Helping those with BBS and their families and carers

Special Educational Needs Support and Education, Health and Care Plans

Information and Guidance

This information sheet is for parents and carers of children and young people who have Bardet-Biedl Syndrome (BBS) to ensure they have a good understanding of Special Educational Needs (SEN) provision in schools, to enable them to effectively advocate for their child/young person and ensure they are given the best support possible.

Produced: October 2018
Reviewed: June 2020
Next Review: June 2021

Contents

Special Educational Needs Support and Education, Health and Care Plans

SEND Provision

It is the duty of nurseries, schools and colleges to use their best endeavours to meet the needs of children and young people with special educational needs and disabilities (SEND). All schools should have a Special Educational Needs Co-ordinator (SENCo), Special Educational Needs (SEN) policy and a governor who is responsible for SEN. The SEN Code of Practice details the legal duties of education providers in relation to SEND provision for children and young people aged 0-25 and there is a lot of emphasis on identifying problems and supporting children as early as possible. Early years providers, health visitors and schools need to be alert to identifying problems, meeting them and reviewing progress. They must not discriminate against someone because of disability and schools cannot refuse to admit a child because of learning difficulties. If parents/carers feel that a place in a mainstream setting is best for their child/young person it must never be denied, on the basis that mainstream is unsuitable, or that their needs/disabilities are too great or complex. If parents/carers feel that a place in a specialist setting is best for their child/young person, an Education, Health and Care (EHC) Plan will need to be put in place first.

SEN Support

SEN support is the statutory provision in schools for children and young people with SEND. A baseline should be established when a child starts school so that progress can be monitored. If a child isn't making adequate progress, the first step is usually for the school to provide SEN support. This should give the child access to high quality teaching which is differentiated for individual pupils.

If a child does not make adequate progress when on SEN support, consideration should be given to applying for an EHC needs assessment which may lead to an EHC plan. The criterion for requesting an assessment is simply whether the child has SEN and whether they will benefit from additional funding over and above the normal SEN schools' budget.

What is an EHC plan?

The EHC plan has replaced the statement of special educational needs (Statement) and is for children and young people with complex needs that cannot be met through SEN support. The EHC plan is meant to be a holistic document recognising that children with SEND often have complex medical, social and educational difficulties and should ensure that appropriate provision is made available to meet the needs of the child/young person aged up to 25yrs, to secure the best outcomes for them across education, health and social care. The advantage of having an EHC plan is that it summarises the child's needs and sets out in detail what support they should receive so that school staff know precisely how they should be helping. The EHC plan brings extra funding where necessary and the special educational provision required to meet SEN support needs (section F) can be enforced by law, with the help of Legal Aid in the child's name.

Requesting an EHC assessment

The local authority (LA) are responsible for EHC assessments, requests can be made by:

- The school or college, health and social care professionals, early years' practitioners or anyone else who thinks an assessment may be necessary.
- Parents and carers including foster carers.
- A young person can request an assessment themselves if they're aged 16 to 25.

Application Timeframe

Weeks 1 to 6

The LA must reply to an assessment request within six weeks. Parents should make a note on the calendar and not be afraid to chase if the LA doesn't respond in time (template letters are available on the IPSEA website, see 'Resources'). During this period, the LA should consult with you and consider the information sent with the request. There is a right to appeal to a SEND Tribunal if the needs assessment request is refused.

Weeks 6 to 16

If the LA decides to proceed with the needs assessment, they will seek information from the school, from relevant medical professionals involved in the care of the child and from an educational psychologist. They should also include other appropriate reports or reports which you may reasonably request, for example, from speech and language therapists or occupational therapists. If the LA decides against issuing an EHC plan, you again have the right to appeal.

Weeks 16 to 20

The draft EHC plan is issued. Where significant amendments are requested a second draft may be issued which may delay the overall timescale, otherwise the final EHC plan should be produced by week 20.

The EHC plan

There are twelve sections in an EHC plan:

A: The views, interests and aspirations of the child and their parents, or of the young person

An aspiration is a hope or ambition of achieving something, for example, to be independent, healthy, gain employment, go to college and so on. The aspirations of you and your child should be recorded and it is essential that children, young people and their parents/carers are at the centre of decision making during the process of developing an EHC plan.

