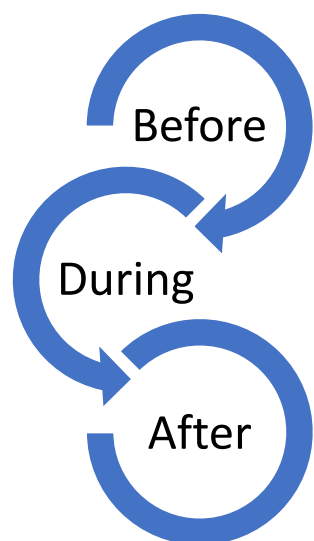


## Information and supports for parents and carers of children who have neurodevelopmental differences in East Lothian

Your child's development is unique and may vary in comparison to other children. You may notice neurodevelopmental differences in your child that are observed at home and/or in nursery/school. These differences can be in the areas of communication, memory, relationships, balance and coordination, emotional well-being, play, learning, flexibility, attention or senses. Schools and organisations make adjustments with the aim of ensuring neurodiversity is celebrated and understood so that all children can feel included and progress. It is important to discuss concerns and share information with school professionals or other services that may be involved with your child. Sometimes, a request for a Neurodevelopmental (ND) assessment may be submitted after your discussion with professionals or you may decide to monitor your child's development over time. In East Lothian, Health Visitors and schools can make a request for ND assessment provided your consent has been given.

This guide provides you, as the parent and carer, with information about how to access resources and supports for a neurodivergent child and their family. This guide is divided into different stages (Before, During and After) in relation to the ND referral, assessment and receiving an assessment outcome such as a diagnosis. Please note there are resources and supports that will appear throughout all the phases and that it indicates that they can be accessed at any point and do not require a diagnosis.










**Before** – refers to you as a parent noticing ND differences in your child or a family member, friend or professional mentioning these differences to you. You may decide to discuss this with a school professional and in some instances a GP, and then as a result may ask for a ND assessment through your child's school.

**During** – refers to when education or health professionals may submit a ND request for assessment into the Single Point of Access. If it is agreed that the request is appropriate, you will receive communication about gathering information and an appointment. During this period of waiting for an appointment and for other assessment appointments, you can access this guide to identify appropriate resources and supports.








**After** – once the assessment process has been completed, you will be asked to attend a feedback meeting to discuss the outcomes of the assessment and if any diagnoses can be made. In a feedback meeting, a clinician will give you helpful information. This guide indicates that some resources are available only when a child has been diagnosed.

## BEFORE<sup>1</sup> (Noticing concerns and making a request for ND assessment):

Resources	Support for children and family	Advocacy and direct parent support
<p><b>EPIC (Edinburgh Psychoeducation Intervention for Children)</b> - information on how to identify and support children and families:  <a href="http://www.ed.ac.uk/clinical-brain-sciences/research/epic-edinburgh-psychoeducation-intervention/epic-resources">www.ed.ac.uk/clinical-brain-sciences/research/epic-edinburgh-psychoeducation-intervention/epic-resources</a></p> 	<p>In nursery and school, please discuss supports available for you and your child available in the classroom, across the school and community. This can include access to wellbeing resources, Occupational Therapy and Speech and Language Therapy.</p>	<p><b>Carers of East Lothian:</b>  <a href="http://www.coel.org.uk">www.coel.org.uk</a></p> 
<p><b>Dimensions Tool</b> - a screening tool that can identify differences and lists resources:  <a href="https://dimensions.covwarkpt.nhs.uk">https://dimensions.covwarkpt.nhs.uk</a></p> 	<p><b>Number 6</b> - for children over 16 years - the one stop shop for autistic adults:  <a href="http://www.number6.org.uk">www.number6.org.uk</a></p> 	<p><b>The Action Group East Lothian</b> - for children and adults with additional support needs and learning disabilities and carers:  <a href="http://www.actiongroup.org.uk/east-lothian">www.actiongroup.org.uk/east-lothian</a></p> 
<p><b>National Autism Society:</b>  <a href="http://www.autism.org.uk/advice-and-guidance">www.autism.org.uk/advice-and-guidance</a></p> 	<p>Parent programmes can be signposted via school, health visitor or Speech and Language Therapy.</p>	<p><b>Kindred</b> - provides support to parents of children with complex needs and this includes individual support, groups and events:  <a href="http://kindred-scotland.org">kindred-scotland.org</a></p> 

<sup>1</sup> When resources are first mentioned, they will have the website or email contact beside it.


