

Summary of the Parent Carer Voice Herefordshire Annual Survey Autumn 2024



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1. Executive Summary

The PCV 2024 Annual Survey for parent carers in Herefordshire was co-produced with PCV Herefordshire, Herefordshire Council and Herefordshire and Worcestershire Integrated Care System. The purpose of the survey was to gain an overview of the experiences of SEND (special educational needs and disabilities) for families in Herefordshire who have a child with any disability or additional need (aged 0-25 years). The survey was live from 14th October 2024 until 30th December 2024 and 124 responses were received which is a decrease from the 166 responses received for the same survey in 2023. The survey was shared widely through multiple social media channels, via educational settings, by practitioners working directly with families and at in person PCV events.

During the time that the PCV 2024 Annual Survey was live, Herefordshire Local Area SEND Partnership was inspected by Ofsted and CQC, who also ran a wide-ranging survey of parents and carers of children and young people with SEND. Parent carer respondent numbers for the Ofsted / CQC survey were much greater than for the PCV 2024 Annual Survey (approximately 500 responses) and this may have had an impact on the engagement of parent carers with the PCV survey, with some respondents commenting that they were “all surveyed out”.

This report provides an overview the experiences of parent carers of the education, health, and social services support available to children and young people with Special Educational Needs and Disabilities (SEND) in Herefordshire. The aim is to assess the current provisions, identify areas for improvement, and recommend strategies for enhancing support across these key sectors.

Education:

Herefordshire offers a range of educational provisions tailored to the needs of children with SEND. Mainstream schools provide differentiated support and interventions, while special schools and alternative provisions offer more specialist support. However, parent carers believe that challenges persist in ensuring consistent access to specialised services, particularly for those with more complex needs. There is also a need for more comprehensive staff training and resources to support inclusive education across all settings.

Health:

Health services for children and young people with SEND in Herefordshire are provided through a collaborative approach between the NHS, local authorities, and voluntary organisations. The provision includes speech and language therapy, occupational therapy, and mental health services. However, parent carers feel that delays in access to some services and limited coordination between healthcare providers remain areas for improvement. There is also a growing need to address mental health concerns within this group, given the increased prevalence of anxiety, depression, and other conditions among children and young people with SEND and the apparent lack of capacity within the CAMHS service.

Social Services:

Social services play a crucial role in supporting families and young people with SEND, offering early intervention, safeguarding, and family support services. However, parent carers believe that there is a need for more robust support for transitions from childhood to adulthood, particularly in terms of independent living, employment opportunities, and long-term care. The integration of social services with education and health providers requires further strengthening to create a seamless experience for families.

2. Background and Objectives

PCV Herefordshire are the recognised parent carer forum in Herefordshire and work as a strategic partner with the Herefordshire SEND Partnership, which includes Herefordshire Council and Herefordshire and Worcestershire Integrated Care Board.

Every year, PCV Herefordshire produce a survey for parent carers of children and young people with SEND. The annual survey includes questions about core health, social care and education services. The information received within the responses is used to inform future service delivery and help to identify what is important to families of children and young people with SEND.

The annual survey is an opportunity for families to share their experiences and influence the design of future service delivery in response feedback received. All responses are included in the reporting which is shared with all stakeholders of the Herefordshire SEND Partnership. The report is shared publicly and forms part of the You Said, We Did process which tracks how parent carers have influenced services for children and young people with SEND. You can find out more about this on the [PCV Herefordshire website](#).

Questions in the survey were categorised into 6 sections:

- About You (Parent / Carer)
- About Your Child / Young Person
- About Your Child / Young Person's Childcare / Educational Provision
- Health and Social Care
- Home and Family Life
- Service Improvement

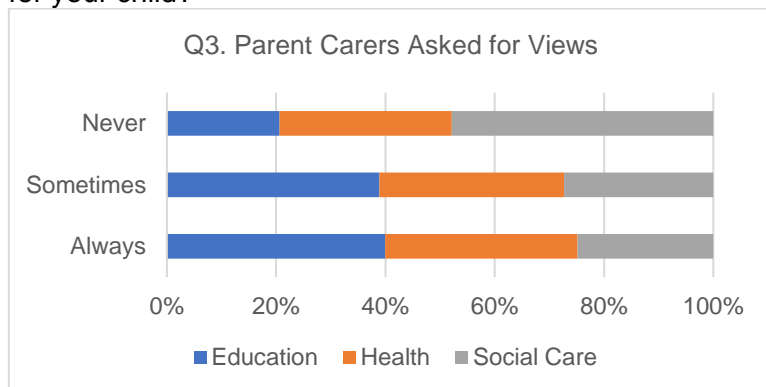
3. Results

Not all respondents answered every question in the survey where it was not applicable to them or their child / young person. Where not all 124 respondents answered, the percentage and number of respondents are recorded for each question. This needs to be taken into account where there are small numbers of responses in terms of its weighting of percentage based questions.

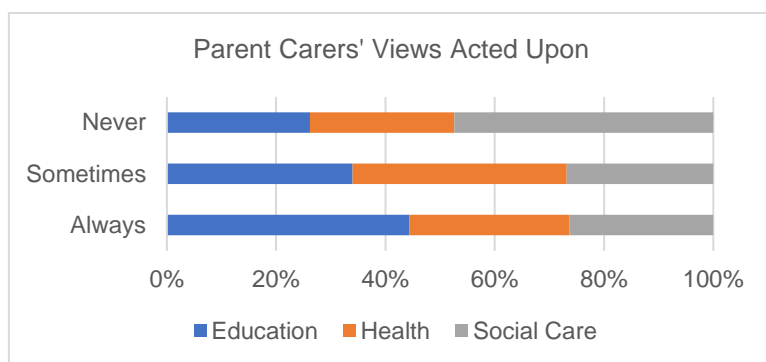
About You (Parent / Carer)

Most respondents were female (94%) with the remaining respondents identifying as male (Q1). When asked if, as parent carers, they were asked for their views about the support required for their child / young person, there were mixed responses for Education, Health and Social Care, with the majority only being asked, and those views only being acted upon by practitioners / professionals, 'sometimes'.

Q3. Have you been asked for your views by practitioners / professionals to get the right support for your child?

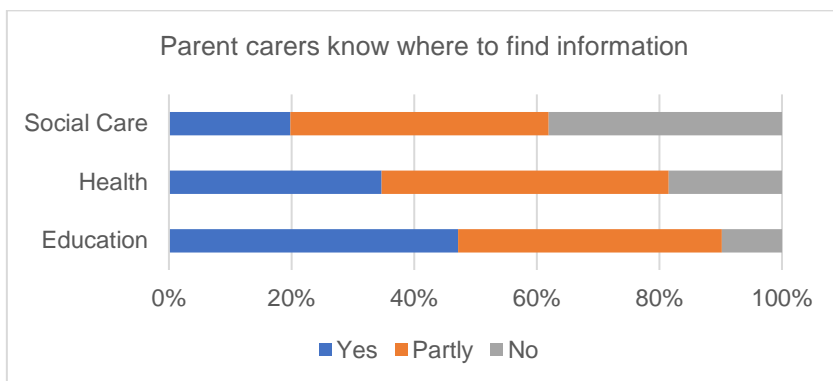


Q4. Were your views acted upon by practitioners / professionals?



When parent carers were asked whether they knew where to get information and support for concerns about their child / young person's Education, Health or Social Care, parent carers showed greater confidence in finding information about their child / young person's educational needs than their health or social care needs.

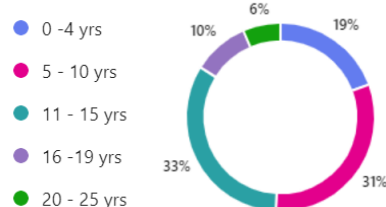
Q5. Do you know where to get information and/or support if you have concerns about your child / young person's education, health or social care needs?



55% of respondents had visited the SEND Local Offer website, 15% weren't sure if they had visited and 40% had never visited it (Q6). 47% of respondents gave a rating scale to the SEND Local Offer website, with the average rating of the site overall at 5.2 / 10 (Q7).

About Your Child / Young Person

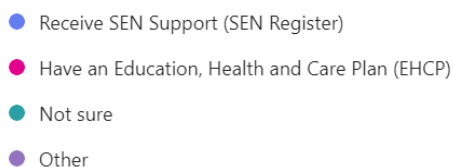
The majority of respondents were completing the survey about compulsory school-aged children (64%) with the next largest group of respondents having a child of early years age (10%) (Q8).



18% of respondents confirmed that their child or young person was eligible for Free School Meals (FSM), 66% were not eligible and the remaining 16% were not sure (Q10).

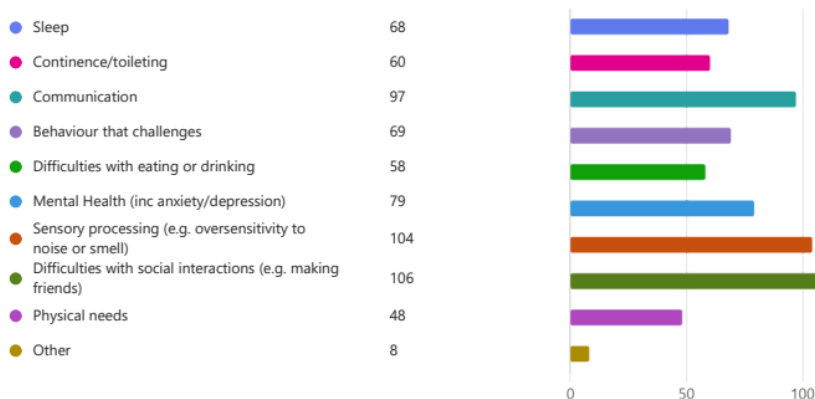
**99% (123) respondents answered this question*

Most respondents had a child / young person with an Education, Health and Care Plan (EHCP) (64%), 21% were receiving SEN support and the remainder either weren't sure or cited 'other' support was being provided such as being on the school's 'monitoring' list or being home educated (Q9).



