

LEEDS PCF

PARENT CARER FORUM

Leeds Parent Carer Forum

Annual Survey 2026

Final Full Report

Based on 154 responses

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1. Executive summary

What families told us — and what needs to happen next

This survey gives a detailed picture of the experiences of 154 parent carers. It is not a statistically representative census of all Leeds SEND families, but it is a substantial evidence base. The strongest message is not that every service is poor, nor that positive examples outweigh concerns. It is that families experience marked inconsistency: good practice exists, but too often depends on the individual professional, school, team or pathway encountered.

1.1 The clearest findings

- Nearly half of respondents answering the question — 73 of 151 (48.3%) — reported difficulty accessing a health service.
- Mental-health unmet need was acute: 42 of 57 (73.7%) answering the access follow-up said they could not obtain the support needed.
- Sleep difficulties were common: 82 of 143 (57.3%); among 80 answering the support follow-up, 61 (76.3%) had not accessed support.
- EHCP concerns were not only about the quality of written plans. Families repeatedly distinguished between provision being written, provision being commissioned and provision actually being delivered.
- Communication problems often formed a chain: no update → chasing → incomplete or conflicting information → unclear ownership → no visible action.
- Hospital care was a relative strength: 53 of 60 (88.3%) said needs were fully or partly met. However, reasonable adjustments were reported by only 23 of 59 (39.0%).

1.2 What the findings mean together

Across education, health and wider support, families described the cumulative burden of navigating a fragmented system. Waiting was rarely experienced as a neutral passage of time. It was often “unsupported waiting”: families lacked practical help, clear information, safety-netting and routes to escalate when needs worsened. Communication, therefore, mattered not simply because families wanted more messages, but because effective communication was part of access, accountability and trust.

Multiple needs, multiple waits: Free-text responses indicate that some families were navigating more than one pathway at the same time; for example, education support alongside neurodevelopmental, mental-health, sleep, feeding or therapy needs. The survey does not provide a valid cross-tabulation to estimate how common this was, so no percentage is reported. Qualitatively, however, overlapping waits and repeated

hand-offs intensified uncertainty and increased the coordination work carried by families.

Key figure: 80 of 148 respondents (54.1%) said their child had needed autism and/or ADHD assessment or support in the previous 12 months.

Impact on family life: Some free-text comments described the time, emotional load and practical disruption involved in chasing updates, repeating information and coordinating services. These experiences should not be generalised to every respondent, but they show why communication and coordination are outcomes for families, not simply administrative processes.

The report also identifies an important positive pattern. Where families felt listened to, knew who was responsible, received support tailored to their child and saw communication lead to action, experiences improved markedly. These are not abstract aspirations: respondents described examples of this practice already happening in Leeds. The task is to make it reliable and system-wide.

2. About the survey and how to read the findings

A transparent account of scope, methods and limitations

Accessibility note: Every chart and dashboard is accompanied by a caption and nearby narrative describing the principal finding.

Children and young people's direct voice: This survey records parent-carer experience. It can describe what respondents reported about their children's experiences, but it is not a substitute for direct engagement with children and young people. LPCF recommends complementary, accessible engagement so that future reporting includes their views in their own words.

The survey was open to all parent carers and promoted through LPCF channels and other routes available to the Forum. It received 154 responses. Because participation was voluntary, the results describe respondents' experiences and should not be presented as statistically representative of all Leeds families.

2.1 How the analysis was undertaken

Closed-question results were recalculated directly from the raw workbook. Percentages use the number who answered each question, not automatically all 154 responses. Free-text responses were manually reviewed and assigned to one or more themes. A single comment could therefore contribute to several themes — for example, waiting, communication and lack of interim support. Qualitative percentages do not sum to 100%.

Evidence source	How it is used
Leeds Parent Carer Forum Annual Survey 2026 – anonymised response data from 154 respondents	Survey counts, percentages, respondent profile and anonymised verbatim quotations
SEND population report v1.1 October 2026	Comparator data for SEND population provided by Leeds City Council

2.2 Important denominator notes

- The mental-health need question had 56 "Yes" responses, but 57 people completed the next access question. The correct reported access result is therefore 42 of 57 (73.7%), not 42 of 56.
- Eighty-two people reported sleep difficulties; 80 completed the support follow-up.

- The feeding/ARFID service question was multi-select. “No support” is 21 of 39 respondents answering that follow-up, not 21 of all 145 answering the prevalence question.
- No headline therapy-access percentage is reported because the survey did not contain one closed question with a valid common denominator.

2.3 Use of respondent quotations

Respondent quotations are indented and italicised, reproduced verbatim. They illustrate one family’s experience and should be read alongside the survey findings; experiences were not independently verified.

2.4 Inspection and survey timing

The Area SEND inspection took place from 27 April to 1 May 2026 and was published on 18 June 2026. The survey ran from mid-June to mid-July 2026, shortly afterwards, but several questions referred to experiences over the previous 12 months. The results are best understood as a baseline around the inspection publication period, not as a measure of post-inspection improvement.

2.5 Limitations

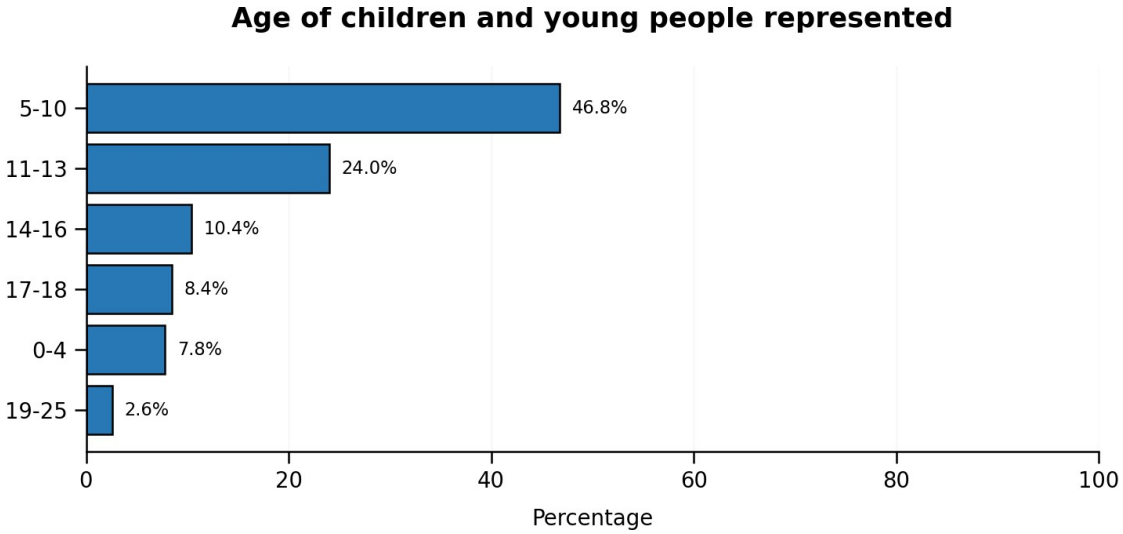
- The sample is self-selecting.
- Families with very positive or very negative experiences may have been more likely to respond.
- Some groups are more strongly represented than others.
- Free-text findings depend on what respondents chose to mention.
- Small conditional bases should be interpreted cautiously.
- Experiences reported by parents and carers were not independently verified.

