

Voice and influence of parents and carers of children with SEND in Leeds

Leeds Area SEND and AP Partnership Board

The Voice and Influence Transparency Working Group report back to the Leeds Area SEND and AP Partnership Board.

The board oversee the Self Evaluation Framework (SEF).

Voice, Influence and Transparency Working Group

The voice and influence transparency working group is a subgroup of the Leeds Area and SEND AP Partnership Board. The group has representatives from Voice and Influence, Leeds Parent Carer Forum, Health, SENDIASS, Customer Relations, Learning and Inclusion, Health and Social Care.

Issues Tracker

All issues raised by families via the Leeds Parent Carer Forum and Parent Carer Support Group network are added to the issues tracker.

The issues tracker is used:

- 1) by the Voice, Influence and Transparency Working Group to further explore the feedback from families and agree next steps and actions with services.
- 2) within the Local Authorities Self Evaluation Framework (SEF). A mechanism to assess performance, identify areas for improvement and influences service plans.

Leeds Parent Carer Forum

Leeds PCF (Parent Carer Forum) is led by local parents working to represent the views of parents and carers of children and young people with SEND while working in partnership with services to make a positive difference for children and families in Leeds.

Parent carer support group network

Representatives from SEND parent carer support groups in Leeds receive bi-monthly check ins and attend three events a year to feedback what they are hearing from the families they work with.





Home to School Transport



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What families have told us...

At the start new school academic year families have feedback issues with home to school transport i.e. transport not turning up.

Transport feels at arms length to provision / school. Families want to receive information about home to school transport as soon as they are offered a place at a school.

Families have said there is a lack of flexibility with transport if a child is on shorter or longer days, and is not available during transitions.

Need a user friendly transport application form.

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What has happened...

New phone line for passenger transport, with an increased capacity to ensure families receive a response.

Launched a user-friendly online transport application form.

Developed FAQs with the Leeds Parent Carer Forum that will be sent out alongside transport confirmation emails, and are available on the [LLO website](#).

Reviewed transport allocation letter in partnership with the Leeds Parent Carer Forum.

Future plans

Children's Transport, Passenger Transport and the Leeds Parent Carer Forum will be:

Developing a 'what to expect from home to school transport' video for families for September 2026.

Developing transport passports for young people and transport staff for September 2026.

Hosting an online home to school transport information session for parents and carers in May 2026.



Post 16 Transitions



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What families have told us...

Families do not understanding what support is available when a child transitions to adult social care.

Transition support should be planned and actioned.

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What has happened...

Transitions information on the Leeds Local Offer website, including criteria for transitions team, has been reviewed and updated.

The Transitions Team are attending events, coffee mornings etc. to raise awareness of their service offer and to support parents and carers to navigate the transitions pathway.

Future plans

The Transitions Team have identified there is a gap in support for ND transitions support, particularly for those with autism and FASD. This will be raised at the Leeds Area SEND and AP Partnership Board.

SENDIASS have appointed a lead officer for Social Care to oversee and develop the social care IAS offer, which will include transition.



Waiting lists for diagnosis and support



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What families have told us...

The waiting lists continue to be extremely long, and families are not getting the support they need.

The delay in diagnosis can affect self esteems and prevent children from learning.

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What has happened...

Health issues in Leeds are ongoing, and the Leeds Parent Carer Forum and Designated Clinical Officer meet regularly to provide updates.

Partners across Leeds and West Yorkshire are working on new support models to reduce waiting times, with a trial planned by the end of 2024/25.

ADHD medication is only available after a NICE-compliant diagnosis and must be managed initially by a specialist.

Children are supported by LCH CYPMHS, and adults by the Leeds Adult ADHD Service, with GPs involved once treatment is stable.

Future plans

The Leeds Parent Carer forum and Designated Clinical Officer will continue to meet on a regular basis and provide updates for families.

Full CAMHS service review.

The neurodiversity working group, which is a subgroup of the Leeds Area SEND and AP Partnership board, aim to ensure children can access prescribing services for ADHD medication and melatonin swiftly when this is appropriate as part of an individualised management plan.



Sleep and melatonin



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What families have told us...

Scope sleep service is no longer available to families.

What support is available for families?

Children not being prescribed melatonin, and no increase in dosage for those already prescribed.

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What has happened...

