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A guide on the support and
services for children and young
people with autism spectrum
conditions.

Welcome to our guide on services in Leeds for children and young people with autism spectrum conditions (ASC).

This guide was put together by a group of people working in education, health and social care services, and parents/carers of children and young people with ASC in Leeds.

If you need more detailed information, you can find it on our Leeds Local Offer website (www.leeds.gov.uk/localoffer) or contact the Leeds SEND information advice support service (formerly known as the parent partnership service) on: 0113 3951200, or email: education.pps@leeds.gov.uk. There are also details of ASC support groups in Leeds at the end of this guide.

What is autism? What are autism spectrum conditions?

The National Autistic Society gives this useful description of autism:

'Autism is a lifelong developmental disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language'

(www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction)

You may also hear the term 'complex communication difficulties' used to describe challenges children and young people may have in communicating with and relating to others.

Within this guide, to keep sentences short and easy to read, we use the term ASC, short for 'autism spectrum conditions' to refer to any form of autism, Asperger syndrome and complex communication difficulties. We also use the term 'SEND' as a short way to say 'special educational needs and disabilities'. When we refer to children and young people, we mean those aged 0-25.

What should I do if I think my child may have ASC?

You can talk to the following people if you have any concerns:

- your GP or health visitor
- your child or young person's early years setting (nursery, preschool or childminder), school or college.

They will be able to advise you and either make a referral, or direct you to another practitioner to make a referral, for assessment and diagnosis if they think this is needed.

What does the assessment and diagnosis process for ASC involve?

If your child is under 5 years old:

The initial assessment of your child will usually involve seeing a speech and language therapist and/or a paediatrician, and having a hearing assessment. If there is still concern after these assessments, your child will be referred to the autism assessment team in a Child Development Centre (CDC). There are 3 CDCs in Leeds, each covering one of 3 areas in the city.

Your child will be assessed by a team of health and education professionals, including a speech and language therapist, a clinical psychologist, a specialist health visitor, an occupational health therapist and an educational psychologist.

You and your child will be seen at home and you will be asked to tell us about your child's early development, share why you have concerns and when you became concerned. This allows the team to learn more and see your child in their own environment. Often children can behave differently in different environments so it is important for the team to see them at home.

Your child will also be seen by members of the assessment team in an education setting (nursery or school), and for a whole morning in the CDC.

The team will observe and assess your child using a range of toys and play equipment. They will look at how your child interacts with others, how they communicate their needs, involving both understanding and expressive communication, and identify any routines or obsessive and repetitive behaviours. They may also assess your child's sensory processing and their learning and play skills. The team will also refer to the International Classification of Diseases 10 (which gives guidance to medical practitioners on how to diagnose accurately) and identify if your child meets the criteria for a diagnosis of autism.

The team will discuss their thoughts with you and you will usually leave the assessment morning knowing whether your child has a diagnosis of autism or not, and with a plan of what will happen next to support your child (whether they have a diagnosis or not).

Sometimes the results of assessment may not be clear and the team may want to review your child about 6 - 12 months later.

The team will also offer training for parents, groups for parents and children, and specific interventions (approaches) to support your child's communication, behaviour and learning development.

If your child is over 5 years old:

If your child reaches school age before difficulties are identified, or if previous assessments have not been conclusive, a referral to the Child and Adolescent Mental Health Service (CAMHS) will be made by your GP.

The assessment process that follows will be very similar to the process for children aged younger than 5 as described previously. It will follow the same approach of having different education and health professionals working together to assess your child, in their home and in their learning environment. The same diagnostic criteria will be used and feedback and support provided will be very similar.

However one important difference is that feedback is not given on the same day as the child's assessment. Instead it will happen at an appointment session for the parents/ carers only.

What happens if my child or young person is not diagnosed with ASC but is still having difficulties and needs support?

The assessment team (see previous section) will aim to understand your child's difficulties and discuss these with you, and will then provide a plan to support you and your child with their communication, behaviour and learning. There will still be support available, this may involve input from any of the members of the assessment team or from community or school based services. All early years settings and schools in Leeds provide a 'core offer' of support for children and young people with SEND of all kinds, including ASC, and they all have budgets to offer this support.