3. Who responded?

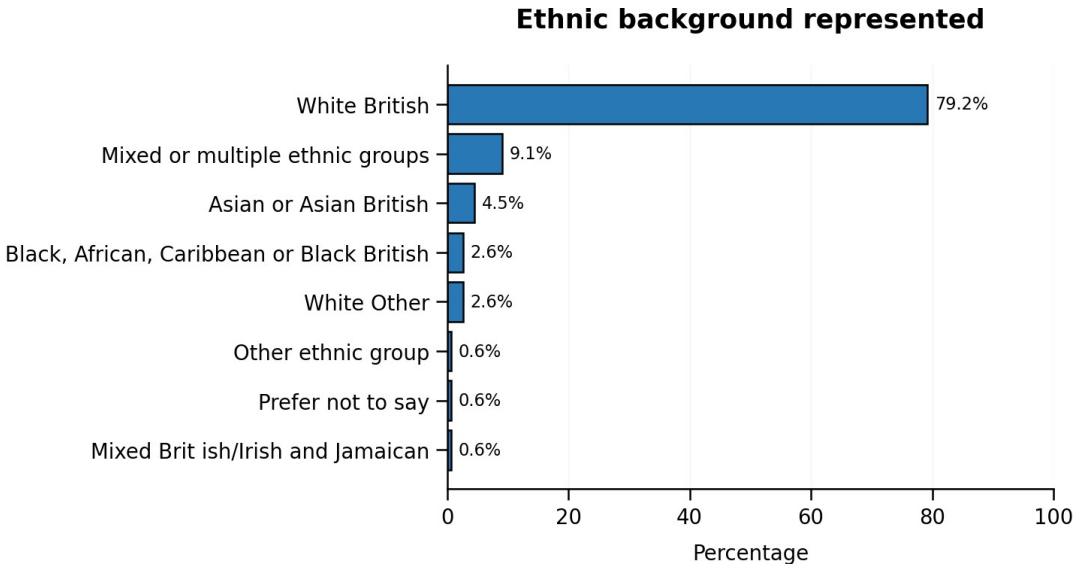
The people and settings represented in the survey

3.1 Respondent profiles

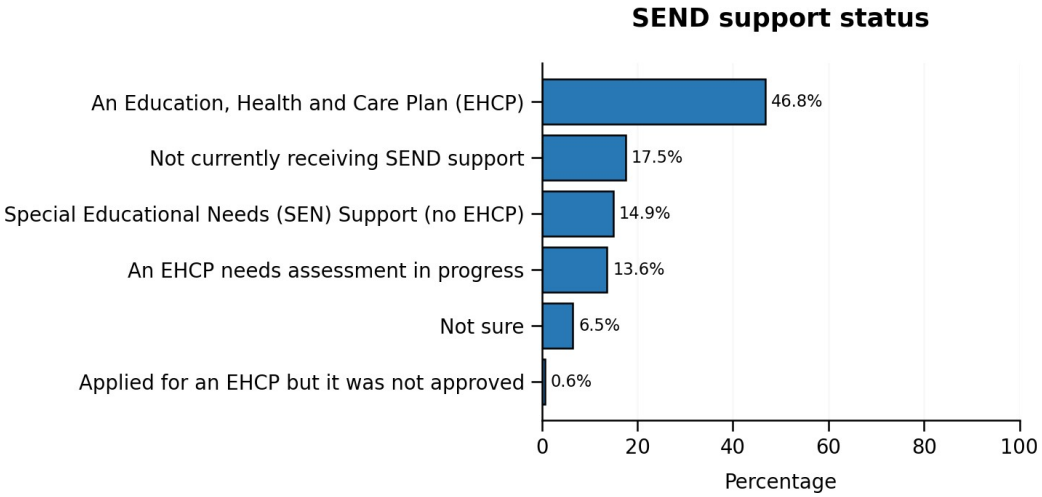
The profile helps readers understand whose experiences are most visible in this report.



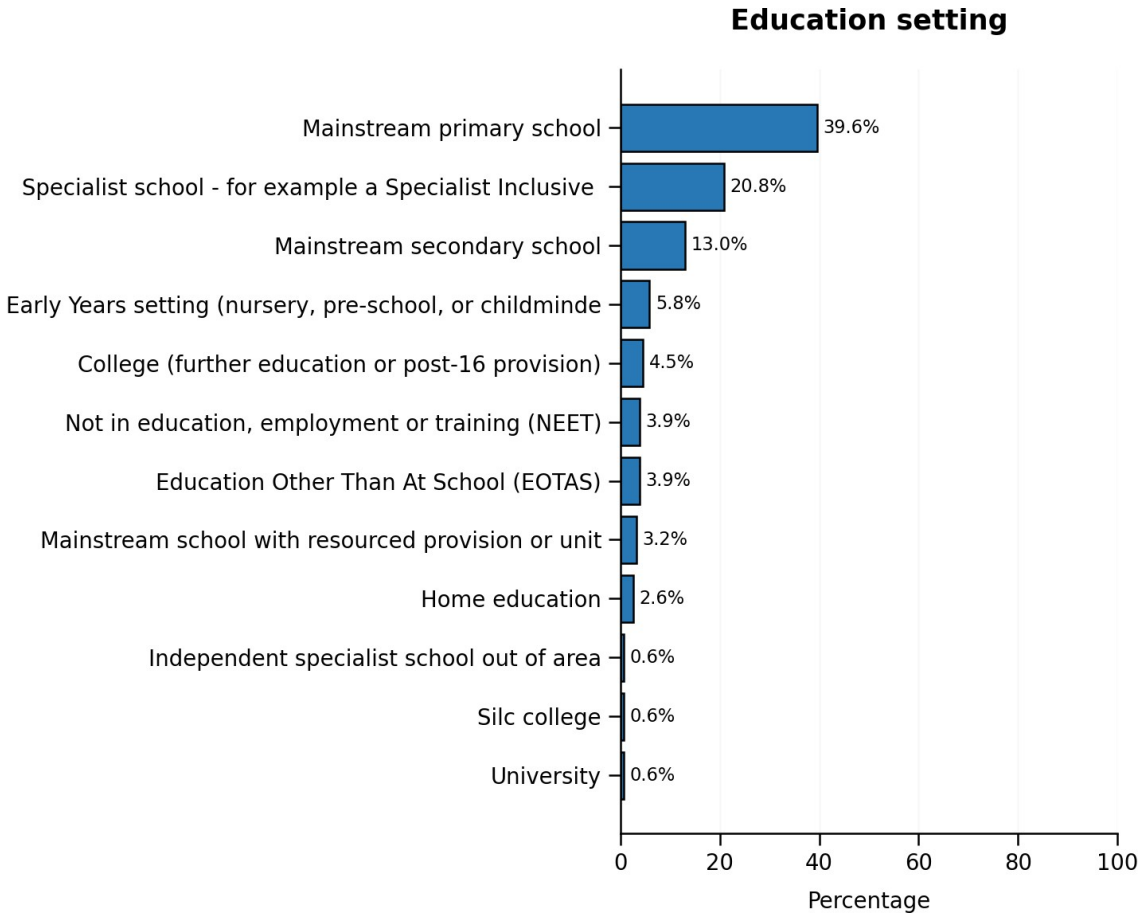
Base: 154 respondents. The largest age band was 5–10 years: 72 of 154 (46.8%).



Base: 154 respondents. White British was the largest reported group: 122 of 154 (79.2%).



Base: 154 respondents. The largest single category was an Education, Health and Care Plan: 72 of 154 (46.8%).



Base: 154 respondents. Mainstream primary was the most frequently reported setting.

3.2 How well does this sample reflect the wider Leeds SEND population?

The survey provides substantial evidence about the experiences of the 154 parent carers who responded, but it is not a statistically representative sample of every SEND family in Leeds. Comparison with current Leeds administrative data suggests that White British families and families with a final EHCP are more strongly represented in the survey. Whilst families from ethnically diverse communities, families receiving SEN support without an EHCP and older young people are less visible.

White British children and young people accounted for 79.2% of survey responses, compared with 65% of Leeds pupils with an EHC plan and 63% of those receiving SEN support. Final EHCPs were reported by 72 respondents, compared with 23 reporting SEN support without an EHCP. The survey was also concentrated in the 5–10 age group, while only four responses related to young people aged 19–25.

Dimension	LPCF survey	Current Leeds comparator	Assessment
Ethnicity	White British: **122/154, 79.2%**	White British: **65% of the EHC-plan cohort; 63% of the SEN-support cohort; 58% of the overall school population**	**Clear over-representation of White British responses** and corresponding under-representation of ethnically diverse communities.
Age	**46.8% aged 5–10**; only **4 respondents, 2.6%, aged 19–25**	The largest EHC-plan age group is **11–15, at 38%**; Leeds has relatively higher proportions aged **16–19 and 20–25** than comparator areas	**Likely over-concentration on primary-age experience and under-coverage of older young people**, although survey and administrative age bands are not fully aligned.
Gender	Male: **105/154, 68.2%**	Male: **70% of the Leeds 0–25 EHC-plan cohort**	**Broadly aligned** for the male/female distribution. The administrative report does not provide a comparable non-binary category

Dimension	LPCF survey	Current Leeds comparator	Assessment
SEND support status	Of respondents whose child had either a final EHCP or SEN Support only (n=95), **72 (75.8%)** had a final EHCP and **23 (24.2%)** were receiving SEN Support without an EHCP.	In Leeds schools, **5,213 pupils (18.6%)** have an Education, Health and Care Plan and **22,765 pupils (81.4%)** receive SEN Support without an EHCP.	Families with children who have EHCPs are strongly over-represented in the survey, while families whose children receive SEN Support are under-represented. Findings should therefore be interpreted in the context of this respondent profile.
Geographical coverage	153 respondents (99.4%) provided a valid postcode district, representing **26 postcode districts** across the Leeds City Council area.	SEND pupils are distributed across all areas of Leeds, with higher concentrations in some of the city's most deprived communities.	**The survey achieved broad city-wide geographical coverage**, although representativeness by locality or deprivation cannot be assessed from postcode district data alone.
Type of need	Autism and ADHD were frequently selected, but respondents could choose several needs	Administrative data assigns one primary need; Leeds' most prevalent school-level primary needs are SLCN, SEMH, autism, MLD and SpLD	**Do not make a direct prevalence comparison.** The classification and denominator are different.