B: Special educational needs (SEN)

A 'need' is a state of requiring help. It's not just the diagnosis that is considered, but the needs that arise from this, for example, your child may need help with their personal care or they may need help with their learning such as constant repetition or materials adapted to be accessible. Each and every need must be specified whether it is to be provided for by the school/further education college, the LA, a health service or any other provider and if a need requires more than one type of provision, for example physio and occupational therapy, it must be split into more than one need.

C: Health needs related to SEN

Some children and young people with SEN may need to use dentists or other health professionals trained for people with SEN for their dental or other health needs. If relevant to your child, you should try to ensure that these needs are recorded so that commissioners of services are aware of the demand.

D: Social care needs related to SEN

An EHC plan assessment must include an assessment of your child's social care needs. If appropriate, this will entail a statutory assessment under children's or adults social care legislation.

E: Outcomes - how the extra help will benefit your child

An outcome may be the most important part of the EHC plan. It is a change or achievement that you and your child would like to see by the next Key Stage or the next two to three years in a number of areas, for example improved vocabulary, social interaction or independent travel. Professionals should work with you and your child to decide outcomes to put into the reports that are used during the EHC needs assessment. They should take on board your child's views, interests and aspirations and ensure you and your child are happy with the development of the plan from an early stage. It is much easier to make changes while the plan is being developed than to wait until the draft plan has been issued.

The SEN caseworker is responsible for making sure that all outcomes in the EHC plan are written in a way that is SMART (Specific, Measurable, Achievable, Realistic, Timebound) so that it can be monitored closely.

F: Special educational provision (support)

A provision is the action of providing or supplying a service (physiotherapy, speech and language therapy) or a resource (Ipad, laptop). All special educational provision required to be put in place to support your child in education and training should be specified. If it is needed it must be included, without regard to cost or convenience.

G: Any health provision reasonably required by the learning difficulties or disabilities which result in the child/young person having SEN

This provision should be detailed and specific and should normally be quantified for example, in terms of the type of support and who will provide it. Health care provision reasonably required may include specialist support and therapies, such as medical treatments and delivery of medications, occupational therapy and physiotherapy, a range of nursing support, specialist equipment, wheelchairs and continence supplies.

H: Social care provision

Provision should be detailed and specific and should normally be quantified, for example, in terms of the type of support and who will provide it (including Direct Payments). It should be clear how the provision will support achievement of the outcomes.

I: Placement - type and name of school or other institution

These details are only included in the final plan so that the LA does not pre-empt consideration of any preference for an institution which the parents or young person may state, in favour of a non-maintained institution.

J: Personal budget arrangements

A personal budget is 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. Any amount of money specified in this section must be enough to secure the provision specified. LAs must provide information on personal budgets as part of the Local Offer.

K: Advice and information

The list of the information gathered during the EHC needs assessment should include brief details of who gave the advice and when. Copies of all the advice and information gathered during the statutory assessment process should be attached to the EHC plan as appendices.

Important:

The EHC plan has twelve sections, however an appeal can only be made against three of them:

- Section B: Special Educational Needs
- Section F: Special Educational Provision
- Section I: School or other setting to be attended

It is therefore important to get as much information into these three sections as possible and to check the wording very carefully, in case an appeal is ever needed; LAs like to use the word ‘SHOULD’ which in sections B,F and I, should be replaced with ‘MUST’. For example, if the Plan says ‘Zac should have 10 minutes of one to one reading every day’, this could mean during busy times he only gets one to one reading three times a week. If the Plan says ‘Zac must have 10 minutes of one to one reading every day’, the school must provide this regardless of how busy the staff are.

Top Tips for EHC planning

- Any person should be able to pick up the EHC plan and get a detailed understanding of your child. Make sure all the positive things about your child are included and that professionals can see how your child likes to be worked with and get a good understanding of their needs.

- Include your child in as much of the process as possible. The EHC plan is about them, so it is important that their views and wishes are heard.

- All the professionals should be using a 'person centred' approach which puts the child and their family at the centre of all decision-making. It is their responsibility to ensure that the assessment process works for you and that you are happy with the EHC plan.

- Make sure you tell all the professionals who work with your child that you are going through the EHC planning process; they may be asked to supply up to date information.

- Reports that are older than a year or two may need to be updated. Even recent plans may not reflect your child's needs so you may want to ask for new assessments to be conducted.

