the practitioners have not observed. This enables a broader view of what the child or young person is capable of, so practitioners can make better judgements about their future abilities and adjust outcomes accordingly. Based on this, the committee agreed that children and young people should have the opportunity to invite siblings or friends to share their views.

Moderate-quality qualitative evidence indicated 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 multidisciplinary and interagency team 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.

How the recommendations might affect practice

Practitioners might need more time to plan how to involve children and young people in discussions and meetings. Meetings may also need to be longer, with more breaks, potentially taking more time. However, this should result in children and young people being able to more effectively participate and engage in discussions and decisions about their care and support, saving time later on by leaving fewer problems to deal with. Engagement with care will positively impact their care and outcomes and will outweigh any additional costs. In addition, if care is not person-centred, children and young people may end up with support that does not meet their needs. This may cost services much more further down the line.

Holding review meetings outside of a school day might result in health and social care practitioners working alternative hours, and schools will need to negotiate patterns of annual directed time flexibly, including allowing teachers to use their planning, preparation and assessment time if meetings have to be held outside of the school day.

Services that want to record meetings may have to buy equipment to do this. However, the recommendations allow them to use written records instead if needed.

Return to recommendations

Using a consistent approach

Recommendation 1.1.35

Why the committee made the recommendation

There was moderate-quality qualitative evidence that using a consistent approach when interacting with children and young people was beneficial, in terms of making services more predictable across education, health and social care. This aligned with the experience of the committee that interacting in a consistent way helps children and young people know what to expect and feel more safe and confident in their interactions with services, so they made a recommendation in support of this.

How the recommendation might affect practice

Services across education, health and social care services will have to share knowledge about the child or young person’s preferences, such as method of communication, way they like to be addressed, how they express agreement or disagreement, and positive behaviour support, so that all practitioners can use this consistently.

Return to recommendations

Decision making

Recommendations 1.1.36 to 1.1.41

Why the committee made the recommendations

There was moderate-quality qualitative evidence that parents did not always feel comfortable making decisions about their child's care, because they sometimes lacked the knowledge and expertise to do so. The committee believe it is very important for children and young people and their parents and carers to be involved in decision making as much as they are able to, so they made a recommendation in support of this. This recommendation also aligns with the SEND code of practice.

In some situations children will be unable to formulate a view. The committee wanted to ensure that practitioners still tried to identify their preferences in these situations, to ensure their care and support is appropriate and to meet the requirement in the SEND code of practice to establish the views of children and young people.

The SEND code of practice specifies that the views of parents must not be used as a proxy for the views of the child or young person, and that practitioners should work impartially to address disagreements. However, the committee agreed that this is not consistently done in practice. In particular, members of the committee who had been through this process themselves as young people explained that they were sometimes ignored, with practitioners assuming they did not understand and primarily addressing their parents.

The SEND code of practice briefly covers what to do when disagreements between parents and their children cannot be resolved. There is also other relevant legislation and guidance on consent (such as the Mental Capacity Act and guidance from professional governance organisations). However, the committee are aware that practitioners need more guidance, as issues around decision making are complicated and practitioners are not always well informed in this area. The committee made recommendations to help practitioners when disagreements between parents and children or young people cannot be resolved, or when there are capacity issues.

How the recommendations might affect practice

The guidance in this area will make practice more consistent. Practitioners might need more time to communicate with children and young people, provide them with information, and help them formulate their views. Additional time may also be needed for getting the views of parents and carers, resolving disagreements and reaching shared decisions. However, if practitioners spend more time helping children and young people to communicate, they are likely to be more engaged with the process and have fewer queries, complaints and problems, resulting in time savings later on.

Return to recommendations

Information sharing and privacy

Recommendations 1.1.42 to 1.1.48

Why the committee made the recommendations

There was moderate and high-quality 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
- 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)
- it was important to respect children and young people’s rights to privacy and rights to be involved in decisions
- not all services could access online electronic patient records, and that practitioners believed that being able to access these records would improve joint working, information sharing, and identification of severe complex needs in disabled children and young people.

The committee agreed that information sharing does not always happen effectively and that concerns about confidentiality, privacy, consent and security can have an impact. They therefore made recommendations to promote effective information sharing and address the concerns highlighted by the evidence.

The committee noted that while individual services have electronic patient record systems, there is no interagency record system across education, health and social care. This kind of system could be very useful, but it would be very expensive to develop and there would be data protection issues to consider. Therefore, the committee agreed that they could not make a recommendation in support of a shared electronic patient record system. Instead, they recommended that services work actively to ensure that other services can access relevant information when needed.

One specific area of information sharing highlighted by moderate-quality qualitative evidence was the development and sharing of behaviour management plans. The committee did not make a recommendation specifically on behaviour management plans, because not all disabled children and young people with severe complex needs will need a behaviour management plan. However, they agreed that when any specialised care plans have been made, these should be shared with all practitioners working with that child or young person, to improve their knowledge and understanding of the child or young person's needs.

How the recommendations might affect practice

Practitioners might need a little more time to find out about the information sharing preferences of children and young people and their families. Services across education, health and social care may need to establish processes to share those preferences more effectively, if they have not already done so. Effective information sharing will ensure that children and young people and their families and carers do not have to repeat the same information to multiple practitioners, which can be distressing. Ineffective information sharing may lead to children and young people being provided with support that does not meet their needs and result in low satisfaction and complaints. This may cost services much more further down the line.

Return to recommendations

Identifying needs and involving other services

Recommendations 1.2.1 to 1.2.8

Why the committee made the recommendations

There were only a few small studies in this area. Most of these studies focused on children and young people with autism, were very low quality, and reported on waiting times only. The committee did not feel the evidence could be generalised to the much wider population covered by the guideline and subsequently made recommendations based on their knowledge and experience.

In the committee's experience severe complex needs and disabilities are normally first identified by health services. The SEND code of practice requires health services to discuss these needs with parents and carers and inform the local authority, so the committee made recommendations to emphasise this. In line with the SEND code of practice, the committee also recommended informing parents and carers about voluntary organisations that can provide advice or assistance, because in their experience this does not always happen and can result in parents independently sourcing inaccurate information. To ensure that children and young people receive the support they need, the committee agreed on the importance of linking health services up with education and social care services as soon as possible. They highlighted that appropriate consent is needed for this, in line with the SEND code of practice.

Sometimes severe complex needs and disabilities are first identified by education services. In line with the recommendations for health services, the committee made recommendations for education services on involving health and social care services and starting discussions with children and young people and their families and carers. They also recommended informing parents and carers about support organisations in the Local Offer, in line with the SEND code of practice.

Based on their experience, the committee made a recommendation on referrals for social care assessment for family support. The reasons for these referrals are often unclear, particularly around the emerging needs, and this can delay social care involvement and provision of support for the child or young person. The committee felt strongly that such preventable delays need to be avoided and were confident that including the emerging needs in the referral would resolve this. They also agreed it was important to include any barriers to engaging with healthcare services in the referral to social care service, because in their experience families on low income may not be able to afford to travel to attend all health appointments, or be able to afford the equipment needed to attend appointments remotely. Including such barriers in the referral should result in potential solutions to this issue being explored.

Low-quality qualitative evidence showed that families can be reluctant to engage with social care services because of fear and perceived stigma. The committee agreed that families can be confused by the difference between child protection social services and family support services, and made a recommendation to address this.

In the committee's experience, disabled children and young people are at increased risk of vulnerability, abuse and neglect, but it is often incorrectly assumed that if the child or young person has a social worker from a disabled children's team that this individual will pick up any safeguarding issues and there is less need to report concerns. The committee were confident that making a recommendation on the action needed if a safeguarding concern is identified would correct this misunderstanding.

How the recommendations might affect practice

Professionals might need more time to assess the needs a child or young person may have, and to share these with other services. They might also need more time to explain the education, health and care needs assessment process to children and young people and their families and carers. However, if practitioners spend more time on this, there will likely be fewer queries, complaints and problems, resulting in time savings later on.

If practitioners spend more time thinking about what support children and young people need from other services, services may start communicating with each other sooner and there may be fewer delays in making referrals. Practitioners may also make a small number of extra referrals to other services, because they have better knowledge of other agencies that can support the child or young person and their family and carers.

Return to recommendations

Requesting a needs assessment

Recommendations 1.3.1 to 1.3.4

Why the committee made the recommendations

There was low-quality qualitative evidence that families and carers often felt that children and young people had to reach a crisis point before an EHC plan was considered necessary. The committee were confident that encouraging services to explain the process to families when special educational needs are first suspected should help to prevent children and young people reaching a crisis point. While the SEND code of practice already specifies that the information covered in this recommendation needs to be provided, the committee agreed that it would be more accessible if individual practitioners could provide it.

There was low-quality qualitative evidence that some practitioners felt like they were pressured to not apply for EHC plans because of a lack of funding, even though this would be a breach of the SEND code of practice. In the committee's experience this risk should be reduced if local authorities explain that an EHC needs assessment should be requested based on a child or young person's needs.

There was moderate-quality qualitative evidence that children and young people and their families and carers did not understand the EHC plan process. They also experienced a lack of transparency around how decisions about EHC plans were made, the timings of reviews, and the processes for appeals and complaints. Explaining the process to people helps them to participate and reduces uncertainty. The 20-week period specified in the recommendation for the EHC plan process is taken from the SEND code of practice.

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. While the SEND code of practice allows local authorities to develop criteria to help decide if an EHC needs assessment is needed, they must be prepared to depart from these criteria if there is a compelling reason to do so. The SEND code of practice also specifies that '…local authorities must not apply a "blanket" policy to particular groups of children or certain types of need…'.

How the recommendations might affect practice

Practitioners may need more time to explain the EHC needs assessment process. However, if practitioners spend more time on this, families will likely have fewer queries, complaints and problems, resulting in time savings later on. It should also help prevent children and young people from getting to a crisis point, which is detrimental to their quality of life and costly to address.

More disabled children and young with severe complex needs may be able to access services earlier if they are not excluded for not having a specific diagnosis. Similarly, if parents and carers have a better understanding of the EHC needs assessment process, they may be more likely to request an assessment and more children and young people may be accessing services.