3.3 What this means for interpretation

The concentration of respondents in some age, ethnicity and support-status groups makes caution essential. The report does not assume that the experiences of

respondents from the largest groups apply equally to families from under-represented communities, to young adults or to families less connected to LPCF and SEND networks.

These differences do not invalidate the findings. They mean that the report should be read as a strong account of respondents' lived experience rather than an estimate of how common each experience is across Leeds. Findings from small or under-represented groups should be treated as prompts for targeted follow-up and direct engagement.

3.4 What we cannot conclude

- Percentages are not estimates of prevalence across Leeds;
- Small subgroups should not be ranked;
- Setting comparisons require matching by EHCP/SEN-support status;
- Multiple-choice need data cannot be compared directly with administrative "primary need" data.

Government Social Research guidance states that self-selection approaches can be valuable but do not support inference to a wider population; it recommends inclusive recruitment, disaggregation where robust and clear reporting of participant demographics and limitations.

4. What families told us is working well

Good practice to retain, learn from and spread

Positive practice was not universal. Other respondents, including those discussing schools and settings, described very different experiences. This chapter therefore identifies practices valued by some respondents; it does not make a blanket judgement that any whole sector is performing well.

Good practice and what families value

Examples some respondents wanted to see more consistently

People who listen Families valued professionals who understood the child and took concerns seriously.	**Clear communication** Timely updates, named contacts and honest explanations helped families navigate support.
Supportive settings Some respondents praised SENCOs, schools, nurseries and educational psychologists.	**Person-centred health care** 53 of 60 respondents said hospital needs were fully or partly met.
Useful information Some families valued practical information, the Local Offer, LPCF activity and information shared through parent networks.	**Tailored support** Specific, reliable provision worked best when suited to the individual child.
Early help Families valued practical support before needs escalated.	**Partnership** Positive experiences involved families in decisions and linked communication to action.

Experiences varied across families, services and settings.

4.1 The common ingredients of positive experience

Being listened to

Families valued professionals who understood the child, took concerns seriously and treated parent-carer knowledge as evidence.

Clear communication

Timely updates, an identifiable contact and honest explanations reduced uncertainty and repeated chasing.

Support tailored to the child

Specific, reliable provision mattered more than a generic offer that the child could not use.

Partnership

Positive experience was associated with family involvement in decisions and communication that led to action.

Reasonable adjustments

When professionals anticipated sensory, communication or practical needs, families described services as more accessible and humane.

Useful information and peer support

The Local Offer, SENDIASS, LPCF and parent networks were valued where information was current, practical and easy to navigate.

> *“My childrens school senco is very understanding and supportive of both my childrens needs and always does her best to help both children and myself”*

> *“The educational psychologist was excellent and our nursery (their nursery) were also great at helping with the assessment”*

4.2 A central implication

The survey does not suggest that Leeds lacks good practice. It suggests that good practice is too dependent on where a family lives, which professional they meet, the capacity of a particular team or the persistence families can sustain. Improvement therefore requires consistency and spread, not only new initiatives.

5. Concerns, challenges and improvement priorities

The barriers that cut across services and pathways

The inclusion of strengths is not intended to soften or “wash” the concerns. Repeated barriers remain prominent and, in several areas, severe.

Concerns and improvements needed

Repeated barriers and priorities identified by respondents

Waiting and delay Families described waits across EHCP, health and neurodevelopmental pathways.	**Unsupported waiting** Parents wanted practical interim help and clear escalation routes during waits.
EHCP quality and delivery Comments identified missing provision, outdated plans and delayed amendments.	**Mental-health access** 42 of 57 follow-up respondents could not access the support needed.
Sleep support 61 of 80 follow-up respondents had not accessed sleep support.	**Communication** Families reported missing updates, delayed responses and repeated chasing.
Accountability Hand-offs and communication without action left families coordinating the system.	**Inconsistency** Positive practice existed, but respondents did not experience it consistently.

Experiences varied across families, services and settings.

5.1 Waiting was a system experience

Waiting appeared across EHCP processes, health services, therapies and neurodevelopmental pathways. The most important analytical distinction is between waiting time and unsupported waiting. Families often described needs worsening while they waited, with no interim advice, practical help or clear route back into the system.

5.2 Communication was part of delivery

Respondents did not treat communication as separate from service quality. A missed update could mean a missed opportunity to escalate. Conflicting information could delay action. A reply without ownership could leave the family coordinating professionals. This is why better communication should be interpreted as clearer responsibility, reliable follow-through and visible action — not simply more emails.

5.3 Accountability was the connecting issue

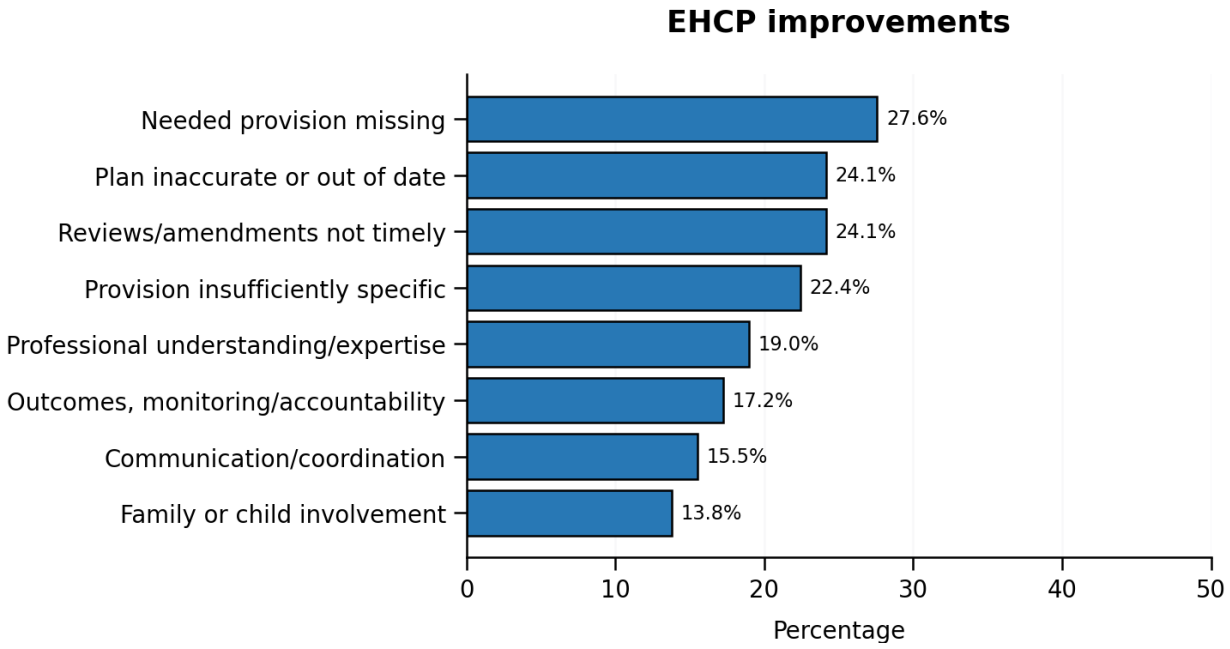
Across EHCPs, referrals and health pathways, families described a gap between acknowledgement and delivery. A meeting could happen without agreed support starting. A referral could be sent without a family knowing whether it had been accepted. A plan could list provision without anyone ensuring it was commissioned. The report therefore places accountability alongside access and quality.

6. Education, settings and EHCPs

From plan-writing to provision that changes everyday life

The education evidence shows variation. Some respondents praised individual schools, SENCOs, nurseries and educational psychologists. Others described plans that were out of date, missing provision or only partly followed. The findings are therefore about the experiences reported by respondents, not a judgement about all Leeds schools.

6.1 EHCP improvement themes



Themes are non-exclusive; base = 58 analysable comments.

