

The Special Educational Needs and Disability (SEND) reforms in England



An introductory guide for families of children and young people with life-limiting and life-threatening conditions aged 0-25



The special educational needs and disability (SEND) reforms in England: an introductory guide for families of children and young people with life-limiting and life-threatening conditions aged 0-25

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This publication will be reviewed on an annual basis and amended as needed, at our discretion.

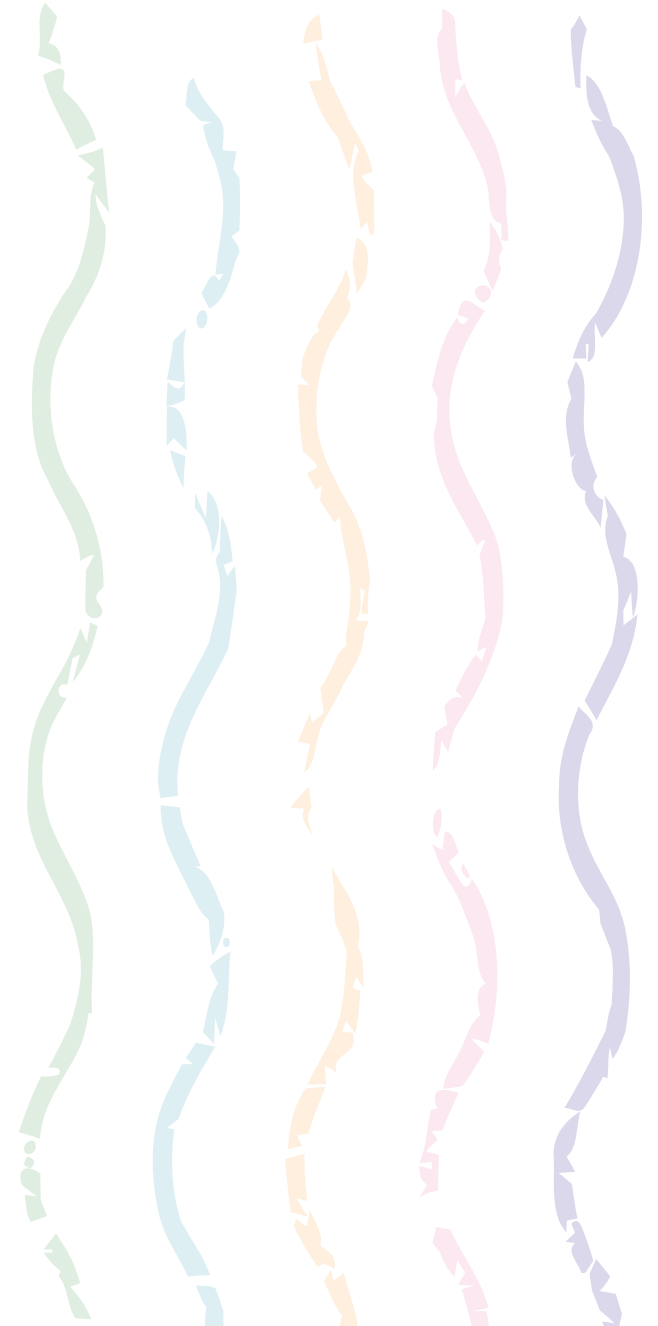
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Introduction: What is this guide about, what does it cover?

This guide has been developed to help you navigate the new special educational needs and disability (SEND) system in England, brought in by the **Children and Families Act 2014**¹ (CFA). It's designed to help you understand what the new SEND system could mean for you, learn how to navigate it and explain who's here to help.

Together for Short Lives wants to support families by informing them about these new ways of working, about their rights and those of their children and young people. In this short guide we will refer to:

- what the law says
- the [SEND code of practice](#) (or "the code")² which is statutory guidance from the Department for Education (DfE)
- a straightforward [DfE guide for parents](#).³

We will also be signposting you to some other trusted and valued information sources that are available.

Who is this guide for?

This guide has been written specifically for families of children and young people with [life-limiting and life-threatening conditions](#). Whether or not a child or young person has been diagnosed with a life-limiting condition or uses children's palliative care services is not relevant here; this guide and the SEND reforms in general are about a child or young person's needs and not their condition or diagnosis. The term parent means anyone with a parenting responsibility. The definition of when a child becomes a young person as recognised under the act is covered later.



Who wrote this guide and why?

This guide complements the range of Together for Short Lives [resources for families](#) and has been funded by the DfE as part of the charity's wider SEND Project. It has been written by the [Council for Disabled Children](#)⁴ (CDC) on behalf of Together for Short Lives. The CDC is the DfE's strategic reform partner for the SEND reforms and has a very comprehensive [resources](#) list on its website.

1. Children and Families Act 2014. (Part 3) London: HMSO. Available at: www.legislation.gov.uk/ukpga/2014/6/contents/enacted.

2. DfE, 2015. *SEND Code of Practice January 2015*. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf [Accessed 31 March 2016].

3. DfE, 2014. *SEND Guide for Parents and Carers*. Available at: www.gov.uk/government/publications/send-guide-for-parents-and-carers [Accessed 31 March 2016].

4. Council for Disabled Children 2015. Available at: www.councilfordisabledchildren.org.uk [Accessed 31 March 2016].

Important definitions: What do we mean by the terms SEN and SEN provision?

“It is really important that we help families understand that these definitions have not changed – the context has, but not the legal definitions that are the basis of the decision making.” **SEND Information Advice and Support Service (IASS) Officer**

Section 20 of the Children and Families Act 2014 states that a child or young person has **special educational needs**:

if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age

or

- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

Section 21 of the act defines **special educational provision** for children over two and young people as:

educational or training provision that is additional to, or different from, that made generally for others of the same age in:

- mainstream schools in England
- maintained nursery schools in England
- mainstream post-16 institutions in England
- places in England at which relevant early years education is provided.

Special educational provision for a child aged under two means educational provision of any kind.



The majority of children and young people with life-limiting conditions have SEN and would benefit from more joined-up assessments, plans and services as highlighted on the [Together for Short Lives website](#)⁵:

The SEND reforms have the potential to transform the lives of the 40,000 children and young people with life-limiting and life-threatening conditions and their families in England who may use palliative care services. Their need for integrated care is perhaps the most challenging and urgent of any group of children, given the complexity of the care required and the pressure of time.

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Important definitions: What do we mean by the terms SEN and SEN provision?



The decision whether or not a child or young person has SEN, is based in law as described above and is not linked in any way to a specific diagnosis or condition but on their needs. Some children such as those with genetic disorders, or metabolic diseases such as Batten disease, will have profound and/or multiple needs, such as associated learning, physical or sensory difficulties and have considerable support needs that require provision 'additional to, or different from' their peers. Some children are diagnosed at birth, whilst others such as those with Duchenne muscular dystrophy are diagnosed later on in childhood and as their needs increase so will the need for special education provision.

Chapters five and six of the code outline how these duties need to be applied in early years settings and in schools. More detailed information about SEN and assessments can be found through the [resources](#) list at the end of this guide.

It must be remembered however, that although many children and young people requiring palliative care have SEN, not all do. Those affected by conditions such as cancer, heart disease or cystic fibrosis, would have rights under the Equalities Act 2010⁶. [Early years settings, schools, colleges and local authorities have clear legal duties to act to prevent unlawful discrimination, whether directly or indirectly](#)⁷. They must ensure that they do not treat children and young people with disabilities less favourably than others. They also have a duty to make 'reasonable adjustments' to ensure a child or young person is not disadvantaged or discriminated against. Support to understand your child's rights is available and covered in the [rights](#) section of this guide.