Return to recommendations

Supporting children, young people and their families during a needs assessment

Recommendations 1.3.5 to 1.3.9

Why the committee made the recommendations

There was moderate and high-quality qualitative evidence that:

- children and young people and their families and carers do not receive the level of support or input that they had expected from services
- they feel frustrated because it is not clear how resources are allocated
- children and young people, families and carers, and service providers felt that the level of support provided did not always reflect the needs of the child or young person, and that more assertive people were more likely to get the support they wanted.

Based on this evidence, the committee made recommendations to ensure that children and young people and their families and carers are better informed about what services are available, the criteria for accessing these services, and the criteria for funding and support. The committee also noted, based on their experience, that children and young people and their families and carers are not always asked for their views as part of the EHC needs assessment. This is required by the SEND code of practice, so the committee made recommendations to support this.

There was moderate-quality qualitative evidence that children and young people, their families and carers, and service providers all felt there was a lack of urgency about providing support until the child or young person reached a crisis point. Similarly, all these groups also felt that the crisis point could be avoided if support was provided earlier. This evidence aligned with the committee's experience, and they believed a lack of resources, issues with prioritisation, use of threshold criteria for accessing support, and statutory obligations all affected the situation. In response to this, the committee made a recommendation for services to work together before an EHC plan is issued to provide interim support and a simpler transition from interim support to the EHC plan, to keep people from reaching a crisis point. The EHC needs assessment process can take several weeks to complete, but the committee agreed that support from education, health and social care was still needed during this process. These recommendations are in line with the SEND code of practice, which specifies that if services are assessed as being needed, they should be provided rather than delayed until the EHC plan is complete.

How the recommendations might affect practice

Professionals may need slightly more time to explain what services are available and the criteria for accessing them. Services may need to work together to provide interagency training for education, health and social care practitioners on other services and their roles and responsibilities, to ensure practitioners can provide clear and relevant information. Providing this support to children and young people and their families is part of person-centred care. It may help children and young people in making decisions, and ensure that they get support that meets their needs. This prevents scarce resources from being wasted. It ultimately results in better choices, care and outcomes for disabled children and young people with severe complex needs.

Commissioners will have to set up commissioning frameworks (or use existing frameworks), to reinforce a more coordinated approach to EHC needs assessments. This coordinated approach may mean holding more interagency team meetings and more effective communication between education, health and social care services.

However, it will mean services and practitioners are able to work together more effectively to provide the support that is needed by children and young people.

Return to recommendations

Carrying out the needs assessment, timescales for the assessment and when parents or carers decline an assessment

Recommendations 1.3.10 to 1.3.13

Why the committee made the recommendations

The committee agreed it was important to make recommendations on the EHC needs assessment process, to make it more streamlined. In the committee's experience, children and young people need a more personalised plan that is specific to their age, level of understanding, communication needs, and circumstances. This was supported by moderate-quality qualitative evidence that the involvement and understanding of the child or young person was dependent on their level of ability.

There was moderate-quality qualitative evidence that some practitioners felt they did not have the chance to contribute relevant information they had about a child or young person to assessments led by other services. The committee considered it was very important that specialist knowledge about the needs of the child or young person from practitioners outside of the interagency team is included in the EHC needs assessment in order to fully assess a child or young person's needs.

There was low-quality qualitative evidence that early identification of needs and referral can be helpful in securing support for children and young people. To make sure that services are ready to provide support when it is needed, the committee felt strongly that practitioners and services need to make referrals as needs are identified, without waiting for the assessment process to finish. They were confident that doing this would help children and young people get the support they need sooner.

There was low-quality qualitative evidence that children and young people and their families and carers felt that the process of getting an EHC plan took too long, and needed a lot of effort on their part. Moderate-quality qualitative evidence showed service providers thought there was a lack of transparency about how decisions on EHC plans were made, timescales for review, and processes for appeals or complaints. The SEND code of practice specifies time limits for local authorities, services and practitioners on each stage of the process for EHC needs assessments and EHC plans, so the committee could not make different recommendations on this. However, they did highlight the time limits from the code of practice, as the evidence and their own experience suggest that these time limits are not always adhered to.

There are circumstances when parents or carers decline assessments. This was reflected by moderate-quality qualitative evidence that parents and carers felt disillusioned with statutory provisions and thought there was little point in requesting help, so opted out of the process. The committee agreed that the reasons for declining assessments were varied, so this should be discussed with parents or carers to ensure that the best possible support can be provided for the child or young person. They also thought it was important to ensure parents and carers understood how to request an assessment in future (because their circumstances and views may change), and for professionals to consider whether declining an assessment may cause a safeguarding issue. The committee were confident that making this recommendation was necessary to ensure appropriate support could be given to parents and carers.

How the recommendations might affect practice

Services will need to work in a more coordinated way, for example by ensuring a consistent approach when carrying out assessments, or by holding more meetings with each other. Commissioners across education, health and social care will have to set up or reinforce commissioning frameworks, to encourage a more coordinated approach to EHC needs assessments.

Making referrals as needs are identified (without waiting for the assessment process to finish) may result in earlier referrals and quicker turnover between services.

The recommendation on timescales for completing a needs assessment and producing an EHC plan helps spread awareness of existing statutory guidance and may reduce variation in practice.

Return to recommendations

Deciding on outcomes for the plan

Recommendations 1.4.1 to 1.4.6

Why the committee made the recommendations

There was moderate-quality qualitative evidence that practitioners can have low expectations of disabled children and young people with severe complex needs and may underestimate their potential. This reflected the committee's experience that many children and young people have not had the chance to consider their aspirations for employment, independence, relationships and community involvement. This can lead to restricted goals and ambitions, and an EHC plan that does not reflect the genuine strengths, abilities and interests of the child or young person. The committee therefore highlighted ways to address this in the recommendations.

The SEND code of practice specifies that parents and carers must be consulted throughout the EHC plan process. However, moderate-quality qualitative evidence suggested that sometimes this is limited and only done in a tokenistic way. Based on this, the committee emphasised the need to take the views of parents and carers into account throughout the process.

There was moderate-quality quantitative evidence that a lack of specific, measurable, attainable, relevant and timely (SMART) outcomes in EHC plans made it unclear what support will be needed, and who is responsible for providing it. The SEND code of practice specifies that SMART outcomes should be used, but in the committees' experience this is not always done. The committee recommended that practitioners consider using the outcome sandwich, because in their experience it is a helpful tool that can help practitioners to write meaningful outcomes.

Support needs are individual to each child or young person, and not everyone with the same diagnosis will need the same support. In the committee's experience, this is sometimes overlooked, and they made a recommendation to remind practitioners of this point.

How the recommendations might affect practice

The recommendations reflect effective practice, but are currently implemented to varying degrees by different services and will involve a change of practice for some providers. Longer consultations or additional follow-up may be needed to fully discuss the outcomes for EHC plans with children and young people and their parents and carers. Spending sufficient time deciding on outcomes for the EHC plan will help practitioners to provide person-centred care. It ensures children and young people are engaged with the process and that EHC plans align with their aspirations. If not done correctly, it can lead to restricted goals and ambitions, poor engagement, and ultimately lower quality of life and general wellbeing. A good process for developing outcomes will help children and young people with making decisions, ensures that they get support that meets their needs, and ensures that scarce resources are not wasted.

Return to recommendations

Writing the plan

Recommendations 1.4.7 to 1.4.16

Why the committee made the recommendations

Currently, individual services often complete their sections of the EHC plan independently, which can lead to inconsistencies and an EHC plan that is not practical to implement. The SEND code of practice states that ’EHC plans should be clear, concise, understandable and accessible to parents, children, young people, providers and practitioners’. Therefore the committee felt strongly that recommendations were needed to address this issue. Based on their experience, the committee were confident that coordination between services was needed to develop EHC plans that made sense and would support the agreed outcomes for each disabled child or young person with severe complex needs.

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.

Different NHS services need 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. The committee were confident that including this information correctly in EHC plans would resolve these issues so that children and young people are provided with the support they need.

Moderate-quality qualitative evidence indicated that children and young people, their families and carers, and service providers thought that EHC plans were not clear on who is responsible for providing the support specified in the plan. Therefore, the committee recommended specifying the support needed to help children and young people achieve the outcomes in their EHC plans.

Moderate-quality qualitative evidence also indicated that children and young people and their families and carers did not receive all the support listed in their EHC plans. The SEND code of practice provides guidance on detailing the resources needed to provide the support specified in an EHC plan, but in the committee's experience these sections are often not completed well. Therefore they made a recommendation highlighting the relevant section of the code of practice to make local authorities aware of it.

Moderate-quality qualitative evidence indicated that service providers lacked the expertise and knowledge needed to complete EHC plans. In addition, the committee's experience was that EHC plans are often based on old information and therefore do not fulfil their purpose. As preparing good-quality EHC plans is crucial to achieving the aims set out in the SEND code of practice, the committee made recommendations for local authorities (who are ultimately responsible for the EHC plan process) to ensure plans are brought up to the correct standard.

Moderate-quality qualitative evidence showed that children and young people's views are not always captured accurately, and that it is important to make sure views are not rewritten in a way that changes the meaning. Based on their experience, the committee recommended ways in which the child or young persons’ voice could be preserved when recording their views.

Moderate-quality qualitative evidence identified that it can be difficult for children and young people and their families and carers to understand the complicated terminology used in EHC plans. The evidence further highlighted that using accessible language would make it easier for children and young people to get involved, and improve accountability by ensuring everyone knows who is responsible for each part of the plan. The committee noted that certain sections of the plan would need to be written in technical language (for example information about health), but recommended that the outcomes and support provision sections should be written in clear language that can be understood by the child or young person. This aligns with the SEND code of practice, which states that ’EHC plans should be clear, concise, understandable and accessible to parents, children, young people, providers and practitioners’.

As part of ensuring that children and young people understand and agree with the plan, the committee recommended that practitioners check it with them during the planning process. Moderate-quality qualitative evidence indicated that parents and carers felt more positive about the EHC process when their involvement was clearly valued and they had the chance to make amendments to the EHC plan. Parents and carers have valuable experience from caring for their child, including an understanding of their child’s needs, so their contributions to the plan are useful. In addition, explaining how their concerns have been addressed in the plan is a simple way of showing how their involvement is valued.