**97.5% (121) respondents answered this question*

Q11. When asked which difficulties their child / young person was affected by, the respondents mostly cited social interactions as the primary difficulty, followed by sensory processing and communication difficulties. Many of the respondents' children / young people had difficulties with mental health and/or behaviour that challenges which was similar in number to those who had difficulties with sleep.



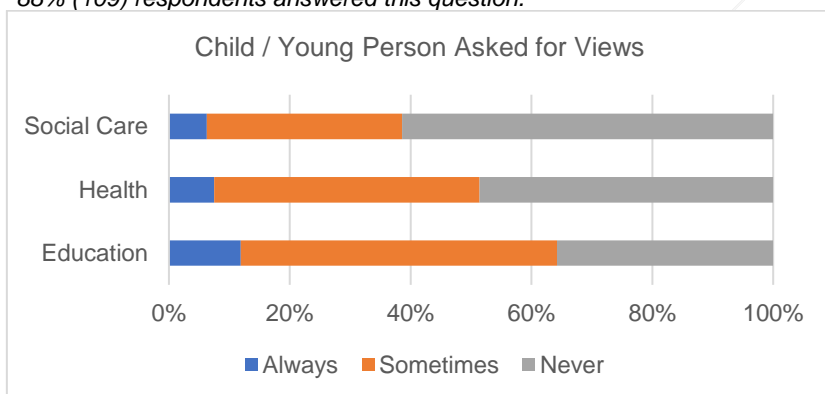
When respondents started to have concerns about their child's development, the majority initially raised this with their early years setting (27%) or their health visitor (24%). The remainder said that they discussed concerns with their GP (20%), school / educational setting (20%), a family support worker (2%) or cited 'other', which included the hospital, paediatrician or healthcare professionals who were involved from birth (Q12).

*97.5% (121) respondents answered this question

About Your Child / Young Person's Childcare / Educational Provision

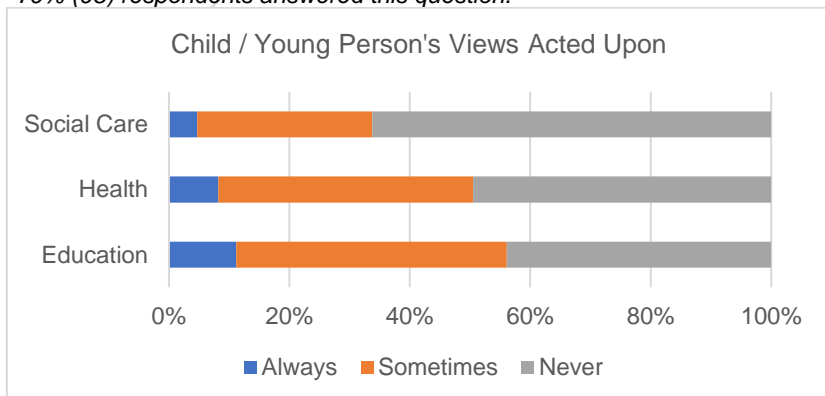
Q13. Respondents were asked whether their child / young person had been asked for their views by practitioners / professionals to get the right support.

*88% (109) respondents answered this question.



Q14. And as a follow up, respondents were asked whether their child / young person's views were acted upon by practitioners / professionals.

*79% (98) respondents answered this question.



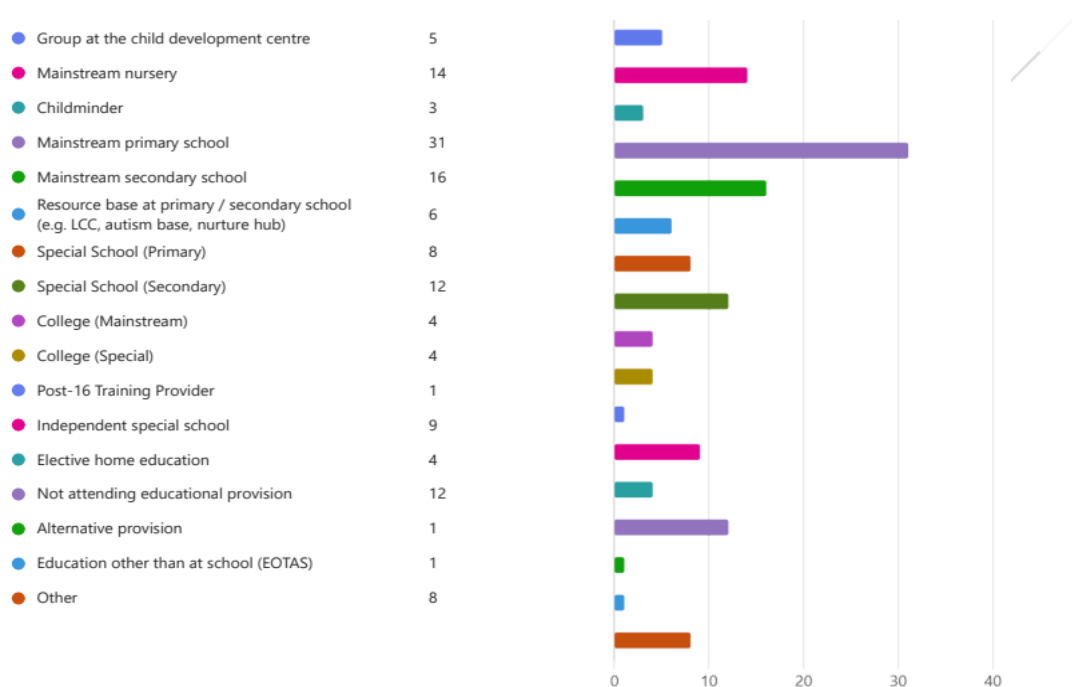
Q15. Just under 60% of the respondents had sought **paid childcare** for their child / young person (not including Short Breaks) and of those, 47% found it extremely difficult to source and 25% found it difficult. The remaining respondents had not experienced difficulties sourcing paid childcare when they looked for it.

**99% (123) respondents answered this question*

Those that were using or had used paid childcare sourced it from a range of services including private nurseries, childminders, school clubs, forest school etc (Q16).

**22% (27) respondents answered this question*

Q17. 22% of the respondents had a child / young person who attend a mainstream primary school, 12% attended a mainstream secondary school and 10% attended mainstream nursery. The remainder (56%) attended a range of educational provisions with 4% attending more than one provision.



Q18. When asked if the educational provision is meeting their child / young person's needs, 40% agreed that it was, 34% felt it was only partly meeting needs and 17% felt it wasn't meeting their needs at all.

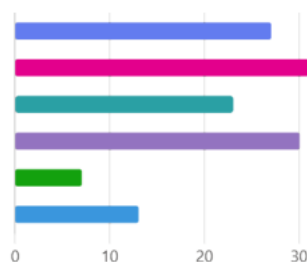


Q19. For those respondents who felt the provision only partly met needs or is not meeting needs at all, the main reason cited was a lack of appropriate training for staff (24%), a general lack of support available (23%), a more detailed assessment of needs was required (21%), the setting is not providing everything in the EHCP (18%) or the EHCP is out of date (5%). Other reasons cited

included not enough funding provided, lack of information sharing and delays in receiving an EHCP.

*51% (63) respondents answered this question

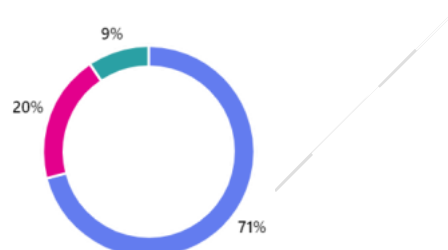
More detailed assessment of my child/young person's needs is required	27
Staff do not have appropriate training	31
The educational provision is not providing everything in their EHCP	23
There is a lack of support staff available	30
The EHCP is out of date	7
Other	13



Q20. 71% of respondents confirmed that their child / young person was receiving a full-time education, 20% were on a part-time timetable and 9% were not in education full time with their parent / carers consent.

*94% (120) respondents answered this question

Yes	83
No - they are on a part-time timetable	23
No - with my consent	11

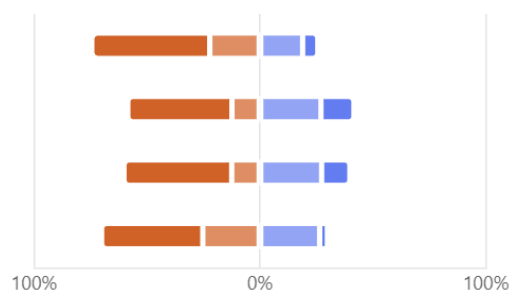


Q21. Where the respondent's child / young person had an EHCP they were asked about the support being provided and whether it was provided and sufficient, provided but insufficient, needed but not provided or not needed.

*72.5% (90) respondents answered this question.