*Supporting Pupils at School with Medical Conditions*⁸ is powerful new statutory guidance that has been welcomed by parents and condition specific charities. Parents and young people may find this useful to read and discuss with their school, as it deals with school trips and other issues beyond the classroom.



6. The Equalities Act 2010. London: HMSO. Available at: www.legislation.gov.uk/ukpga/2010/15/contents.

7. CDC, 2015. *My Rights, Your Responsibility* [pdf] Available at: www.councilfordisabledchildren.org.uk/resources/my-rights-your-responsibility [Accessed 31 March 2016].

8. DfE, 2014. *Supporting Pupils at School with Medical Conditions*. Available at: www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3 [Accessed 31 March 2016].

What are the SEND reforms and how did they come about?

Detailed background to the SEND reforms, including why they are important for children and young people with the most complex health needs, is detailed on the [Together for Short Lives website](#)⁹:

Evidence shows that parents of children with SEN had very little confidence in the previous system. Young people with SEN were doing worse than their peers at school and college and were more likely to be out of education, training and employment at age 18¹⁰.

The government wanted to make sure that the Children and Families Act 2014 was a direct response to these and other such issues raised by families and the professionals who support them and commission services for them. Families were at the heart of the work to develop the act and many parents were actively involved in consultations and workshops to inform it. They still have a **strategic role** in the ambitious programme of work to implement the act:

“Our vision for children and young people with special needs is the same as for all children and young people – that they achieve well in their early years, at school and in college; lead happy and fulfilled lives; and have choice and control.” **DfE and Department of Health 2014**



9. Together for Short Lives, 2016. *About SEND reform*. Available at: www.togetherforshortlives.org.uk/professionals/projects/send_project/about_send_reform [Accessed 31 March 2016].

10. Lamb, 2009. *Lamb Inquiry Review of SEN and Disability Information*. [pdf] available at: <http://webarchive.nationalarchives.gov.uk/20100202100434/http://dcsf.gov.uk/lambinquiry/downloads/Lamb%20Inquiry%20Review%20of%20SEN%20and%20Disability%20Information.pdf> [Accessed 31 March 2016].

What are the key aspects that might affect me, my child and/or my family?

Opposite are just the top level explanations for children, young people and parents. If you would like to explore these in more detail and have a deeper understanding of the legal basis and your or your child's rights then we would suggest the newly published [Disabled Children: A Legal Handbook 2nd Edition](#) that is also free to access online¹².

How is the new SEND system different?	What has stayed the same
<ul style="list-style-type: none">• New duties on local authorities to have regard to the views of children, young people and their parents Section 19 Duties• New duties across education, health and social care 0-25• New duties around integration and joint commissioning between health and social care• Education, health and care (EHC) plans to gradually replace statements of SEN• Personal budgets extended to education• The local offer	<ul style="list-style-type: none">• The legal definitions of SEN (as above)• The threshold for getting an assessment and receiving an education, health and care (EHC) plan is exactly the same as it is for a statement of SEN• An assumption in favour of mainstream education• Legal protections for children and young people have been added to and strengthened

Top tips from other parents:

1. The national charity Independent Parental Special Education Advice (IPSEA) has very useful frequently asked questions (FAQ) pages on their website that are updated regularly. These authoritative and factual information pages are very useful for counteracting the many myths surrounding the reforms, and can help you understand the changes in a clear and factual way¹³.
2. Don't believe everything you are told, check it out for yourself – this is a new world for everyone including those working in the system.



11. Mencap, 2015. *SEN – what's changed and what's stayed the same*. [online] Available at: www.mencap.org.uk/about-learning-disability/education-and-special-educational-needs-sen/special-educational-needs-resources/sen- [Accessed 31 March 2016].

12. Broach, S., Clements, L., Read, J., 2016. *Disabled Children: a Legal Handbook*. 2nd ed. London: LAG. and [e-book] Available through: www.councilfordisabledchildren.org.uk/11566 [Accessed 31 March 2016].

13. IPSEA, 2015. *FaQ sheets*. [online] Available at: www.ipsea.org.uk/what-you-need-to-know/frequently-asked-questions-by-topic/sen-and-disability-law-faqs [Accessed 31 March 2016].

Aspirations and outcomes

Aspirations are hopes, wishes, and plans for the future. In paragraph 9.69 the code states that Part A of an EHC plan should include:

details about the child or young person's aspirations for the future, including aspirations relating to paid employment, independent living, and community participation.

The word 'aspirations' appears many times in the code and underpins the new approach to joined up, integrated planning for *all* children and young people not just those with an EHC plan. This is a new way of thinking and although really welcomed, it is a concept that is proving to be challenging for the families of disabled children and those with SEN. However, for the parents of the most complex and often very ill children where any future is at best uncertain, it is particularly difficult. It is very often scary to think about, let alone discuss with people who do not know your family well or fully understand the emotional rollercoaster of living with a child who is likely to have a short life. This quote is very typical:

"It's all very well people talking about long term goals, aims for future and stuff like that, but we've only ever been able to think about and hope for another six months at a time, and that's hard enough."

Parent

"Aspirations can be whole family things like actually going out to have a family fun day together – kids are kids and we need to remember that, even it takes loads of planning, we all want to go."

Parent

Some of the most important, and indeed fundamental changes in the new act are the **Section 19 principles** which state that a local authority (LA) **must** have due regard to:

- the views, wishes and feelings of the child or young person, and the child's parents
- the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions
- the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood.

The word **must** in law describes a legal duty on a person or organisation to take a particular action. It also means that children, young people and their families have a right to expect that a person or organisation takes that particular action. The wording in Section 19 means that local authorities must have regard achieving the 'best possible outcomes' for children and young people – crucially, not just educational outcomes. It is really important that you know your new rights under these reforms.



"When he was 15 or 16, I let him make his own decisions and take his own risks as you would any teenager. But when he said he wanted to leave home, that was his aspiration not mine and certainly that got really scary. I strongly believe in people's rights to autonomy, and the need to let him be his own person; I just had to realise it's his aspiration that must lead the way and I must support him to do this."

Parent





Even if the future for a child or young person is unknown and by no means certain, they or their families shouldn't miss out on this new approach. Children, young people, families and the professionals working with them should be supported to think about *all* children and young people having aspirations, even if they may be different to or have a shorter life-expectancy than many of their friends.

“We never dared plan much beyond the next school year, but all I have ever wanted is for my son to be happy, pain free and as confident as he could be: his own person. He will always need 24-hour support but that hasn't stopped him having dreams, in fact for a long time his dream was to marry Kylie Minogue! That's changed now, and things do change, I've learnt that, as we have gone along this journey.”

Parent

A parent of a child or young person who has very complex needs may well be thinking 'how do I really know what their aspirations are?' We recommend that parents take a step back and think about what it is in life they really enjoy; is it music, cuddles, a warm bath, playing with brothers or sisters, going outside, going to school? These are the best indications of their wishes and what motivates them, what is important to them regardless of whether or not they can tell us verbally. **These are every bit as important when thinking about what should go into a child or young person's plan – whether it's a care plan or an EHC plan. Then all their aspirations (hopes, wishes and feelings) will need to be captured too; it's this powerful combination that makes sure a child or young person's 'voice' is at the heart of any planning.**

Describing all of this can seem quite daunting, although there is [support](#) available. One excellent and very popular way to show and share a child or young person's thoughts and wishes, needs and support required is a one page profile which is literally what it says – a visual and short summary on one page of who they really are, and what they need to have a good day in any setting. To see some examples and find out more [visit the Helen Sanderson Associates website](#)¹⁴.