How the recommendations might affect practice

The recommendations reflect effective practice and guidance in the SEND code of practice, but are currently implemented to varying degrees across education, health and social care. Some providers will need to change their practice, and more staff time may be needed to coordinate and agree the content of the plan. EHC plans are crucial, as they identify the educational, health and social care needs of disabled children and young people with severe complex needs and specify what support must be put in place to help achieve the desired outcomes. If EHC plans are not coordinated and agreed on by all parties involved, it can lead to inconsistencies and inaccuracies and an EHC plan that is challenging to implement. This will affect the care and support received by children and young people and have detrimental consequences on their ability to achieve the desired outcomes.

Some providers may need to change their practice, and more staff time may be needed for follow-up and discussions of EHC plans with children and young people and their families and carers. Checking the draft plan with children, young people and their families will ensure that they understand the content of the plan and support that must be put in place to help them. This will help them to engage with the process and will make it more likely that the agreed care and support will be effective. All of this will positively impact their care and outcomes.

Return to recommendations

Checking the draft plan with children, young people and their families

Recommendation 1.4.17

Why the committee made the recommendation

The committee highlighted important relevant requirements around the process from the SEND code of practice. It is important that local authorities follow these requirements and make the process clear, because children and young people and their families and carers will not always understand the process themselves or be aware of their rights. They may also be isolated, have English as a second language or have other difficulties accessing information, so highlighting these requirements should help to reduce inequalities. This was supported by moderate-quality qualitative evidence that there is a lack of transparency about the processes for appeals and complaints about EHC plans.

How the recommendation might affect practice

The recommendations reflect statutory guidance in the SEND code of practice so should already be followed.

Return to recommendations

Implementing the plan, review and re-assessment

Recommendations 1.4.18 to 1.4.22

Why the committee made the recommendations

There was high-quality qualitative evidence that adding in additional assessments (for example schools conducting their own assessments) caused delays to the implementation of EHC plans. The committee noted that implementing the EHC plan was key to providing the necessary support, so recommended that this should happen without waiting for the results of other assessments or for a final draft to be agreed. This is in line with the SEND code of practice.

The SEND code of practice states that EHC plans must be reviewed by the local authority at least every 12 months. However, in the committee’s experience, the needs and circumstances of some disabled children and young people with severe complex needs will change more frequently than this. Therefore, the committee highlighted that reviews need to be regular, and potentially more often than specified by the code of practice but could not specify exact timings as this would vary for different individuals. They also provided detail about when to conduct a re-assessment, to ensure the necessary support can be put in place.

The local authority is responsible for making decisions about whether an EHC plan is still fit for purpose, whether any changes to the plan are needed, and whether to conduct a re-assessment. To help local authorities with these decisions and ensure they have the latest information, the committee recommended that the results of any re-assessments conducted by individual services are shared with local authorities.

Low-quality qualitative evidence indicated 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. They were confident that the level of support provided should only be reduced if the child or young person no longer needs it, otherwise there was a risk that the improvements may not be maintained.

How the recommendations might affect practice

Services will have to start implementing EHC plans sooner, without waiting for any other assessments. The recommendations on review and re-assessment of EHC plans reinforce statutory requirements and current practice, so should represent no change in practice for services.

The recommendation to reduce the level of support only if the child or young person no longer needs it may mean a change in practice for some services. However, this will prevent avoidable crises that are caused by services reducing the level of support too early.

Return to recommendations

Funding

Recommendations 1.4.23 and 1.4.24

Why the committee made the recommendations

There was moderate-quality qualitative evidence in this area, based on the views of practitioners. They reported a decrease in funding that has reduced availability of services and prevents them from providing person-centred, joined-up care. In response, the committee highlighted statutory requirements on funding the SEND code of practice.

There was also moderate-quality qualitative evidence that practitioners’ requests for additional funding to support a child or young person can be refused without a reason being provided. This causes frustration, stops practitioners from providing clear information to children and young people and their families and carers, and can make it difficult to appeal the decision. Therefore, the committee recommended making the reasons for refusing additional funding clear to both practitioners and families.

How the recommendations might affect practice

The recommendations repeat guidance in the SEND code of practice, so there is no change in the resource impact on services. More funding may be needed in areas where local arrangements are not compliant with legislation and statutory guidance.

Practitioners may need more time to explain why funding has been denied, and to explain the appeal process. It is difficult to say what impact this will have on the appeals process. There may be more appeals because families understand the process better, or there may be fewer appeals because the reasons for not providing additional funding are clearer.

Return to recommendations

If children, young people and their families decline an EHC plan

Recommendation 1.4.25

Why the committee made the recommendation

There are circumstances when parents or carers can decline an EHC plan. For example, if they are unhappy with the school named in the plan they may decline it, as accepting would mean they were legally obligated to send their child to that school. The committee were confident that in these circumstances it is important to still engage with parents and carers, so that their children do not become lost to services and miss out on support.

How the recommendation might affect practice

Practitioners may need more time for discussions with parents or cares who decline an EHC plan. However, this only happens rarely, so the overall time impact will be small.

Return to recommendations

Personal budgets and direct payments

Recommendations 1.5.1 to 1.5.5

Why the committee made the recommendations

There was moderate-quality qualitative evidence that:

- personal budgets and direct payments can increase flexibility and give families greater choice about which services they use, but that they can also create additional responsibility for the family

- families are unclear about whether they were entitled to a personal budget or direct payment, or how useful these were
- families were unsure what they could use the funds for, whether personal budgets and direct payments improved their child’s access to services, or whether either option would be applicable to their individual circumstances
- parents were not always sure if they were able or willing to take on the responsibility of a personal budget or direct payments, and they questioned whether they had sufficient knowledge to make care decisions
- parents were uncertain if choosing a personal budget or direct payments would affect how professionals were involved in their support.

The SEND code of practice requires local authorities to provide all parents, children and young people with impartial information, advice and support in relation to special educational needs, which includes information on personal budgets. Based on the evidence, the committee supplemented this statutory requirement with a recommendation on specific information that local authorities should provide on personal budgets and direct payments.

In the committee’s experience, when services are commissioned through direct payments and families become the commissioners of care, there can be loss of coordination between support purchased through direct payments and statutory support provided directly through health and social care providers. Given the emphasis in the SEND code of practice on services working together, the committee used their experience to recommend that local authorities and health commissioners continue to ensure services coordinate even if they have been commissioned using direct payments.

Personal budgets are mandatory for people aged 18 and over if they have a care and support plan, but they can choose whether or not to receive this budget as a direct payment. The committee agreed it was important to make people aware of this, as the difference between personal budgets and direct payments is not well understood.

There was moderate-quality qualitative evidence that families were concerned that personal budgets and direct payments would lead to uneven provision, shortages in provision and a reduction in services. Families did not want to be disadvantaged, and were concerned about having to prioritise within the constraints of a limited budget. They were also concerned that the budget may not be equivalent to the level of funding that is already available. In the committee's experience, direct payments are sometimes only large enough to cover the service itself but not any related costs (such as transport costs). As a consequence, activities that the child or young person enjoyed previously may no longer be affordable, which could impact on their quality of life and ability to achieve the outcomes in their EHC plan. The committee were confident that if local authorities assessed the full cost of providing the services proposed in the needs assessment, this would help to address this problem.

How the recommendations might affect practice

Practitioners may need more time to advise children and young people and their families about personal budgets (including personal health budgets) and direct payments. As a result of this advice, there may be a change in the uptake of personal budgets and direct payments.

For families receiving direct payments, health and education services are already required to assess the full cost of providing services proposed in the needs assessment. However, this may represent a change in practice for social care. Services may be encouraged to think differently about the approach to funding and provision, and consider including support costs (for example transport costs or variable costs of accessing different provision) in direct payments.

Existing frameworks and processes (for example on training and competency, information sharing, monitoring and review) produced and used by local authorities and health commissioners to ensure the quality of statutory support commissioned directly through health and social care services will need to be applied to support that is commissioned by families through direct payments. This will ensure that all services supporting children and young people will receive the information needed to provide effective advice and support.

Return to recommendations

Supporting parents and carers, and training

Recommendations 1.6.1 to 1.6.12

Why the committee made the recommendations

There was evidence that parent training provided numerous benefits to parents and carers, improving their:

- communication
- ability and confidence to meet the needs of their child
- range of social contacts, providing them with social, emotional and practical support.

However, the evidence varied between very low to high quality. Important differences were seen when the outcomes were measured on some scales, but not on others, indicating uncertainty in the results. Therefore, the committee interpreted the results with caution and used the evidence to recommend general elements of the interventions rather than recommending any specific intervention. They also supplemented the evidence with their own knowledge and experience.

In the committee's experience, families often report a desire to have been directed to services that can provide emotional and practical support to enable them to come to terms with their child's diagnosis. Directing to sources of support is in line with the SEND code of practice.

There was very low to low-quality evidence that person-centred planning approaches were beneficial in helping to include parents and carers in care planning, so the committee recommended that these were considered. Moderate-quality qualitative evidence, supported by the committee's experience, showed that different families and carers want different levels of involvement in decision making. Some families want to be regularly involved in making decisions, while some prefer to be guided by professional advice.

Moderate-quality qualitative evidence showed that parents felt that they coordinated most of the services for their child and were worried about what would happen if they could no longer do this. To ensure parents are prepared, the committee recommended that practitioners should consider providing information about available support options.

There was very low to high-quality evidence that training for parents and carers was beneficial, and low-quality qualitative evidence showed that families needed more support to provide care for a disabled child or young person with severe complex needs. Therefore the committee recommended that services consider jointly developing training for parents and carers and identified areas that this training could cover, based on the evidence.

In the committee's experience there is variation in the level of training that each family needs, and they felt strongly that it is important to tailor training so that families are able to learn at the level that will be most beneficial to them. The committee felt equally strongly that practitioners who lead the training need to have skills that are appropriate for the content of the training, so that people are not going beyond their skillsets, because this could make the training ineffective. In addition, the committee agreed that people all learn differently, so using different teaching styles in training would be sensible.

Some of the parent training interventions in the evidence were conducted in group format, and provided parents and carers with an opportunity to engage with each other and share experiences. The committee agreed that providing such opportunities would likely have a positive impact on parents and carers by helping them to learn from each other and develop support networks.

The committee have seen that not all families are ready to start training immediately (for example, if they have just received a diagnosis). Some families need more time, and the committee were confident that being able to access training when they are ready for it, would increase the effectiveness of the training as parents would be more receptive to it.