Provided and sufficient Provided but insufficient Needed but not provided Not needed

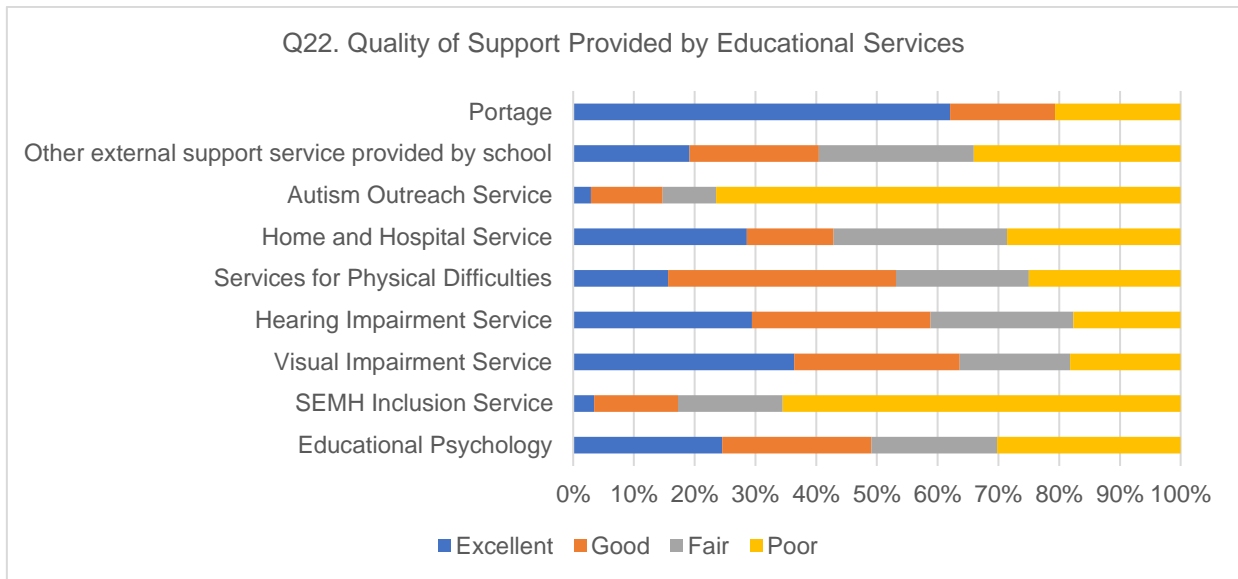
Support in the classroom
 Support at lunchtime/breaktime
 Support to go on school trips
 Pastoral / wellbeing support



- Support in the classroom was provided and sufficient for 52% of respondents' children / young people. For 22.2%, support in the classroom was provided but insufficient. 18.9% of respondents' children / young people needed support in the classroom but it was not provided.
- Lunchtime and breaktime support was provided and sufficient for 46.1% of respondents' children / young people. For 12.4% of respondents, support was provided but insufficient. 27% of respondents' children / young people needed support at lunchtime and breaktime but it was not provided.
- Support to go on school trips was provided and sufficient for 47.7% of respondents' children / young people. For 12.5% of respondents, support was provided but insufficient. 27.3% of respondents' children / young people needed support to go on school trips but it was not provided.
- Pastoral and wellbeing support was provided and sufficient for 44.8% of respondents' children / young people. It was provided but insufficient for 25.3% and needed but not provided for 26.4% of respondents' children / young people.

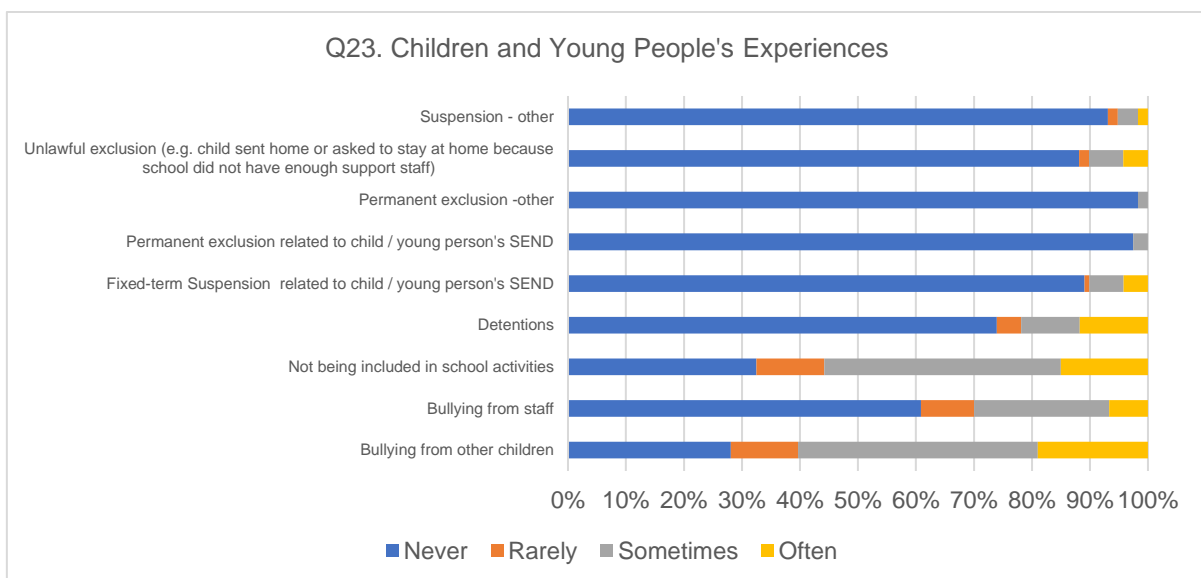
Q22. Respondents who had used educational support services in the past 2 years were asked to rate the quality of support. Not all respondents had used each service listed so the number of responses for each rating is illustrated within the graph. Where the service had been used, respondents were asked to rate the quality as excellent, good, fair or poor. Respondents only rated those services they had used.

**91% (113) respondents answered this question*



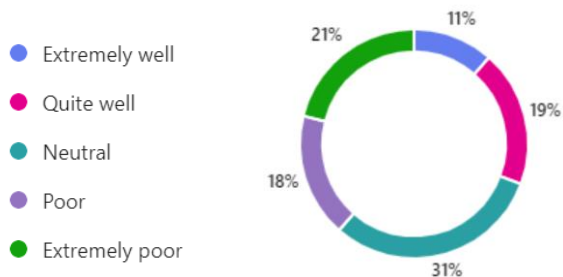
Q23. Respondents were asked about their child or young person's experiences of bullying, inclusion and suspensions / exclusions.

**97.5% (121) respondents answered this question*

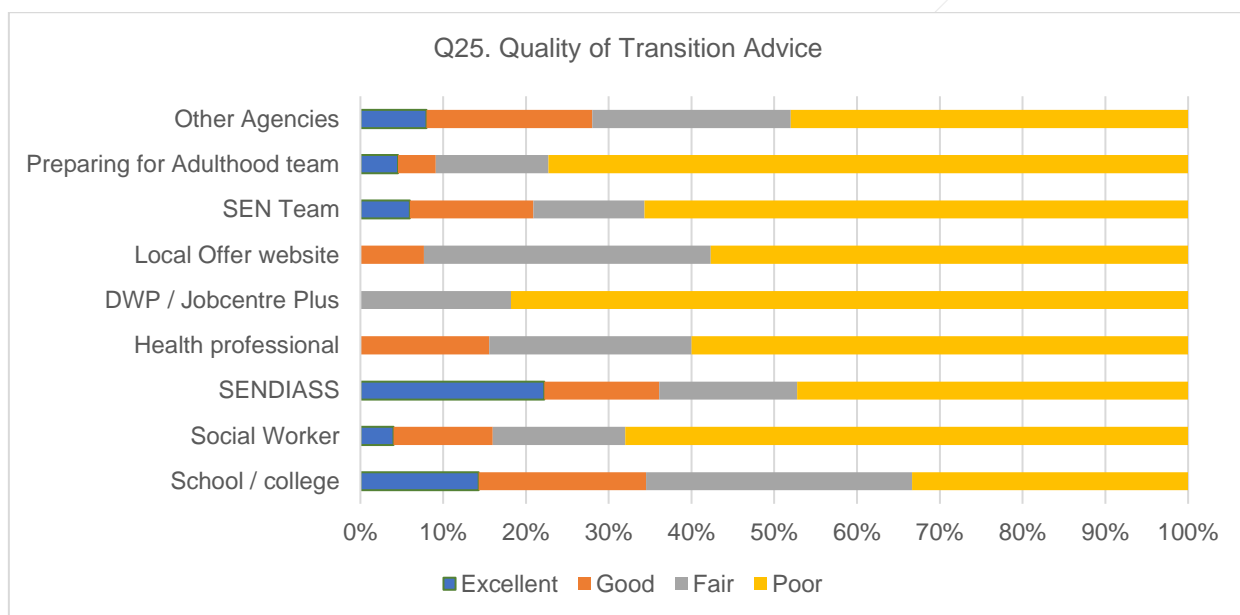


Q24. In relation to transition / moving on from one setting to another e.g. nursery to primary school, secondary to post-16, respondents were asked how well their child / young person was prepared for this change. 30% felt their child / young person was extremely or quite well prepared

for this transition, 31% were neutral and 39% felt their child / young person's transition preparation was poor or extremely poor.
 92% (114) respondents answered this question