In some cases it may be helpful to have a further assessment to help your child access the right support and services.

What other assessments might my child have to help meet their needs?

Early help (at any age):

Children's services in Leeds all aim to provide what we call 'early help', which means we aim to help families resolve any difficulties they have, as early as possible, before things get any worse. Sometimes people think the term early help means support for children in their early years (0-5), but this is not the case. Early help is for children and young people of all ages and their families.

Often families can get extra early help they need through their local community and through their child's education setting. All schools, colleges and early years settings must provide a support for those with SEND and they have budgets to do so. See more about this later in this guide.

If your child or young person is having difficulties and you cannot get the support you need in your local community or through their school, college or early years setting, it might be useful to have something called an early help assessment (formerly known as a CAF or common assessment framework).

The early help assessment is a way to bring practitioners from different services together to meet with you and help identify what your family's needs are, and find positive solutions to any problems you have. This might involve getting some extra support from targeted services (services who work with your family for a period of time) if you need it.

Your child does not have to have any specific diagnosis to have an early help assessment. If you think an assessment could help you, you can ask any education practitioner (for example the special educational needs coordinator or 'SENCO' in your child's setting or school) or any health worker (for example your GP or health visitor) to start the process of an early help assessment. If you have any difficulties with this, you can contact the integrated processes team, who look after early help assessments in Leeds. to contact the integrated processes team, telephone: 0113 247 6830.

Education Health and Care (EHC) needs assessment and plans for those with the most complex needs:

The majority of our children and young people in Leeds who have SEND needs will get any support they need through early help as above.

However, if your child or young person has very complex needs which cannot be met through early help, they might need to have an EHC needs assessment and an EHC plan. This replaces statutory assessment and statements from September 2014.

The EHC needs assessment involves practitioners from education, health and social care services meeting with you to talk about your child's needs and deciding with you if an EHC plan is needed.

If it is, they will work with you to make a detailed EHC plan describing the support and services your child will access to help them achieve the best outcomes. You will help to make decisions about this and you will also help to decide how to spend any budget available for your child's support (this is called a 'personal budget'). In some cases, you might choose to manage all or some of the personal budget yourself, through a direct payment into a special bank account. This can give you more choice and control over the services your child accesses.

The assessment process and the production of the EHC plan will take up to 20 weeks.

EHC plans and personal budgets can seem complicated. More information, including a short film and a guide to personal budgets, is available on our Leeds Local Offer website (www.leeds.gov.uk/localoffer). You can also contact the Leeds information advice support service (see first page for contact details) for free, impartial advice about your situation.

What services are available to support my child or young person if they have ASC?

The services your child or young person accesses will usually be decided during the different assessment and planning processes described previously.

Every child or young person is a unique individual and the services they access will depend on their individual needs and circumstances.

In this section we tell you a little bit more about some of the services your child or young person may access. If you need more detailed information please see our website at www.leeds.gov.uk/localoffer or for advice over the phone, contact the Leeds SEND information advice support service (see first page for contact details).

The complex needs service:

The complex needs service is part of Leeds City Council. The service is responsible for supporting children and young people with complex SEND to achieve good outcomes and get ready for adult life. There are several teams in the service who may be involved in supporting your child or young person:

The educational psychology (EP) team: The EP team works with schools and other settings, parents/ carers and children and young people aged 0 - 25 years with SEND of all kinds.

They support inclusion of children and young people through the application of psychology. When working with an individual child or young person, they may support the assessment and diagnosis processes described previously and/or provide general consultation, support and advice to the child or young person's education setting.

The team also provide training to settings and help to plan how support is delivered across Leeds.

The team all have the skills to support children and young people with all kinds of needs, including ASC. They work with children and young people with and without a formal diagnosis.

Some of the team maintain specialist knowledge in ASC which they then share with the rest of the team to make sure everyone has the most up to date knowledge about best practice in supporting ASC needs.

EP support is accessed by education settings. You can talk to your child's setting about the support they access from the team, or contact the team directly on: 0113 395 1039.