More flexible options around training delivery, including session times, locations and formats, would make training sessions more accessible to parents and carer. Flexibility is particularly important for parents and carers of disabled children and young people, because their substantial caring responsibilities make it difficult to find time for the training.

How the recommendations might affect practice

Practitioners may need more time to include and support parents and carers, (for example by directing them to sources of support and including them in care planning). However, all local areas should already have processes for doing this, so there should be no significant impact.

Parent and carer training is currently available and there are examples of good practice across the country. However, practice is variable, and the recommendations may result in additional costs for some services. For example, training content may need to be slightly modified, and group activities included to provide opportunities for parents and carers to discuss their experiences. Currently, services commission parent and carer training in isolation, or with only 2 services working together. There might be costs associated with setting up the framework for a collaborative approach if services choose to do this, for example, more meetings and communication between services may be needed. However, collaborative working will make the training approach coordinated, cut out duplication of effort and result in efficiencies and cost savings to the organisations involved. It will also make practice more consistent. Most importantly, supporting parents and carers may avoid a breakdown in care, preventing crises and expensive care placements.

Return to recommendations

Social participation

Recommendations 1.7.1 to 1.7.7

Why the committee made the recommendations

In the committee’s experience, social inclusion is as important as care and education for improving the quality of life of disabled children and young people with severe complex needs, but this may be more difficult for children and young people who are not in education or work. So the committee made recommendations to raise awareness of this.

There was very low-quality evidence from 1 study that an adapted fitness programme increased positive social interactions for disabled children and young people with severe complex needs during group activities. The committee recommended considering adapted group activities (such as theatre) because some children and young people may prefer these to sports, and the committee agreed that children and young people are likely to have positive social interactions in other group activities as well. The committee agreed that the adaptations included in the fitness programme were an important part of the intervention and, therefore, recommended that providers adapt activities as needed.

Local authorities have a duty to provide short break services, but they will need to collaborate with voluntary and community organisations to provide a wide range of meaningful activities as part of these services. Moderate-quality qualitative evidence highlighted that short breaks provide benefits for children and young people, but also that services may only provide limited opportunities for activities, so the committee made a recommendation to address this. Local authorities will need to think about options for people living in rural areas, to prevent inequalities in access to these social activities.

The committee used their experience to make recommendations on ways services and practitioners could help children and young people to participate in social activities. This aligns with the SEND code of practice, which requires that social inclusion is included as a preparation for adulthood outcome in all EHC plans and reviews from year 9 onwards. The examples given are important areas of social participation that most people take for granted, but that disabled children and young people with severe complex needs may need assistance to get involved in.

There was some limited quantitative evidence that collaboration between health and education services can improve the ability of disabled children and young people with severe complex needs to communicate in classrooms. The main limitations with this evidence were that it was from only 1 study, and there were issues with the study design. However, this evidence was consistent with high-quality qualitative evidence that education practitioners valued the opportunity to learn from health professionals. The committee were confident that this collaboration is important to ensure that:

- unaddressed health needs do not get in the way of social participation

- the way that health needs are addressed is not itself a barrier to social participation (for example, healthcare appointments are not scheduled during activities that children and young people want to participate in).

The committee agreed that similar benefits could be seen in other settings if health and social care services collaborated.

How the recommendations might affect practice

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. Short breaks are integral to any support package. They allow young people with disabilities and severe complex needs to meet friends, take part in activities, develop independence, and improve their quality of life.

More children and young people may be able to attend education settings or community activities. There may be a higher cost to services, but there will be improvements in the quality of life and wellbeing of disabled children and young people with severe complex needs.

Because there is already a legal duty to make reasonable adjustments, which would include the adaptations specified in the recommendation, there should be no change in practice or resource impact to making these adaptations.

Services will need to set up or use existing frameworks for a collaborative approach for commissioning and providing activities that can help improve social participation.

Services may need to hold more joint and coordinated meetings to allow them to work together more closely on supporting social participation.

Return to recommendations

Transition

Recommendations 1.8.1 to 1.8.13

Why the committee made the recommendations

Some parts of the SEND code of practice related to transition are not consistently being followed. The committee made recommendations to emphasise these parts of the code.

There was low and very-low-quality quantitative evidence that participation and inclusion were improved when a young adult team approach was used to facilitate transition from children's to adults' services. There were important limitations to this evidence. In particular, the evidence came from only 1 study, and there were issues with potential bias. However, this quantitative evidence was consistent with moderate-quality qualitative evidence that practitioners valued a child- or young-person-centred approach that encouraged a multidisciplinary team working around the child or young person to identify and meet their needs. The SEND code of practice states that high aspirations are crucial to the success of the child or young person and that discussions should focus on their strengths, capabilities and the outcomes they want to achieve. However, in the committee's experience, some practitioners are not following this approach and instead are focusing on short-term support that can more easily be achieved. So they agreed it was important to promote a focus on goals for adulthood and maximising independence.

The SEND code of practice states that local authorities should ensure there are pathways into employment, independent living and participation in society, and that they must work with children, young people and families to develop coordinated approaches to securing better outcomes for adult life. However, in the committee's experience, because most of the work on preparing for adulthood is done in educational settings, the focus is often on staying in education. In addition, there was qualitative evidence that young people need more support to understand their options and reach their full potential. The committee wanted to ensure that young people understood all their options and had time to prepare for them, so made recommendations to address this.

The qualitative evidence highlighted various problems with preparations for adulthood:

- there was low-quality evidence that education, health and social care services used different age thresholds for transition to adult services
- there was low- to moderate-quality evidence that the process lacked coordination, and caused uncertainty and stress for young people
- there was moderate-quality evidence that preparation is insufficient and left too late.

In the committee's experience, the variation between services in the age at which transfer occurs creates gaps in the services that young people can access. This is significantly detrimental to the care and support young people receive and potentially exposes them to harm, so the committee were confident that a consistent approach was needed.

The committee felt strongly that services needed to work together to better coordinate transition, and needed to read the sections of the plan produced by other practitioners. If this is not done, they were confident that it would lead to a plan that is not practical to implement. They also recommended areas that young people and their families and carers should be given information about so that they know what to expect and experience less uncertainty and stress.

In the committee's experience, practitioners do not always focus on long-term goals throughout the transition process. Planning and goals for adult life are only raised near the point of transition, which can make them seem overwhelming and unachievable for young people and their families. It is important to include short-term goals, to break down the long-term goals into manageable steps and help young people see how they can progress.

There was moderate-quality qualitative evidence that having the same named worker throughout the process helped maintain consistency and a positive relationship between young people and services (named workers are recommended by the NICE guideline on transition from children's to adults' services). It would not be possible to have the same named worker before and after transition, so the committee made a recommendation on handing over these responsibilities to maintain consistency and continuity of care.

Moderate-quality qualitative evidence showed that parents felt shut out once their child reached adulthood, so the committee recommended that parents are given information to help them prepare for the change in their involvement.

There was evidence relevant to other parts of the process:

- limited, low-quality quantitative evidence that involving managers and parents in steering groups reduced levels of unmet needs and improved parents' satisfaction
- low to high-quality qualitative evidence that young people and their parents and carers felt more positive when they were involved, and that the input of young people leads to a more accurate understanding of their needs
- low to moderate-quality quantitative evidence that parents were more satisfied with services when they had a transition worker.

These areas are covered in the NICE guideline on transition from children's to adults' services. Because of this, the committee did not make new recommendations in these areas.

How the recommendations might affect practice

The recommendations reflect current practice and existing NICE guidance, and align with the SEND code of practice. However, more practitioner time might still be needed to meaningfully involve children and young people in transition planning. And education, health and social care practitioners might need to hold more joint and coordinated meetings, for example, to ensure that young people understood all their options, undertake planning and setting goals. Early planning will ensure that there is plenty of time to achieve the outcomes specified and everything is not left to the final review, by which time it is too late to do any developmental work. Transition planning done in the right way will result in more efficient person-centred processes. It may potentially result in better long-term outcomes, with goals being achieved and overall savings to the services. It can also have important economic consequences in terms of an individual not going into employment or volunteer work.

There is variation in how far children and young people are involved in transition planning, and the recommendations should make practice more consistent.

There may be a greater uptake of certain services, such as supported internships.

Return to recommendations

Recommendations on specialist support for disabled children and young people with particular needs

Palliative care

Recommendations 1.9.1 to 1.9.9

Why the committee made the recommendations

It was not possible to determine which aspects of practice and service delivery models improved outcomes, based on the limited, very-low-quality quantitative evidence available. So the committee made recommendations based on their knowledge and experience.

Health services will be the first to know when a child or young person needs a palliative or end of life care plan. It is important that this information is shared with other services. In the committee's experience, other services are not always notified and this can cause interruptions to the support provided to the child or young person. Health services should also consider providing training for other services, to help them understand how to best meet the changing needs of children and young people with palliative or end of life care plans.

The committee felt strongly that all services should continue to be involved. They were confident that doing this would improve planning, provide stable and consistent support, and give children and young people flexibility in which activities they want to continue. In their experience, there is a widespread belief that when children enter an end of life care pathway, they do not need much provision beyond that offered by health services. This can lead to things that are important to the child or young person, such as community participation and maintaining social relationships, being overlooked.

There was moderate-quality qualitative evidence that EHC plans are not always viewed as a live document that needs reviewing and updating. However, the SEND code of practice requires EHC plans to be reviewed when there are significant changes in need, and the need for palliative or end of life care is a clear example of this. Changes in support need to be implemented as soon as possible because of the time pressures associated with end of life care. Similarly, regular reviews of the palliative or end of life care plans are needed as the child or young person's needs can change frequently. The committee were not able to be more specific about the frequency of reviews because this would depend on individual circumstances.

It is important to consider the support needs of the child or young person's family, because these can be overlooked during palliative and end of life care, and families may not feel able to seek support in this situation if practitioners do not offer it.

How the recommendations might affect practice

It may be a change in practice for some services to continue social care and education support at the end of life. Services may need to work in a more coordinated way and be more explicit about the roles and responsibilities of different professionals.

Services will have to consider how support might need to change for a child or young person who has an end of life care plan. As a result, they may request more reviews of EHC plans. Services will also need to consider how to provide interagency training, to ensure that practitioners can provide better palliative and end of life support to children and young people and their families and carers.