Sixteen of 58 analysable comments (27.6%) identified needed provision missing from the EHCP. Fourteen (24.1%) described a plan that was inaccurate or out of date, and the same number described delayed reviews or amendments. Thirteen (22.4%) said provision was not specific enough. These themes overlap and often describe a single chain of failure: changing need was not captured promptly; provision was vague or omitted; and accountability for delivery was unclear.

6.2 The difference between a plan and provision

One of the richest findings is that families did not judge success by whether an EHCP existed. They judged it by whether the plan reflected the child now, whether provision

was specific enough to be enforceable and understood, and whether the support actually happened. This moves the improvement question beyond plan production to plan quality, timeliness and delivery.

> *"He had a place at a specialist school which is better than mainstream but only about 2/3 of the ehcp is followed"*

6.3 What positive school-based experience looked like

Positive comments were often relational and practical: a SENCO knew the child; staff responded quickly; a nursery helped with assessment; or professionals tried to adapt support. This should be read as evidence of what works in some settings, while recognising that LPCF also receives negative school-based feedback both inside and outside this survey.

6.4 EHCP-related quotes demonstrating the different key themes

EHCPs – Positive practice

Illustrates: professionals listening to families and understanding the child as an individual

> *"The educational psychologist was a real positive. She listened, validated our concerns, and asked for plenty of information about (child name), including videos of him at home. It meant the assessment reflected how he functions day to day, not just a snapshot from one appointment."*

Survey question: What worked well during the EHCP needs assessment process?

EHCPs – Delays obtaining assessments

Illustrates: delays in professional input

> *"The time it took. The agreement to assess was quick but it took over a year for an ed psyc to be available to come visit my son"*

Survey question: If you could change one thing about the way the EHCP needs assessment process was conducted, what would it be?

EHCPs – Delays causing plans to become outdated

Illustrates: timeliness affecting quality and relevance of plans

> *"The current waiting times are totally unacceptable. We ended up waiting over 3 months for the draft to be issued following the assessment. By that time it was completely out of date."*

Survey question: If you could change one thing about the way the EHCP needs assessment process was conducted, what would it be?

EHCPs – Provision not reflected in the plan or delivered

Illustrates: assessed provision not translating into support

> *"The EHCP needs to reflect the EOTAS provision and include all relevant recommendations from the independent experts. Currently speech and language therapy and occupational therapy recommended but not in place several months after evidence received."*

Survey question: What needs to improve in your child's EHCP?

EHCPs – Lack of specificity and accountability

Illustrates: concerns about vague wording, implementation and measurable outcomes

> *"Evolving needs are not identified, support is not specified or quantified and implementation is not consistent. Progress and outcomes are not smart and not tracked. Really poor input from school, professionals and Sensap."*

Survey question: What needs to improve in your child's EHCP?

EHCPs – Good school support but poor system communication

Illustrates: variability across parts of the system

> *"The process done by the school was excellent. We were told decision would be made 6 - 8 weeks. It has been months we have not heard anything with regards the outcome. This is disappointing because we are left in limbo. The school is excellent but not knowing the outcome from the assessment is disheartening."*

Survey question: What worked well during the EHCP needs assessment process?

6.5 Administrative context

The survey's concerns about delay, plan quality and delivery should be placed alongside the administrative context that, in 2025, **7.3% of plans were issued within 20 weeks and 54.2% were issued after 52 weeks**; recorded annual-review and notification performance was also below comparator figures.

This does not prove that each respondent experienced those administrative outcomes, but it shows that the lived-experience findings sit within documented system pressure.

6.6 Education and EHCP recommendations

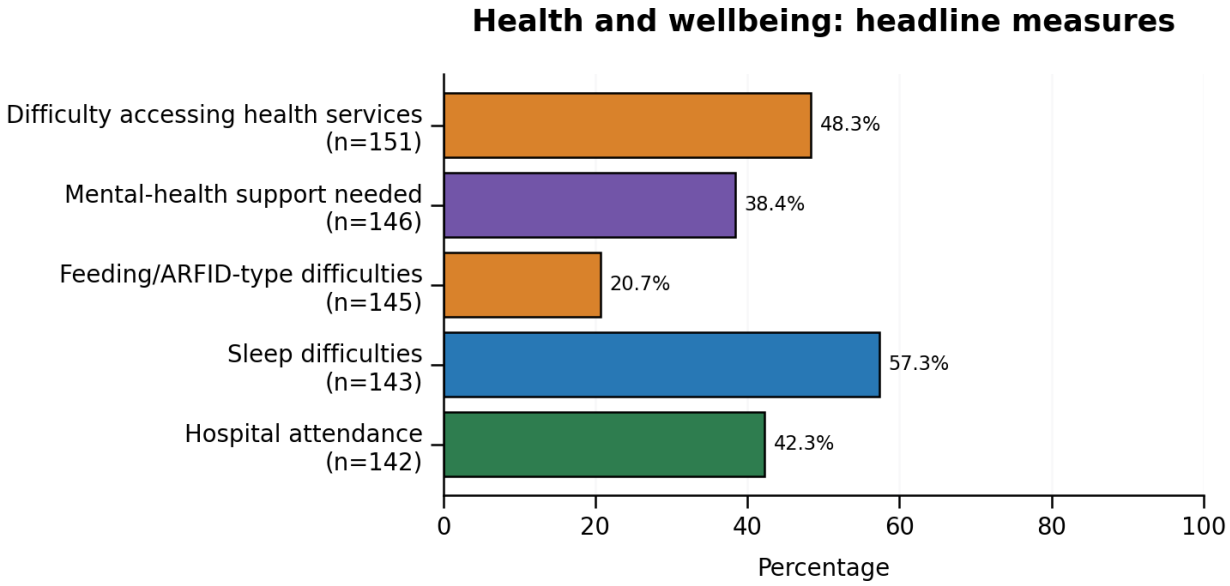
Recommendation	**What families should experience**
Improve plan quality	Needs and provision are current, clear and specific
Complete reviews and amendments on time	Less drift and fewer outdated plans
Track delivery	Families can see whether agreed provision has started
Named responsibility	One person or team owns unresolved gaps
Strengthen participation	Children, young people and parents influence decisions
Spread effective practice	Less variation between settings and professionals

7. Health and wellbeing — detailed findings

High need, serious access barriers and areas of positive practice

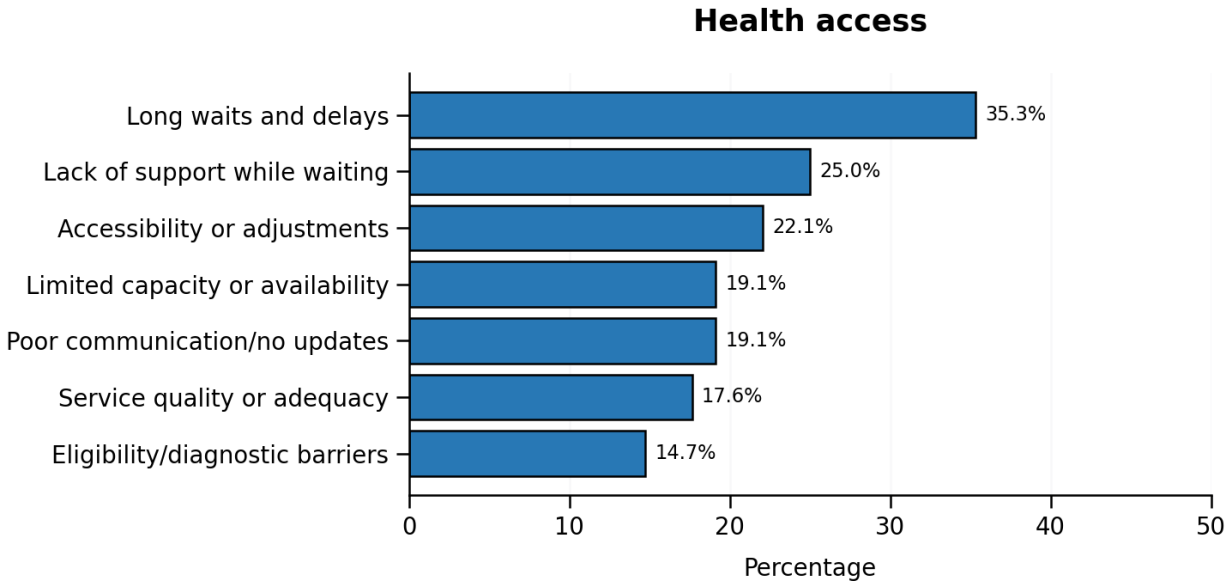
Health findings were among the strongest in the survey. They show both unmet need and a comparatively positive hospital care picture. The analysis looks beyond isolated services to the whole pathway families experience.