The SEN inclusion team (SENIT): This team aims to promote inclusion, support social and emotional needs, and improve outcomes for children and young people with SEND of all kinds, including ASC.

The SENIT team works with those aged 0 – 25, with and without a formal diagnosis. They work closely with parents, carers and practitioners to support the development and inclusion of children and young people.

The team provide a range of training for early years settings to help them provide high quality support to under 5s with SEND needs, including those with ASC. All of the teams early years practitioners have a good knowledge of ASC and several of them have specialist knowledge.

The team also provide advice for schools to support pupils with SEND of all kinds, including ASC. This may focus upon social, emotional needs or aspects of teaching and learning.

SENIT support is accessed by education settings. Talk to your child's setting about the support they access from the team, or contact the team direct on 0113 395 1039.

The SENSAP team (the team who look after EHC needs assessment and plans in Leeds): The SENSAP team manage all the processes related to EHC

needs assessment and plans (see previous pages). If your child has an EHC needs assessment, a dedicated SENSAP casework officer will work with you throughout that process. Find out more about this on the Leeds local offer website www.leeds.gov.uk/localoffer or email the team direct via SENSAP@leeds.gov.uk. For free, impartial advice about the assessment process, you can also contact the SEND information advice support service (contact details available on first page).

The child health and disability (CHAD) team: The CHAD team works within social care to provide support for children with disabilities. A range of support for families is available through this service, for example support for families seeking rehousing to a suitable property, or advice such as safe moving and handling techniques. A qualified social worker will do an assessment of needs to access support. You can find out more by calling 0113 222 4403 between 8am and 6pm for an initial discussion.

The specialist training in autism and raising standards (STARS) service:

STARS are an autism outreach service which aims to empower education practitioners to have a better understanding of autism. The STARS team work mostly in mainstream early years settings and primary and secondary schools offering them free autism awareness training. Speak to your child's school or nursery to find out if they have accessed STARS training.

STARS also run a monthly drop in service for professionals and parents. To find out more, call 0113 3368287 or email stars@nwsilc.org

Health services:

The child and adolescent mental health services team (CAMHS): The CAMHS team are part of Leeds Community Healthcare. They coordinate the assessment and diagnosis process for children and young people aged over 5 years, as described above. They can also provide ongoing mental health support if it is needed. Find out more at www.leedscommunityhealthcare.nhs.uk, checking the 'A to Z' list to find the CAMHS section.

The speech and language therapy (SLT) team: The SLT team are also part of Leeds Community Healthcare. They support the assessment and diagnosis processes described previously.

They also run a 'stay and play' group for preschool children with ASC. This gives parents and carers an opportunity to meet other parents with a pre-school child who has been recently diagnosed.

The SLT team also work with other professionals to run the National Autistic Society 'early bird' programme, a 12 week course which aims to help parents of pre-school children to understand autism, help their child to communicate and to reduce difficult behaviours.

They also offer individual support to parents and carers and to education settings to help them support a child or young person's communication development. You can talk to your GP, or the special educational needs coordinator in your child or young person's education setting to find out about accessing speech and language therapy.

The children's occupational therapy service (OT): The children's community

occupational therapy service provides advice and support for children with a range of difficulties, including ASC where needed. The service helps children with daily activities including:

- self-care - such as dressing, eating, toileting and getting ready for school
- school work - such as recording work, joining in with PE and accessing the curriculum
- play and leisure - such as riding a bike, using a computer, and socialising with others

The service works from accessible health centres across the city, the support provided depends on the identified needs of each child and the goals set by themselves and their family. You can talk to your GP about the service and they can make referrals to the service.

Social care services:

Short breaks and fun activities: short breaks and fun activities give children and young people with SEND of all kinds a fun experience in a safe place while their parents or carers have break. There is a wide range of short break activities in Leeds, from activities that everyone can attend like Scouts or Brownies, to activities targeted to those with a specific need, like ASC. There are also specialist services for those with very complex needs.

Scope in Leeds are commissioned by Leeds City Council to give families advice and support on short breaks and fun activities. To find out more call: 0800 085 1879 or 0113 272 7531.