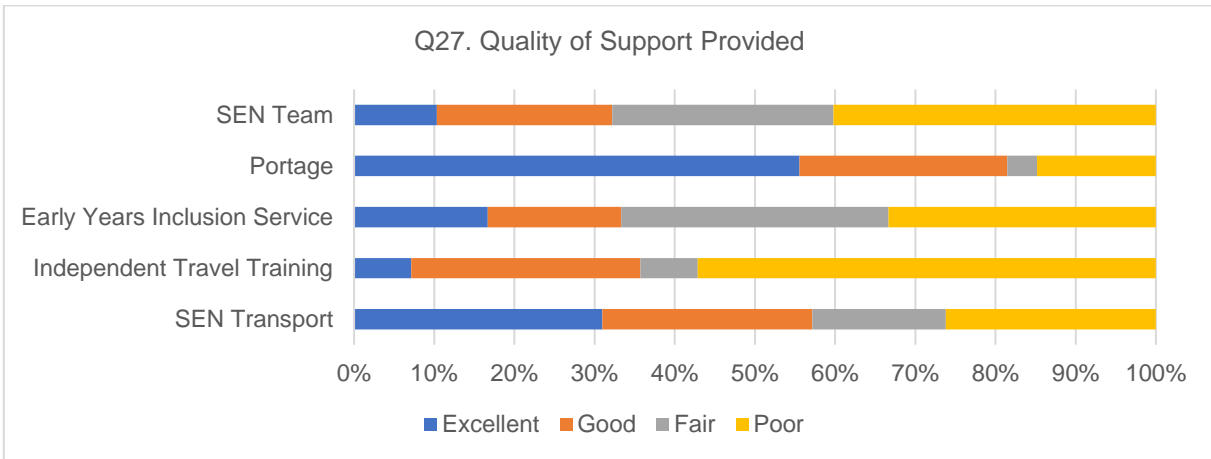


Q25. Where information, advice and support were given by different services and organisations regarding transition, respondents were asked to rate the quality. Respondents only rated those services they had used.
 94% (117) respondents answered this question



Q26. Additional comments received from respondents in response to this question were mixed, with many experiencing good support from services and others receiving little to no support. Some primary schools had prepared the children well for transition, but this wasn't followed through in the receiving secondary school. Other respondents experienced very good support from their receiving school / educational setting. See Appendix 1 for full comments.
 56% (70) respondents answered this question

Q27. Where respondents had used the services below, they were asked to rate the quality of the support provided. Not all respondents had used every service so only rated those services they had used.
 97% (120) respondents answered this question



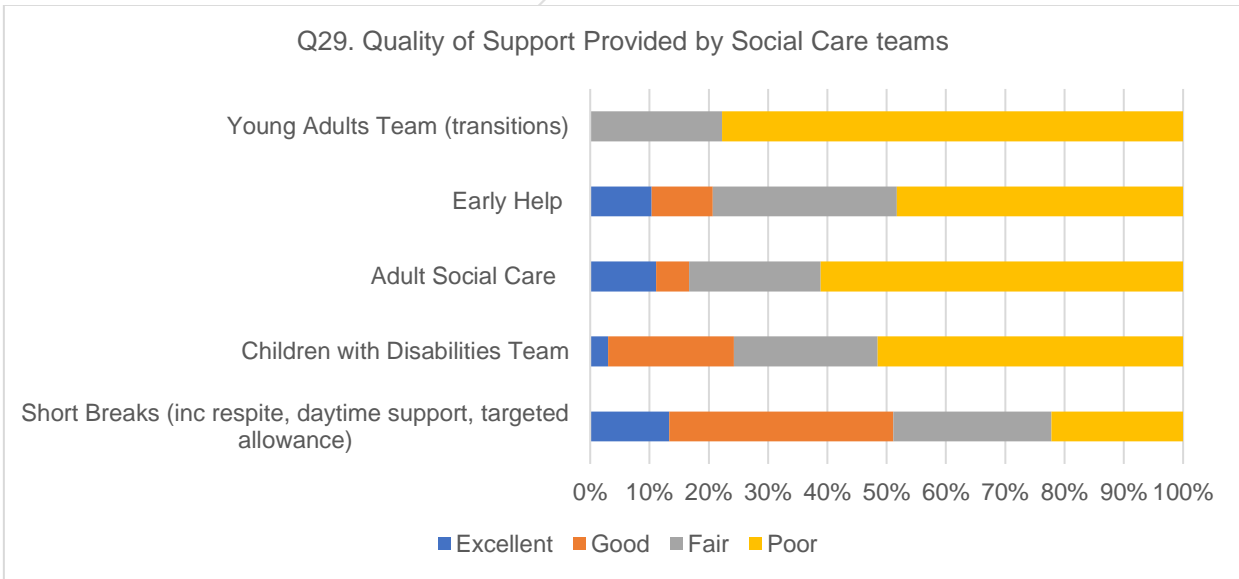
Q28. Additional comments received from respondents in relation to their experiences of the service above were mixed. Many respondents felt their child / young person struggled until they were moved to a new placement but that their child / young person is now thriving. Some referenced long waiting lists for assessments, others referred to poor response times from some teams and having to frequently chase for updates. Some respondents commented on how hard their educational settings have tried to support their child or young person and that it is lack of funding that causes more difficulty. See Appendix 1 for full comments.

40% (50) respondents answered this question

Health and Social Care

Q29. Where applicable to their child / young person, respondents were asked to rate the support received from different social care teams / services. Respondents only rated those services they had used.

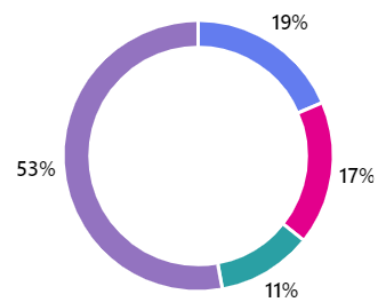
49% (61) respondents answered this question



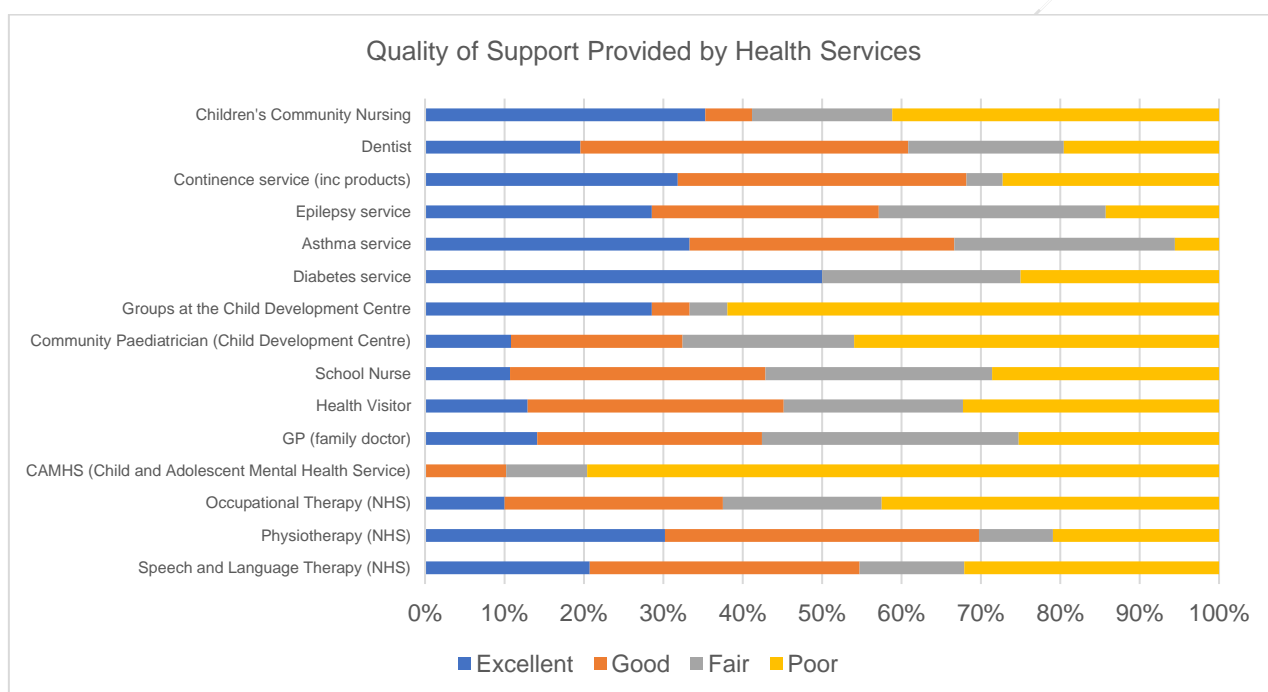
Q30. Where the respondents' family have a social care package, they were asked how they feel about the level of support it provides in terms of meeting their needs.

