

**Voice and influence of parents and cares of children with SEND**

***Issues raised tracker: update September 2025***

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| **SEND Transport** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Children’s Transport**  At the start new school academic year families have fedback issues with home to school transport i.e. transport not turning up, families not knowing what is happening etc.  Families have said transport feels at arm’s 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.  Not always a designated driver, can be a different driver every day.  Doesn’t cater for split families, and only pick up from one address.  Families are not aware of the process for cancelling transport etc.  Need a user-friendly transport application form. | 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](https://www.leedslocaloffer.org.uk/transport).  Reviewed transport allocation letter in partnership with the Leeds Parent Carer Forum. | 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 2025. |

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| **Social Care** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Transitions**  Families not understanding what support is available when a child transitions to adult social care.  Transition support should be planned and actioned. | 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 support parents and carers to navigate the transitions pathway. | 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.  The SENDIASS Social Care Support Officer to further explore transitions, and include this within their service offer. |
| **Support for adoptive parents / carers**  The support for adoptive parents of children with SEND isn’t clear.  Adopted young people have the same trauma etc. as children in care yet young people and families do not have the same access to support and services. | The Leeds Parent Carer Form and adoptive parents will be meeting with a representative from the Learning and Inclusion service to explore the gaps in service and support for adoptive parents and what the One Adoption offer is for families. | A representative from One Adoption will be invited to join the Leeds Area SEND and AP Partnership Board.  Leeds City Council are working with One Adoption to review their support offer to families. |
| **Families in crisis**  Families have fedback that they are having to ring the police on their own children due to violence and or mental health issues.    When the police arrive they advise that it is not a police matter and a report will be submitted to social care. If this child is taken into custody, they are often realised with no further action.    If a child is taken to A&E by the police, they are often discharged on the day as they are not  ‘severe’ enough to fully section under the mental health act, or there are no beds available.    Within days or even hours families often have to call the police again; as the violence has escalated or the child has gone missing.    These children are not in the youth justice system, so are not picked up by them but in a vicious circle of police being called reports to social care etc    Families have fedback that they are in crisis, however when they approach services for support they are not meeting their thresholds for crisis intervention. |  | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |
| **Social care support and accessing PAs**  Families have shared they don’t feel there is enough support from social care, and they are experiencing difficulties in recruiting PAs. |  | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |
| **Respite and short breaks**  Families have shared there is a lack of respite / short breaks to give parent carers a break from their caring responsibilities.  Families feel social isolation due to not having time away from their caring responsibilities. |  | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |

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| **Health** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Waiting lists for diagnosis and support**  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. | The Leeds Parent Carer Forum and Health colleagues meet on a monthly basis to feedback parental voice and views. As part of these sessions, we have themed updates where services from across Health are highlighted and discussed.  Medication reviews for those who are stable on their ADHD medication (i.e. good symptom management, no changes to treatment required) will now move to yearly reviews. This is a change from every 6 months to yearly as per NICE guidelines (point 1.10.1): A healthcare professional with training and expertise in managing ADHD should review ADHD medication at least once a year and discuss with the person with ADHD (and their families and carers as appropriate) whether medication should be continued. It also says in 1.8 regarding maintenance and monitoring, that those under 10 need physical health reviews every 3 months and those 11 and older every 6 months, which we will providing in the Physical Health Monitoring Clinic. Families can also decide to do this monitoring at home or a local provider such as a pharmacy if required.  During the face-to-face physical health monitoring appointment, any concerns can be shared to the CYPMHS assistant about the medication, and this will be discussed with a prescriber regarding next steps. This may include bringing the appointment forward if this is clinically indicated. For those who complete the monitoring at home they can submit text with the readings for review as per the face to face option.  Please note this is common practice for ADHD medication management.  Please see above for NICE guidelines detail. Most ADHD medications are Amber Drugs within Leeds, which means that GPs can provide repeat prescriptions but will not make alterations to the treatment plan. The GP may help with the physical health monitoring but not medication changes; all changes need to be provided by the specialist – which is Leeds CYPMHS.  **Update about Oakdale** The process for individuals who have been assessed through Oakdale and live in Calderdale who want to access ADHD medication has been successful. Therefore Oakdale have now extended the offer of medication to Leeds and the rest of West Yorkshire for Young People who were assessed by Oakdale.  Next steps following this will be to look at whether the medication offer can be extended to patients who have been diagnosed by other providers.  The ICB is working with getting a list of providers like Mantle, Oakdale and Evolve that will agree to local standards so there is more consistency.   The list of providers who will be offering the service with these standards for assessment or medication or both should be available from late spring.  They are also producing a leaflet with frequently asked questions to go out to families and GPs about Right to Choose to inform people so they can make the right choice for their Young Person. This information is now available online.  **Leeds Community Health care ADHD medication clinics**  The Children and young people’s mental health service is working hard to reduce waiting times for ADHD medication.  Actions currently underway include;   * Working with primary care colleagues (GPs) to see if we can set up a “shared care” approach to medication where we prescribe the meds initially and get young people established on them and then the GP takes on the 6 month review.  This will free up appointment slots for young people from the waiting list.  We are in the early stages of letting GPs know how many young people this would be in their practice. This approach is likely to be specific to GP practice individual agreements at first and not a wholesale approach.  We will let families know if this is going to happen with their medication care/follow up. * Using extra waiting list money which has been allocated to the service to employ more prescribers until at least the end of March 2025 * Calling families to get further information prior to their 1st medication appointment which helps to reduce the appointment time when young people actually attend clinic – this frees up more prescribing appointment time in the long run | As the health issues are a challenge to the health system and will not be fully resolved easily, the Leeds Parent Carer Forum and the Designated Clinical Officer will review regularly and provide updates.  CAMHS full service review. |
| **Sleep and melatonin**  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. | 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, with a decision expected in May 2024.  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. | As the health issues are a challenge to the health system and will not be fully resolved easily, the Leeds Parent Carer Forum and the Designated Clinical Officer will review regularly and provide updates.  Development of pathways across services to deliver offers for behaviour, eating, drinking, nutrition, continence and sleep. |
| **Bloods**  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. | 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. | 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)**  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. | 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. | 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**  Parents have been advised by professionals that Hydrotherapy cannot be documented as a support option as there no services available in Leeds | Information about how to access and book hydrotherapy pools is now available on the Leeds Local Offer website. | Health are reviewing the information about accessing hydrotherapy through EHCPs. |

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| **Education:** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Education Other Than At School (EOTAS)**   * Parents and carers have fedback that they are increasingly having to give up work to support their child at home as they cannot attend school due to school not being able to meet their needs. How do families challenge this? * Families have shared that the LA do not support EOTAS packages and naming them in EHCPs. * Families wanting to undertake the EOTAS package have shared that there is no support available. | The Educational Psychologist Team have consulted with the Leeds Parent Carer Forum, to look at attendance barriers and what support can be developed for parents.  Resources have been developed by the Educational Psychologist Team for school staff (and professionals) provide support with attendance.  The Educational Psychologist Team have a central training offer to school staff and wider professionals on ESNA and how to understand and support the needs of C&YP and their families. | The Educational Psychologist Team set up a working group with representatives from across services to consider service perspective and understanding. The working group will be looking at two areas: resources for schools and parental support / guidance.  Work and consultation with families to find creative solutions to ensuring schools, settings and appropriate provisions are in place.  The Voice, Influence and Change Team to explore how the voices of elective home educated and those in education other than at school are gathered. |
| **Extended school non-attendance (ESNA)**   * C&YP are unable to go to school for a range of reasons, this may be due to anxiety. * More C&YP being given part time timetables * There is increased reports and concerns in relation to ESNA. * Parents and carers report having to give up work to support their child at home. * Not all C&YP have EHCP’s. * Parents and carers have fedback a lack of understanding and/or support from school. * Families do not feel they are receiving support around exclusions. * There has been a rise in families of C&YP who attend mainstream schools contacting the SILC Cluster. |  | Whilst our Area Inclusion Partnership (AIP) and Alternative Provision (AP) model is a strength within Leeds there are plans to review our approach to devolving funds to partnerships of school leaders in AIPs, responding to the national focus on the use of AP and enabling them to co-design an offer of inclusion support and alternative provision that reflects their local area’s context and needs. We are aware there are too many children within AIP settings that require more long-term support and AIP provision is not always been seen and used as an intervention. In addition, we have plans to develop a guidance document for schools and commissioners outlining the LAs guiding principles for alternative provision and emphasising the school responsibilities in relation to alternative provision. E.g., exit planning; expectations on use of provision maps, integration with Fair Access Panel; how to record in their school registers to improve data available in School Census and implications for CYP with EHC Plans.  Continued identification of where new specialist provisions can be established in within existing settings and continued expansions where able with our established SILC provisions.   * A focus on attendance from our SEND teams when supporting schools and settings with individual case work. * Continued support from attendance team to improve attendance in schools and settings. * Review our approach to develop devolving funds to partnership of school leaders in AIP‘s enabling them to design an offer of inclusion support and alternative provision that reflects their local areas context and needs. * Guidance document for all schools/commissioners outlining the LA guiding principles for arranging AP and setting out schools responsibilities in relation to AP. * Health to be involved in the planning and development of Specialist places. * The council will be investing in special and resource provision within mainstream settings. * Leeds City Council are developing an alternative provision strategy which will be co-produced with partners. |
| **Education, Health and Care Plans**  Key challenges faced by families:   * Application process not clear for families, and professionals not understanding the process. * Waiting times for assessment. * Case worker communication. * 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. | 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. We are working with both internal and external resources to procure more assessments  New mediation provider who have a range of resources to support families with understanding the EHC process including videos and other online tools. | 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 |
| Support, information and resources for all key stages of transition. (primary to secondary, secondary to post 16, post 16 to next steps). |  | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |

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| **Preparation for adulthood** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Preparation for adulthood**  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. | 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. | Further explore with families the support required for PfA.  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. |

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| **Training and awareness of professionals** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Professionals’ knowledge of SEND services**   * Families have told us that they feel school staff require further SEND training to ensure they understand how to meet the needs of their children. * School staff require more awareness of masking and need to reduce parent blame. * Families would like professionals to show more empathy and understanding to families. * Families would like to be involved in training and feel all training should include should lived experience. * Lack of neurodivergent expertise within leadership. * Families feel professionals they come into contact with require more in-depth knowledge of SEND services available in Leeds. * Families feel they receive different messages about service depending on who they speak to i.e. GPs, schools etc. * Training for all services not just SEND i.e. housing. | 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. | Workforce Development are developing a basic SEND awareness training package for all children and families staff.  Learning Inclusion will be reviewing the training for schools, which school staff have attended what training.  Customer Relations are asking complainants if Leeds City Council can use their complaint as anonymous 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. |
| 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 CYP. Then it would be a setting for Autistic CYP. * A CYP can be neurodivergent - having a neurotype which differs from the majority. * A CYP cannot be neurodiverse. * Most mainstream schools are neurodiverse with a proportion of neurodivergent CYP. | The local authority currently use the DfE terminology, and within EHC plans there is certain legal terminology that has to be used.  One SEND Team inclusivity working group have focussed on language and terminology.  The Leeds Parent Carer Forum have developed a terminology / jargon buster for families. | The Learning Inclusion Service are setting up a communities of practice to address terminology (Lisa Atkin) |

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| **Information, advice and support** | | |
| **Parents / carers said…** | **What has happened…** | **Future plans** |
| **Information about SEND services**   * Advocacy for families 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. | The Leeds Local Offer website has been furthered developed, and information about services reviewed. .  The Leeds Local Offer introduction to SEND services booklet is available on the Leeds Local Offer website, and in hard copy format. The booklet is reviewed and updated annually.  Monthly SEND parent carer information drop ins including focussed workshops run in partnership by Leeds Local Offer, Leeds Parent Carer Forum, SENDIASS, Carers Leeds, CHAD and Speech and Language.  Annual Leeds Local Offer Live market place event for families to find out about SEND services in Leeds.  The Leeds Local Offer team host a facebook group, and post daily to share information about SEND services with families.  The Leeds Parent Carer Forum deliver workshops for families based on need.  SENDIASS deliver their offer via their website, social media, youtube, workshops etc. SENDIASS will have increased capacity in 2025/26.  Seven new Family Hubs across the city, each hub has a SEND Coordinator. | 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 accessing SEND services and information**   * 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. | Cultural buddy programme.  SENDIASS, Leeds Local Offer and the Leeds Parent Carer Forum have been visiting visit support groups within the community to share information about SEND services. | 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**   * 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 | 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. | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |
| **Support for wider family**   * Support for siblings and partners. * Mental health support for families. |  | *Issue to be explored by the Leeds Parent Carer Forum and Voice, Influence & Transparency Working Group.* |