“My son loved independently preparing his own one-page profile. It gave him the opportunity to explore in reality what he might want to do in the future and clarify what was needed to get there.”

Parent

Another word you will come across is 'outcomes'. The code describes an outcome as 'the benefit or difference made to an individual as a result of an intervention' and it is really the 'so-what' aspect of any support or service (called provision) that a child or a young person receives. These are explained further in the next section. **Outcomes are not just for those with an EHC plan – as Section 19 says, meeting best possible outcomes are the new rights of all children and young people with SEND.**

It may help you to think about how important a child or young person's aspirations are by looking at this diagram that shows how theirs or their family's aspirations for them should lead the way (set out at the top of the pyramid). Aspirations should be identified and reflected in the plan so that children's lives are not defined by their needs or their diagnosis. The letters A-K are the different sections of an EHC plan and are shown in more detail in the next section.

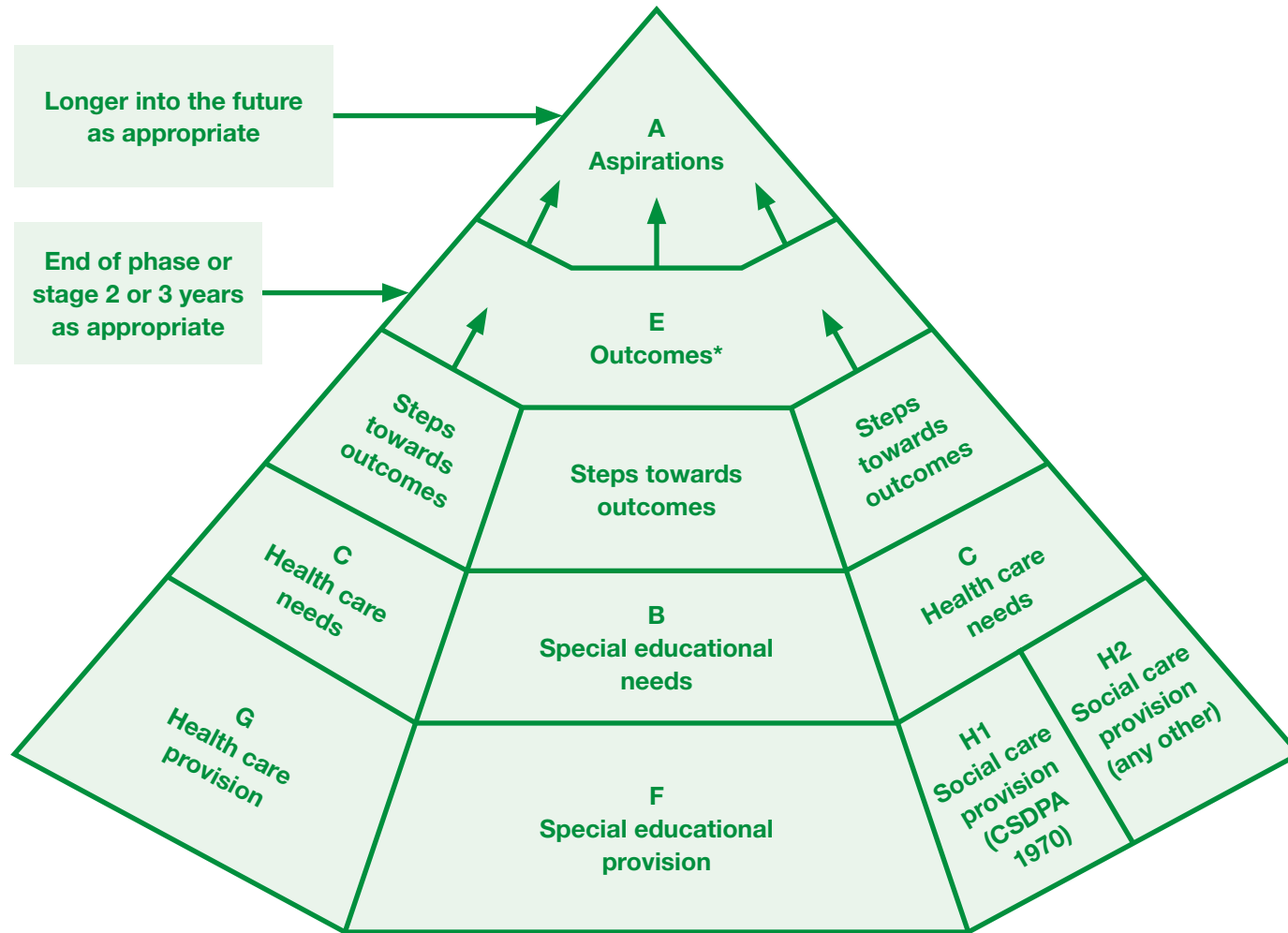
Please see the [Outcomes Pyramid](#) diagram on the next page.

Together for Short Lives has a whole suite of [Family Factsheets](#); some of these may be helpful to parents when thinking about planning for the future and having the confidence to broach what are often very challenging conversations. See *Family Factsheet 10 'Care planning in advance'* and *Family Factsheet 21 'Talking with your Child about their Life-Limiting Condition'*.

Top tips from other parents:

1. When thinking about aspirations think big, think fun and don't be constrained by what other people think is a good, practical or 'reasonable' aspiration. If a child or young person says they want to be an astronaut, be a fairy, meet someone famous, go to university, have a job and their own home, then capture that and share it as this is who they are. It is their aspiration not who other people think they should be or should do or indeed are even capable of.
2. Remember that aspirations do not have to be delivered by a LA (nor can they be appealed against in a Tribunal) so parents should feel free to share what they feel people need to know about their child in their one page profile or [Part A of an EHC plan](#).
3. Not all aspirations are about education and passing exams; if you are a parent, have a look at the *Family Factsheet 7 'Grants and Wishes'* to see who might be able to make your child's dreams come true.
4. Many children and young people will be very able and happy to share their own ideas, hopes and wishes for the future. Parents of those who are less able should not forget that they are their voice and that they know them best.

Outcomes Pyramid



What is an EHC plan?

“When I first saw my son’s EHC plan I could finally see an overall picture of what needed to be achieved for him rather than it being split by discrete services who previously were not concerned about issues beyond their own boundaries. They finally realised that they were part of a wider plan.”

Parent

Since September 2014 no new statements of SEN have been issued. Instead, children and young people between 0-25 are assessed under the new system which states that local authorities have a clear duty to assess a child or young person’s EHC needs where they may have SEN and they may need special educational provision. ‘Special educational provision’ is that which is ‘additional to, or different from’ that normally provided in mainstream settings. This assessment is called an EHC needs assessment.

EHC plans are being phased in and are gradually replacing statements between September 2014 and April 2018. Details of how this is being planned and delivered in your local area are set out in ‘Transitional Arrangements’ and have to be published as part of your [local offer](#). [Updated government advice has also been published](#)¹⁵.