56% (70) respondents answered this question

- I am happy with the level of support we receive 13
- I just about manage with our current package of support 12
- I am happy with the package but provision is not available 8
- I don't feel our package is enough to meet our needs 37

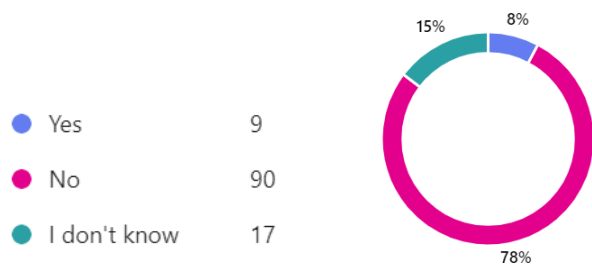


Q31. Where children / young people have used a health service listed below in the last two years, they were asked to rate the quality of support provided. Respondents only rated those services they had used. Respondents only rated those services they had used.
 94% (117) respondents answered this question

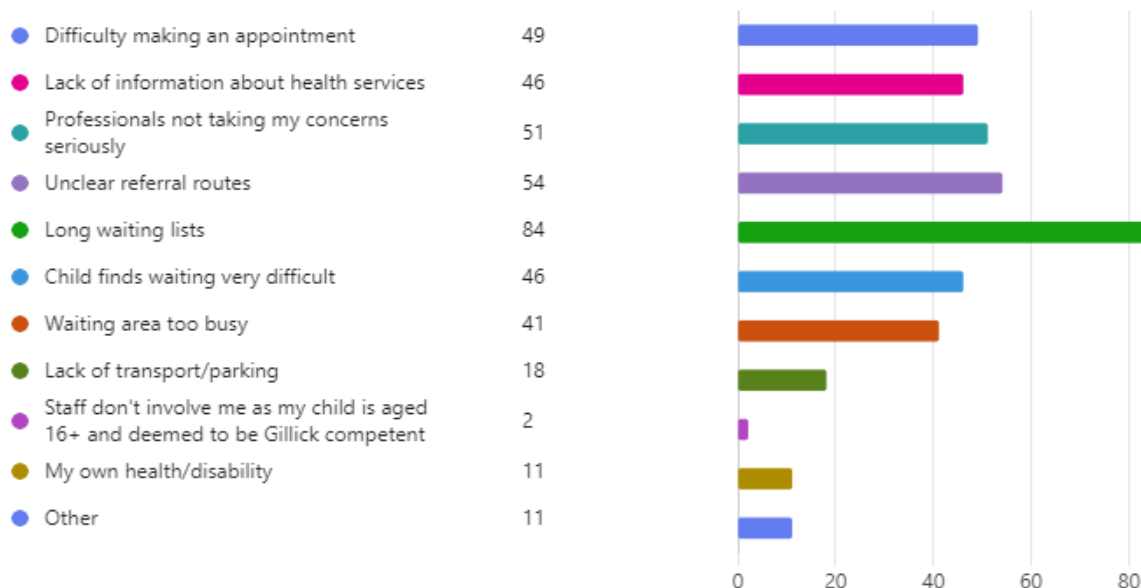


Respondents were invited to comment on any other community, hospital health service or health assessments they had accessed in the previous two years (Q32). Many cited long waiting lists, particularly for autism assessments and therapy services. Others commented on a lack of access to mental health services, particularly CAMHS. The CDC team and Health Visitors received positive comments. Some families were paying privately for services such as counselling, speech and language therapy and psychiatrists. See Appendix 1 for full comments.

Q33. When attending health appointments, respondents were asked if their child / young person has a Hospital Passport or One Page Profile.
 93.5% (116) respondents answered this question



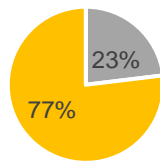
Q34. Respondents were asked if anything makes it difficult to access health services.
83% (103) respondents answered this question



Q35. Where respondents selected 'other' they cited difficulties including their young person being too anxious to attend, a lack of changing places toilets at medical appointments, problems with parking and not being allowed to take younger siblings to appointments. See Appendix 1 for full comments.
10% (12) respondents answered this question

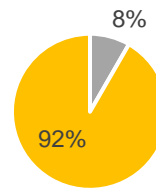
Q36. Respondents were asked about their experience of transition from children's to adults' Health and Social Care services. Those respondents whose child / young person had transitioned from one service to another rated their experience.
10.4% (13) respondents answered this question

Transition to adult social care



■ Excellent ■ Good ■ Fair ■ Poor

Transition to adult health services

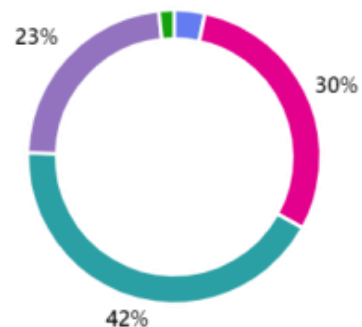


■ Excellent ■ Good ■ Fair ■ Poor

Q37. Respondents were asked whether, overall, they felt their child / young person's health needs were being met by health professionals / practitioners.

95% (118) respondents answered this question

● Yes, all of the time	4
● Yes, most of the time	35
● Some of the time	50
● Not at all	27
● Other	2



Q38. 33 respondents (27%) added further comments about their child / young person's health needs being met, including references to a lack of mental health support, particularly from CAMHS, and a lack of multi-agency assessments of children and young people with complex needs / interrelated difficulties. Refer to Appendix 1 for full comments.

Home and Family Life

Q39. Respondents were asked if they would like to share what they find most difficult about caring for a child or young person with SEND at the moment. Many cited behaviour that challenges, their ongoing battle with services in order to receive the right support, exhaustion from caring responsibilities and the financial impact. Full responses are included in Appendix 1.

80% (100) respondents answered this question

Q40. Respondents were asked if any training or workshops would help them with their caring role. Several respondents mentioned support around autism, some would like advice around transition / preparing for adulthood and others suggested it is the professionals that need more training. Full responses are included in Appendix 1.

51% (63) respondents answered this question

Q41. A small number of respondents (10%) are caring for someone over 25 in addition to their child / young person with SEND.

Service Improvement

Q42. Respondents were asked to share examples of things that **have** worked well for their child / young person and/or family in the last 12 months including educational services, leisure providers, health services, social care etc. Several respondents had positive experiences with

horse riding, the Portage team, their child's nursery, Halo Leisure and others – full comments are included in Appendix 1.

52% (64) respondents answered this question

Q43. Respondents were asked to share examples of things that have **not** worked as well for their child / young person and/or family in the last 12 months including educational services, leisure providers, health services, social care etc. CAMHS was mentioned by several respondents, as well as long waiting times for a range of services and a lack of appropriate support in educational settings. Full comments are included in Appendix 1.

54% (67) respondents answered this question

Q44. Respondents were invited to recommend what the top priority should be for improvement for SEND in Herefordshire. Several respondents said reducing waiting times for services should be a priority, along with improving the SEN Team by investing in additional staff and training. Several respondents also wanted to see parents and carers being listened to more and more parent / carer involvement and partnership working. Full comments are included in Appendix 1.

67% (83) respondents answered this question

4. Conclusion and Recommendations

In conclusion, the views gathered from parent carers regarding Special Educational Needs and Disabilities (SEND) services in Herefordshire reveal both areas of strength and opportunities for improvement. While many parents expressed satisfaction with the support provided, several key issues were raised, including the need for better communication, more timely assessments, and increased access to resources. Improvements are necessary to ensure that children with SEND and their families receive the full support they require.

The feedback from parents should serve as a valuable tool for shaping future policy and service delivery, ultimately working towards a more inclusive and responsive system in Herefordshire. It is crucial that these voices continue to be heard as part of the ongoing efforts to improve SEND services in the region.

The SEND support system in Herefordshire, while providing essential services, faces challenges related to accessibility, coordination, and resources. Key recommendations include:

1. Enhancing partnership working between education, health, and social services to improve the holistic support for SEND children and young people.
2. Expanding specialised training for educators and service providers to ensure more inclusive environments.
3. Addressing delays and improving access to health services, particularly in areas such as mental health and certain therapies.
4. Strengthening support for transitions into adulthood, focusing on independent living and employment opportunities.

By addressing these gaps, Herefordshire can further enhance its support for children and young people with SEND, ensuring better outcomes for this vulnerable group.

5. Appendix 1

Where comments were received from respondents for open text questions, they have been collated below. The comments below have been anonymised where they included reference to a

specific educational setting or provider, a child's / professional / practitioner's name, or any other information that would lead to a child or adult being identifiable.

Q26. Respondents' comments on the transition support received for their child / young person.

All set from school and some info from my support worker I've had to find it all out myself with no help from others.
Although the primary school provided my son's secondary school with all the relevant information they had, including sensory processing issues and learning difficulties, nothing was automatically put in place for his transition to secondary school. The primary school talked to the children a lot about the transition, but there was no support provided in the new setting everything that is now in place has had to be fought for and there is still little support in place for his dyslexia.
Always told that we don't have any to add from school as they don't see any kind of behaviour. But is always sent home when the Behaviour has escalated
Basic inductions completed
Because my child was not following the typical pattern for the county we received absolutely no support whatsoever from anyone at all, not from the original school, county, services and PCV included in transition
Child has only just started nursery
Child not in school due to EBSA. Delay in section 19 being actioned. Request for needs assessment declined as child not able to attend school due 'evidence' despite child having trauma around school due to continued unmet needs.
Extra transition days given.
Group at child development centre was crucial in support for moving into school from nursery
Has had no education since 14 years old as struggling in high school, we removed her, offered no other help, she is now 21. Social services will not help as they say she has no learning difficulties. Council removed her EHCP as she was not receiving any education so they said the plan was not needed.
He was gradually transitioned over to secondary school over a 6 week period and kept the same teacher he had in yr 6
I do not feel enough information or support was given.
I EHE my SEND child so all of his needs are met at home. If any support is needed we seek it from our GP who has taken the time to grow a good relationship with my child. We have received little to no support from anyone els
I feel more could be done to support transition for SEN and families to provide better support.
I had to request information that wasn't provided.
I have not heard from SEN team in the whole years my son has had a EHCP 7yrs
I was involved the whole time and my opinion was concerned. Also the primary school is attached to the secondary so it was a familiar environment.

In date EHCP my child's fully time 1-1 has been changed twice we had a first Sen EHCP meeting to be told that they may not be able to meet his needs and we may need to start looking a SEN school

It's the amount of time taken to contact them or have answers back specially the local authority - i have a better experience with other Agencies .

