LEEDS PCF
PARENT CARER FORUM

Leeds Parent Carer Forum Annual Survey 2026

A short summary for parent carers

What 154 parent carers told us about SEND services in Leeds

154	26	2026
parent carers responded	Leeds postcode districts represented	survey year

This summary pulls out the main findings from the full report. It uses plain language and focuses on the issues families raised most often. The full report contains more detail, quotations, methods, comparisons and recommendations.

The most important message

Families described both good support and serious difficulties. Positive experiences were most likely when professionals listened, communicated clearly, understood the child and followed through. Difficulties were most likely when families were left waiting without support, had to repeat their story, or had to coordinate services themselves.

A note about the findings

- The survey was voluntary. It describes the experiences of the people who responded; it does not represent every SEND family in Leeds.
- Percentages use the number who answered each question. This means the total can be different for different questions.
- Quotations are respondents' own words. They illustrate individual experiences and were not independently verified.

For more detail, see Sections 1–3 of the full report.

What families said is working well

Families did not describe every service as poor. They gave examples of support that made a real difference.

- Professionals who listened and took concerns seriously.
- Schools, SENCOs, nurseries and educational psychologists who understood the child.
- Health staff who made reasonable adjustments and helped children feel comfortable.
- Clear explanations, timely updates and a named person to contact.
- Support tailored to the child, rather than a one-size-fits-all response.
- Practical information and support from the Local Offer, LPCF and other parent carers.

One positive hospital experience

> *“My sons hospital stay was actually very positive and they went out of their way to support both myself and my son, made him feel comfortable and listened to all his needs.”*

What good support had in common

Good experiences were built on listening, clear communication, partnership, reasonable adjustments and action. Families wanted these approaches to be consistent, not dependent on which professional or service they happened to reach.

For more detail, see Section 4 of the full report.

The biggest concerns across services

Three issues connected many of the survey findings.

Waiting without enough help

Families described waits across EHCP, health, mental health and neurodevelopmental pathways. The problem was not only the length of the wait. Families also described limited updates, unclear escalation routes and too little practical support while waiting.

Communication

> *“Information does not flow between services. Education, health and social care do not share information, so we repeat the same history again and again, and things fall through the gaps. The coordination that should sit with services falls entirely on us.”*

Accountability

Families wanted clear ownership: who is responsible, what happens next, when they will hear back, and what they can do if support is delayed or refused.

What families want

- Regular updates, even when there is no change.
- A named contact and clear next step.
- Useful help before needs reach crisis point.
- Services to share information appropriately so families do not have to keep repeating their story.
- Visible action after families give feedback.

For more detail, see Sections 5, 9 and 13 of the full report.

Education, settings and EHCPs

Families described a mixed picture. Some praised supportive schools and SENCOs. Others described delays, outdated plans, missing provision and poor communication.

Key messages

- An EHCP only helps if the provision written in it is actually delivered.
- Delays can mean that a plan no longer reflects the child's current needs.
- Families want clearer communication during assessment, review and amendment.
- Children on SEN Support also need visible, accountable help.
- Positive school experiences were linked to staff who understood the child and worked in partnership with families.

Communication about EHCPs

> *"Sensap don't communicate or respond to emails even after stage 2 complaint asking for ehcp to be updated."*

Who responded

Families whose children had an EHCP were over-represented in the survey compared with the wider Leeds SEND population. The findings should therefore be read as strong evidence about respondents' experiences, not as a population estimate for every family.

For more detail, see Sections 3 and 6 of the full report.

Health and wellbeing

42 of 57	61 of 80	21 of 39
could not access needed mental-health support	had not accessed sleep support	selected “None” for feeding support

The health findings covered access, mental health, sleep, feeding, hospital care, therapies and specialist pathways.

What families described

- Referrals being rejected or delayed without clear communication.
- Services passing responsibility between one another.
- Long, multi-stage routes to sleep support.
- Gaps in feeding and dietetic support.
- Difficulty accessing therapy and specialist pathways.
- Positive hospital care where staff listened and made adjustments.

