

**Smith Magenis Syndrome and
Education, Health, and Care (EHC)
needs assessments and EHC Plans: a guide for parents
and carers.**

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About this guide

This guide aims to:

- Explain the processes for securing special educational needs support brought in by the Children and Families Act 2014, Special Educational Needs and Disabilities (SEND) Regulations 2014 and SEND Code of Practice 2015
- Explain how to request an Education, Health and Care (EHC) needs assessment, what happens if the assessment is agreed and what an EHC Plan should look like
- Provide a description of the Education, Health, and Care needs of a child/young person with Smith Magenis syndrome and provide some tips and examples of best practice for EHC plans

What is an Education, Health and Care (EHC) plan?

An EHC plan is a legal document which describes a child (0-16) or young person (16-18) or adults (19-25 if there is a continuing need for education) with special educational needs, the support they need, and the outcomes they would like to achieve. They may also have additional health and social care needs and those can be included in the plan so long as they relate to education. You cannot have a freestanding EHCP for health or social care reasons alone.

An EHC plan can only be issued after a child or young person has gone through the process of an EHC needs assessment if the Local Authority (LA) agrees to issue an EHC plan.

There are three key decision points:

1. whether to carry out an EHC needs assessment
2. whether to issue an EHC plan or not, and
3. the content of EHC plan

Education, Health and Care needs assessments

Who can request?

- The child's parent
- A young person over the age of 16 but under the age of 25. At age 16, the legal rights pass from the parent to the young person if they have mental capacity
- A person acting on behalf of a setting, school or post 16 institution (with the permission of the parent or young person)
- Anyone else - for example, health or social care (with the permission of the parent or young person).

Important Note: It is only the first three that would open up the right of appeal to the SEN & Disability (SEND) Tribunal if the LA refuses to carry out the assessment.

Independent Provider of Special Educational Advice (IPSEA) have a template letter to request an EHC needs assessment at [To request an Education, Health and Care needs assessment \(Template letter 1\)](#)

Legal Threshold for an EHC Needs assessment

CFA 2014 Section 36 (8) LA must assess where:

- The child or young person has or may have special educational needs, and

- It may be necessary for special educational provision to be made for the child or young person in accordance with an EHC Plan.

For the LA to apply a stricter test is unlawful but common reasons for refusal are:

- A lack of diagnosis on the special educational needs of the individual
- No report from an educational psychologist
- The child or young person is not deemed to be far enough behind their peers.
- There has not been at least 3 reviews of the SEN Support Plan.

Judge Jacobs stated *“the issue at the initial stage is a provisional and predictive one; it is only when an assessment has been made that a definitive decision has to be made”*. In other words, how do you know whether provision needs determining in an EHC plan unless an assessment has been carried out in the first place.

The LA has six weeks from receiving a request for an EHC needs assessment to make a decision whether to assess or not. If the LA refuses to carry out an EHC needs assessment, you will be given the decision in writing with details of the Mediation Service and the right of appeal to the SEND Tribunal

You have 2 months from the date on the decision letter to lodge an appeal to the SEND Tribunal or 1 month from the date on a Mediation Certificate whichever is the later.

Timescales for EHC Needs Assessments

- 6 weeks: LA considers request and gathers information (3 weeks if a reassessment)
- 6 weeks - 12 weeks: LA gathers advice and information
- 4 weeks - 16 weeks: LA considers whether to issue an EHC Plan – either to issue a refusal decision letter or a draft EHC plan
- Draft issued to parent or young person with 15 calendar days to respond
- A further 15 calendar days for the LA consult with educational setting of parental preference and any other educational setting they deem suitable
- 20 weeks: EHC Plan is finalised

Education, Health and Care (EHC) needs assessment

Advice should be requested from the following:

- Child's parent or young person
- Educational advice (usually from the setting manager, head teacher or principal of post-16 institution)
- Medical advice and information
- Psychological advice and information from an educational psychologist
- Social care advice and information (it is not enough to say not known to this service)

The first five are statutory advice so the LA must seek this advice but in addition they should also seek advice from the following, if appropriate:

- Advice and information from any other person the local authority think is appropriate e.g. hearing or visually impaired from a suitably qualified person.
- Where the child or young person is in or beyond year 9, advice and information in relation to provision to assist the child or young person in preparation for adulthood and independent living

- Advice and information from any person the parent or young person reasonably requests that the local authority seek advice from, for example: speech and language therapist, Child and Adolescent Mental Health Service (CAMHS).