7.1 Health headline measures



Question bases vary and are shown on the chart.

7.2 General access to health services themes



Themes are non-exclusive; base = 68 analysable comments.

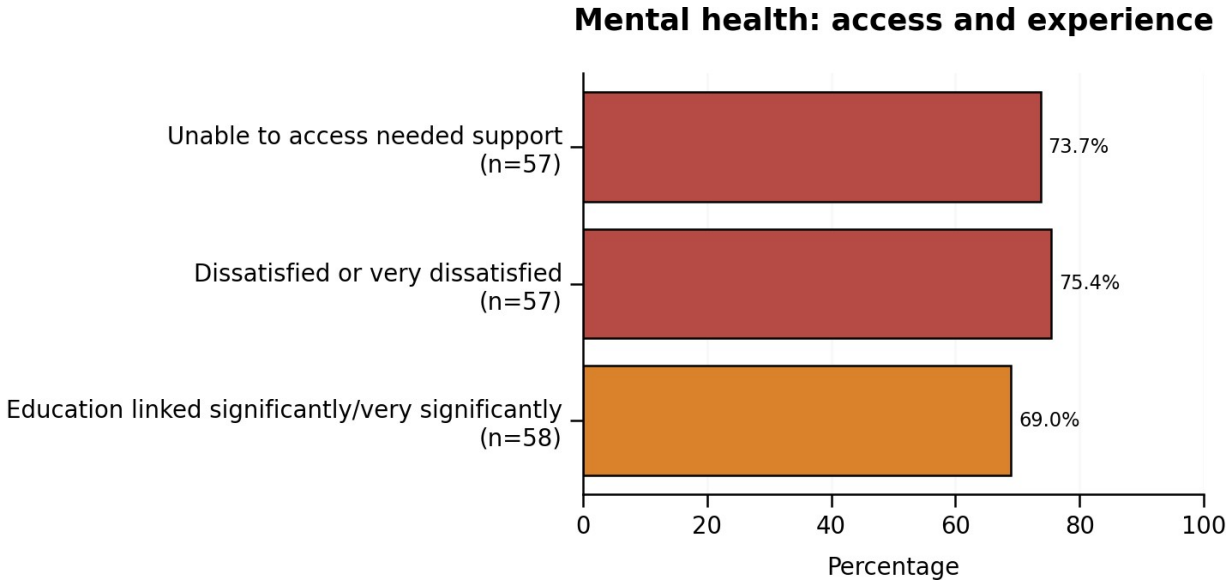
Seventy-three of 151 respondents (48.3%) reported difficulty accessing a health service. Long waits were the most frequent coded theme, occurring in 24 of 68 comments (35.3%). Seventeen (25.0%) referred to a lack of support while waiting. Accessibility or adjustment barriers appeared in 15 comments (22.1%); limited capacity and poor communication each appeared in 13 (19.1%).

> *“OT referrals by the Paediatrician were being rejected but not communicated to us so we only found out when we chased it up. WIth this, we would still be thinking we are waiting on a waiting list. The "referral rejection" communication to parents is really bad in Leeds. This should be automatic”*

This pattern reinforces the distinction between queue length and pathway quality. Even when an immediate appointment is impossible, families can still receive confirmation, advice, safety-netting, progress updates and escalation routes. Their absence turned waiting into abandonment for some respondents.

> *“My son is under the orthotics team but appointments are very sporadic and he keeps outgrowing his splints with no updates about a next appointment”*

7.3 Mental health and emotional wellbeing



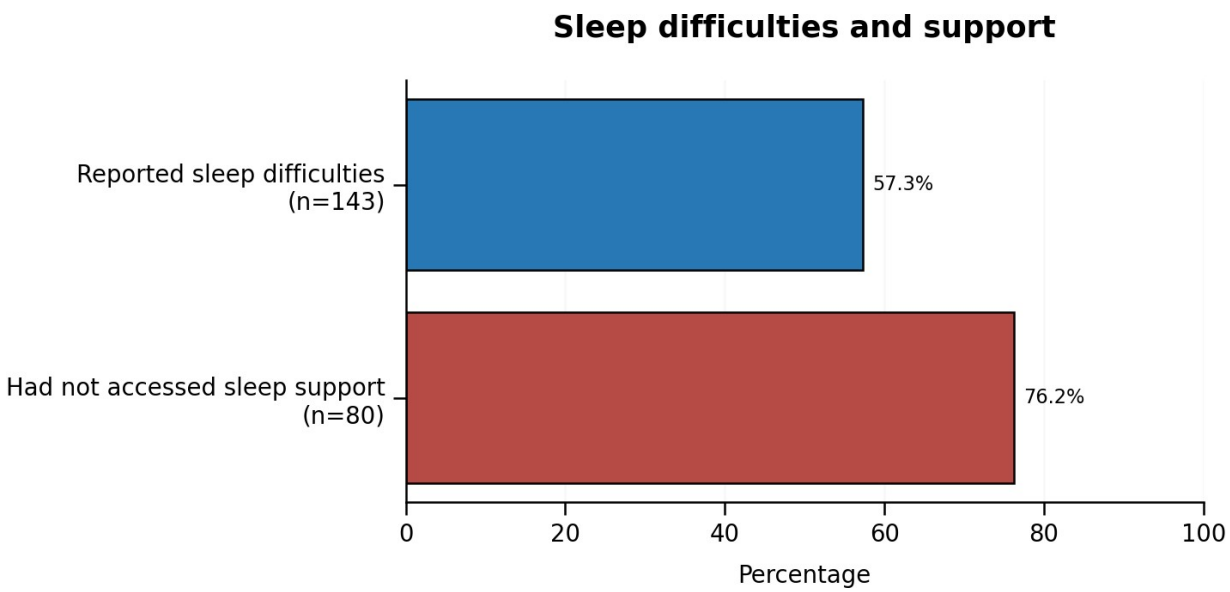
The access denominator is 57 because one additional respondent completed the follow-up.

Fifty-six of 146 respondents (38.4%) said their child had needed mental-health or wellbeing support. Of 57 answering the access follow-up, 42 (73.7%) could not access the support needed. Forty-three of 57 (75.4%) were dissatisfied or very dissatisfied. Education and mental health were closely connected: 40 of 58 (69.0%) said the link was significant or very significant.

The education link matters. Families were not necessarily describing separate “school” and “health” problems. Anxiety, attendance, unmet support and school avoidance can amplify one another. Earlier, jointly owned responses are therefore needed before difficulties become crises or prolonged absence.

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

7.4 Sleep



Two people reporting sleep difficulties did not complete the support follow-up.

Eighty-two of 143 respondents (57.3%) reported sleep difficulties. Among 80 answering the follow-up, 61 (76.3%) had not accessed sleep support. Sleep should not be treated as a minor lifestyle issue: persistent sleep difficulty can affect the child's regulation, attendance, health and learning, while also affecting the wellbeing and resilience of the whole household.

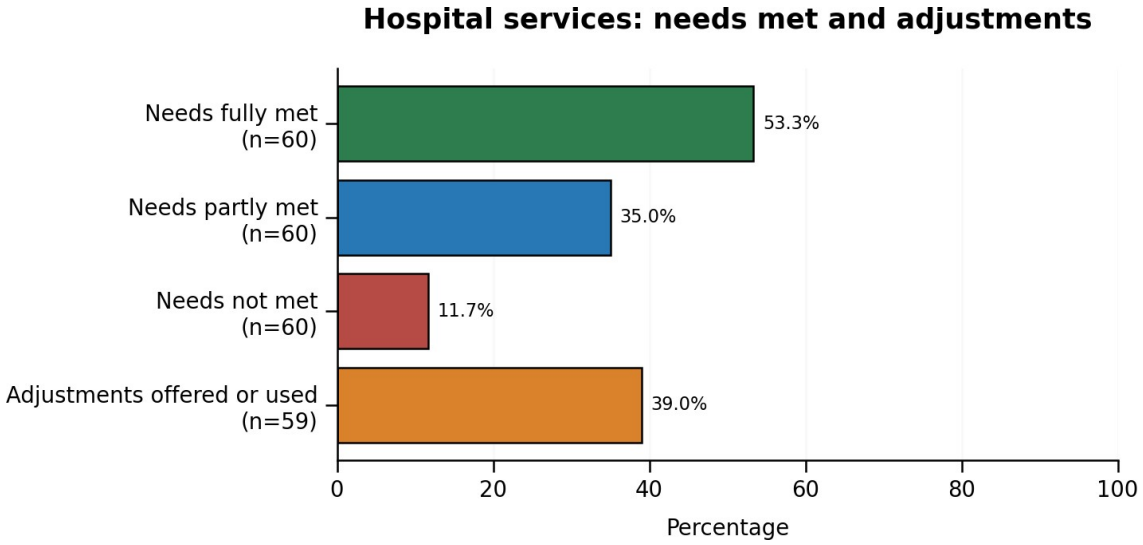
> *"It has taken years to get the support. First did the scope sleep clinic which was great but did not help. Then waited 2 1/2 years to see a pediatrician who wouldn't prescribe melatonin because he was trialing ADHD medication. Then had to move from Right To Choose provider who was prescribing medication to CAMHS to try and get melatonin. Finally after CAMHS saying they only prescribe tablet form did we finally get melatonin in liquid form."*

7.5 Feeding and ARFID-type challenges

Thirty of 145 respondents (20.7%) reported feeding difficulties or ARFID-type challenges, and a further 10 (6.9%) were unsure. Of 39 answering the service follow-up, 21 (53.8%) selected "None". Because this was multi-select, the denominator is those answering the follow-up and service percentages are not mutually exclusive.