Health issues in Leeds are ongoing. The Leeds Parent Carer Forum and Designated Clinical Officer will meet regularly and share updates.

The Leeds Health and Care Partnership is considering a new sleep support programme for families.

Melatonin can be prescribed by ICAN paediatricians after assessment. Families are encouraged to use the One Minute Guide and online resources first.

Sleep support is also available through ICAN health visitors, PHINs, CAMHS, and Leeds Mencap, which offers workshops for parents and carers.

Future plans

The Leeds Parent Carer forum and Designated Clinical Officer will continue to meet on a regular basis and provide updates for families.

Development of pathways across services to deliver offers for behaviour, eating, drinking, nutrition, continence and sleep.



Taking bloods



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What families have told us...

Taking bloods is traumatic and this impacts on the child, and wider family, and could lead to poor health outcomes if bloods cannot be collected or are delayed.

Families have shared issues in accessing the service and bloods being taken in a supportive clinic.

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What has happened...

The Leeds Parent Carer Forum have shared the feedback from families with Health colleagues who recognise the issues raised.

Leeds Teaching Hospitals already offer SEND sessions where play specialists can be made available.

Future plans

A pathway to be established on support available to collect bloods and what the offer looks like.

Further information to be scoped and shared shortly.



Avoidant/restrictive food intake disorder (ARFID)



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What families have told us...

Families feel services do not have the knowledge to support them with eating difficulties and there is no clear pathway for support / signposting to resources to support. This impacts on the child and their wider family and can limit social interactions and schooling.

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What has happened...

Health issues in Leeds are ongoing. The Leeds Parent Carer Forum and Designated Clinical Officer will meet regularly and share updates.

The Leeds Parent Carer Forum and Health delivered an ARFID support workshop for parents and carers at the 2025 Leeds Local Offer Live event.

The Leeds Parent Carer Forum have surveyed parents at the Leeds Local Offer Live event (March 2025) around ARFID support.

Information about ARFID support has been added to the Leeds Local Offer website.

Future plans

An online survey will be developed by the Leeds Parent Carer Forum to further explore and gather the views of parents and carers.

Information about ARFID support / link to eating and drinking support will be added to the MindMate ND information hub .

The Leeds Parent Carer forum will be holding an ARFID support coffee morning for families in September 2025.



Hydrotherapy



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What families have told us...

Parents have been advised by professionals that Hydrotherapy cannot be documented as a support option as there no services available in Leeds

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What has happened...

Information about how to access and book hydrotherapy pools is now available on the Leeds Local Offer website.

Future plans

Health are reviewing the information about accessing hydrotherapy through EHCPs.



Education, Health & Care Plans



What families have told us...

Application process not clear for families.

Long waiting times for assessment.

Poor communication and case work officers awareness of law and practice.

Outcomes not consistent within EHCPs.

Health and Care should be as equal as Education in EHCP's.

Children and young people are not involved in their plans and have a lack of understanding about them.



What has happened...

There has been a 45% increase in requests for EHC needs assessments

Communications and Resolutions Officer recruited to the SENSAP Team in June 2025.

Further resources have been secured to increase the number of EHC assessments we can commission.

New mediation provider who have a range of resources to support families with understanding the EHC process including videos and other online tools.

Future plans

Will be focus of the September 2025 Voice, Influence & Transparency group meeting

Pilot communication study to build effective and timely communications between Local Authority and Schools

New annual professional development cycle in place for casework officers to ensure the right skills and knowledge to support families

Co producing a communication charter within the service

QA framework is being further developed around the quality of EHC plans

Additional recruitment in Autumn 2025 into 2026.



Preparing for Adulthood (PfA)



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What families have told us...

There is no preparation for adulthood for children who are highly anxious.

Lack of post 16 provision.

Careers advice given in schools but families not aware of the options available for their child.

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What has happened...

Employment and Skills, LCC, run the annual SEND Next Choices: preparing for adult life event.

Information about preparing for adulthood on the Leeds Local Offer website has been reviewed and updated.

The Leeds Local Offer Team worked with East SILC to pilot a localised PfA event for their families.

Child Friendly Leeds are working with ambassadors and specialist post 16 provisions to enhance learn to work opportunities for students.

Future plans

Further explore with families the support required for PfA.

The Voice, Influence and Transparency will focus on PfA in December 2025.

The Voice, Influence and Change Team and SENDIASS are working in partnership with young people to develop PfA resources and information.