You can submit privately commissioned reports, but the LA will usually take the advice from their own professionals and/or NHS.

Advice givers have six weeks to respond to the request; however, the LA does not need to request advice if it already exists. If the local authority is unable to obtain one of the necessary pieces of advice, they would be expected to obtain an independent report in its place. This is particularly important given the national shortage of educational psychologists.

By week 16 the LA must notify the parent or young person whether they intend to issue an EHC plan or not.

In making this decision the local authority should take into account:

- Whether the special educational provision required to meet the child or young person's needs can reasonably be provided from within the resources normally available to mainstream early years providers, schools and post 16 institutions, or
- Whether it may be necessary for the local authority to make special educational provision in accordance with an EHC Plan.

If the LA decides not to issue an EHC plan you must be informed in writing giving the reasons for the decision with the Mediation Service details and giving the right of appeal to the SEND Tribunal. You have 2 months from the date on the decision letter to lodge an appeal to the SEND Tribunal or 1 month from the date on a Mediation Certificate whichever is the later.

If the LA decides to issue an EHC plan, it should be issued in draft form for consultation to the parents or young person giving 15 calendar days to respond.

Education, Health and Care Plans

An EHC plan is made up of the following sections:

Section	What's included in this section?
Section A	The views, interests and aspirations of the child, their parents or the young person
Section B	The child or young person's special educational needs (not what they need) – this includes all SEN and not just SMS.
Section C	The child or young person's health needs which are related to their SEN.
Section D	The child or young person's social care needs which are related to their SEN.
Section E	The outcomes sought for the child or young person. Review and monitoring arrangements.

Section F	The special education provision required by the child or young person. This should be detailed and quantified.
Section G	Any health provision reasonable required by the learning difficulties or disabilities.
Section H1	Any social care provision which must be made for a child or young person under 18 resulting from section 2 of the Chronically Sick and Disabled Persons Act (CSDPA) 1970 for example adaptations to the home.
Section H2	Any social care provision reasonably required and not provided by section 2 of the CSDPA for example overnight short breaks. Safeguarding information can be included but only with the permission of the parent and/or young person.
Section I	The name of the educational provider and type of the educational setting.
Section J	Details of any personal budget and how it will support particular outcomes and arrangements for any direct payments.
Section K	The advice and information gathered during the EHC needs assessment must be attached and listed.
If the young person is in year 9 or above the EHCP must include (in sections F, G, H1 or H2 where appropriate) the provision required in relation to preparing the young person for adulthood and independent living. e.g., support for finding employment, housing, or for participation in society.	

An EHC plan

- Should be “clear, concise, understandable and accessible to parents, children, young people, providers and practitioners”.
- The needs and provision should be detailed and specific and quantified, e.g. in terms of the type, hours and frequency of support and level of expertise.
- Where the health or social care provision educates or trains it should be treated as educational provision, for example occupational therapy.
- For each identified need there should be an outcome and provision, the ‘golden thread’.

It is vitally important that the provision is specified and quantified.

This is partly so each and every teacher, assistant, etc., dealing with the child or young person knows precisely what they should be doing to help and if provision is not specified and detailed in Section F, it would be difficult to enforce.

If an EHC plan provides, for example, that ‘*X will have access to a social use of language programme with opportunities to work in a small group*’ - this is largely meaningless and difficult to enforce.

Alternative wording – ‘*X will receive a 30 minute session twice a week focusing on developing his social use of language. The sessions will be delivered by a teaching assistant with one other child (1:2). The programme will be developed by a Speech and Language Therapist who will train the TA in delivering the sessions and review his progress termly*’.

This is very easy to check whether that is happening and to enforce it if it is not.