The responses point toward a pathway problem rather than an issue for one profession. Dietetics, SALT, OT, paediatrics, mental-health services and education can all be relevant. Families need clear entry points, defined roles and coordination where nutrition, growth, school participation or family functioning are affected.

7.6 Hospital care and reasonable adjustments



Positive overall care and inconsistent adjustments can both be true.

Of 60 respondents whose child had used hospital services, 32 (53.3%) said needs were fully met, 21 (35.0%) partly met and seven (11.7%) not met. Together, 53 of 60 (88.3%) said needs were fully or partly met. This is an important strength. However, only 23 of 59 (39.0%) said reasonable adjustments were offered or used; 29 (49.2%) said no and seven (11.9%) were unsure.

> *“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.”*

The two findings should remain side by side. Families can value the overall care and individual staff while still experiencing avoidable barriers. Proactive adjustments — such as health passports, quieter waiting, communication support, flexible processes and preparation for procedures — would make positive experience more reliable.

What would improve your child’s experience of hospital services:

> *“Appointments running to time. Appointments or services available in the community. Reduced waiting lists.”*

7.7 Therapies and specialist pathways

References to OT, SALT, physiotherapy, orthotics, continence, dentistry and paediatrics appeared throughout the survey and supporting analysis. The survey does not support one overall therapy-access percentage, but it does support a qualitative conclusion: families experienced capacity constraints, hand-offs, unclear thresholds and responsibility gaps across specialist pathways.

> *“I'm trying to get a diagnosis but on waiting list for nearly 2 years”*

7.8 Final health recommendations

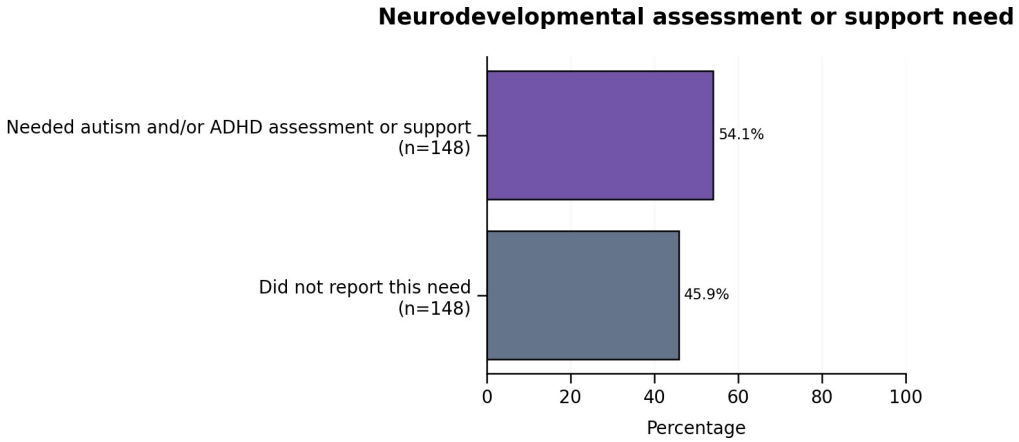
Recommendation	**Family-visible outcome**
Support while waiting	Advice, safety-netting and escalation before assessment
Make referrals visible	Confirmation, status, threshold rationale and next step
Prioritise mental health before crisis	Earlier help and joint work with education
Create a clear sleep offer	Consistent first-line advice and specialist escalation
Coordinate feeding/ARFID support	Defined roles and named coordination
Standardise adjustments	Accessible processes across community and hospital care
Improve specialist pathways	Fewer hand-offs and clearer alternatives
Measure change	Publish access, waiting, interim-support and adjustment measures

8. Neurodevelopmental assessment and support

Need-led help before and after diagnosis

8.1 Assessment or support need in the previous 12 months

Eighty of 148 respondents (54.1%) said their child had needed autism and/or ADHD assessment or support over the previous 12 months.



Base: 148 respondents answering the question.

8.2 The pathway, not only the diagnostic decision

Families wanted shorter waits, but the analysis also identified needs before, during and after assessment. A diagnosis may unlock understanding or services, but children may require adjustments and family support long before a formal outcome. Conversely, receiving a diagnosis without practical post-diagnostic help can leave families with information but little change in daily life.

- Provide need-led interim support before diagnosis.
- Make referral status, thresholds and next steps visible.
- Offer practical family and education support after diagnosis.
- Coordinate neurodevelopment, mental health and education.
- Plan capacity against demand and publish progress.

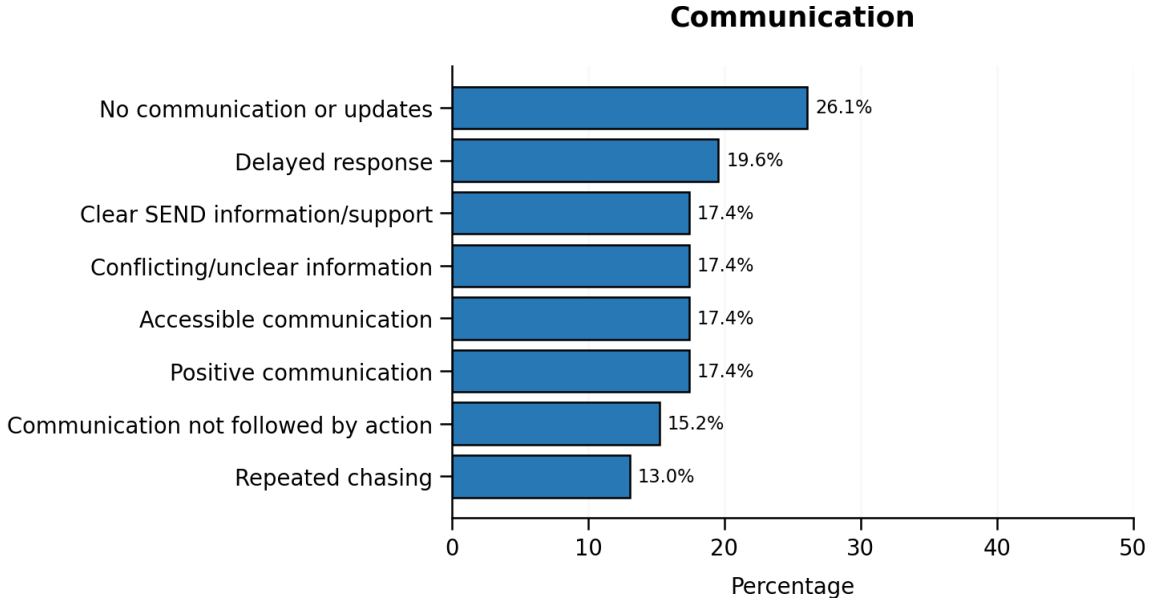
“More proactive support after diagnosis rather than just a report and vague advice.”

9. Communication and navigation

From information-giving to action and accountability

9.1 Communication themes

Communication was both a distinct theme and a mechanism that shaped experience across every chapter.



Themes are non-exclusive; base = 46 analysable comments.

Twelve of 46 analysable comments (26.1%) described no communication or updates; nine (19.6%) described delayed responses. Eight (17.4%) described positive communication. Other comments concerned conflicting information, accessibility, communication not followed by action and repeated chasing.

> “Sensap don’t communicate or respond to emails even after stage 2 complaint asking for ehcp to be updated.”