Return to recommendations

Communication aids

Recommendations 1.10.1 to 1.10.7

Why the committee made the recommendations

There was very-low-quality evidence that assistive technology may increase interpersonal interactions, participation and inclusion. There were issues with the quality of the evidence (for example, there was only 1 study and it was not conducted in the UK) and at follow-up not all of the participants had received the recommended assistive technology. This evidence was from a service that made recommendations on assistive technology but did not fund or provide this technology. Therefore the committee agreed that a greater benefit may have been expected if the technology was provided.

There are existing augmentative and alternative communication services that provide support for people with communication needs, but in the committee's experience these services are not well known and so are underused. This experience is consistent with moderate-quality qualitative evidence that practitioners and other staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people. It is important that staff are made aware of augmentative and alternative communication services, so that lack of knowledge is not a barrier to children and young people receiving support, and that they refer children and young people if they meet the eligibility criteria. The committee were aware that referrals are usually made by occupational health and speech and language therapists. However, the services accept referrals from other education, health and social care practitioners, so it is important that education, health and care services do not cause delays by putting extra restrictions on who can make a referral.

Moderate-quality qualitative evidence highlighted that more training and multi-agency work is needed to communicate effectively with disabled children and young people. The committee also felt strongly that there needs to be agreement about who will maintain, service and insure communication aids that are provided, and that people know how to get support if equipment is damaged. In the committee's experience, these issues are often not resolved effectively, which means the equipment does not get used and children and young people's needs are not met. The committee were confident that making the responsibilities around these areas more explicit would resolve this issue. There was moderate-quality qualitative evidence that using a consistent approach was beneficial for children and young people as it is more predictable and helps them to generalise across different settings. As part of this, the committee encouraged services to think about how equipment can be used in multiple settings and across transitions.

There was moderate-quality qualitative evidence that children and young people and their families and carers need more information and support to understand the services available to them to empower them to make decisions and access services. To address this, the committee made a recommendation about providing information on support groups for children and young people who use assistive technologies. The SEND code of practice also specifies that the Local Offer must include information about support groups.

There was a lack of evidence on whether assistive technology enabled disabled children and young people with severe complex needs to express their views. Because getting their views is central to the EHC needs assessment process and ensures that services and resources are allocated appropriately, the committee made a research recommendation on this.

How the recommendations might affect practice

In some areas, specialised augmentative and alternative communication services are underused. The recommendations may lead to an increase in referrals to these services. However, the specialist services are already funded by NHS England so will not lead to an increase in costs for local education, health and care services.

The availability of training on communication aids is variable, so providing training might represent a change in practice for some services. And practitioners will need to spend more time showing children and young people and their families and carers how to use communication aids. The amount of time required will vary depending on the complexity of the equipment and the number of people that need to be trained to use it. Training practitioners properly to use the equipment 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.

There are established frameworks in place for maintaining, servicing and insuring communication aids, for example provided by the augmentative and alternative communication services. This particular recommendation is only highlighting that responsibilities around these areas should be stated more explicitly.

Return to recommendations

Environmental adaptations

Recommendations 1.11.1 to 1.11.6

Why the committee made the recommendations

There was very-low-quality evidence that assistive technology may increase interpersonal interactions, participation and inclusion. There were issues with the quality of the evidence (for example, there was only 1 study and it was not conducted in the UK) and at follow-up not all of the participants had received the recommended assistive technology. This evidence was from a service that made recommendations on assistive technology but did not fund or provide this technology. Therefore, the committee agreed that a greater benefit may have been expected if the technology was provided.

In the committee's experience, training would also be useful for children and young people who are using environmental adaptations, as well as for their families. This is particularly important because there would be safety concerns if environmental adaptations are not used correctly, so the committee made recommendations on training staff and families in how to use environmental adaptations. The committee also felt strongly that there needs to be agreement about who will maintain, service and insure the equipment and that people know how to get support if it is damaged. In the committee's experience these issues are often not resolved effectively, which means the equipment does not get used and children and young people's needs are not met. The committee were confident that making the responsibilities around these areas more explicit would resolve this issue.

There was moderate-quality qualitative evidence that children and young people and their families and carers need more information and support to understand the services available to them to empower them to make decisions and access services. To address this, the committee made a recommendation about providing information on support groups for children and young people who use environmental adaptations. The SEND code of practice also specifies that the Local Offer must include information about support groups.

There are existing environmental control services that provide support for people with physical disabilities and multi-sensory impairments that restrict their ability to independently operate standard controls, but in the committee’s experience these services are not well known and so are underused. This experience is consistent with moderate-quality qualitative evidence that practitioners and other staff lack the necessary skills and knowledge to work effectively to meet the needs of children and young people. It is important that staff are made aware of environmental control services, so that lack of knowledge is not a barrier to children and young people receiving support, and that they refer children and young people if they meet the eligibility criteria. The committee were aware that referrals are usually made by occupational health. However, the services accept referrals from other education, health and social care practitioners, so it is important that education, health and care services do not cause delays by putting extra restrictions on who can make a referral.

How the recommendations might affect practice

In some areas, specialised environmental control services are underused. The recommendations may lead to an increase in referrals to these services. However, the specialist services are already funded by NHS England so will not lead to an increase in costs for local education, health and care services.

The availability of training on environmental adaptations is variable, so providing training might represent a change in practice for some services. And practitioners will need to spend more time showing children and young people and their families and carers how to use these adaptations. The amount of time required will vary depending on the complexity of the equipment and the number of people that need to be trained to use it. Training practitioners properly to use the equipment 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. There may also be fewer injuries resulting from children and young people knowing how to use the equipment correctly.

There are established frameworks in place for maintaining, servicing and insuring environmental equipment, for example provided by the environmental control services. This particular recommendation is only highlighting that responsibilities around these areas should be stated more explicitly.

Return to recommendations

Environmental accessibility

Recommendations 1.11.7 to 1.11.12

Why the committee made the recommendations

There was no comparative evidence in this area. However, there is best practice and statutory guidance on environmental accessibility that the committee referred to. The Department for Education already requires regular assessment of the accessibility of education environments, but in the committee's experience this statute is not well known and is poorly understood. The committee agreed that health and social care services should also conduct annual assessments, to ensure that children and young people can access the full range of services they need and prevent barriers to access.

In the committee's experience, the results of accessibility assessments provide important information to help children and young people and their families and carers make decisions about which services to use. The SEND code of practice specifies that education services should publish this information on their websites, but the committee agreed that it could also be helpful for health and social care services to make this information publicly available because it would help inform decision making.

Staff knowledge of disability and accessibility should also be assessed because, in order for environments to be fully accessible, staff need to be committed to this ideal and to making reasonable adjustments; physical adaptations alone are not enough. This is consistent with SEND code of practice guidance that the expertise and training of staff to support children and young people with special educational needs must be assessed.

Accessibility assessments should be available for key places that disabled children and young people need to access, to ensure they can access the provision specified in their EHC plans and to allow them to participate and feel included (for example, in after-school clubs that are not held at their school). Publicly funded organisations have a statutory duty to make reasonable adaptations to promote accessibility, but in the committee's experience some community organisations might not be aware of this duty or have sufficient knowledge about the required adaptions. Therefore, the committee agreed that interagency teams should ensure accessibility assessments are available.

The committee have seen that services do not always think about how environmental adaptation equipment will be used across multiple settings. Often, equipment is provided to a specific service rather than the child or young person, preventing them from using it in other places. The recommendation on this is supported by moderate-quality qualitative evidence, which showed that children and young people benefited from a consistent approach as it is more predictable and helps them to generalise across different settings.

There was no comparative evidence available on the effectiveness of adaptations to physical or sensory environments. Therefore, the committee recommended further research in this area.

How the recommendations might affect practice

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. 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.

Assessing staff knowledge of disability and accessibility as part of annual accessibility assessments should already be a part of any properly conducted assessment. However, this may represent a change in practice for underperforming services, which will have to improve their annual assessments.

Return to recommendations

Travel training

Recommendations 1.12.1 to 1.12.5

Why the committee made the recommendations

There was some very-low-quality evidence that travel training increased independent public transport use by disabled children and young people with severe complex needs. The evidence was focused on travel to and from school, but the committee agreed it is important that training helps children and young people to go anywhere they need to, in order to increase independence and participation. Providing help with travel to education and training for young people aged over 16 is covered by the Department for Education’s statutory guidance on post-16 transport to education and training for local authorities. However, the committee were confident that training needed to begin earlier than this to enable children and young people to develop the necessary knowledge and skills by the time they are 16, so they did not specify an age threshold for the training. 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, such as using powered wheelchairs, taxis or learning to drive adapted vehicles. The committee were confident that there was no plausible reason the training would not work equally as well for these additional scenarios.

Based on their experience, the committee agreed that local authorities should consider providing a training framework to support travel training for all disabled children and young people with severe complex needs. This was because local authorities sometimes commission third party organisations to provide the training. The committee agreed that an organisation needed to have overall responsibility for implementing travel training to ensure that it happens. They were confident that local authorities were the appropriate organisation to direct the recommendation to.

The topics that travel training could cover were based on topics covered in the study the committee reviewed, and on their knowledge and experience of some of the challenges and risks children and young people face when travelling independently.

Providing information to parents, carers and relevant professionals was a key component of the travel training in the evidence so the committee recommended that local authorities should provide this. This aligns with the requirements about information provision in the Department for Education’s statutory guidance for local authorities.

There was moderate-quality qualitative evidence that professionals and staff lack the necessary skills and knowledge to work effectively to meet the needs of disabled children and young people. The study on travel training also included providing disability awareness training for staff as part of the intervention. Therefore, 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. Providers of public transport have a statutory duty under the Equality Act (2010) to provide disability awareness training to their staff.

How the recommendations might affect practice

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). 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.

Return to recommendations

Employment

Recommendations 1.13.1 to 1.13.11

Why the committee made the recommendations

The evidence on joint-working practices to prepare disabled children and young people for employment ranged from very low to low quality. Concerns included a risk of bias, the small number of studies, and the fact that the studies were not conducted in the UK. Therefore, the committee supplemented the evidence with their own knowledge and experience.

In the committee's experience, there is variation in the assistance provided to guide children, young people and their families and carers through employment options in the Local Offer and the information is not always easy to understand. To improve consistency, the committee recommended using the Gatsby benchmarks, which are also recommended in statutory guidance from the Department of Education.