Some LAs have a tendency to set out support in very vague terms – using wording such as “will benefit from”, “access to”, “opportunities are”, “regular”, “up to”, “as advised”, “as required”, “may be helpful”, “contacts”, and “adults.” Such terms, if they appear in draft EHC plans, should always be challenged; there is simply no reason why the EHC plan should not state that the child or young person “will receive” the support in question, or specify precisely how often “regular” is, how long a “contact is”, and who the “adults” should be (e.g. TA, teacher etc).

Many draft EHC plans do not detail the necessary adult support, for example referring to 1:1, small group or whole class, access to adult support, adult support to be available. This is vague and meaningless. The level of adult support should be specified and quantified, for example ‘*A daily check in session when X arrives at school for 15 minutes on a 1:1 basis with the trained key worker*’.

The EHC plan should be so specific and clear as to leave no room for doubt as to what has been decided and what is needed in the individual case.

IPSEA have an EHC plan checklist at [EHC plan checklist](#) to see whether your EHC plan complies with the law.

Legal responsibilities

- The LA is responsible for the drawing up, the educational provision (section F) and the maintaining of the EHC Plan
- Provision in the health section must be agreed by Health, and if included must be secured by Health but only if reasonably required. Health can still refuse, and this section is open to provision not being included on grounds of cost or convenience.
- Provision in the social care section H1 assessed under the CSDPA 1970 must be included and provided.
- Provision in social care section H2 only if reasonably required so the LA can take cost and convenience into account.

Understanding what a personal budget and direct payments are

Once your child or young person has an EHC plan, the LA must ensure the support set out in the EHC plan is made for them. You can request a personal budget once the EHC needs assessment is completed and the LA issues a draft EHC plan.

Normally, the LA will do this by providing the necessary funding to your child or young person’s setting, school or college, in order for them to deliver the educational support needed, and by arranging any external therapies or other provision that may be specified. However, it is also possible for the LA to consider making a payment to the parent, the young person, or another nominated person so that you can organise the provision yourself. This is called a direct payment. In order for you to request a direct payment, the LA must first identify a personal budget.

The personal budget is the notional amount of money that would be needed to cover the cost of making the special educational provision specified in the EHC plan. Your LA must consider identifying a personal budget for educational provision if you request it.

If you do request a personal budget from your LA, you can at the same time ask it to identify which elements or parts of the personal budget you could then receive as a direct payment. This is an actual amount of money that you would receive so that you could commission or arrange the provision in the EHC plan yourself. The direct payment must be enough to cover the cost of arranging the provision.

The LA can refuse your request for a personal budget for a number of reasons for example it would destabilise an existing service. If the request relates to funding being made available to the school or college, this can only be given with the Headteacher or Principal's agreement.

Information on personal budgets can be found on your LA Local Offer website. The Local Offer gives children and young people with SEND, and their families, information about what support services the local authority think will be available in their local area. Every LA is responsible for writing a Local Offer and making sure it is available for everyone to see.

Detailed information about personal budgets and direct payments are contained in Chapter 9 of the [SEN and Disability Code of Practice](#).

Placement requests

Once the draft EHC plan is issued you will have the opportunity to express a preference for a specific educational placement.

The details of the placement will only be included in the final plan so that the LA does not pre-empt your right to express a preference for an institution including any representations for an independent school or institution. The LA must consult with your preference, unless it is an independent school, but this does not mean that they agree with your request.

You can request a school outside of your LA area, as long as you can maintain that there is no suitable school within your LA.

According to The Children and Families Act 2014 Section 39 (6) the local authority must secure that the EHC Plan names the school or other institution specified in your request, unless:

- the school or other institution requested is unsuitable for the age, ability, aptitude or special educational needs of the child or young person concerned, or
- the attendance of the child or young person at the requested school or other institution would be incompatible with the provision of the efficient education for others, or
- the efficient use of resources

The above does not apply if you are requesting a place at an independent school. Where parents or a young person are making representations for an independent setting, the LA must have regard to the general principle that pupils are to be educated in accordance with the wishes of their parents, so far as that is compatible with the provision of efficient instruction and training and the avoidance of unreasonable public expenditure (section 9 Education Act 1996). If a young person is requesting an independent school or college, the LA should consider this as part of their duty to consider the young person's views, wishes and feelings (section 19 CAFA 2014).