Transitions: The transitions team is a team of social workers and nurses who provide specialist advice and support to young people aged 14-25 with complex needs of all kinds, including ASC. They work with young people and their families during the journey from childhood into adulthood or 'transition' as it is called.

They work closely with social workers, education practitioners, health professionals and voluntary and independent services to develop the support for a young person's needs to be met as an adult.

They work with young people who have the most complex needs and have a statement or an EHC plan and a social worker who has identified they need this support.

Support in education:

The following tables give you an overview of the support you can expect from the different education settings your child or young person may attend. This is described in more detail in the 'education' section of the Leeds Local Offer (www.leeds.gov.uk/localoffer). More information about funding for inclusion (FFI) is also available on the Leeds Local Offer website.

This is general guide only, if you need advice about your child's individual situation, you can contact the Leeds SEND information advice support service (see first page for details).

Early years education:

Type of setting	What support will they offer?
<p>A local children’s centre, a private, voluntary or independent nursery, a pre-school, a school nursery, a childminder, or combination of any of these.</p>	<p>All early years settings will have a system to assess and identify additional needs. Throughout this process parents and carers should be fully involved.</p> <p>All settings will have access to outside agencies who can offer advice, support and staff training, for example teams in the complex needs service, or the STARS service (for more information see previous section).</p> <p>All settings will devise and follow specific individual programmes of support for young children who need it. These programmes should be reviewed and monitored regularly, including at least six monthly formal reviews with parents.</p> <p>Early years settings can also apply for additional funding called early years funding for inclusion or EYFFI. This is money that Leeds City Council can provide to settings who need extra resources to support young children with complex needs. The setting can apply for funding if they think the child has a certain level of need as set out in the EYFFI funding criteria.</p> <p>Everyone involved in supporting the child should work together to support child’s transition into school age provision.</p>
<p>Home based programmes</p>	<p>The portage service provides support for young children aged 0 - 3 years old with SEND of all kinds, including those with ASC, in the home. A portage home visitor works alongside parents and carers to establish both short and long term goals and work towards them through a programme of activities. The portage service in Leeds is a commissioned service provided by Barnardo’s (0113 272 0832).</p> <p>Parents may choose to follow specific programmes at home, for example Son Rise or ABA. If the child has an education health and care plan then this must be formally reviewed in line with statutory (legally required) processes.</p>

School education: primary

Type of setting	What support will they offer?
A local mainstream school.	<p>All mainstream schools will have a system to assess and identify any children they think may have additional needs. This is coordinated by the special educational needs coordinator (SENCo). Throughout this process parents and carers should be fully involved.</p> <p>All mainstream schools have access to outside agencies that can offer additional advice, support and staff training. Agencies might include the educational psychology team, the SENIT team or the STARS service (for further information see previous sections).</p> <p>Mainstream schools will devise and follow specific programmes of support for children who need it. Programmes should be reviewed regularly, including formal reviews with parents.</p> <p>Schools and/or external agencies can also apply for additional funding called funding for inclusion (FFI). This is money that Leeds City Council can provide to support settings who need extra resources to support children with complex needs. The school can apply if they think the child has a certain level of need as set out in the funding criteria.</p> <p>Everyone involved in supporting the child should support their transition on to secondary education.</p>
A resourced provision in a mainstream school	<p>Complex communication resourced provisions are mainstream schools that have a set number of places for children with complex communication difficulties, which are a big factor in ASC. Children who go to a resourced provision can still access mainstream education alongside the other children, but can also spend some time accessing specialist support, resources and/or environments to meet their individual needs.</p> <p>Resourced provisions are for children with complex needs who have an education health and care plan or statement stating that they need to attend this kind of setting.</p> <p>All resourced provisions have access to outside agencies that can offer additional advice and support and staff training, just as mainstream schools do.</p> <p>Resourced provisions will devise and follow individual programmes for all children. These programmes should be reviewed regularly, including formal reviews with parents.</p> <p>Everyone involved in supporting the child should support their transition on to secondary education.</p>