There was no evidence on supported internships. However, there was evidence that follow-on support increased independence in disabled young people with severe complex needs. The components of follow-on support in this study and supported internships in the UK are similar, so the committee used this evidence to make recommendations on supported internships. In addition, the SEND code of practice focuses on preparing for adulthood outcomes (which includes employment) in EHC plans from year 9 onwards. However, young people with severe complex needs have a very low chance of progressing to employment without assistance. The committee were aware of evaluations of supported internship programmes that have been undertaken by the Department for Education and UK Government. These evaluations concluded that supported internships are effective at helping young people with severe complex needs into employment. Therefore, the committee were confident that supported internships should be made available.

There was very-low-quality evidence that a named responsible practitioner improved young people’s ability and confidence in meeting workplace expectations. This supported the committee’s experience and they were confident that an essential component of supported internships is the provision of support to the young person by a lead employment practitioner. This lead practitioner provides one-to-one support to the intern, to coach them on the satisfactory level of performance in skills and operations that are required by the workplace. Without this support, the committee agreed that employment outcomes would be much less likely to be successful.

The committee also agreed that the same benefit was likely to be seen for young people with employment as an outcome in their EHC plan but who were not undertaking a supported internship. To support implementation of this, they recommended that providing a lead employment practitioner should be a requirement in service specifications for employment support services. In the committee’s experience, the lead employment practitioner function would usually be fulfilled by a person with the existing role of job coach. However, as there are other roles that could undertake this function, they did not limit it to this in the recommendation.

There are existing professionals who are trained to perform the role of lead employment practitioner. However, many people who are not trained are still delivering such employment support. It is essential to have someone trained in employment support because the complex needs of this group of young people mean that additional and bespoke support is to help them get employment.

There was moderate-quality qualitative evidence that preparations for adulthood are insufficient, inconsistent and left too late. In the committee's experience, families and young people are left to research employment options at the point when the young person is looking for a job. Preparing for adulthood early on would lead to better outcomes, so the committee made recommendations to support this.

The committee agreed that vocational profiles can help young people to find the type of work they would be good at.

In the committee's experience, it is important for practitioners from all services to work together and consider what employment support the young person may need, to prevent barriers to young people effectively participating in employment support. The committee were confident that practitioners should do this so that the responsibility does not fall on the young person and their family or carers.

Based on their experience, the committee recommended actions that supported internship providers can take to help young people move into paid employment or volunteer work when their supported internship ends, as they will have additional hurdles to overcome compared with non-disabled people who are competing for the same jobs. Doing this will support employers to make reasonable adjustments around recruitment.

The committee agreed that young people and their families are not always aware about the support available from support workers and job coaches and so recommended local authorities signpost to these services in the Local Offer. It is a requirement of the SEND code of practice that the Local Offer contains information about all services available in that local area.

In the committee's experience, mentors and workplace buddies are a useful source of support for young people, and make the start of their job go more smoothly for both the young person and the employer. It is important that workplace buddies are not the young person's line manager because the young person has to be able to share their anxieties with their buddy, so they can receive effective support before this results in a performance issue.

How the recommendations might affect practice

Commissioners are already required to make suitable arrangements for disabled young people who are eligible to access supported internships, where these are provided as part of the post-16 Local Offer. The recommendations on this should make practice more consistent and effective, but may represent a change in practice for underperforming services or poorly served localities.

More practitioners will need to be trained to provide employment support for young people, so that every young person who is undertaking a supported internship can be provided with a lead employment practitioner. Further practitioners will need to be trained if local authorities also decide to provide a lead employment practitioner to those young people who have employment as an outcome in their EHC plan. However, because this is an outcome in the EHC plan, funding already exists to enable this training to happen. Therefore there will not be a significant resource implication.

Return to recommendations

Recommendations on working culture, training, service organisation, integration and commissioning

All education, health and social care practitioners

[Recommendations 1.14.1 to 1.14.3]

Why the committee made the recommendations

There was moderate-quality qualitative evidence on the experience of practitioners from different services working together:

- there can be negative relationships between professionals, leading to disagreements
- practitioners agreed it was important to put aside their differences, to work together for the good of the child or young person
- mutual respect and viewing other practitioners as equal partners made it easier to voice opinions and challenge each other, which was seen to improve joint working
- practitioners valued each other’s skills and knowledge, and wanted opportunities to learn from each other and build their expertise
- working relationships improved when practitioners worked together frequently or for extended periods, and when they had the opportunity to meet face-to-face.

To address this evidence, the committee made a recommendation on collaborating to develop a positive working culture.

Moderate-quality qualitative evidence also showed that using a consistent approach when interacting with children and young people was beneficial. It made services more predictable for children and young people, and made things easier for them to understand when dealing with a new service. The recommendation on arranging handovers will help to improve consistency and reduce the need for children, young people and their families and carers to repeat information.

There was limited quantitative evidence that having a local assessment team reduced waiting times for assessment. However, there was only 1 study in this area that focused on children and young people with autism, it was very low quality, and reported on waiting times only. Because of these problems with the evidence, local assessment teams were not recommended.

The committee did agree that practitioners would be better able to coordinate with each other and provide information to children and young people if they understood the responsibilities of other practitioners and services involved in the EHC needs assessment, review and re-assessment process. The need for more coordinated support was highlighted by moderate-quality qualitative evidence that service providers value the different skill sets and knowledge of others and opportunities to learn from each other and build expertise. In the committee's experience, getting an understanding of the responsibilities of other people and services already happens in an ad hoc way; the recommendations would simply make this approach happen more proactively.

How the recommendations might affect services

The recommendations reinforce principles of good practice and should not represent a change for most services. However, some underperforming services may have to implement more effective practices, for example around arranging handovers.

Services will also have to develop interagency training for practitioners on other services and their roles and responsibilities. Extra practitioner time might be needed to provide more wide-ranging and coordinated support. However, if practitioners are better trained on the roles and responsibilities of other services this may lead to more efficient and timely delivery of care, with less duplication.

Return to recommendations

Education, health and social care services

Recommendations 1.15.1 to 1.15.3

Why the committee made the recommendations

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.

There was very-low-quality quantitative evidence that when practitioners work together as part of an interagency team, rather than working individually, children and young people benefit through increased participation, inclusion and educational achievement. Despite the low quality of the evidence, the committee were confident that working together in a coordinated way across education, health and social care services would improve care and support for children and young people. It is also important to ensure that interagency teams have the right practitioners, with the skills and experience to meet all of the child or young person's needs. Moderate-quality qualitative evidence reflected that a lack of skills, knowledge and training among practitioners was preventing them from working effectively to meet the needs of children and young people.

In the committee's experience, working relationships between practitioners improve when there is an opportunity to air and resolve disputes. The committee agreed that most services have existing procedures and policies to do this internally, but policies and procedures for resolving interagency disagreements were needed to facilitate the joint integrated working emphasised by this guideline and the SEND code of practice.

How the recommendations might affect services

Services will need to give practitioners dedicated time for team and relationship building.

Interagency teams already exist. The recommendation on this reinforces current practice, and may mean that interagency teams include a more comprehensive range of practitioners, with the skills and experience to address all the needs of the child or young persons.

Return to recommendations

Key working support

Recommendations 1.15.4 to 1.15.15

Why the committee made the recommendations

There was no evidence comparing services that did and did not have key workers, so the committee made a research recommendation about the effectiveness of dedicated key workers. However, moderate-quality qualitative evidence showed 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. Moderate-quality qualitative evidence also highlighted that having a single person for families to contact would simplify processes and be beneficial to joint working. The SEND code of practice specifies that local authorities should adopt a key working approach, but in the committee's experience this is not happening consistently and there is variation in understanding of what key working may involve. The committee were confident that providing effective key working support to everyone who needs it requires flexibility in the support that is provided, tailoring of the support to individual needs and consideration of family circumstances.

Very-low-quality qualitative evidence highlighted that families are less accepting of key workers who have not had much involvement with the family. To address this, the committee made a recommendation on how to choose a key worker that could actively engage and work well with the family.

Low and moderate-quality qualitative evidence also showed that:

- children, young people and their families spent a considerable amount of time chasing and coordinating services, conducting administrative work and arranging meetings
- 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.

The committee made a recommendation on the responsibilities of the practitioner providing key working support, to address the problems identified in the evidence. These responsibilities align with the key working functions set out in the SEND code of practice.

Based on their experience, the committee were confident that key working support can only work if senior managers support practitioners, ensuring they have the training, time and resources needed and understand what key working support involves. Without involvement from senior managers, there is inconsistent provision. Some children and young people miss out on key working support, and others do not receive good-quality support.

In the committee's experience, information sharing and governance arrangements are needed to ensure that the key working support functions outlined in the SEND code of practice can be delivered across different services.

Moderate-quality qualitative evidence showed that the 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. Staff turnover is inevitable, so it is important that good handover and contingency plans are in place to maintain consistency and minimise the impact of changes on children and young people.

In the committee's experience, some families do not have a permanently fixed location and move frequently. This can cause difficulties with effective coordination of care and support and timely transfer of information. The committee made recommendations on the actions needed when families move to a new area to prevent inequalities in access.

How the recommendations might affect services

A key working approach is recommended in the SEND code of practice. However, this part of the code has never been fully implemented, and practitioners providing key working support do not have enough allocated time to provide all these functions. Since the recommendations on key working support reiterate guidance in the SEND code of practice there should not be a significant resource impact. However, practice is variable, and the implementation of these recommendations might require additional resources for services with suboptimal practices. Services will need to make changes to enable key working approaches. They will also need to ensure caseloads are manageable and practitioners have dedicated resources to deliver effective key working.

A dedicated key worker role would be preferred, with a separate job description and role specification, rather than key working functions being allocated to members of the team on top of their existing roles. However, there was no evidence of effectiveness or cost effectiveness to justify a specific key worker post.

Using a key working approach will ensure a single point of regular and consistent contact to help ensure holistic provision and coordination of services and support. It will reduce the burden on families to coordinate care, meaning they no longer have to spend as much time away from their other commitments, including care for siblings and time off work, which should increase their ability to manage at home, avoiding the cost of expensive care placements. Because of the current lack of key working support, there are routine reports of communication and coordination failures (that is, different services not working well with each other), leading to inefficient processes, missed meetings and poor information provision. Using a key working approach will counteract this and ensure coordinated and seamless care, joined-up outcomes, and a reduction in complaints.