Paragraph 9.5 of the code states that:

EHC plans should be forward-looking documents that help raise aspirations and outline the provision required to meet assessed needs to support the child or young person in achieving their ambitions. EHC plans should specify how services will be delivered as part of a whole package and explain how best to achieve the outcomes sought across education, health and social care for the child or young person.

Guidance and information is supplied for parents by the national charity IPSEA and is a very good place to find out more about parents’, children’s and young people’s rights. It is also helpful in understanding the systems, processes and paperwork involved¹⁶.



If a child or young person does not currently have a statement of SEN here are a few key points to be aware of:

- Parents or young people themselves can request an EHC needs assessment; the request does not have to come from a professional or school setting. They can usually make the request to their local SEN team or department at your LA. A local SEND Information, Advice and Support Service (SENDIAS) service will help parents and young people to find out who to make their request to and how – see more below in the rights section of this guide.
- A request can be made at any age up to a child or young person’s 25th birthday. An assessment can be requested if a child or young person has a learning disability assessment (LDA) or if they are currently out of education and over the age of 18.
- The LA must respond to a request within six weeks to say if they are going to assess or not. The LA officers making this decision have to contact the child or young person’s education setting for their opinions. They will be able to make a much better decision if they have as detailed information as possible. So it is vital that parents work with their child’s education setting (such as nursery, school or college) to explain their child’s needs, what has been put in place so far and why they or their child is still not making as much progress as they could do. All this will help them understand why an assessment would help a child or young person achieve their best possible outcomes.
- If the LA refuses to assess, the parent, child or young person **must** be informed; they have the right to appeal to the [Special Educational Needs and Disability Tribunal](#).

15. DfE, 2015. *SEN reforms transitional statutory guidance Sep 2015*. [pdf] Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/463320/Transition_Dept_advice_sept15.pdf [Accessed 31 March 2016].

16. IPSEA, 2015. Available at: www.ipsea.org.uk [Accessed 31 March 2016].

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What is an EHC plan?



- If the LA agrees to assess, it has a further 10 weeks before it is required to issue a draft EHC plan. During the period in which it carries out the assessment – during which information or reports (called advice) have to be requested from key professionals – it must also have a face to face meeting with the parent, child or young person.
- If the LA refuses to issue an EHC plan, a parent or young person **must** be told why. The parent, child or young person has the right to appeal to the Special Educational Needs and Disability Tribunal.
- If the LA decides to issue an EHC plan, it must first issue a draft plan for the parent, child or young person to consider. This has to be within 16 weeks of the request to assess.
- At this stage, a parent, child or young person will be asked to name the type of school or college they want (for example, a mainstream or special school) and the individual school or college they want to have named in the EHC plan. The parent, child or young person will have 15 days to do this.
- The LA will then consult with that school or college about being named in the EHC plan. Within 20 weeks, the final plan should be issued.

These stages are described in the [timeline for new requests](#).

If a child or young person already has a statement of SEN, then they are legally entitled to have an EHC needs assessment. They will go through what is called a transfer review, which is usually held when their annual review is due. As there are so many children in England with a statement of SEN, the transfers are being phased in gradually.

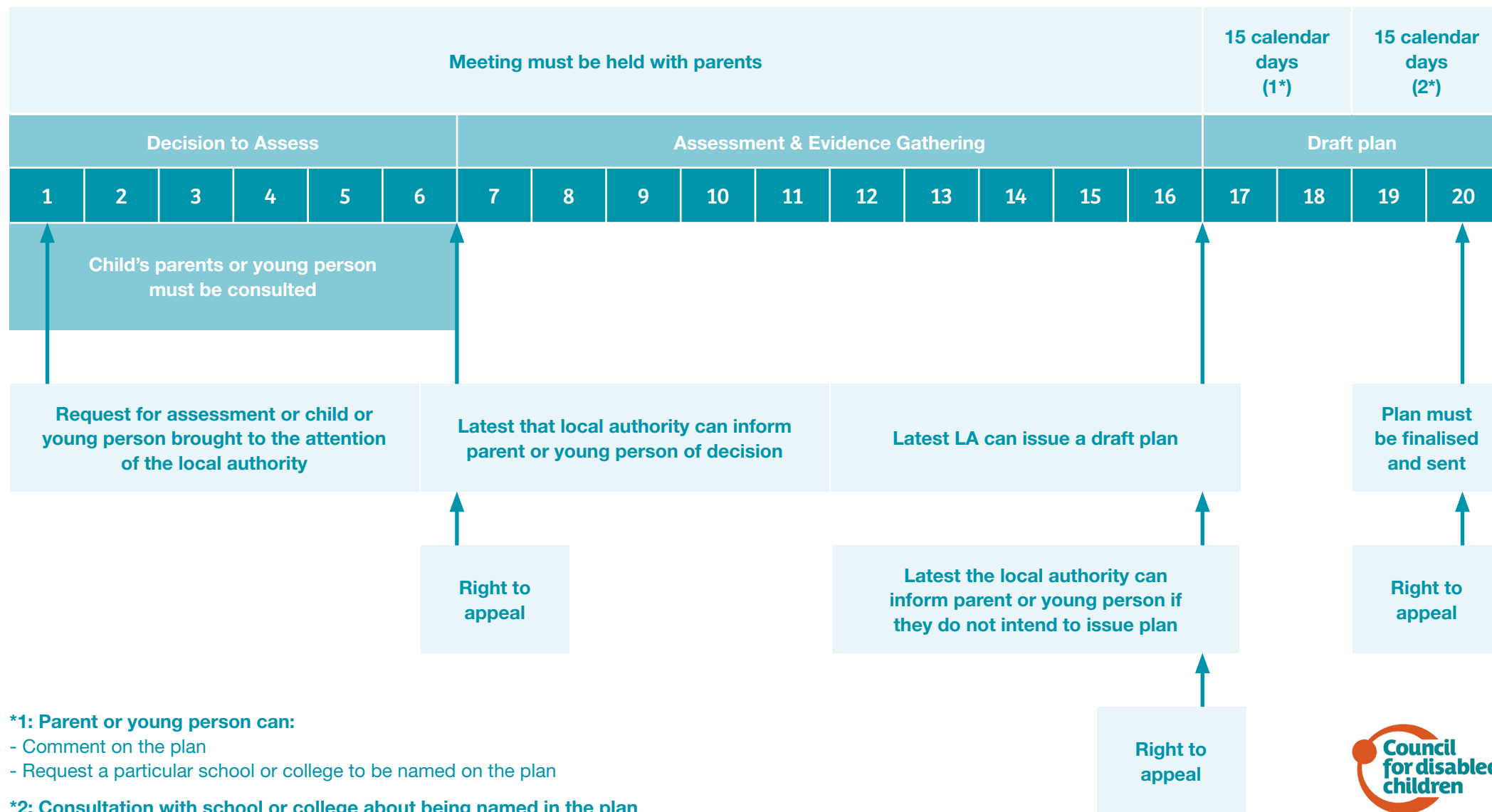
A few key points to remember about 'transfers':

- Until a child starts their transfer review and throughout the EHC needs assessment their statement remains in place exactly the same as before.
- A child won't 'miss out' – the priority group of pupils each school year are those in year 9 and all those due to transfer from one stage of education to another.
- The government has made it very clear that they do not expect any child to lose their statement, and not be issued with an EHC plan instead, just because the system is changing.
- The legal status and the rights (to meetings or to challenge, for example) of a child or young person going through a transfer review are exactly the same as for new requests.
- The requirements for an EHC plan are different to the statement, so it is not simply a matter of copying and pasting information from the statement to the EHC format. It is a new assessment *but* existing information and reports about a child or young person may be used if a parent or young person, the person who wrote the advice and the LA *all* agree that it is still current and valid.