<p>A SILC partnership school</p>	<p>A SILC partnership school is a mainstream school that works in close partnership with a Leeds SILC (specialist inclusive learning centre).</p> <p>Children with complex needs attend a SILC partnership if they would benefit from time in mainstream environment, but also need the specialist support and facilities offered by a SILC. They will be on the roll/register of the SILC and the SILC will be ultimately responsible for their outcomes, but they will spend all or some of their time at a SILC partnership base within a mainstream school which caters for ASC needs.</p> <p>The partnership base will have staff with expertise in ASC, and it will have an environment that can be adapted to meet the needs of children with ASC.</p> <p>SILC partnership schools are for children with complex needs. They will have an education health and care plan which will state that they need to this kind of setting.</p> <p>All resourced provisions have access to outside agencies that can offer additional advice and support and staff training, just as mainstream schools do.</p> <p>SILCs and their partnership schools will devise and follow individual programmes for all children. These programmes should be reviewed regularly, including formal reviews with parents.</p> <p>Everyone involved in supporting the child should support their transition on to secondary school.</p>
<p>A Specialist Inclusive Learning Centre (SILC)</p>	<p>SILCs provide a high level of specialist support, expertise and facilities for children and young people with the most complex needs, including ASC needs, who cannot flourish in a mainstream environment.</p> <p>There are 5 SILCs in Leeds, one in each area of the city, to support children with the most complex needs in that area.</p> <p>SILCs are for children and young people with the most complex needs. They will have an education health and care plan which will state that they need to attend this kind of setting.</p> <p>All SILCs will have close working relationships with outside agencies that can offer additional advice, support and staff training. Agencies might include the educational psychology team, the SENIT team or the STARS service.</p> <p>SILCs will devise and follow individual programmes for all children. These programmes should be reviewed regularly, including reviews with parents.</p> <p>Everyone involved in supporting the child should be involved in supporting their transition on to secondary school.</p>

Elective home education	<p>Parents have a legal duty to make sure that their child receives full-time education suitable to their age and ability and to any SEND needs they have, either by regular attendance at school or otherwise. This could be at home if they choose to and are able to offer suitable education at home.</p> <p>Parents will have certain responsibilities if they choose to educate at home. If their child has an education health and care plan, the law says that they will need to have approval to educate their child at home. For more information, contact children's services on: 0113 395 1183, or email: educ.eotas@leeds.gov.uk</p>
Home based programmes	Parents may choose select to follow specific programmes at home, for example Son Rise or ABA. If the child has an education health and care Plan then this must be formally reviewed in line with statutory (legally required) processes.

School education: secondary

Type of setting	What support will they offer
A local mainstream school.	<p>All mainstream school settings will have a system to assess and identify additional needs. This is coordinated by the special educational needs coordinator (SENCo). Parents and carers should be fully involved.</p> <p>All mainstream schools have access to outside agencies that can offer additional advice and support and staff training. Agencies might include the educational psychology team, the SENIT team or the STARS service (for more information see previous sections).</p> <p>All mainstream schools will devise and follow individual programmes of support for children and young people who need it. These programmes should be reviewed regularly, including formal reviews with parents.</p> <p>Schools and/or external agencies can also apply for additional funding called funding for inclusion (FFI). This is money that Leeds City Council can provide to support settings who need extra resources to support children with complex needs. The school can apply if they think the child or young person has a certain level of need as set out in the funding criteria.</p> <p>Everyone involved in supporting the young person should be involved in supporting their transition on to post-16 education.</p>
A SILC partnership school	<p>Support offered to secondary school pupils in a SILC partnership school will be very similar to support provided to primary school pupils in a SILC partnership school, as described previously. Entry is arranged in exactly the same way.</p> <p>Everyone involved in supporting the young person should be involved in supporting their on to post-16 education.</p>

A Specialist Inclusive Learning Centre (SILC)	Support offered to secondary school pupils in a SILC will be very similar to support provided to primary school pupils in a SILC, as described previously, entry is arranged in exactly the same way. Everyone involved in supporting the young person should be involved in supporting their transition on to post-16 education.
Elective home education	Please see information in the previous table, 'primary education', about parents' responsibilities if they choose to educate at home.
Home based programmes	Parents may select to follow specific programmes at home, for example Son Rise, ABA. If the child has an education health and care plan then this must be formally reviewed in line with statutory (legally required) processes.
Free schools	Leeds also has a specialist free school, The Lighthouse School, which is a secondary school (11-19) catering only for children and young people with ASC. A free school is set up and governed independently of the local authority and receives funding directly from national Government.