> “Once your child is put on the SEND register, there is absolutely no communication nor explanation from the school/LEA/council as to what that actually means, involves, what frameworks there is in school regarding paperwork/meetings etc...”

> *“NHS needs to get better at communication - updates regarding waiting lists etc ”*

9.2 The communication chain

The survey supports a more precise account than communication needs to improve. For some families the pathway was: no update → repeated chasing → conflicting or incomplete information → unclear responsibility → no visible action. Each stage created additional work and uncertainty for the family.

> *“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.”*

9.3 What good communication should achieve

- Confirm that a referral or request has been received.
- Explain who owns the next step.
- Give an update even when there is no change.
- Use accessible channels and plain language.
- Explain decisions and thresholds.
- Close the loop by stating what action will happen, by whom and when.

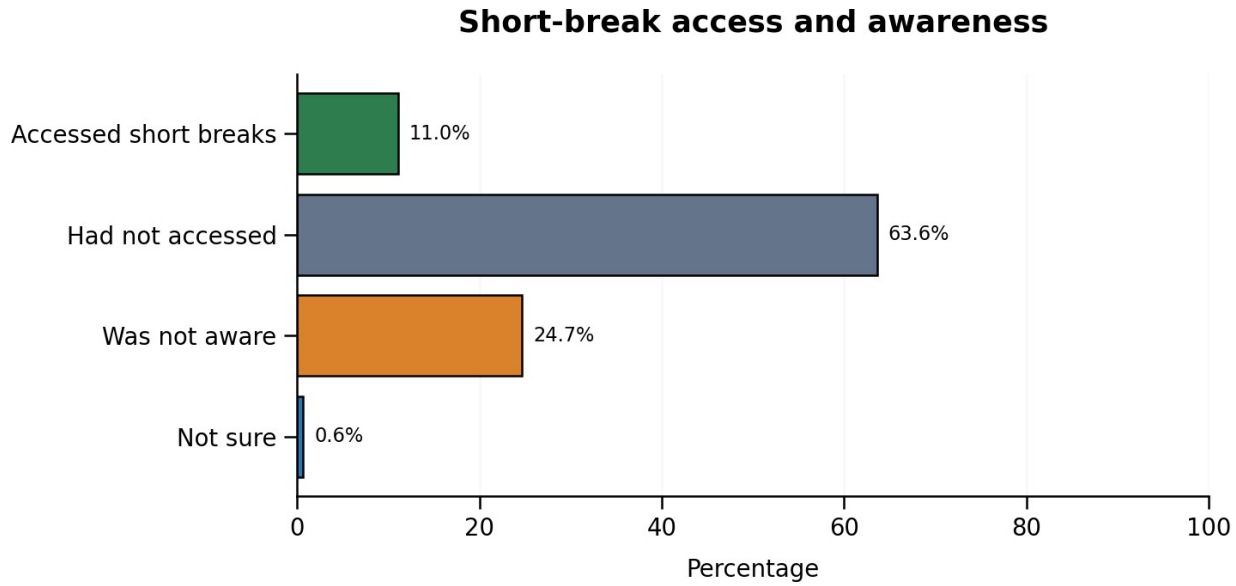
> *“When communication is good, it changes everything. The educational psychologist who listened, validated our concerns and took time to understand [our child] showed what good looks like. It should be the standard, not the exception.”*

10. Short breaks

Awareness is only one part of access

10.1 Short break access and awareness key figures

17 of 154 respondents (11.0%) had accessed short breaks. Thirty-eight of 154 (24.7%) said they were not aware of them.



Base: 154 respondents.

Low use should not be interpreted simply as low demand. The wider comments pointed to awareness, eligibility, availability and suitability. A family may know that short breaks exist but still be unable to access an option acceptable for a child with complex, sensory, communication or behavioural 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."*

> *"For it to be accessible and targeted for physical disabilities and medical needs- tube feeding and wheelchair accessible activities with 1:1 care."*

10.2 Short break priorities

- Explain clearly what short breaks include and how to enquire.

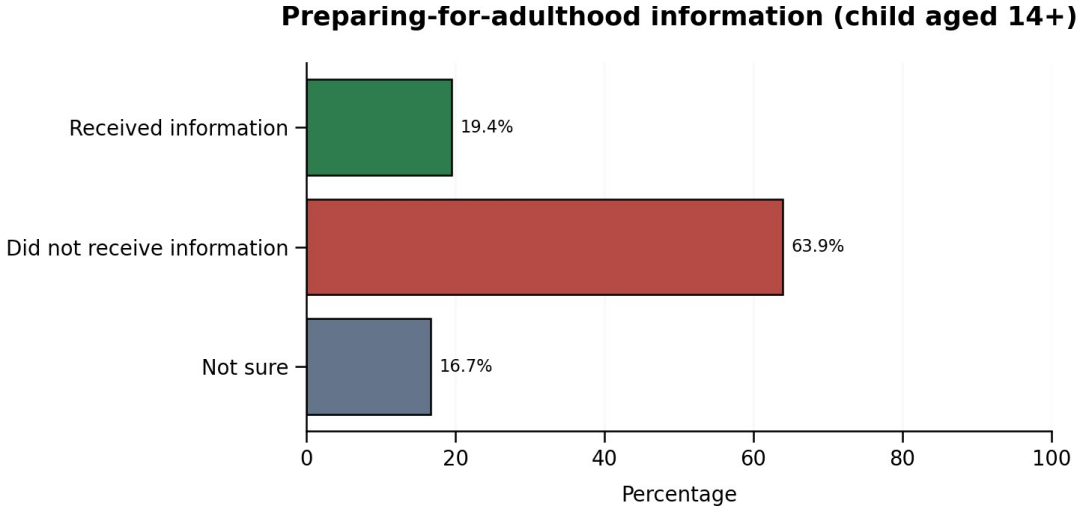
- Promote information through multiple community and professional routes.
- Monitor unmet demand, not only take-up.
- Provide options suitable for a wider range of needs.
- Learn from provision that families describe as reliable and enjoyable.

11. Preparing for adulthood

Earlier, repeated and practical planning

11.1 Preparing for adulthood key figures

Among 36 respondents with a child aged 14 or over, 7 (19.4%) had received preparing-for-adulthood information, 23 (63.9%) had not, and 6 (16.7%) were unsure.



Base: 36 respondents with a child aged 14 or over.

Preparing for adulthood should not be a one-off information event or a late transition conversation. Families need staged, practical planning covering education, employment, benefits, housing, independence, community participation, adult health and social care. The low information reach in this sample suggests the offer needs to start earlier and be repeated.