However, when a parent or young person asks for an independent setting as part of their 'representations' on the draft EHC plan, the onus is on them to prove that none of the schools the LA is offering can meet

the child or young person's needs, **or** that the cost of the placement will not constitute unreasonable public expenditure.

If a school is named in Section I of the final EHC plan it must admit the child or young person. The only schools it does not apply to are wholly independent schools as they manage their own admissions and even the SEND Tribunal cannot order them to be named unless they have made an offer of a place.

The Final EHC plan

The LA has to finalise the EHC plan within 20 weeks. Once finalised, you will be given the details of the Mediation Service plus the right to appeal to the SEND Tribunal. You can appeal the following sections:

- Section B (description of needs)
- Section F (provision to meet needs)
- Section I (placement)

Under the Tribunals extended powers to make non-binding recommendations you can also appeal:

- Section C (health needs)
- Section D (social care needs)
- Section G (health provision)
- Section H1 and H2 (social care provision)

You have 2 months from the date on the letter issued with the final EHC plan to lodge an appeal to the SEND Tribunal or 1 month from the date on a Mediation Certificate - whichever is the later.

Following finalisation of the EHC plan, the LA has a duty to review the EHC plan at least annually.

How do I resolve issues around my child or young person's EHC plan?

There are several steps to consider when trying to resolve any EHC plan disagreement:

- 1) Try and resolve any issue by having an informal discussion or meeting with school staff and/or the local authority. These would normally be expected as the first step in seeking to resolve any issues or disagreements. However, it is important not to miss an appeal deadline whilst any discussions are ongoing
- 2) Consult the SEND Information, Advice and Support Service (IASS). Every LA must provide or commission an impartial, confidential and accessible information, advice and support service for children, young people and parents in relation to SEND. It includes offering support to resolve disagreements and help in managing mediation, appeals to the SEND Tribunal and complaints relating to SEND
- 3) Contact the Mediation Service: Every LA must commission an independent mediation service that is available to parents and young people. Before making an appeal to the SEND Tribunal, unless the application is about placement only, (Section I) parents or the young person must contact the Mediation Service to discuss whether mediation might be a suitable way of resolving the disagreement (this is known as 'mediation advice'). The subsequent decision whether or not to take-up mediation is voluntary for parents or young people. If you choose not to engage with a mediation session you should receive a mediation certificate within 3 working days

- 4) If mediation is chosen, the meeting should take place within 30 days of the LA being informed, they must attend, and the attendee must be a decision maker. If the meeting cannot be arranged within 30 days, you should receive a mediation certificate to enable you to appeal
- 5) The parent or young person can lodge an appeal with the SEND Tribunal when in receipt of a mediation certificate unless the appeal relates to Section I only
- 6) Submit a formal complaint to the LA about any matter that cannot be appealed to the SEND Tribunal

For information relating to the SEND Tribunal, what it involves, what its powers are, and how to prepare can be found on the IPSEA website [here](#).

The Educational, Health and Care needs of children and young people with Smith Magenis Syndrome (SMS)

This section will describe the general EHC needs of children and young people with Smith Magenis Syndrome (SMS). This list is not exhaustive, as no two individuals with SMS are identical and different individuals with SMS may have very different EHC needs.

However, these are some of the needs that you may wish to consider for Sections B, C, and D of the EHC plan – some of these issues may affect your child or young person's learning (in section B), health (in section C), social needs (section D) and as a result **should be covered in the relevant sections**.

When considering the needs of your child or young person, you may want to consider their whole school day and the minute-by-minute support they may need - from finding the way to their classroom and unzipping their coat, all the way to leaving at the end of the day. This may not be simple, and because of this you may wish to consult your child or young person's teacher.