The stages are described in the [transfer review timeline](#).

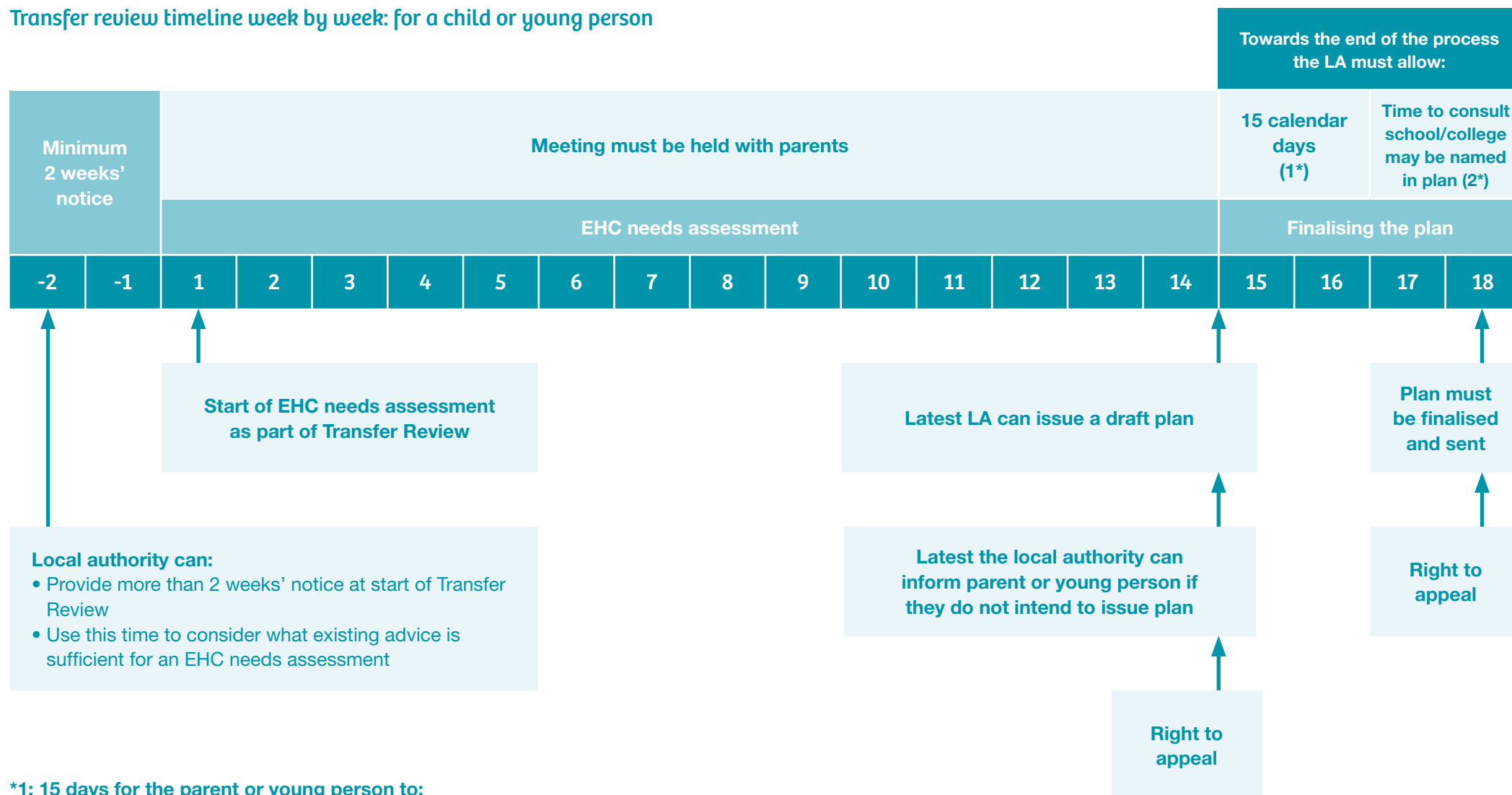


EHC assessment and plan: week by week timeline for new requests





Transfer review timeline week by week: for a child or young person



***1: 15 days for the parent or young person to:**

- Comment on the draft plan
- Request a particular school or college be named in the plan
- Meet the LA to discuss the draft plan

***2: School or college should respond within 15 days**

What does an EHC plan look like?

Wherever you live in England there are certain sections of the plan that are laid out by law. These can be seen clearly in the code in paragraph 9.69, where each section is explained. Different LA areas will have slightly different layouts and designs but they must all contain these clearly labelled sections A-K.

The diagram below (taken from a Department of Health presentation) names the sections and highlights. Section A is a child's views, wishes and dreams and their parents' aspirations for them as discussed above.

“Professionals were interested to see our contribution to the EHC plan as they finally realised that there was a need to plan for a longer term, rather than the short term views they had previously taken.”

Parent

See [Section A: The starting point](#) diagram on the next page.

The SEN officers who write plans, are informed by section A which 'is all about me' and by the advice and information from professionals which are 'all about my special needs' (sections B, C and D) and then have to write outcomes that are agreed by all those involved (Part E).

Outcomes must be challenging, stretching but realistic. They also need to look towards the future. For children and young people who need palliative care, their high levels of need and the complexity of their conditions have to be taken into account; however, we mustn't lose sight of the fact that they too have the capacity to really 'reach for the stars' in their own individual way.

“It's very hard to think about what you want in the future, so we think in smaller steps and really divide outcomes in my daughter's plan into longer term ones such as next year, but also some outcomes are much shorter term. Because she spent 115 days in hospital one year her outcomes are also things that are really important to us as a whole family. I'm talking about keeping her as healthy as possible, which needs lots of support so she can attend school with her brother and her friends.”

Parent

See [Section E: The benefit or difference](#) diagram on the next page.

Then come Parts F, G and H which are called the provision sections. These include details of the services which will be provided to the child or young person and will include what is going to be put in place, by whom and how often. Paragraph 9.69 of the code states that this must be detailed and specific.

Part I is the name of the placement (only in final version not in the draft see – paragraph 9.77 of the code).

Part J is personal budgets (see below).

Part K is all the advice and information given to inform the plan.

Keeping EHC plans up to date

EHC plans must be reviewed by the local authority as a minimum every 12 months. If a child or young person has an EHC plan, it is worth them or their families bearing in mind that their review process will:

- consider whether the outcomes and supporting targets set out in the child or young person's plan are still appropriate – and if not, set new ones
- gather and assess information so that it can be used by early years settings, schools or colleges to support the child or young person's progress and their access to teaching and learning
- review the special educational, health and social care provision made for the child or young person to make sure it is being effective in ensuring access to teaching and learning and good progress towards outcomes
- consider the continuing appropriateness of the EHC plan in the light of the child or young person's progress during the previous year (or any change in their circumstances)
- set new interim targets for the coming year and where appropriate, agree new outcomes

Reviews **must** be undertaken in partnership with the child and their parent or the young person. They must take account of their views, wishes and feelings, including their right to request a personal budget. The first review must be held within 12 months of the date when the EHC plan was issued. After this, it must be within 12 months of any previous review. The LA must notify the child or young person within four weeks of the review meeting. The notification must be sent no later than one year after the EHC plan was issued or the previous review took place.