Mental health

> *“Services passing responsibility to each other. No one taking accountability.”*

Hospital care

Of 60 respondents answering the question, 53 said hospital services met their child’s needs fully or partly. Families valued staff who listened, supported the parent as well as the child, and made the child comfortable.

Important denominator note

The mental-health, sleep and feeding figures above are based on follow-up questions, not on all 154 respondents. They should not be compared as if they had the same base.

For more detail, see Section 7 of the full report.

Assessment, short breaks and preparing for adulthood

Neurodevelopmental assessment and support

Families wanted support before, during and after assessment — not only a diagnostic decision. They asked for clearer routes, practical help while waiting and better joint working between education, health and families.

> *“More proactive support after diagnosis rather than just a report and vague advice.”*

Short breaks

Some families described good short-break provision, but raised concerns about availability, continuity and whether activities could meet physical, medical and one-to-one support needs.

> *“The short breaks I have accessed have been fantastic but there is not enough of them and now they have stopped the residential ones this is going to have a big impact on us as a family.”*

Preparing for adulthood

Families wanted planning and information to start earlier. Clear information could reduce anxiety, but transition should not rely on parent carers finding out about services by chance.

> *“I am less nervous about the next stages thanks to the session LPCF put on about the transitioning team”*

For more detail, see Sections 8, 10 and 11 of the full report.

Information and support services

98 of 154	30 of 67
had heard of the Leeds Local Offer	rated LPCF good or very good

Leeds Local Offer

Almost two-thirds of respondents had heard of the Leeds Local Offer: 98 of 154 (63.6%). Of the 74 people who rated it rather than choosing “Not used”, 19 rated it good or very good, 24 rated it OK, and 31 rated it poor or very poor.

> *“Both excellent services and online website so can look in own time. Leeds local offer are really good with the open days in colleges and events pop up as can speak directly to services. Leeds local offer is excellent source of information.”*

> *“The local offer emails are hard to read.”*

Leeds Parent Carer Forum

Of the 67 people who rated LPCF rather than choosing “Not used”, 30 rated it good or very good, 19 rated it OK, and 18 rated it poor or very poor. LPCF will use this as a baseline, find out more about neutral and negative experiences, and report back on changes.

> *“I find that I get a lot of info by attending things such as PCF and listening to other parents.”*

SENDIASS

SENDIASS was included within a wider information and support category. The survey did not ask a separate SENDIASS rating question, so no separate satisfaction percentage can be given.

For more detail, see Section 12 of the full report.

What needs to happen next

The full report sets out recommendations for services and the SEND partnership. In plain language, families want:

- Support before crisis, including useful help while families wait.
- Clearer EHCP processes and delivery of the provision written in plans.
- Better access to mental-health, sleep, feeding, therapy and specialist support.
- Clear communication: named contacts, regular updates and understandable decisions.
- Better information-sharing and coordination across education, health and social care.
- Short breaks that are available, reliable and accessible for different needs.
- Earlier, clearer preparation for adulthood.
- Information that is current, easy to find, easy to read and available in different formats.
- Feedback to lead to visible action, with progress reported back to families.

How progress will be checked

LPCF plans to use the 2026 findings as a baseline. The full report proposes monitoring change in 2027, using consistent questions and clear measures so families can see whether experience is improving.

Read the full report

The full Leeds Parent Carer Forum Annual Survey 2026 report includes detailed findings, quotations, comparisons, methodology, limitations and recommendations. Section references throughout this summary show where to find more information.

Need this summary in another format?

Please contact LPCF via email info@leedsparentcarerforum.co.uk or phone 07423 436813 if you require this summary or the full report in another accessible format.

Thank you

Thank you to every parent carer who shared their experience. Your feedback will be used to support challenge, improvement and accountability across SEND services in Leeds.