Moving to a specialist setting in another local authority was daunting. Not enough communication with the new school was had and the first year was extremely stressful. However, the school has improved so much and is now much more supportive. I don't think there's been enough oversight out out of county placement by Herefordshire and there wasn't anyone from the SEN team at the annual review. Things were not in place quick enough and there was difficulty accessing allied health which resulted in 9 months with no SALT/OT etc.

My child attended the nursery at his primary school. There were many opportunities to meet the staff and visit the classrooms before transitioning from nursery to Reception.

My child hasn't had any transitions from nursery to school or school to school since being placed on the SEN register

My child is stuck in the middle and is missing education he needs his EHCP completed in order for him to go back into a school Full time. I am Being blamed for my children missing education. When we are (myself and my children) ready and waiting for the correct provision.

My child was given no support at all. I had to contact the school and put it all in place for when she started.

My child wishes to go to *Educational Setting* next September I would appreciate more input into this transition from secondary education to college education

My daughter feels like she hasn't/still doesn't get the support she needs and is really struggling. School don't seem to care and don't check on her enough

My daughter is at extreme risk of daily self harm and suicidal thoughts and despite this social services have not offered any support and closed the case as she does not meet the criteria she has never been supported until she started attending her new special school in *County* the whole process in Hereford has been abismal from schools social workers camhs hospitals medical professionals wvery where in this county have failed and ate continuing to fail her

N/a

Nine was given it was during covid

No support at all. No where for my child to go

No support was given from both schools

No support was offered anywhere

Nobody in hereford social services or in the mainstream schools cares about SEN children. For the schools they are cash cows. The funding is not visible.

Noone knows what each other is doing or you get sent round in circles.

Not applicable

Not enough support from CAMHS and CDC - my child desperately needs further help & assessments but waiting lists are so long, meaning we are going without much needed support and awareness of my child's difficulties

Not reached transition phase yet as still at nursery.

Paediatrician dropped him without reason or explanation, camhs are useless and dropped him despite him still having significant need based on one very biased teacher, *Educational Setting* actively tried to interfere and obstruct transition because they didn't like that he was going to a different school than the rest of his cohort. *Educational Setting* are a disgrace they would not even let him speak about his new school let alone support him, they have cause trauma we will spend years rectifying

Placed in school prior to transitional age due to knowing he would cope and the school is 7 to 18yrs

Poor communication from SEN team

Portage stepped out way to early, was left with no support with funding

Primary school did not handle her anxiety well - claimed NVR training told them to just ignore the anxiety and push through, so the secondary school did not really know her needs until we had a long meeting with the secondary SENCO. Initial SEN taster day with secondary school focussed too much on the rules and punishments, which scared our daughter. On the plus side, there were several taster days arranged, and the SENCO at secondary was aware that she had some support needs before we arrived.

Primary school did not provide enough transition support, he was thrown in to secondary school without support.

Primary school experience wasn't tailored to need, but secondary school was excellent and radically improved child's experience & opportunities to thrive my child's ex

Referral made to adult social care/ transition team when daughter was 17, first contact by the adult team was 1 month before daughter turned 18. It was rushed and chaotic.

Secondary provision is fine, primary provision was terrible and experienced very unprofessional behaviour from staff at the primary school

Sen team were poor in communication and the whole transition process.

Provider so far are the only service that seem to know the proper process and law when it comes to my child's rights.

Some of the answers were about the *Educational Setting* not the *Educational Setting*

The fact there was none, if not for *Provider* I would not have known where to go, or what I should access for my son

The SEN team do the bare minimum they are required to do by law. *Provider* offer you a copy and pasted answer via email. The Local Offer website is dull and looks like an ordinary council webpage.

There was a short brief on what the school could provide, however it lacked, what could be use to help your child behind the scene. No linking (from what I saw) up from the Primary SEN with the Secondary School SEN.

<p>There was very little support from the SEN team. A few options for post 19 were considered but our first choice was refused. The reason given was that my daughters needs could be met where she is, however she has not had hydrotherapy for over two years even though it is in her EHCP</p>
<p>Transfer from mainstream to specialist school was seamless with an intervention stage complete that continued on to full time. Transition of a few days to start over a few weeks gaining days into a full week.</p>
<p>Transferring from a village school to *Educational Setting* within a large school was daunting throughout school life did not enjoy high school/college</p>
<p>transition to secondary school was during covid. it was supported well by both schools in so far as possible</p>
<p>Transition was impacted by covid. SEN at primary school didn't advise that he was on SEN register before transition</p>
<p>Truth</p>
<p>Very little or no support</p>
<p>Village school very good but struggled at high school/college as busier environments</p>
<p>Virtual school also supported</p>
<p>Wasn't offered an support</p>
<p>wasn't really talked about</p>
<p>We found, unless we asked for information and updates, we were rarely kept informed of the next steps.</p>
<p>We have been in Herefordshire since March 23. The Herefordshire send have only recently contacted us with draft EHCP over a year after initial review. The draft was completely ineffectual and was rejected by us. His current school is very good and support meets his needs but suitable support in secondary school will be more difficult to find.</p>
<p>We only realised that our child was autistic at the end of year 6. Neither primary nor secondary school explained how traumatic this transition would be and did not appropriately prefer us or our child. The CAMHS worker only told us that she did not think our child would manage the transition well AFTER they stopped attending school.</p>
<p>We were living in another LA for transition for primary to secondary and the transition was poor and led to a mental health breakdown. Transition to new specialist provision was amazing with great support from the school</p>
<p>When we have been involved with social care, they are completely useless. Three social workers in six months, no support, needed to put in two formal complaints over the six months. College seem to be doing well, with support and transition.</p>
<p>Where not applicable is stated, we have not been offered these</p>
<p>*Educational Setting* have been a great help getting *child* transitioning to be there</p>

Q28. Comments on the educational provision the child / young person is currently receiving.

He is not being supported as outlined in his EHCP, communication is poor. Not enough support staff trained in autism and communication difficulties, or to notice when children are masking. If they are compliant they are overlooked in mainstream settings and no one checks the impact of masking all day long.

The Sen team have poor communication. Do not meet legal deadlines

I have had to argue that my child needs additional support until the school gate is locked as she is a flight risk. The school have finally agreed to put something in place.

Very happy with school placement

Now that she is in *Educational Setting* *Child* her needs are being met.

Our son is doing well in a mainstream setting and is learning lots. If anything, he could do with being challenged/stretched more, we sometimes feel that being in a large class holds him back from achieving his potential.

EHCP took 9 months to amend following annual review- and only when chased numerous times.

My child attended mainstream until year 7. He managed 9 months there until he refused to go due to bullying and his SEN not being met! I had raised concerns during that 9 months numerous times. My child was traumatised by his experiences. He was completely failed by the educational system. His EHE commenced about 2 1/2 years ago. I personally engaged in the EHCP process- gaining one was reasonably straightforward- I attended a *Provider* workshop that was very informative. I requested my child be educated with EOTAS and was turned down. I believe the entire process would benefit from a more in person experience. I will continue to EHE for as long as he needs it but at 14 working at an 8 year old level we will need to be looking for what next very soon and anticipate it being a challenge!

We are very lucky to have a placement that is working well for our child but it was exceptionally difficult to obtain, no parent should have this amount of distress and fight to help their child thrive

Now that she is in *Educational Setting* she is getting fantastic support.

Transport provision has improved my SEN child was having to spend around 20 hours a week in a taxi to and from primary school, contributing to poor behavior when raised was told by the *Provider* employee sarcastically that I should have considered where I live (by my support network) and that maybe I should ask Hereford council to build my son a private "special" school in the rural village I live in or stop complaining that my 7 year old child was spending 20 hours a week on a taxi and having increased meltdowns

We have really struggled to engage with the SEN Education team - emails and calls not returned, no updates, outside of timescales.

Currently refused an assessment for ADHD by CAHMs and their suggestion of accessing Early Help was also rejected (awaiting appeal).

Working alongside the schools Children and Family Support Worker to support kids in primary school setting without an EHCP or diagnosis, but mainly left to manage by ourselves.

My child's attendance was below 50% for the last academic year due to anxiety and, through work we did at home during the summer holidays, he has managed to increase it to around 70% so far this year, but there have been few changes made within the setting to support his needs and make him feel capable within the school environment. After providing a part-time timetable and seeing little improvement in attendance they referred us to Early Help, we were allocated a Family Support Worker who has done little more than call TAF meetings, write up reports, and tell my son that he needs to build resilience to cope within the setting as it is rather than expecting change to support his needs.

When at school their needs were not met they were constantly being punished for things that were caused by their condition hence they are EHE. Sen team communication and support is poor.

The teaching and support staff at his school know him very well and demonstrate understanding of his differences, especially with regard to dysregulation. His learning environment has been adapted to include an individual desk, ear defenders, Rubik's toy, etc. There is a behaviour support plan in place that is accessible by all staff and available for supply. He doesn't receive any differentiation or intervention as he is academically able, but I think he would benefit from this.

The current provision is not enough. This is not a criticism of the setting its excellent but it's a stepping stone and my child needs a full time education. The difficulty has always been as the amazing EP got to very quickly in her assessments that 1:1 people can miss judge him. The lack of Autism understanding and lack of in depth knowledge of masking and autism burnout is frankly shocking.

School are not supporting my son to achieve his potential. He is put on the tablet to do spelling or times tables when he could be doing catch up work. He isn't supported to attend extra activities such as 'Young Voices'.

We have had some excellent services but have had to wait a long time for any assessments or support beyond the school. We have not yet been able to access sensory assessment or support (after 2 years of trying). *Provider* supported the school but not my child as she was still in the long, long process of gaining a diagnosis but did not at that point have one. My impression was that there was a primary school focus on the support from the outreach service too.