- Outcomes are the key to a good plan so think about how you would like to describe your child in two or three years' time. For example, 'Sami goes on a play date once a week', 'Charlie goes to the toilet with no support', 'Taylor eats vegetables once a day', 'Tyson travels independently to college.'

Qualified Teacher of Vision Impairment (QTVI)

For a child or young person with vision impairment the SEN Code of Practice says a qualified teacher of vision impairment (QTVI) should be involved; they can help in the following ways:

- Provide support and information services to those with a vision impairment from birth to 25 years.

- Work with the child (and their family and friends) in the home, early years, school and post 16 settings.

- Provide knowledge of the referral routes and eligibility criteria in the local area.

- Assess functional vision.

- Advise on and provide low vision aids or refer as appropriate.

- Teach specialist skills such as Braille, ICT and independent living and learning skills or refer as appropriate.

- Provide support for effective transition at each key stage including into post 16/further education provision and into independent adulthood.

Your child/young person does not need to have an EHC plan to have the support of a QTVI. Your child's GP/hospital will be able to make a referral to the local sensory support service if this is not accessed via the education setting. If you are struggling to gain access to a QTVI for your child, you should contact your BBS UK Support Officer.

Parental Advocacy and Engagement

When you have a child with additional needs, just managing their medical appointments, school meetings and disability benefits can seem like a full time job and a very stressful one at that. Here are some tips, courtesy of Amaze, to help you keep on top of managing your child’s support and hopefully make the process less stressful and more effective for you and your family.

Good habits to develop:

- Keep a ‘contacts’ diary – note down the names of any professionals you’ve had contact with and the department they work in. Make a brief note of any conversations so you can refresh your memory if need be.
- Keep copies of everything you send and ask for copies of any paperwork made by others.
- Keep all paperwork about your child in one place – buy a box file (or a set of box files) and as soon as you get any paperwork store it in there.
- Develop a good relationship with receptionists and secretaries – they are the gatekeepers and can smooth contacts or speed up waiting times.
- Make sure you meet deadlines: it’s in your interest to complete forms and attend appointments on time. If you can’t, or you do miss them, contact people as soon as possible.

Before meetings:

- Gather relevant paperwork together so you can go through it beforehand. For example, before an annual review, make sure you’ve read over your child’s EHC plan or ask to see copies of SEN Support records.
- Think about what you want to get out of the meeting and prepare a list of questions. Perhaps you want speech and language therapy or extra support in the classroom. This will help you to keep focused if the meeting seems to drift.
- If English isn’t your first language, ask for an interpreter.
- Ask a friend to go with you. Show them your list of questions and tell them what you want out of the meeting. Apart from moral support, they can prompt you on things you’ve forgotten.
- Be prepared food-wise. If your child is coming to the meeting, bring snacks, drinks and games in case it overruns. And get something easy in for tea afterwards.

At meetings:

- Arrive on time or even a little early. You’ll feel less flustered and have time to gather your thoughts
- Be positive – most professionals want to do the very best for your child and if you keep this in mind, the meeting is likely to go more positively.

- Ask for the names and roles of all the people at the meeting and write them down.
- Ask if you don't understand anything and keep asking! It's your child and it's ok to ask for clarification.
- Don't allow yourself to be rushed – take time to think.
- At the end of the meeting, summarise what has been discussed and agree what happens next – what interventions have been agreed and when they will be reviewed.
- Ask for any notes or minutes to be sent to you.

After meetings:

- Talk over what happened with your friend/partner in case you missed anything and don't be afraid to go back to professionals with further queries.
- Follow up the meeting with a call or email to the professionals involved and chase up paperwork if necessary.
- If you're not happy with how a meeting went or what was agreed, don't be afraid to say. Health, education and social care services all have complaints procedures and your concerns will be taken seriously.

Involving young people in decisions

It's easy for parents to go on making decisions for young people with SEND as they grow into adulthood, especially if it seems hard to be sure what their views are, or be confident that they are able to make informed choices. But, whatever your fears, young people themselves are the ones most likely to know what they like and don't like and what kind of life they may want in future. The law says that once your child is 16, they have the right to make their own decisions unless they lack the mental capacity to do so, so it makes sense to help them practise making decisions as early as possible.