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

> *“It needs to start way earlier”*

11.2 Administrative context

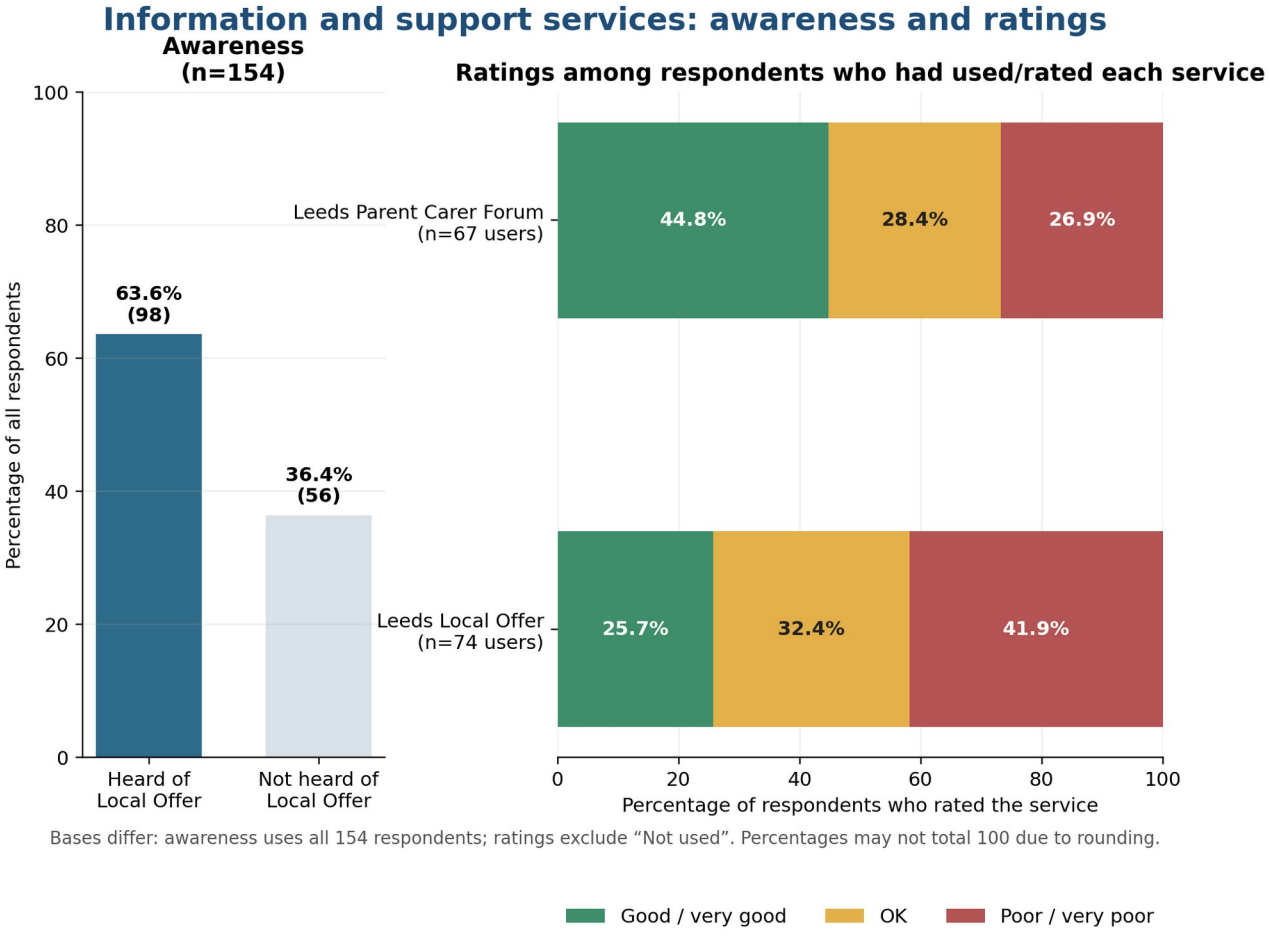
Leeds has a relatively high share of older EHC-plan holders, while further-education and older-age respondents were sparse in the survey. This strengthens the case for a separate 14–25 engagement exercise.

12. Information and support services

Access to information, advice and peer support

Almost two-thirds of respondents had heard of the Leeds Local Offer (98 of 154; 63.6%). Among the 74 respondents who gave a rating rather than selecting “Not used”, 19 (25.7%) rated the Local Offer good or very good, 24 (32.4%) rated it OK and 31 (41.9%) rated it poor or very poor. These results point to a need to improve both awareness and the usefulness, currency and navigability of information.

Among the 67 respondents who rated Leeds Parent Carer Forum rather than selecting “Not used”, 30 (44.8%) rated LPCF good or very good, 19 (28.4%) rated it OK and 18 (26.9%) rated it poor or very poor.



Awareness of the Leeds Local Offer and ratings of the Leeds Local Offer and Leeds Parent Carer Forum. Rating percentages exclude respondents selecting “Not used”.

“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.”

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

The qualitative responses reinforce the mixed ratings. Some families valued information that was practical, available online and linked them directly with services. Others described information as difficult to read, unclear or out of date, and highlighted the importance of sharing material online for families unable to attend events in person.

LPCF will use this feedback as an accountability baseline: retain what families value, examine the reasons for neutral and negative ratings, and report back on resulting changes.

SENDIASS formed part of the wider information and support category within the survey. Some respondents described the value of information that was current, practical and easy to navigate, but the survey did not ask a separate SENDIASS rating question. No service-level satisfaction percentage or separate assessment of SENDIASS should therefore be inferred.

13. Cross-cutting interpretation

What families appear to be telling the partnership as a whole

The deepest value of the survey comes from connecting findings across chapters rather than treating every question separately.

13.1 Support before crisis

Mental-health, sleep, neurodevelopment and health-access findings all point toward the same principle: families need meaningful help while waiting and before needs escalate. Crisis should not become the de facto eligibility threshold.

13.2 Consistency is as important as innovation

Respondents already described examples of excellent practice. The central problem was that it was not reliably available. Improvement therefore requires defining, spreading and monitoring expected practice across settings and pathways.

13.3 Families are carrying coordination work

Repeated chasing, retelling the child’s story and navigating hand-offs transfer system work onto families. For households already managing disability, sleep deprivation, appointments and school difficulties, that administrative burden is itself a source of harm.

13.4 Access must mean usable access

A service may technically exist but remain inaccessible because of thresholds, unsuitable appointments, communication barriers or a lack of reasonable adjustments. Availability and accessibility should therefore be measured separately.

13.5 Voice should lead to visible change

Families do not only want to be asked for views. They want evidence that what they say changes decisions, provision and outcomes. Co-production should be judged by its effect, not by the number of engagement activities undertaken.

14. Relationship with the Area SEND inspection

Using the survey as a family-experience baseline

The survey and inspection used different methods, but they overlap around delays, EHC plan quality, health pathways, communication and family voice. The survey adds detail about how those issues accumulate in everyday family life.

System theme	What the survey adds
Timeliness	The experience of waiting without support or information
EHC plan quality	The gap between written provision and delivery
Communication	The chain from missing updates to missing action
Health pathways	Mental health, sleep, feeding, therapies and adjustments
Family voice	Whether participation changes decisions
Improvement	Whether families feel and see change, not only recorded actions

14.1 LPCF core statement

“The central test of improvement is whether families feel and see change in everyday practice, provision and outcomes — not only

whether problems are acknowledged or actions recorded as complete.”

15. Final recommendations

A practical agenda for family-visible improvement

The recommendations below draw together the quantitative findings, thematic coding and cross-cutting interpretation. They are framed around what families should experience differently.

	Priority	**Action**	**What families should notice**
1	Communication	Minimum update standards and named contacts	Less chasing and uncertainty
2	Waiting	Interim support, safety-netting and escalation	Help before appointment or crisis
3	EHCPs	Quality assurance plus delivery tracking	Plans that are current and implemented
4	Mental health	Earlier support and joint work with education	Fewer crises and prolonged absence
5	Sleep	Visible first-line and specialist pathway	More families accessing appropriate help
6	Feeding/ARFID	Coordinated multidisciplinary pathway	Clear entry point and ownership
7	Adjustments	Standard anticipatory reasonable adjustments	Services that are usable
8	Neurodevelopment	Need-led pre- and post-diagnostic support	Help not dependent on diagnosis alone

	Priority	Action	What families should notice
9	Short breaks	Awareness, suitability and unmet-demand monitoring	More accessible respite options
10	Adulthood	Earlier, repeated practical planning	Families better prepared for transition
11	Accountability	Publish owners, timescales and outcome measures	Visible follow-through
12	Co-production	Show how feedback changed practice	Trust that voice has impact

16. Monitoring change in 2027

Keeping comparable questions and reporting direction of travel

The next LPCF annual survey, to be conducted in May 2027, will retain core wording and denominator rules so LPCF can report whether families' experiences are improving. New questions will be added, but the baseline measures will not be lost.

16.1 Measuring the 2027 direction of improvement

2026 baseline	2027 direction of improvement
42/57 unable to access needed mental-health support	Lower proportion
61/80 had not accessed sleep support	Lower proportion and better pathway awareness
21/39 selected no feeding/ARFID support	More coordinated support
23/59 reported hospital adjustments	Higher and more consistent adjustment rate
24/68 health-access comments mentioned long waits	Fewer long and unsupported waits
12/46 communication comments mentioned no updates	Fewer missing updates and more positive experiences
16/58 EHCP comments mentioned missing provision	Fewer gaps and stronger delivery evidence
38/154 were unaware of short breaks	Improved awareness

2026 baseline	2027 direction of improvement
7/36 aged 14+ had received adulthood information	Improved information reach

16.2 Monitoring and accountability 2027

Theme	2026 baseline	2027 direction	Proposed owner/data source	Reporting point
Mental health	42/57 unable to access needed support	Lower proportion	Health partnership / repeat LPCF survey	After May 2027 survey
Sleep	61/80 had not accessed support	Lower proportion	Health partnership / repeat LPCF survey	After May 2027 survey
EHCP delivery	16/58 comments identified missing provision	Lower theme frequency; delivery evidence improves	Local authority / LPCF coding	Annual report
Communication	12/46 comments described no updates	Fewer no-update comments; more positive experience	SEND partnership / LPCF coding	Annual report
Short breaks	38/154 unaware	Higher awareness	Local authority / repeat LPCF survey	After May 2027 survey
Preparing for adulthood	7/36 received information	Higher information reach	Local authority and partners / repeat LPCF survey	After May 2027 survey