- **Language and communication difficulties:** language may be a challenge for individuals with SMS, with them relying on forms of non-verbal communication to express their needs and thoughts
- **Cognition and learning:** attention, reading, writing, as well as number development may cause a challenge. There may be issues with working memory and, because of such, working memory aids such as tokens may help learning
- **Motor delays:** individuals with SMS may have weaker gross motor development due to weaker muscle tone and issues with balance stemming from issues such as ear infections. This may impact on their writing ability but also their ability to stand for long time, to walk long distances across a school building, or on school trips – this may also impact toilet training and getting dressed
- **Eating difficulties:** individuals with SMS will often seek food and will likely be hungry despite eating on a regular basis. This hunger may be distracting to the individual causing issues with attention
- **Personal hygiene:** individuals with SMS may face difficulties with toilet routines and personal hygiene

- **Sensory needs:** individuals with SMS may have complex sensory needs including persistence on routine, hypersensitivity to sounds, restricted interests, sensitivity to certain textures, obsessions and favourite topics
- **Friendships:** although most children and young people with SMS are extremely social and like interactions with others, their relationships with peers may be restricted. Their limited language abilities, and limited understanding of what is appropriate within certain contexts and how to maintain communication, may prevent young people with SMS from building up personal relationships with peers
- **Affectionate behaviour:** individuals with SMS are likely to be overly affectionate, including hugging. This is likely to be directed at whoever is perceived to be in charge e.g., the teacher. This may be distracting to the SMS-er and may limit learning – they may also be distressed if this affection is not reciprocated or if it is directed to another pupil
- **Sleep:** due to an inverted circadian rhythm, the young person is likely to be tired and may require frequent naps throughout the day to maintain energy levels required to learn
- **Self-injurious behaviours:** individuals with SMS may show self-injurious behaviours such as biting, scratching, skin pulling, and nail pulling. This is likely to distract the young person and may also cause distress for others
- **Recurring dental anomalies:** this may cause pain which is a distraction and may elicit self-injurious behaviour to control the discomfort
- **Chronic ear infections:** this may cause pain which is a distraction and may elicit self-injurious behaviour to control the discomfort
- **Visual problems:** there may be a need for visual aids as well as being placed near the front of a class. If the child or young person is unable to see they may become distressed
- **Auditory problems:** due to reoccurring ear infections, the child or young person may struggle to hear or may experience pain from loud environments. This may lead to breakdowns or outbursts
- **Weight and mobility issues:** there are two ways in which this may present. Individuals may have a larger stature which in turn causes issues with mobility, but they may also be failing to thrive and because of such may require aid to move
- **Impulsivity:** individuals with SMS may be impulsive, they may wander or start to work towards their own agenda
- **Breakdown and Outbursts:** when overwhelmed or overstimulated, the child or young person may express their emotions through breakdowns or outbursts. These may be self-directed through the form of self-injurious behaviour but may also be directed at others through acts of aggression

For children and young people with Smith Magenis Syndrome (SMS) it is important to:

- Start the EHC needs assessment process as soon as possible as delays are not uncommon, especially when your child or young person is transitioning between phases of education/schools or into a new local authority
- Provide your advice givers and the LA with information about Smith Magenis syndrome (see information available from the SMS Foundation UK website)
- Check your Local Offer to see what support services are available in your area
- Gather evidence from relevant professionals. You should not need to access professionals privately, but GPs, paediatricians, and other professionals can provide useful advice about your child or young person's development and needs
- The EHC needs assessment process is an evidence based one, so it is important that all areas of need are identified and assessed

Useful Links

Department for Education:

- Special educational needs and disability code of practice: 0 to 25 years statutory guidance: [SEND Code of Practice January 2015.pdf \(publishing.service.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/362822/SEND_Code_of_Practice_January_2015.pdf)

Independent Provider of Special Education Advice (IPSEA):

- Website: www.ipsea.org.uk
- IPSEA template letters: www.ipsea.org.uk/template-letters
- IPSEA Appeal information: www.ipsea.org.uk/appealing-to-the-send-tribunal

Special Needs Jungle: Parent led information, resources and informed opinion about children and young people 0-25:

- www.specialneedsjungle.com