Post 16 education support:

Some young people with ASC over the age of 16 may continue to access their mainstream or specialist school as described previously.

Others may choose to move on to a local college or training provider. All post-16 colleges and training providers in Leeds will have a system to assess and identify any young person who they think may have additional need or may require extra support. They will all devise and follow specific individual programmes if required and they will all provide support as young people with SEN of all kinds, including ASC needs, prepare for the next steps of further learning or employment.

The offer of support expected from all post-16 settings is described in more detail in the 'education' section of the Leeds Local Offer website (www.leeds.gov.uk/localoffer) and individual details of post -16 settings, including options for those who need specialist support, are available in the Leeds Pathways website (www.leeds.gov.uk/pathways - see 'supported learning' section).

Support groups and parent forums:

There are support groups in Leeds for families of children and young people with SEND of all kinds. You can find all the groups in your area using the Leeds Local Offer site (www.leeds.gov.uk/localoffer) or call the Leeds SEND information advice support service using the details on the first page. Two of the groups that have asked for their details to be included here are as follows:

The leeds and district autism behaviour communication support group (known as Leeds ABC support group) aims to provide help, support and advice about services, facilities, education, care and welfare for parents and families of children and young people with ASC, including Asperger's Syndrome, in the local community in Leeds and surrounding areas. The Leeds ABC website is a welcoming place where adults, youngsters and parents can share views and experiences. Find out more at www.abcleeds.org.uk or email info@abcleeds.org.uk

The Jigsaw Tree provides an online community for people affected by and involved with ASC in Leeds. They also offer a parent and carer's support group in East Leeds. The group is a friendly informal place for parents and carers of children and young people with or without a diagnosis of ASC to meet up. Find out more at www.thejigsawtree.org or email Helen@theJigsawTree.org

The Department for Education also provides funding for participation forums for parents and carers of children with SEND of all kinds, in every local authority. In Leeds, the forum is called **EPIC Leeds**. **EPIC Leeds** aims to empower parents/carers and families to work in partnership with services locally to improve choices for children and young people with SEND and their families. Find out more at www.epicleeds.com or email epic.leeds@gmail.com.

What do I do if things aren't going well?

If you have concerns about the support you are getting from a particular service, we suggest you talk to them first to give them the chance to discuss the issues and resolve problems.

However if this isn't helping, you can get impartial advice from the Leeds SEND information advice and support service (see first page for details).

If you want to make a complaint about a Leeds City Council service, you can complete a 'contact us' e-form on the Leeds City Council website at www.leeds.gov.uk. You can also speak to an advisor on 0113 222 4405.

You can also raise a concern about any state school with Ofsted, the office for standards in education. You can contact Ofsted by email: enquiries@ofsted.gov.uk, or telephone: 0300 1234 234.

Ofsted does not manage complaints about academies or free schools. To make a complaint about an academy or free school, you must visit the Department for Education website at www.education.gov.uk/form/school-complaints-form. If you need help to access the web, you can visit any Leeds library or one stop centre.

What if I've got a question that isn't covered here?

If you need more detailed information about the things in this guide, you may be able to find it on our Leeds Local Offer website (www.leeds.gov.uk/localoffer). You can also use the 'feedback' pages of the site to let us know what you think of this guide and if we should add anything to it, or email the complex needs service best practice team at bpteam@leeds.gov.uk

You can also call the Leeds SEND information advice support service on: 0113 3951200, or email: education.pps@leeds.gov.uk, for advice and support about any issue related to children and young people with SEND.

If you need more detailed information, you can find it on our Leeds Local Offer website (www.leeds.gov.uk/localoffer), or contact the Leeds SEND information advice support service (formerly known as the parent partnership service): telephone: 0113 3951200, or email: education.pps@leeds.gov.uk

There are also details of ASC support groups in Leeds at the end of this guide.