<p><b>Salvesen Mindroom</b> - resource guides, real life stories and lived experiences, and advocacy support for young people. No diagnosis is required:</p> <p><a href="http://www.mindroom.org">www.mindroom.org</a></p> 	<p><b>Active East Lothian</b> - a partnership between Council teams including <a href="#">Sports Development</a>, <a href="#">Active Schools</a>, <a href="#">Outdoor Learning Service</a> and <a href="#">Community Sport Hubs</a>:</p> <p><a href="http://www.activeeastlothian.co.uk">www.activeeastlothian.co.uk</a></p> 	<p><b>Enquire</b> - Scottish Support Service for additional support needs:</p> <p><a href="https://enquire.org.uk/">https://enquire.org.uk/</a></p> 
<p><b>Scottish ADHD Coalition</b> - for young people, adults and families to get information and local support:</p> <p><a href="http://www.scottishadhdcoalition.org">www.scottishadhdcoalition.org</a></p> 	<p><b>Star Youth Club</b> - Weekly youth club for East Lothian teenagers (12-18 years) with additional support needs.</p> <p><a href="http://www.autism.org.uk/directory/s/star-youth-club">www.autism.org.uk/directory/s/star-youth-club</a></p> 	<p><b>STAND East Lothian (Stronger Together for Autism and Neurodiversity)</b> - parent support group (Facebook):</p> <p><a href="https://www.facebook.com/groups/5974467872574164/">https://www.facebook.com/groups/5974467872574164/</a></p> 
<p><b>Branch Out Together</b> - formerly the Lothian Autistic Society and provides social activities and events:</p> <p><a href="http://www.branchouttogether.org">www.branchouttogether.org</a></p> 	<p><b>Basecamp</b> - a club for children aged 5-13 years with ASD that focuses on themes which aim to develop the child's ability to cope in a group setting (Facebook):</p> <p><a href="http://www.facebook.com/LothianAutistic">www.facebook.com/LothianAutistic</a></p>	<p><b>NHS24:</b> call 111 for urgent care advice and support</p> <p><b>ParentLine Scotland:</b> 08000 28 22 33</p> <p><b>Family Lives UK:</b> 0808 800 2222</p>

		
<p><b>RNIB Bookshare</b> - Children with a visual impairment, dyslexia, autism or ADHD are eligible to sign up for RNIB bookshare. The scheme provides electronic book resources including the regular reading schemes but in flexible fonts/colors/sizes/audio. Law Primary can set a child up with an account:</p> <p><a href="http://www.rnibbookshare.org/cms/me/information-parents-about-rnib-bookshare">www.rnibbookshare.org/cms/me/information-parents-about-rnib-bookshare</a></p> 	<p><b>Children 1st</b> - parentline and supports for families:</p> <p><a href="http://www.children1st.org.uk/help-for-families">www.children1st.org.uk/help-for-families</a></p> 	<p><b>Children 1st</b> - parentline and supports for families:</p> <p><a href="http://www.children1st.org.uk/help-for-families">www.children1st.org.uk/help-for-families</a></p> 
<p><b>FASDHub Scotland</b> - resources, training and parentline:</p> <p><a href="http://www.adoptionuk.org/fasd-hub">www.adoptionuk.org/fasd-hub</a></p> 	<p><b>The Yard</b> - runs adventure play services for disabled children, young people and their families. You can reach The Yard team during office hours by calling us on <b>0131 476 4506</b>.</p> <p><a href="http://www.theyardscotland.org.uk/the-yard-edinburgh">www.theyardscotland.org.uk/the-yard-edinburgh</a></p> 	<p><b>Boparan Charity</b> - provide funding to children with disabilities, life-limiting illnesses and those who are in extreme poverty across the UK. Grants can fund specialist equipment such as wheelchairs, trikes, sensory toys not available on the NHS, and treatments such as Speech &amp; Language Therapy and Behavioural Therapy:</p> <p><a href="http://www.theboparancharitabletrust.com">www.theboparancharitabletrust.com</a></p> 



<p><b>Autistic Girls Network</b> - information about autism in girls and women, and resources on school and healthcare accommodations (eg. school and hospital passport resources):  <a href="https://autisticgirlsnetwork.org">autisticgirlsnetwork.org</a></p> 	<p><b>Social Security Scotland</b> – what benefits are available for your family:  <a href="https://socialsecurity.gov.scot">socialsecurity.gov.scot</a></p> 	<p><b>Children with Disability Team, East Lothian Council</b> - Provides information and advice on how to access direct support for your child outside of school:</p> 
<p><b>Autism Understood</b> - information about autism, designed for and by autistic young people:  <a href="https://autismunderstood.co.uk">autismunderstood.co.uk</a></p> 	<p><b>Salvesen Mindroom</b></p>	<p><b>FASDHub Scotland</b> - resources, training and parentline:  <a href="https://www.adoptionuk.org/fasd-hub">www.adoptionuk.org/fasd-hub</a></p> 
<p><b>Young Scot "Escape Connect Relate"</b> - Books about neurodiversity for children and young people, selected by librarians:  <a href="https://young.scot/wp-content/uploads/media/14948/neurodiversity.pdf">https://young.scot/wp-content/uploads/media/14948/neurodiversity.pdf</a></p> 	<p><b>Team United:</b>  <a href="https://www.team-united.org.uk">www.team-united.org.uk</a></p> 	
	<p><b>Venturing Out ASN</b> - free activities to children and their families living with additional support needs:  <a href="https://www.venturingout.org.uk/asn-activities">www.venturingout.org.uk/asn-activities</a></p>	