Section A: The starting point

A. Views, interests and aspirations of the child or young person, and their parents

- The child or young person's aspirations and goals for the future
- Play, health, schooling, independence, friendships, further education and future plans including employment (where practical)
- How to communicate with the child or young person and engage them in decision-making
- The child or young person's history

A. Views, aspirations

B. SEN needs

C. Health needs

D. Social care needs

E. Outcomes

F. SEN provision

G. Health provision

H. Social care provision

I. Placement

J. Personal budget

K. Advice and information

Section E: The benefit or difference

E. The outcomes sought for the child or young person

- A range of outcomes over varying timescales, covering education, health and care as appropriate
- Steps towards meeting the outcomes, arrangements for monitoring progress
- Forward plans for key changes in a child or young person's life, such as changing schools, moving from children's to adult care and/or from paediatric services to adult health, or moving on from further education to adulthood

A. Views, aspirations

B. SEN needs

C. Health needs

D. Social care needs

E. Outcomes

F. SEN provision

G. Health provision

H. Social care provision

I. Placement

J. Personal budget

K. Advice and information

Getting help with EHC plans

Although this may all sound pretty daunting at this stage, there is specialised support out there for families. This includes that offered by independent supporters¹⁷, who are there to help children, young people and parents through this new process.

Independent supporters are individuals who are recruited and managed by the private, voluntary and community sector. They provide advice and support for parents of children with SEN, and young people with SEN, through the statutory assessment and EHC plan processes. They are working in every English LA area and there is no charge to use the services they offer. To find out how to contact the services in your area visit

<https://councilfordisabledchildren.org.uk/independent-support/where-find-my-independent-support-provider-until-31-july-2018>



17. CDC, 2015. Independent Support. Available at: www.councilfordisabledchildren.org.uk/what-we-do/our-networks/independent-support [Accessed 31 March 2016].

Case Study

A mum, Jackie, has shared her family's experience of the new system for this guide. Ellie (aged 5) and Mathew (aged 12) are a brother and sister who both have very different complex medical and physical needs. They really enjoy accessing support from Chestnut Tree House Children's Hospice where these photos have been taken.

Their mum, Jackie says

“Mathew is at a wonderful specialist school and we really wanted his sister to be able to join him as there are nurses on site and Ellie’s care is very complex. She has spent many months in hospital and all her medical needs really impact on her educational needs. We applied for an EHC plan but the process didn’t go very smoothly as we were the first family in the area to go through it so were testing the new system. However, as we went along we learnt to navigate the system and with some really good specialist advice and support we made sure we got the best for Ellie. Although we were concentrating on her education in her plan we were actually looking at all her needs and the impact on the whole family. We learnt to clearly describe her needs and have the experts back this up with their reports, so the people writing the EHC plan could really understand the importance of what we were all saying and the need to support Ellie’s overall development to give her the best possible chances in life.”

Jackie, mum

Top tips from other parents:

Jackie's top tips for other parents going through the EHC plan process, in no particular order are:

1. Keep calm at all times.
2. Keep copies of all your records, documents and communications with everyone involved.
3. Don't be afraid to seek out help and specialist advice if you feel you may need it.
4. Do as much research as you can.
5. Work with people not against them, be professional in your approach.
6. But never give up.
7. Don't be frightened to challenge – they are only human and this is a new system!
8. Believe in your child and what you want for them.
9. Believe in yourself and your knowledge about your child.



Personal budgets

The code describes personal budgets as:

9.95 an amount of money identified by the LA to deliver provision set out in an EHC plan where the parent or young person is involved in securing that provision.

The two key points for children, young people and parents to understand are that:

9.97 personal budgets are **optional** for the child's parent or the young person but local authorities are under a duty to prepare a budget when **requested**.

What this means is that children, young people and parents have a legal right to request a personal budget when their LA has completed an EHC needs assessment – and confirmed that it will prepare an EHC plan. This is optional, however, a child or young person with an EHC plan does not have to have a personal budget.

Together for Short Lives has produced a detailed and informative [Guide for Young People on Personal Budgets](#) which includes descriptions of the different types of personal budgets, along with your rights and who can support and help you.

Top tips from other parents:

1. Be creative and think outside of the box. This is a nice quote to remember from a father about his family: “we are not here to fit in your box, we are here to help you realise there is NO box”.
2. Consider asking for a continuing care assessment¹⁸, as your child may be eligible for a personal health budget or to be joint funded with social care and/or education to meet their specific needs.
3. Support your child to express what it is that they want from life; if they are a teenager you may well need to help them a bit to really think about the future and to allow for personal growth – not speaking for them, but gently prompting as they don't have the experience in life that you have, or the necessary knowledge to get the best out of the system, to get what they really need now and in the future.
4. Be organised, keep on top of the paperwork and accept any help and support you feel you need. If your son or daughter is managing their own budget in their own right (as a young person or young adult) then assist them to do as much as they can. This could include choosing and organising personal assistants, for example. If the paperwork or other 'boring stuff' starts to slip offer to help them with this!



The local offer

One of the most powerful and indeed empowering aspects of the 'SEN world' that families find, is the passion and knowledge that parents eventually gain – and their willingness and enthusiasm to share information with each other. Some parents meet others:

- at the school gate
- at support groups
- through accessing the same services such as child development units, clinics, hospitals or children's hospices.

But far too many are actually very isolated, receive limited information about what is available for their child and their family and can get very lost in the system.

“As my daughter grew up, I realised that the majority of useful information I'd had was from other parents – how to get a Blue Badge, what benefits we were entitled to right down to the place where she now lives so happily.”

Parent



During the period before the Children and Families Act came into force, the Department for Education consulted with those working in the SEND field and with children, young people and their families, asking them what needed to change. **One key message that has been expressed loud and clear for many years now is that families want access to easy-to-understand, impartial, accurate and accessible information.**

As a result, section 30 of the act requires local areas to publish information about provision expected to be available within and outside LA's area.

This is called the local offer and is explained fully in chapter four of the code, which includes:

4.1 Local authorities must publish a local offer, setting out in one place information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled, including those who do not have EHC plans. In setting out what they 'expect to be available', local authorities should include provision which they believe will actually be available.

4.2 The local offer has two key purposes:

- To provide clear, comprehensive, accessible and up-to-date information about the available provision and how to access it
- To make provision more responsive to local needs and aspirations by directly involving disabled children and those with SEN and their parents, and disabled young people and those with SEN, and service providers in its development and review



It goes on to detail what must be included, and how children, young people and their parents **must** be involved in both developing and reviewing their local offer.

4.21 Local authorities must publish comments about their local offer received from or on behalf of children with SEN or disabilities and their parents and young people with SEN or disabilities.

4.22 Comments must be published if they relate to:

- the content of the local offer, which includes the quality of existing provision and any gaps in the provision
- **the accessibility of information in the local offer**
- how the local offer has been developed or reviewed.

All local offers have to have a feedback mechanism – either an online form, phone number, email address or ‘feedback’ button to ensure everyone can have their say.

How do I find my local offer?

Some local offers are on their LA website and some are ‘standalone’ websites. The easiest way to find your local offer is to use a search engine such as Google and enter the name of your local upper tier authority (usually a county, city or London Borough) and the term “local offer” and the link will come up. You can find out what your local authority by entering your postcode to this [Directgov webpage](#)¹⁹. As this has been a core duty outlined in the act since September 2014, every local area now has published a local offer that can be found this way.