The Leeds Local Offer team will provide support specialist provisions to host localised PfA events within their settings..



Professionals knowledge of SEND services



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What families have told us...

Families feel school staff require further SEND training to ensure they understand how to meet the needs of children., are require more awareness of masking and need to reduce parent blame.

Families would like professionals to show more empathy and understanding to families.

Families feel professionals they come into contact with require more in-depth knowledge of SEND services available in Leeds.

Training for all services not just SEND.

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What has happened...

Workforce Development subgroup (SEND and AP partnership board).

Consulted via an online survey for parents and carers to identify schools and area of need that requires further training (96 parent carer responded).

Wide SEND training offer for school staff and SENCOs delivered by Learning Inclusion.

Promotion of the Leeds Local Offer to education, health and social care professionals.

Developing a basic SEND awareness training package for all children and families staff.

Future plans

Reviewing the training for schools, which school staff have attended what training.

Using complaints anonymously as case studies in training and also to learn from.

SENDIASS will be expanding training offer for professionals and parents, with the potential for bespoke training.

Continue to promote the Leeds Local Offer to families and professionals.



SEND Terminology



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What families have told us...

Terminology used by the Local Authority, schools and parents.

For example:

- *A setting can be neurodiverse - having different neurotypes - as long as it isn't, say a setting just for Autistic child. Then it would be a setting for Autistic children.*
- *A child can be neurodivergent - having a neurotype which differs from the majority.*
- *A child cannot be neurodiverse.*
- *Most mainstream schools are neurodiverse with a proportion of neurodivergent children.*

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What has happened...

The local authority currently use the DfE terminology, and within EHC plans there is certain legal terminology that has to be used.

The Leeds Parent Carer Forum have developed a terminology / jargon buster for families.

Future plans

The Learning Inclusion Service are setting up a communities of practice to address terminology.



Information about SEND Services



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What families have told us...

Families need advocacy when attending meetings with schools and SEND services.

Support for families to navigate SEND services and not just signpost.

Sharing information about SEND school support with families.

Information about youth groups and activities available.

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What has happened...

Leeds Local Offer website and SEND services info have been updated.

The SEND booklet is online and in print, reviewed yearly.

Monthly drop-ins and workshops are run with local partners.

Annual Local Offer Live event.

Daily SEND updates are shared via the Leeds Local Offer Facebook group.

The Leeds Parent Carer Forum runs need-based parent workshops.

SENDIASS offers support online and in-person, with more capacity in 2025/26.

Seven new Family Hubs each have a SEND Coordinator.

Future plans

Developing inclusive mainstream provision resources, and information for schools and families which will be available via the Leeds Local Offer website.

Continue to work with families and young people to review and develop the Leeds Local Offer website and offer.



Families where English is a second language



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What families have told us...

Families where English is a second language struggle to access SEND services and information.

Families cannot always read written information and require it in a different format.

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What has happened...

Leeds City Council have set up a cultural buddy programme. The programme supports services to translate information for families where English is a second language.

The Leeds Local Offer website development included being able to translate the website into languages other than English.

Future plans

SENDIASS, Leeds Local Offer and the Leeds Parent Carer Forum are working together to produce short videos for families to explain some of the key SEND services in alternative languages. These will be shared with SENCOS and hosted on relevant websites.

SENDIASS, Leeds Local Offer and the Leeds Parent Carer Forum will continue to visit support groups within the community to share information about SEND services.



Financial support for families



What families have told us...

Support around trusts and wills

Support applying for PIP

DLA claims taking 5 to 6 months to process

Impact on families financially due to caring responsibilities



What has happened...

A section has been developed on the Leeds Local Offer about financial advice and support and also cost of living support.

Financial advice and support information has been added to information booklet as part of the 2025 refresh.

The Leeds Money Information Centre provides free, confidential, and impartial help and advice on a range of money-related matters.

Future plans

The Voice, Influence and Transparency Working Group will further explore this in 2025/26.

Issues to be discussed



Support, information and resources for all key stages of transition.

Support for adoptive parents.

Families in crisis.

Social care support and accessing personal assistants.

Short breaks.

Education other than at school (EOTAS).

Extended school non-attendance (ESNA).

Education, Health and Care Plans.

Preparation for adulthood.

Financial support.

Support for the wider.