There is no bespoke training for practitioners who will be providing key working support. The essential skills needed involve project management, negotiation and communication, and usually involve component-based training.

Return to recommendations

Making processes easier to understand

Recommendation 1.15.16

Why the committee made the recommendation

Moderate-quality qualitative evidence highlighted that there is a lack of transparency about how decisions are made on EHC plans, the timescales for reviews, and the processes for appeals or complaints. Although the evidence was only about the EHC plan process, the committee agreed, based on their experience, that having increased transparency about what services do and how they work together would improve the child or young person’s understanding of how to navigate the system. It would also increase their confidence in the care and support they are receiving and empower them to be more assertive about their needs. So the committee agreed services should consider doing this.

How the recommendation might affect services

Making processes more consistent and transparent may mean more practitioner time is needed, to improve coordination and joined-up working, and for learning about the roles and responsibilities of other practitioners.

Return to recommendations

Training

Recommendations 1.15.17 to 1.15.26

Why the committee made the recommendations

The committee used themes from the qualitative evidence to make recommendations on training for education, health and social care services.

Moderate-quality evidence showed that joint working was negatively affected when practitioners did not understand the roles, responsibilities and expectations of other practitioners or services. Based on their experience, the committee agreed that training could help.

Moderate-quality evidence showed that education providers need support and training to help them integrate disabled children and young people with severe complex needs into mainstream education.

High-quality evidence showed that practitioners do not always understand the social, emotional and mental health needs of disabled children and young people with severe complex needs. When these needs are not recognised and addressed they can make it more difficult for children and young people to get EHC plans. The committee agreed that training was needed to help practitioners recognise these needs.

Moderate-quality qualitative evidence showed that:

- services often do not adequately capture the child or young person’s perspective on what support they needed
- there is a lack of available training in how to adapt communication and make better use of communication aids for children and young people with communication difficulties; multi-agency work is needed to improve this.

The committee were confident that parents and carers need to be involved in developing awareness training programmes that are either for them or that help practitioners work more effectively with them and their children, to ensure that training is targeted and relevant. This was supported by moderate-quality qualitative evidence of parents and carers feeling positive when given the opportunity to provide their views and having praise for practitioners who valued the expertise of parents but maintained appropriate boundaries. In the committee’s experience, the development of training programmes did not always involve parents and carers.

There was very-low-quality quantitative evidence that practitioners were better able to meet the needs of disabled children and young people after gaining experience working in other settings. Although this experience was referred to as a secondment in the evidence, the committee agreed that the intervention more closely resembled short-term placements, and made recommendations in support of these. This was supported by moderate-quality qualitative evidence that service providers value the different skill sets and knowledge of practitioners from other sectors and opportunities to learn from each other and build expertise. Regular contact among professionals was valued as a way to improve relationships and effective team working. Low-quality evidence also suggested that sharing staff across multiple settings improved knowledge of the child or young person.

How the recommendations might affect services

Currently, while training is provided within each sector about support needs presenting across settings (for example, safe eating and drinking and personal care), this training is not run jointly. Doing so would be a change in practice. Services will have to develop interagency training for practitioners, but this will reduce conflicting advice, encourage all 3 sectors to work together more efficiently, and cut out duplication, and potentially reduce training costs to individual services. Funds to provide the training already exist. Services will only need to reprioritise and reorganise their existing training budgets to deliver this. Such joint training will enable practitioners to get insight into other professional perspectives, which should ultimately improve the support provided to disabled children and young people with severe complex needs.

Other recommended training already exists (for example, training on the EHC needs assessment process, and recognising social, emotional and mental health needs). However, it is not available everywhere, and the recommendations may represent a change in practice for some services. This training could be provided in various low-cost ways, for example remotely, as pre-recorded sessions. The benefits of these training programmes could be substantial. For example, training to recognise social, emotional and mental health needs should result in those needs being identified earlier so that earlier, less intensive interventions can be provided. It should also help prevent children and young people from reaching a crisis point that significantly affects their quality of life and is more costly to address.

Providing short-term placements so practitioners can gain experience in a different sector is not widespread current practice. However, it is unlikely to have significant resource implications because employers already have funds set aside for training their workforce, and some of these funds could be used to fund the placements.

Parents and carers are not always involved in the development of awareness training programmes, so this recommendation may represent a change in practice for some services. There may be some additional resources required, such as extra practitioner time, to help parents and carers get involved.

Return to recommendations

Competency in delegated clinical tasks and feedback

Recommendations 1.15.27 to 1.15.32

Why the committee made the recommendations

There was moderate-quality qualitative evidence from both families and service providers that professionals and staff lacked the necessary skills and knowledge to meet the needs of disabled children and young people with severe complex needs.

In moderate-quality qualitative evidence, families who were delivering interventions reported anxiety about not having enough time to discuss these interventions with professionals and staff and make sure they were doing them properly. The committee directed people to guidance from the relevant professional governance organisations because they provide advice on training and competency in delegated clinical tasks. Separate guidance was made for staff, support workers, and parents and family members, to reflect variances in the training, competency and support needs of these groups.

The committee were confident that children, young people and their families and carers are asked for feedback because they may have different perspectives from practitioners and it is important to get this input to ensure they are getting effective care and support. Processes should be in place for addressing this feedback, so that improvements can be made.

How the recommendations might affect services

The recommendations in this area make other guidance more explicit. There are wide variations in practice across the country about how this guidance is understood and implemented, including some poor practice. The recommendations should make practice less variable. They may also prevent a breakdown in interagency working and prevent critical incidents that could have a detrimental effect on children and young people and substantial financial implications for services.

Return to recommendations

Interagency teams

Recommendations 1.16.1 to 1.16.4

Why the committee made the recommendations

There was evidence of an important benefit of a collaborative life skills programme involving an active partnership of parents, teachers and school clinicians in increasing the participation and inclusion, and educational achievement or attainment in disabled children and young people with severe complex needs. This evidence was very low quality so the committee did not recommend this specific intervention. However, they agreed on the importance of collaborative working across education, health and social care services to ensure that the child or young person's needs are accounted for in all settings.

Moderate and high-quality qualitative evidence highlighted practitioners need more training to meet the needs of disabled children and young people with severe complex needs. However, there was limited evidence about what the content of this training should be. In the committee's experience, learning from other practitioners in the interagency team can be a useful way of finding out about the child or young person's needs and possible approaches for meeting those needs. This was consistent with low-quality qualitative evidence that sharing information increases understanding of the child or young person and their needs. There was also moderate-quality qualitative evidence that practitioners value the skills and knowledge of others, and want opportunities to learn from each other and build expertise.

There was limited evidence, based on the experiences of a traumatic brain injury consulting team, that workshops, inter-professional education and ongoing supervision improved the team's ability to meet the needs of children and young people. However, this approach was not recommended because the evidence was limited in terms of both quality and the population it covered, and it did not report how effective the consulting team were at supporting other practitioners.

In the committee's experience, individual members of the interagency team often have a wealth of specialist knowledge and information that can be used to improve the care and support provided to disabled children and young people with severe complex needs. The committee felt strongly that this knowledge and information should be shared between members of the interagency team and were confident that doing so would mean they can provide more comprehensive care and support and meet the child or young person's needs more effectively. Based on their experience, they suggested areas of specialist knowledge that could be shared.

Moderate-quality qualitative evidence showed that there can be negative relationships between professionals, leading to disagreements. In the committee's experience, interagency teams need the opportunity to air and resolve disputes to improve working relationships guided by policies and procedures that have been created for resolving interagency disagreements.

How the recommendations might affect services

The recommendations imply greater sharing of knowledge within existing interagency team meetings. Teams that do not do this will have to set dedicated time at team meetings to discuss changes in practice, legislation or statutory guidance. Interagency teams already have ways of resolving disagreements between different practitioners. Some resources might be needed to agree and formalise these practices.

Return to recommendations

Local authorities and health commissioners

Recommendations 1.17.1 to 1.17.10

Why the committee made the recommendations

The committee agreed that early interagency involvement will help to identify, assess and address the needs of disabled children and young people with severe complex needs. This was supported by moderate-quality qualitative evidence reporting that services can be slow to provide support until children and young people reach crisis points.

Some disabled children and young people with severe complex needs are cared for in specialist residential placements that may be some distance from their home. The committee agreed that, for some children and young people, this may be the most effective option, because it is difficult to meet their support needs any other way. However, in the committee’s experience, long-distance placements are also made for some children and young people because there are no local services available to provide the care they need, or because they do not meet the eligibility criteria for local services. The committee were confident that providing care within their community would be beneficial for children, young people and their families and carers, improving their quality of life and maintaining their family and social relationships. The committee therefore agreed, based on their experience, to recommend exploring all local options before using long-distance placements. They also made a research recommendation to establish the most effective commissioning, practice and service delivery models for enabling children and young people to stay close to home.

In the committee’s experience, it is widespread practice for services to be commissioned and developed based on replicating existing services rather than based on services that meet the needs of the population. This approach does not necessarily consider what the outcomes of such services should be. Specifying outcomes in contracts would lead to services that are better equipped to meet the needs of disabled children and young people with severe complex needs.

In the committee’s experience, services often work in isolation and do not consider the effect that changes in service structure or processes may have on other services involved in the care of disabled children and young people. This can cause delays and gaps in service provision.

There was moderate-quality qualitative evidence that the services provided often do not meet the needs of children and young people, because of a lack of funding and resources. This is a particular problem for young people over 16. There was also moderate-quality qualitative evidence that decisions on transition are left too late, further affecting young people. In the committee’s experience, working together to plan how services will be funded and organised once young people turn 18 would ensure continuity of support and lead to more effective use of limited resources.

There may be health reasons to limit some specialised services based on diagnosis. However, in general the committee felt strongly that, in line with the SEND code of practice, support should be provided based on needs rather than diagnosis. This was supported by moderate-quality qualitative evidence from both families and practitioners suggesting that this would minimise gaps in service provision.

In the committee’s experience, services sometimes reprioritise children and young people in their waiting lists to meet organisational and statutory targets. If the statutory deadline for producing the EHC plan has been missed for a child, they may then be forced to wait even longer, as services prioritise meeting the deadline for other children or young people. Although this allows organisations to meet more statutory deadlines overall, in practice it penalises some children and young people for no practical reason and may exacerbate their needs. The committee were confident that a recommendation was needed to discourage this.