		
	<p><b>Young Minds Charity</b> - provides information about emotional wellbeing, and can provide guidance about finding support:</p> <p><a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a></p> <p>Young Minds UK: 0808 802 5544</p> 	
	<p><b>Skills Development Scotland (SDS)</b> - support pupils, parents and teachers with a comprehensive range of career information advice and guidance (CIAG) services.</p> <p><a href="http://www.skillsdevelopmentscotland.co.uk">www.skillsdevelopmentscotland.co.uk</a></p> 	
	<p><b>Play Therapy Base</b> -</p> <p><a href="http://www.playtherapybase.co.uk">www.playtherapybase.co.uk</a></p> 	


## DURING (on waiting list and during assessment appointments)

Resources	Support for children and family	Advocacy and direct parent support
<b>EPIC (Edinburgh Psychoeducation Intervention for Children)</b>	In nursery and schools please discuss supports available for you and your child available in the classroom and school community.	<b>Carers of East Lothian</b>
<b>Dimensions Tool</b> – a screening tool that can identify differences and lists resources	<b>Number 6</b> (for children over 16 years)	<b>The Action Group East Lothian</b>
<b>National Autism Society</b>	Parent programmes can be accessed through school, health visitor or Speech and Language Therapy.	<b>Kindred</b>
<b>Salvesen Mindroom</b> resources	<b>Active East Lothian</b>	Enquire
Information and supports for parents of neurodivergent children – NHS Lothian guide for parents of children who are awaiting ND assessment.	<b>Muirfield Riding</b> - The Children's Therapeutic Riding Service: <a href="http://www.muirfieldridingtherapy.org.uk">www.muirfieldridingtherapy.org.uk</a> 	<b>STAND East Lothian (Stronger Together for Autism and Neurodiversity)</b>
<b>Scottish ADHD coalition</b>	<b>Basecamp</b>	<b>Young Carers</b>
	<b>Children 1st</b>	<b>Parentline Scotland: 0800 028 22 33</b>
	<b>Star Youth Club</b>	<b>Family Lives UK: 0808 800 2222</b>
	<b>The Yard</b>	<b>Young Minds UK: 0808 802 5544</b>
	<b>Social Security Scotland</b>	
	<b>Salvesen Mindroom</b>	
	<b>Team United</b>	
	<b>Venturing Out</b>	
	Parent Information Session on Intellectual Disability through CAMHS ID.	
	<b>Play Therapy Base</b>	

## AFTER (Assessment)

Resources	Support for children and family	Support for CYP and family – diagnosis required	Advocacy and direct parent support
Post diagnosis pack specific to ID/ Autism and ADHD provided by clinicians	In nursery and schools please discuss supports available for you and your child available in the classroom and school community.	<b>Salvesen Mindroom</b> - Post diagnosis sessions for CYP.	<b>Carers of East Lothian</b>
Information and supports for parents of neurodivergent children – NHS Lothian guide for parents of children who are awaiting ND assessment.	<b>Number 6</b> (for children over 16 years)	Medication if appropriate.	<b>The Action Group</b>
<b>National Autism Society</b>	Parent programmes can be accessed through school, health visitor or Speech and Language Therapy.	<b>Barnardo's Cygnet parenting courses</b> - 6-week online parenting course for parents of autistic children: <a href="https://barnardos-parenting.org.uk/">https://barnardos-parenting.org.uk/</a> 	<b>Kindred</b>
<b>Salvesen Mindroom</b> resources	<b>Basecamp</b>	<b>National Autism Society</b> - CYP online	<b>Enquire</b>
<b>Scottish ADHD coalition</b>	<b>East Active Lothian</b>	<b>CAMHS</b> – mental health and sensory supports (Silvercloud online CBT)	<b>STAND East Lothian (Stronger Together for Autism and Neurodiversity)</b>
<b>EPIC (Edinburgh Psychoeducation Intervention for Children)</b> resources	<b>FASDHub Scotland</b>	<b>Can-do playscheme:</b> <a href="https://www.can-do.scot/">https://www.can-do.scot/</a> 	



	<b>Children 1st</b>		
	<b>Star Youth Club</b>	<b>Pasda</b> - offers support to parents, partners, siblings and carers of autistic adults (over 16) who live in Edinburgh and the Lothians: <a href="https://www.pasda.org.uk/">https://www.pasda.org.uk/</a> 	
	<b>The Yard</b>		
	<b>Social Security Scotland</b>		
	<b>Salvesen Mindroom</b>		
	<b>Team United</b>		
	<b>Venturing Out</b>		
	<b>Play Therapy Base</b>		

Information and supports for parents of neurodivergent children on specific topics below can be found on the NHS Lothian Children's Hospital website: [https://children.nhslothian.scot/community\\_services/child-development/](https://children.nhslothian.scot/community_services/child-development/) in the 'support while waiting for an assessment' tab

and

'Wellbeing Hub' area under Neurodiversity & the 'Parents & Carers' page: <https://children.nhslothian.scot/parents-and-carers/support-and-further-information/>

School	Behaviour	Anxiety
Sensory needs	Transitions	General information
Repetitive Behaviour	Sleep	Mentoring and skill development