As described above, this should not be just a service directory and a list of addresses and phone numbers. It should explain what a service does, who it is for and how to access it. The local offer must cover universal services from 0-25 (those that everyone can use such as GPs and schools) through to specialist services such as special schools, community children’s nurses and hospices, for example.

“I see the local offer as the 21st century version of the school gate, but we too need to contribute to it and share our knowledge with the families coming through behind us”

Parent



What happens when a young person reaches adulthood?

Transition to adulthood (transition) is a huge topic in its own right and we can only touch upon it in an introductory guide such as this. Therefore, in this section we are going to look at what the law says and where to find more information and support.

There are many excellent resources and organisations concentrating on transition and Together for Short Lives is leading a UK wide project to try and improve outcomes for young people who are living into adulthood. This project is called the Transition Taskforce. You can find out about the Taskforce, read the newsletters, access useful research and information, and find out about the Regional Action Groups to see what is happening in your own area by visiting <https://www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services/regional-action-groups/>.

Not specific to those with life-limiting conditions, but a source of lots of useful information, guides and tools is the [Preparing for Adulthood \(PfA\) programme](#)²⁰. This is a Department for Education-funded programme to support the SEND reforms. You can also sign up for their regular newsletters.

The importance of transition within the new SEND system is highlighted by PfA in their factsheet about the links between the act and the Care Act²¹, which states:

Part 3 of the Children and Families Act 2014 transforms the system for disabled children and young people and those with SEN, so that services consistently support the best outcomes for them. The reforms create a system from birth to 25 through the development of co-ordinated assessment and EHC plans; improving cooperation between all services responsible for providing education, health or social care; and giving parents and young people greater choice and control over their support.

The SEND reforms focus on the following themes:

- Working towards clearly defined outcomes
- Engagement and participation of parents and young people
- Joint commissioning and developing a local offer of support
- Co-ordinated assessments and EHC plans
- Personalisation and personal budgets.

Preparation for adulthood is a key element of the reforms that cuts across all of these themes. The transformation of the system for disabled young people and those with SEN is intended to ensure that services consistently support the best outcomes for them. The new system should make sure that children, young people and their parents have greater choice and control in decisions and that their needs are properly met.

“The one thing I really want to tell other parents about is something called parallel-planning. My son had been so ill at aged 14 or so that no one talked about the future, let alone us and we didn’t plan as we didn’t expect him to make it to the end of the year or even to sixth form. But then he rallied and suddenly he was 17 and we didn’t have any transition plans in place! That’s when I heard about planning for both possibilities – being well enough to make it to adulthood, whilst at the same time planning in case he would not – makes sense now and certainly better than sticking my head in the sand!”

Parent



21. Preparing for Adulthood, 2015. Available at: www.preparingforadulthood.org.uk [Accessed 31 March 2016].

22. PfA, 2015. PfA Factsheet: The Links between the Children and Families Act 2014 and the Care Act 2014. [pdf] Available at: www.preparingforadulthood.org.uk/media/421323/care_act_revised_march_2016_online.pdf [Accessed 31 March 2016].

What are the specific duties that relate to moving into adulthood?

Chapter 8 of the code concentrates on 'preparing for adulthood from the earliest years' and details what commissioners, health services, local authorities and education providers (including further education settings) must do.

The new duties are very wide and go up to the age 25. They include joint commissioning and 'co-operation' and offering support and advice directly to young people themselves. There are clear duties from Year 9 onwards, the code states:

8.9 Local authorities **must** ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood. It can be helpful for EHC plan reviews before Year 9 to have this focus too. planning **must** be centred around the individual and explore the child or young person's aspirations and abilities, what they want to be able to do when they leave post-16 education or training and the support they need to achieve their ambition. Local authorities should ensure that children and young people have the support they need (for example, advocates) to participate fully in this planning and make decisions. Transition planning **must** be built into the revised EHC plan and should result in clear outcomes being agreed that are ambitious and stretching and which will prepare young people for adulthood.

Under the act a child becomes a 'young person' at the end of their compulsory education (the end of the school year in which they turn 16). With this comes many specific decision-making rights about EHC plans and for parents this can be a very scary concept. However, the code clearly also says that:

local authorities, schools, colleges, health services and other agencies should continue to involve parents in discussions about the young person's future.

The law about decision making and mental capacity is very clear and there are several useful resources to explain this sometimes complex and difficult topic to family members. Some of these are in the resources list at the end of this guide and Together for Short Lives has produced a new *Family Factsheet 20* on The Mental Capacity Act. This starts with:

as your child approaches adulthood you will need to think about the shift towards their legal status as decision-makers and your role as parent carers in supporting them to make decisions.

"When we did a person centred planning day to help us understand my son's needs for transition it was absolutely irrefutable and acknowledged by the professionals around the table that the key to a successful transition for him would be the need for in-depth planning to fulfil his health needs when he has moved to adult services."

Parent

Top tips from other parents:

1. Don't forget you can request an EHC needs assessment up to age 25, and can keep an EHC plan in place as long as the young person is in education or training – so even if your son or daughter has left school and has no support in place in college or even wishes to start college it's not too late.
2. Not everyone wants to stay in education – that's okay!
3. You are still their mum or dad, most of our young people want us to be involved still in EHC decisions; many of them need us and are totally reliant on us being their voice and their champion – don't be put off!
4. Support them to express their dreams, and to then live them to the best of their ability.
5. Don't be scared of adult health services. Some of us are finding they are actually more joined-up than children's.



What are my rights within the SEND reforms?

Chapter 11 of the code covers how to resolve disagreements and is very detailed about the relevant legislation and the processes involved. The vision behind the act is to try to ensure a less adversarial system that listens to the views and wishes of families earlier (Section 19 Principles) and one where the child's voice is central to their own planning. This is, as we have said, a wonderful vision, but is much harder to put into practice.

Because this vision is not an easy one to turn into reality and things often don't go as they should, the government has also ensured that there is specialist support and advice for children, young people and their parents on EHC issues. This is provided free of charge in every local area by the SEND Information, Advice and Support Service SENDIASS. You may have known this team locally by their previous name Parent Partnership, but their remit has widened considerably now; to find your local service and to understand what information, support and advice they can offer you visit the network website at

<https://councilfordisabledchildren.org.uk/information-advice-and-support-services-network>.



All Local Authorities **must** make disagreement resolution services available for parents and young people, including a mediation service. Use of this service is voluntary and is not just for those who are being assessed for or have an EHC plan.

During the EHC needs assessment process itself there are specific times when a child, parent or young person can appeal and challenge certain decisions made by the LA. There are set timescales and processes involved in appealing to the SEND Tribunal these are marked on the timelines in the EHC section. However, not all decisions can be legally challenged and taken to tribunal. Advice on how to go about making a challenge and more detailed information and individual support can be provided by SENDIASS and by IPSEA²².

These are the decisions in the EHC process that can be taken to the First Tier Tribunal:

In relation to a request for an EHC needs assessment and EHC plan, a child's parent or the young person themselves can appeal:

- LA's decision not to assess or not to issue a EHC plan
- The description of special educational needs or provision in the plan (Sections B and F)
- LA's decision not to reassess or not to amend the plan following a review or reassessment
- LA's decision to cease to maintain an EHC plan
- The school or other institution or the type of school or other institution specified in the plan, or fact that no school or institution has been specified in the plan (section I)

Separate to this is a child, young person or parent's right to make a complaint about any aspect of child or young person's education or care. Some specific resources for families include *Together for Short Lives Family Factsheet 3 'Making a Complaint'* and the Council for Disabled Children has an online module specifically written for parent carers about making complaints within the health system, which can be accessed here: www.councilfordisabledchildren.org.uk/expertparent.