There was low-quality qualitative evidence of a lack of clear pathways for referral between services. This aligned with the experience of the committee, who felt strongly that the processes for referral needed to be more effective. They were confident that doing this will help practitioners provide effective and coordinated care and support to disabled children and young people with severe complex needs. They made recommendations on how to do this.

In the committee's experience, commissioners are not consistently following the guidance in the SEND code of practice on involving children, young people and their parents and carers when commissioning education, health and social services. The committee made recommendations to highlight the areas of the code of practice that are being missed.

Moderate-quality qualitative evidence reported families feeling disillusioned with statutory provisions and seeing little point in requesting help, leading to occasions when they opted out of seeking support. The committee agreed that getting the views of service users on the effectiveness of services could potentially improve statutory provisions and subsequently reduce the disillusionment about current services. This is in line with the SEND code of practice, which specifies that children and young people with special educational needs and disabilities and their parents must be engaged in commissioning decisions, so that users' experiences, ambitions and expectations can shape decisions on the services provided. The SEND code of practice also specifies that children and young people with special educational needs and disabilities and their parents must be consulted when reviewing educational, training and social care provision.

The SEND code of practice recommends that services are commissioned based on the needs of people in that area. However, in their experience the committee has seen the opposite happening, with people being expected to just use services that already exist. The committee made a recommendation to discourage this, and also directed people to the SEND code of practice guidance on joint strategic needs assessments, to help them with commissioning services.

There was some evidence that dedicated funding for services, joint budgets and having a designated service manager improved parents' satisfaction and quality of life. However, this evidence was very limited and was specifically related to the provision of key workers. There was also insufficient information in the studies on the exact funding and commissioning arrangements. Therefore, the committee recommended further research into the most effective joint commissioning arrangements for disabled children and young people with severe complex needs.

How the recommendations might affect services

The recommendations reinforce the SEND code of practice and would only represent a change in practice for services that are not compliant with legislation and statutory guidance.

Coordinated and joint-working practices are not consistent. Commissioners will have to set up or use existing commissioning frameworks to reinforce joint working and to ensure that children, young people, parents and carers are involved in planning services. In practice, this will mean more practitioner time, more meetings and more communication between education, health and social care services.

Education, health, and social care services working together in an integrated way will deliver better, more joined-up, holistic services to children and young people with disabilities and severe complex needs to keep them supported within their families and local communities. This will lead to early identification of need (before they reach a crisis), and reduce the need for expensive, often extended, hospital stays. This may also prevent expensive out of area placements. Ultimately, integrated ways of working achieve better outcomes for children and young people with severe and complex needs, for example maintaining independence, improving health outcomes and quality of life, and general wellbeing. This would also improve educational outcomes by getting the right support for engaging in learning earlier.

Return to recommendations

Coordinating EHC plan process changes with local services, training and short breaks

Recommendations 1.17.11 to 1.17.14

Why the committee made the recommendations

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 more closely in the process.

There was moderate-quality qualitative evidence that both service providers and families have trouble understanding the EHC plan process. Services are concerned about their lack of training and knowledge on how to write EHC plans, which potentially leads to discrepancies and a lack of consistency. Local authorities are responsible for the EHC process, so the committee recommended that they provide training on this for practitioners. Writing good-quality EHC plans is crucial to achieving the aims set out in the SEND code of practice.

In the committee's experience, short breaks help parents and carers with the delivery of care by providing respite. This was supported by moderate-quality qualitative evidence. Although the SEND code of practice requires local authorities to provide short break services, in the committee's experience the range of options can be constrained by the resources currently available in their area. The committee were confident that the most successful and valuable short breaks are those provided in consultation with parents or carers, and tailored to their specific needs. Therefore, they highlighted the requirement in the SEND code of practice that a range of short break options must be provided.

There is no evidence on the effectiveness of short breaks. So it is not clear which aspects of short breaks are most effective or why children and young people and their families and carers prefer some short breaks over others. The committee agreed that a research recommendation was needed to determine which components of short break services are most effective.

How the recommendations might affect services

Local authorities will have to spend more time explaining EHC plan process changes to education, health and social care services. If practitioners understand the process better, this will lead to production of better EHC plans, and ultimately more efficient delivery of services, increased transparency, and more timely care.

Training on the EHC needs assessment process already exists within most services. This training could be provided in various low-cost ways, for example remotely, as pre-recorded sessions. Such training will reduce conflicting advice and encourage all 3 sectors to work together more efficiently, minimising duplication.

There is a duty under the Equalities Act 2010 for providers of public transport to provide disability awareness training for their staff and the Office of Rail and Road provide a framework for them to do this. Similarly, the recommendations on short breaks reiterate the SEND code of practice.

Return to recommendations

What to include in the Local Offer

Recommendations 1.17.15 and 1.17.16

Why the committee made the recommendations

In the committee's experience, not everyone knows that the Local Offer provides information about the services and support that are available for disabled children and young people and their families. To prevent inequality in access they made recommendations about what should be included in the Local Offer.

The SEND code of practice provides guidance about what information must be included in the Local Offer. A variety of themes from the qualitative evidence highlighted areas where information provision was poor or lacking. The committee used these themes to make recommendations highlighting what local authorities should include in their Local Offer, that were consistent with the SEND code of practice.

The committee mentioned thresholds and eligibility criteria used in the EHC needs assessment process in response to low-quality qualitative evidence. This showed that families thought their child had to reach a crisis point before an EHC plan was considered necessary.

In response to low-quality qualitative evidence that practitioners felt pressure not to apply for an EHC plan because of funding pressures, the committee recommended explaining the criteria for an EHC needs assessment.

There was qualitative evidence that children and young people and their families and carers need more information to understand and access available services. Assistive technology is highlighted because there were specific concerns in the qualitative evidence about the lack of training and knowledge of staff in this area.

The committee agreed, based on their experience, that details of social activities should be included. This is because social inclusion is as important as care and education for improving the quality of life of disabled children and young people.

Providing details of employment support is a requirement of the SEND code of practice. In the committee's experience, employment may be a daunting prospect for disabled children and young people, but this can be improved when local authorities make the available services clear.

In line with the SEND code of practice, local authorities must involve children, young people and their parents in planning and reviewing the Local Offer, which gives families the opportunity to say what services they think are needed and raise issues if they are not happy with what is available.

How the recommendations might affect services

The information local authorities include in their Local Offers varies, and the recommendations will help reduce this variation. Local authorities that do not currently provide this information may need to spend more time and resources collecting it and including it in the Local Offer.

Return to recommendations

Improving how local authorities, commissioners and services work together

Recommendations 1.18.1 to 1.18.4

Why the committee made the recommendations

There is a joint commissioning duty in the Children and Families Act 2014, between clinical commissioning groups and local authorities. However, this is only happening in parts of the system. There is no universally established framework at an organisational level to enable joint working across all 3 sectors. Many of the recommendations in this guideline emphasise the need for joint working, but the ability of services to implement these would be limited without a framework being established at an organisational level. The committee noted that the commissioning duty of clinical commissioning groups is being absorbed by integrated care systems and therefore the same duty should apply to the relationship between integrated care systems and local authorities, so they recommended developing a joint commissioning framework.

In the committee’s view, interagency team working will only be effective if there is a formal commitment, setting out how providers and services should work together in an integrated way. The committee were confident that effective interagency team working is of central importance to improving support for disabled children and young people with severe complex needs and so made recommendations on how to achieve this. Based on their experience, they agreed that the mechanisms to achieve effective integrated working would be for commissioners to specify how services should work together in contract requirements; for senior managers in all services to have processes in place to support interagency team working; and for providers to have agreements setting out how they will work together.

How the recommendations might affect services

Integrated care systems are replacing clinical commissioning groups and may need to work collaboratively with local authorities where they are not already doing so, which potentially could have some resource implications. Joint commissioning of services is currently only being done for particular provisions, for example some patient advice and support services, some bespoke packages for post-16s, and some short breaks. Developing a joint commissioning framework would be a change in practice. Given the integral part local authorities play in the identification, assessment, and care pathways for children and young people with disabilities and severe complex needs, joint working (facilitated by a joint commissioning framework) is essential to bring meaningful improvements in the care of these children and young people.

A joint commissioning framework across education, health and social care will enable collaborative working, coordination, consistency and efficiencies for all parties involved. It will enable holistic care and a less fragmented experience. It will also allow practitioners to deliver person-centred care that addresses their needs across the 3 sectors, and ultimately, it will result in better care and support for the person. For example, better joined-up working will lead to early identification of needs (before they reach a crisis). This may prevent expensive out of area placements and prolonged hospital stays. It will improve health outcomes because the right care can be started early, avoiding the delays in care that exacerbate problems. This would also improve educational outcomes by getting the right support for engaging in learning earlier.

Education, health and social care services will have to make their processes more joined-up and coordinated. They may need more joint and collaborative meetings. Commissioners will need to establish frameworks for collaborative and cooperative working.

Return to recommendations

Context

It is important that education, health and social care services work together to effectively meet the changing needs of disabled children and young people with severe complex needs. But there are a variety of challenges to doing so.

The lives of disabled children and young people with severe complex needs can be improved by education, health and social care services that:

- are joined-up
- are tailored to the needs of the individual child or young person
- involve children and young people in decisions about their education, health and social care

- involve families and carers in decisions about their child's education, health and social care
- incorporate support for families and carers.

This guideline focuses on delivering integrated education, health and social care services. It is designed to help local authorities and health commissioners, providers and practitioners implement the Special educational needs and disability (SEND) code of practice in order to improve outcomes for this group of children and young people and their families and carers.

The guideline covers disabled children and young people with severe complex needs who require a combination of education, health and social care support. It covers this group from birth to 25 years. The guideline does not make recommendations specific to particular disabilities or health conditions.

The guideline includes recommendations on:

- involving children, young people and their families in their care
- communication and providing information
- planning and running meetings with children and young people
- identifying needs
- education, health and care (EHC) needs assessment and EHC plans
- support and training for parents and carers
- social participation
- transition
- palliative and end of life care
- environmental adaptations
- employment
- working culture
- training for practitioners
- service organisation
- joint working and integrated support
- joint commissioning.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on children's social care.

For details of the guideline committee, see the committee member list.