Receives no support even though he should

Services overwhelmed resulting in poor service across the board from SEN team, unfortunately never had access to early years inclusion or portage. School catchment WVT SALT failed child with incomplete service and no reviews completed since JAN24-Oct24

Educational Setting needs to be held accountable for it's poor SEND. *Staff* means that children of SEN but aren't disruptive in the class are left failed by this blatant neglect in children's needs.

After having no specific support at primary school we enjoyed a huge support network at *Educational Setting* and excellent special needs provision, we are now finding university support and provision non existent - despite having a full & clear diagnosis.

Where not applicable has been stated, we have not been offered these services or we don't need them. It might be good to add in a 'Not Offered' button

I moved my child due to funds not being used appropriately or in mu child's best interest. Staff are picking at my child daily, confertational when asked why. No understanding and need sen training. The system has massively failed my two children time and time again. No help , they say no funding or can't take on a new case. Constant fight for the basics for my children. Completely unacceptable. I've spent thousands on private care and advocate because of NHS not being there and local sen support being not available no funding can't take another case on. It's ridiculous that everything is such a fight. I get trying to save money but your not listening to what is in the child's best interest. They have a hard enough time as it it without creating more truma because provisions and health care isn't available when needed. It's not just me thousands on hereford sen page saying the same often some don't bother and just home school it's completely unfair. My child transition to highschool won't be happening and will be home schooled it ridiculous my and my husband both work also. It's completely draining and worrying, why there isn't more for m8ddle ground children
School has been nothing but traumatic for both of my children and constantly let down no support and no care just always mentioning money and funding nothing is available

My daughter has had very poor provision whilst being at school and gets punished for failing a test or not completing homework to standard and give her detention

They lack knowledge and understanding in adhd. There's little to no support and a lot of teachers don't believe in adhd or children should be labelled with a title and just blame poor behaviour. They need to listen to the people who live with their child/children

Academically, she's doing fine. She's really struggling with the social and non-verbal expectations of secondary school, though, which makes it very hard to get her to school each day.

Portage are brilliant but massively underfunded. SEN team are poor and kick the can as far down the road as they can until they legally have to deal with a problem.

Parents should be included in who their child's 1-1 support will be and it should be emphasised that changing the 1-1 continuously for a SEN. Child is extremely unsettling! Not including a SEN child on school trips because they cannot provide an adequate fully trained 1-1 SEN trained member of staff in a mainstream school. In a world where we are now supposed to be fully inclusive the children of the next generation are being very poorly treated. (a mother of two autistic boys age 11 & 4

School try their hardest and have received funding for my child within school, however we need an autism assessment and have been told by the Hereford CDC waiting list is two years for an appointment. School have explained my child would benefit from 1:1 support however we cannot access this as need an autism assessment sooner!

Educational support is poor, being refused EHCP by school SENCO, child's needs are not being met.

SEN team have been much more proactive - but still quite hard to get a response from anyone. Currently trying to get SEN transport which has taken a month, just been told we have it.

The support from the school is fantastic but the LA can be slow to respond and get the EHCP finalised. We have been here a year and still do not have the new EHCP finalised following transfer of EHCP from one LA to Herefordshire LA

My daughter is not catered for educationally in this county and has had to seek education in a different county Herefordshire has and is continually failing her

The structure exist but needs to work - a lot of the time you ring and no answer or you ring and you already know this person is working from home and same answer - do not have enough information will come back to you - you give the number and you wait days for a call that never happens you then ring again . Mad really .

M child was supposed to have independent travel training in year 6 and he's now year 11 and it has been constantly put in his Ehcp review each year. I take it that he's been waiting over 5 years for it is the norm ?

Annual reviews not discussed no communication from SEN team have to chase everytime always a new case worker no consistency, liars

My child is in the early stages of seeking an assessment for ADHD (rejected by CAMHs). They've been placed on the SEN register and we've been referred for Home Start help in the mean time. The teacher is aware they may need further emotional support and a fidget for retaining focus

Educational Setting is outstanding :)

Generally good now. It's a specialist school in *County* and it's a shame there wasn't provision in *County* as there's definitely been issues with communication, accessing services etc. The school was quite poorly run initially but they have definitely turned a corner and our experience is definitely more positive now.

The secondary school is working hard, however my child is not predicted to gain any GCSE qualifications. More life skills could be taught to them but there is limited time in the day and limited staff to provide this.

Currently being failed. No provision for her. Mainstream has led to her being in autistic burnout with high levels of EBSA. Keep being told there isn't enough evidence of her need. Section 19 delayed and has extensive barriers due to policy. Legal threshold met for needs assessment but declined and mediation delayed. Ongoing drift and delay from LA

Educational provision in the county is poor, under resourced, underfunded, lack of experience in SEN team, poor communication, every slow to act

The EHCP assessment seems to be swayed by lack of service provision rather than child's actual needs. I.e. no assessment for dyslexia offered. No OT assessment. No 1:1 support even if required will be stated in EHCP. Even once you get document the school cannot provide adequate provision yet states they can meet need. Most of the time I don't believe they read the document. So long process for parents that equals no extra support for child.

The contact with the SEMH team has been poor as the support my child has received hasn't benefited them, they have gone in and observed my child at their setting and then from that have given nursery very little support with how they can support my child to reach their full potential while at nursery. Thankfully the staff at my child's settings (goes to two nurseries) are fully inclusive and doing everything they can do to support my child so be able to cope and find strategies that work for them. The SEMH team coming to observe I feel has had no impact and my child is only progressing thanks to myself and the settings they attend. The only thing the *Provider* has impacted is the fact the paediatrician has now taken my concerns on about absent seizures and my concerns over behaviour because there are reports of evidence from them. The waiting lists to get support out of the nursery setting is too long and I worry that the support in school when my child begins next year will be effected because we will still be waiting to be seen by the community paediatrician even though my child has been under the hospital paediatrician and we have to wait to see so many different professionals which all takes too much time.

The school has woefully inadequate resources for autistic children and many of the staff are unsympathetic and ill informed on the subject.

Recent letter from council who realized son had left 2 years ago *Educational Setting* so say they are ending EHCP plan he has been at home ever since

Left *Educational Setting* in June EHCP now ceased now in limbo

The school he is in are trying their best to heal him, and his traumas caused from Herefordshire SEN school system.

Q32. Respondents' comments about any other community, hospital health service or health assessments accessed in the last 2 years.

2 year wait for autism assessment at cdc. No further ongoing support. No one to help with mental health or anxiety for her. Camhs won't as she has an autism diagnosis and cdc don't. She requires a clinical psychologist but none available. EP's are only doing statutory work

Access specialist consultants in Cardiff which are brilliant. SALT and OT are now through Gloucestershire and they have been very good.

Birmingham Children's Hospital Neurology excellent Urologist Excellent

CAMHS - poor stopped child's medication and continue to put family at risk with zero care or understanding

CAMHS is absolutely abhorrent in the service they 'deliver' to children, disgusting
CAMHS work has only just started, but it has put a programme in place which we have only just started. The team is working hard
Cardiology. Excellent.
Contenance service is awful. Ran by 1 part time worker for the whole of the county. OT are good but again can only offer a very short intervention. SALT are brilliant but the waiting times are huge.
Counselling via *Provider* around anxiety. 6 sessions, didn't make any noticeable difference, and no follow-up or next steps were offered. Have now arranged a private counsellor.
Dental access excellent
Good service at orthotics department
It took 3 years to access assessment appointment - which I imagine would be dangerous for many children without good school support
My son left school over a year ago
No assessments have been done despite asking for mental health asd and others no social services wont even accept her and have closed the case!
No understanding. Often ask questions say they get back to me never do. Constantly chasing them waiting years for appointment ridiculous not taking sen into account at the appointments wait times and judging
Not applicable
Not been able to access dentist since covid. Been removed from nhs dentist he was at since birth, so has need for tooth removal bo no where to get it done.
Our experience with the health team has been very good, I feel it has improved since *Staff* has been doing the follow ups at the CDC, she is very efficient in making referrals needed in a timely manner and communication has been great, we also had support from health visiting at the start of our journey which I felt was supportive as a parent and my child benefitted from it.
Private SALT and OT. Private child psychiatrist
Rheumatology team brilliant
rheumatology team great
Royal Orthopedic Hospital Birmingham is fantastic
Still waiting for NHS OT. Rejected by CAHMS. Need SALT and Physio but again barriers
The transition from having a paediatric consultant as a child to only being able to access a GP as an adult is very difficult.

There is not room to adequately describe the appalling treatment our child received from the SEND team. His absence from school was unnecessarily extended due to their atrocious service and it caused our child a huge amount of suffering.

Used the hospital who have no idea how to support or help ASD and do not listen to parents -disgusting

Waiting list way too long

Waitlist for physio is long (yet to be seen), OT service refused to work directly with child, SALT missed opportunities, peds failed to complete relevant paperwork actions on time. Dietician team are really supportive with innovative workshops to support families further.

We have not been able to access our dentist

We have not been treated very well since moving to Hereford last year. I have not been offered anything for my child and didn't know about half the things on offer.

Q35. Respondents' who had 'other' difficulties accessing Health Services were asked to tell us more.

My child gets extremely anxious about seeing different doctors and what they are going to make her do at the appointment so I can't get her to leave the house

Not being kept informed - have to ring up to ask when we might be seen but just told they can't tell us when, it'll be before he starts school. (CDC - waiting MDA assessment)

No changing places toilets for medical appointments

Wheelchair parking is difficult at Hereford hospital unloading with a ramp.