Who holds the local SEND system to account, and how can I influence what happens?

There are many local accountability systems that you can approach, and individuals such as your MP, local councillors (elected members) or an SEN governor in your child's school. All local offers **must** describe local processes and pathways to make a complaint and to hold the system to account at an individual level and collective level. There are also 'accountable bodies' who can gather evidence and influence how the system is working in your own area.

These include SENDIASS as mentioned above and Healthwatch²³.

As of May 2016, Ofsted and the Care Quality Commission (CQC) are inspecting how effectively local areas are meeting their obligations to children and young people who have SEN and/or disabilities. The exact format of these inspections has not yet been announced but they have been widely consulted on and parent carers have been very involved in both the planning and pilot inspections. Inspectors have made a public commitment to meeting children, young people and their families during their inspections.

Here are a few ways you could get involved:

- Joining a local voluntary support or condition specific group. See *Together for Short Lives Family Factsheet 1 'Parent Support Groups'*.
- Joining the Together for Short Lives family community. If you want to find out more please do contact info@togetherforshortlives.org.uk.
- Joining your local Parent Carer Forum. See details in the resources list below.

We hope this introductory guide is useful for you, but if you have questions or want support, please contact our **Together for Families Helpline free on 0808 8088 100**.

The helpline is open from 10am until 4pm, Monday-Friday. Outside of these hours and on Bank Holidays, do leave a message on our answerphone and we will return your call as soon as we can.

The helpline provides:

- information on how to access and get the best out of services locally
- support in using our materials, resources and tools for families
- detailed information about organisations that provide support in all areas of children's palliative care
- signposting to children's disability charities, grant-making bodies, bereavement support, counselling and benefits information
- time to talk to trained helpline staff
- details of how to link with other parents
- in appropriate circumstances, referral on to our Advocacy Support Service for one-to-one support from a legal advocate



Helpful resources

Together for Short Lives provides a range of resources for families and professionals at www.togetherforshortlives.org.uk.

Understanding the Law

Independent Parental Special Education Advice (IPSEA)

<https://www.ipsea.org.uk/pages/category/sen-and-disability-law>

Disabled Children: A Legal Handbook 2nd Edition

www.councilfordisabledchildren.org.uk/resources/disabled-children-a-legal-handbook

Wider SEND Issues

IPSEA

www.ipsea.org.uk

Contact a Family

<https://contact.org.uk/advice-and-support/education-learning/>

Special Needs Jungle

www.specialneedsjungle.com

Disability Matters

www.disabilitymatters.org.uk

Education, health and care (EHC) plans EHCPs

IPSEA

www.ipsea.org.uk

Independent Supporters Factsheets

www.councilfordisabledchildren.org.uk/what-we-do/our-networks/independent-support

Personal budgets and personal health budgets

In-Control

www.in-control.org.uk/publications.aspx

People Hub

www.peoplehub.org.uk

Reaching adulthood

Stepping Up – Together for Short Lives Transition Guide

<https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/>

Preparing for Adulthood

www.preparingforadulthood.org.uk

Preparing for Adulthood Factsheet on Mental Capacity Act

www.preparingforadulthood.org.uk/media/380898/pfa_factsheet_-_mca-cb_final_versions_3-12.pdf

Disability Matters Mental Capacity Act guidance

www.disabilitymatters.org.uk/course/view.php?id=62

Rights

SENDIASS

www.iasnetwork.org.uk

Independent Support

www.councilfordisabledchildren.org.uk/what-we-do/our-networks/independent-support

Cerebra's problem solving tool-kit for parents

<http://w3.cerebra.org.uk/research/problem-solving-toolkit-for-families/>

My Rights, Your Responsibility – guide to your child's rights from the Council for Disabled Children

www.councilfordisabledchildren.org.uk/resources/my-rights-your-responsibility

Influencing

Contact a Family Parent Carer Participation

www.cafamily.org.uk/what-we-do/parent-carer-participation/

Parent Carer Forums: National Network of Parent Carer Forums

www.nnpcf.org.uk





Glossary of terms

Compulsory school age: A child is of compulsory school age from the beginning of the term following their fifth birthday until the last Friday of June in the year in which they become 16, provided that their 16th birthday falls before the start of the next school year.

Disagreement resolution: This is a statutory service commissioned by local authorities to provide a quick and non-adversarial way of resolving disagreements between parents or young people and bodies responsible for providing education, whether the child or young person has an EHC plan or not, or health and social care in relation to EHC assessments and plans. Disagreement resolution services can also be used in cases of disagreement between local authorities and health commissioning bodies during EHC needs assessments, the drawing up of EHC plans or the reviewing of those plans.

Education, Health and Care plan (EHC plan): An EHC plan details the education, health and social care support that is to be provided to a child or young person who has SEN or a disability. It is drawn up by the local authority after an EHC needs assessment of the child or young person has determined that an EHC plan is necessary, and after consultation with relevant partner agencies.

First-tier Tribunal (Special Educational Needs and Disability): An independent body which has jurisdiction under section 333 of the Education Act 1996 for determining appeals by parents against local authority decisions on EHC needs assessments and EHC plans. The Tribunal's decision is binding on both parties to the appeal. The Tribunal also hears claims of disability discrimination under the Equality Act 2010.

Information, Advice and Support Services: information, advice and support services provide advice and information to children with SEN or disabilities, their parents, and young people with SEN or disabilities. They provide neutral and factual support on the special educational needs system to help the children, their parents and young people to play an active and informed role in their education and care. Although funded by local authorities, information, advice and support services are run either at arm's length from the local authority or by a voluntary organisation to ensure children, their parents and young people have confidence in them.

Local offer: Local authorities in England are required to set out in their local offer information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled, including those who do not have Education, Health and Care (EHC) plans. Local authorities must consult locally on what provision the local offer should contain.

Ofsted: Office for Standards in Education, a non-ministerial government department established under the Education (Schools) Act 1992 to take responsibility for the inspection of all schools in England. Her Majesty's Inspectors (HMI) form its professional arm.

Parent: Under section 576 of the Education Act 1996, the term 'parent' includes any person who is not a parent of the child, but has parental responsibility (see below) or who cares for him or her.

Parent carer forum: A parent carer forum is a group of parents and carers of disabled children who work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families.

Personal budget: A personal budget is an amount of money identified by the local authority to deliver provision set out in an EHC plan where the parent or young person is involved in securing that provision. The funds can be held directly by the parent or young person, or may be held and managed on their behalf by the local authority, school, college or other organisation or individual and used to commission the support specified in the EHC plan.

Special educational provision: Special educational provision is provision that is different from or additional to that normally available to pupils or students of the same age, which is designed to help children and young people with SEN or disabilities to access the National Curriculum at school or to study at college.

Special school: A school which is specifically organised to make special educational provision for pupils with SEN. Special schools maintained by the local authority comprise community special schools and foundation special schools, and non-maintained (independent) special schools that are approved by the Secretary of State under Section 342 of the Education Act 1996.

Young person: A person over compulsory school age (the end of the academic year in which they turn 16). From this point the right to make decisions about matters covered by the Children and Families Act 2014 applies to the young person directly, rather than to their parents.