Prepare the foundations:

- Give your child the belief that their views matter – say it loud and often!
- Encourage your child to take chances and try new things.
- Think aloud when making decisions to show problem solving process.
- Build in opportunities to make everyday choices about things like activities, clothes and food.
- Make decisions as a family to show that its fair for everyone to have a chance to speak, that its ok to have different ideas, to change your mind after hearing what others think and to sometimes go with a majority decision.
- Be truly prepared to accept their choice.

Prepare for meetings:

- Young people need to know about their rights, the options that are available to them, what the meeting is about, who will be there and the sorts of things they can say. If you aren't sure yourself, you need to find out.
- Encourage your child to record their views in a way that suits them, i.e. photographs, drawings,

  video and audio recordings. Questionnaires in word, sign or symbol can help young people to organise their ideas and contribute to their meetings.

At the meeting:

- Make sure your child is presented with no more than one question at a time and encourage open questions. Reflect back to your child what you think they are telling you to check you have understood them clearly and avoid making assumptions about what is important to them.
- Make sure your child's decisions aren't 'cued' and that options aren't limited for the convenience of the meeting or presented in a way that makes them choose an option to please others.
- If it's not clear what your child means, acknowledge that you're lost and start again. Be patient and resist the urge to rush and fill silences. Let them know you won't be cross whatever they say.

Post 16

If your child has an EHC plan you can expect them to be included and involved in making decisions about their future from their annual review in Year 9 onwards. This is called 'transition planning' and will focus on their strengths, interests and aspirations and help identify their future needs around education, health, housing, relationships and work. Post 16 options include:

- 6th Form College to continue general education, study vocational subjects, A-Levels, BTECs
- Specialist College (residential or day) to continue general education, study A-Levels/BTECs plus • independent living skills, mobility skills, braille etc
- Supported Internship
- Apprenticeship/employment.

There are many specialist schools and colleges dotted throughout the UK; those attended by students with BBS include:

- Royal National College for the Blind, Hereford
- New College Worcester
- Queen Alexander College, Birmingham

- WESC Foundation, Specialist Centre for Visual Impairment, Exeter
- Henshaws College, Harrogate
- Dorton College, Bromley.

To search for specialist schools and colleges by location or expertise, go to www.natspec.org.uk.

SEND Code of Practice

Government guidance on the legal duties of education providers in relation to SEND provision for children and young people aged 0-25. www.gov.uk/government/publications/send-code-of-practice-0-to-25

Government information on Special Educational Needs and Disability (SEND):
www.gov.uk/schools-colleges-childrens-services/special-educational-needs-disabilities

Local Offer

Each local authority is required to provide information about local services and support for children and young people aged 0-25 with SEND; your Local Offer can be found on your local authority's website.

www.natspec.org.uk

Natspec is the membership association for organisations which offer specialist further education and training for students with learning difficulties and/or disabilities. The website enables users to search for specialist provision by location and expertise.:

Parent Partnership

Parent Partnership is an impartial service developed to help parents/carers understand how special educational needs are assessed and managed. Your local Parent Partnership will give over the phone advice and can also go to annual reviews to offer support. Details can be found on your Local Offer.

Parent Carer Forums

Parent Carer Forums are parent and carer led organisations which represent the views and experiences of services for children and young people with SEN (and their families). You can 'Google' your area; many will have worked with the LA over the past few years on EHC plans and may be running workshops. Details can be found on your Local Offer.

Useful Websites

https://www.sossen.org.uk

https://www.specialneedsjungle.com/

Acknowledgements

This information leaflet was produced by Tonia Hymers and Angela Scudder for BBS UK. BBS UK extends their grateful thanks to Amaze for kindly allowing us to reproduce information from their fact sheets: ‘EHC Plans’, ‘Involving Young People’ and ‘Meetings and Paperwork’. These fact sheets and additional resources can be found on their website: www.amazesussex.org.uk

This information leaflet has been produced by BBS UK, the only UK charity providing support and information services to those living with BBS, their families and carers. Further resources and information can be found on the charity’s website, or via the contact information below:

www.bbsuk.org.uk

admin@bbsuk.org.uk

Angela Scudder: BBS UK Patient Liaison Officer, London Service
07591 206788 / angela.scudder@bbsuk.org.uk

Amy Clapp: BBS UK Patient Liaison Officer, Birmingham Service
07591 206787 / amy.clapp@bbsuk.org.uk