I haven't but Chams! My child has made previous suicidal attempts and where we lived before we were told he needed prolonged PSycotherapy by Chams in BANES. They referred here and we were told he didn't meet need. Again for the last two years I have had to find my own support for him whilst blamed for his difficulties. He now attends *Provider* the only support we have had through an ASD lens and he is now thriving!

As above

Peds discharged from services once seen, no other professionals involved/unsure how to access services as child gets older

Young people who leave Herefordshire for education (term time only) are in a vulnerable position as there is no continuity and for neurodivergent young adults transition experiences can be truly unmanageable and very confusing, but without anyone looking out for them or helping them access new provision.

We live on the wales border and have a Welsh gp. Our specialist consultants in Cardiff and the community peds team are Herefordshire. He now attends school in *County*. Health/allied health is all over the place and there is such poor communication. There is no communication between community paed and specialists in cardiff, I have to make sure everything is communicated. Keeping up with appointments everywhere is exhausting. Now adding a different LA school into the mix has been very difficult . Accessing SALT/OT was extremely challenging as there was dispute over who was responsible, this led to a 9 month period with no therapy. There is no joined up work whatsoever, I think this should be part of the EHCP but there needs to be a coordinated service to do this as I understand this cannot join onto the EHCP officer role. It is very challenging for parents of complex needs children. Perhaps a care coordination service would help.

Younger children not allowed to appointments, too scared to rearrange as been waiting long enough
Extremely difficult to go out when people are present. MRI arranged an evening appt was more stressful walking past people in corridors than having the MRI.
Talking therapies team 16 appts given 4 over usual but could do with OCD service in Herefordshire as problem that will not go away and will suffer throughout life

Q38. Respondents were asked to share more information about their experiences of health / social care services.

We don't receive any social care provision
Camhs have failed my child
Autism and adhd referral was made - originally we were turned down due the being home educated!! That is unlawful in my personal and a pathway needs to be rolled out nation wide! When we did get on the waiting list March of 2023 we are still waiting!
We don't have any support from anyone other than the school
It's all very poor, no provision for rural services esp "HR2 0" no clarification just terrible as a whole nothing is available, we had to wait 8 years for short breaks to be implemented
We've had to pay privately to get appropriate assessments and diagnosis
Short break services do not accommodate children with physical disabilities
The social care provision through Early Help has been of little use and has actually caused me and the family additional stress due to the lack of consistency and communication, this is not helpful with a child dealing with anxiety.
I believe its a grey area between 16-18. Has some depts want to get rid of them when turning 16 and when question adult dept they say oh no not yet. So it's hard for these kids anyway with change.
Vision and hearing seems to be difficult to obtain appointments for SEN children
Social services do not understand my children they have written a report which I am challenging about their school attendance and no weight is given to their needs and subsequent difficulties within that report
CAMHS have not explored neurodiversity for my son. He is adopted and realise he would have trauma but this doesn't mean he hasn't got any other additional needs which CAMHS won't review.
My child has interrelated physical and mental health needs and it seems impossible to get any overview of these from anybody- we meet a range of professionals dealing with different issues in isolation when they are strongly connected
Social care exceeded needs assessment time frame with recognition that challenges remain due to there being no services child can access at this age/challenging to access when old enough
I think clear advise and pathways need to be given and in writing. Staff need to be conscious that this is hard for people to go through and we are not just numbers
They do not receive support

No real mental health provision available - parents are just expected to cope.
Please see previous answers
Paediatrician was useless, attended first appointment to request an ASD assessment. After meeting my young person for five minutes. They said you are clearly not autistic as you are well presented, wearing make up and you are giving me eye contact. Initial appointment with CAMHS- choice appointment about diagnosis- comment from practitioner- you don't seem autistic. Hereford really need to update staff training on how girls mask. Daughter attended *Educational Setting* and they clearly could see that she was autistic.
The whole Lot of them are useless we have had nothing but disregard and failures
reviews should be every 6 months and not early
CAHMS is the worst service I have ever come across and I work in healthcare
No support from CAMHS despite MH issues, social isolation etc
Community paediatric team needs improving. Children with specialist and complex conditions with health professionals in other areas definitely should be followed up.
Would like to discuss with inspector
The hospital passport I have started using for my son is one I got from Birmingham children's hospital
CDC does not listen
Mental health support for children (age 6) on ASC pathway or diagnosed
The appalling care our child has received has significantly impacted on their life.
Do not have any dealings with social care provision but health looked after
do not have social care provision but health care in NHS have been good
Dropped by paediatrician and by camhs without just reason - disgusting

Q39. Respondents were asked to share what they are finding most difficult at the moment in relation to caring for their child / young person.

Access support In education and helping them thrive socially
Behavioural difficulties
Putting siblings first
Behavioural difficulties
Behaviour
Her anxiety going to school, no support or help with her anxiety and trying to work as well as supporting my child
Repeating myself / remaining patient

Unpredictability, stress and feel like no help, no one cares.
Not having the room at home to give over for a quiet area
No getting a break
The sheer number of appointments for different agencies- health, social care. Trying to navigate the post 18 options/ benefits. The toll it takes on the rest of the family/ relationships.
Sleep and eating difficulties although we are being supported with this.
Having to fight the system just so they can receive what every other child is entitled too
Financially trying to pay for what is needed.
Toilet training and lack of support / showering / finding SEN activities to get us out the house in the evenings
The battle with services
Dealing with untrained, outdated staff and poorly run services that are underfunded and unable to meet need
My child is extremely anxious. She hates leaving the house , we can't get her to attend any medical appointments . She needs support to dress, cook, wash and I also work full time. My daughter won't engage with anyone who she doesn't feel safe with and that can be very draining on myself as I'm her only safe person.
The access to local services, poorly funded, limited to Hereford and towns but no provision in the golden valley for anything!! Medication was stopped during COVID and cahms are useless more interested in saving money despite child has but both parents and siblings in life threatening situations. Told by one Social worker that despite child being assessed as needing 2-1 for dangerous behaviour could be managed between myself and my 13 year old daughter (younger at the time). No local transport for children with disabilities
No respite.
Feeling like we are not believed, the constant fight to get everything in place to support child
Constantly having to fight for everything that will make their life better / easier
The fight you have to education for years and the effect it has on parental mental health going to tribunal for a placement that was cheaper
Teaching regulation skills, whilst also managing my own.
Trying to get him to attend school full-time in order to get an education, he argues he learns more at home than at school and doesn't have to deal with all the issues school presents.
Having to fight to get what they deserve lack of funding, school provision is not fit for purpose.
Nothing
The profound physical disabilities means I have not got the equipment to cater for daily care needs. It is becoming so difficult to have wheelchairs and bathing equipment without the proper wet room and hoists, managed by DFG.

Lack of sleep and seperayion anxiety
Not knowing whether we are doing the best thing for him. Life is exhausting and it feels like we have to educate ourselves and push for everything rather than being offered what we need - sometimes we don't know what that is because navigating the provision is so complicated. We don't understand the system.
The professionals and lack of understanding and lack of speed at providing them an appropriate education. They are continually made to feel they need to change themselves or hide who they are. Except at *Alternative Provision*.
Child's melt downs, sensory needs and his understanding
Other people (uneducated or lack of life experience) trying to tell you what I should do. Feeling overwhelmed by trying to work, support other families members and also fighting for support for my son.
I am exhausted. I am always having to anticipate the next challenge and to avert it or manage it. I have had to adjust my expectations of my won life and work
Lack of support
Helping her to manage her anxiety around being in Year 10 as an Autistic young person (currently undergoing assessment for ASD) It is difficult to get school to understand/ make adjustments for her needs - resulting in EBSA.
No support. Rude professionals who lack experience, compassion, etiquette or training. They don't even know the basics of autism and adhd some of them. The gaslighting of parents is immoral!
Lack of local provision for children with SEN. Options that are available, you're forced to explore them yourself as information is not accessible.
No ability to access childcare services (ability to arrange own respite) - social norm has become parent carers do not work due to challenges (wider society issue) even providers stating care for SEND refused to allow child to attend
Lack of available support in Herefordshire.
The worry of them finding the world (or at least changes in their world) overwhelming and not having access to the network and support they may need but not know they need.
Mood swings
Not understanding her needs completely.
The amount of time chasing professionals takes away my child's time
Anxiety, low self esteem, hygiene, clumsiness, communication
Lack of support
Dealing with mood swings and helping his education
Behaviour and emotions. Anxiety over education
Hours of de-escalation and grounding conversations every day to get her into school.
Not being listened to

Behaviour at home and lack of mental health support for child as in a grey area in terms of age (Camhs he's too young. CDC don't offer that type of support)
Tiredness and cliff edge on carers allowance
DLA provisions not meeting needs
Helping managing and regulating their emotions. Social interactions are very difficult
Ensuring that they are safe and happy at school
not being listened TOO
No support
The unknowns and uncertainty of next steps
Struggling with communication and the waitlist for Speech and language team being so long.
Transitions
Going new places, leaving the house, communication
Lack of sleep
As he's getting older it's more difficult.
Not able to go on family days out, child takes a lot of time, other children feel 'left out'
Absolutely no support from any organisation
Having to deal with untrained staff who do not have a clue. Having to fight for everything to get support that your child needs.
Mentally exhausting fighting for help from services and long waiting lists
I have 2 diagnosed children and 1 I have concerns over but her school does not take me seriously and completed an assessment to see if she has a LD.
The violent outbursts often aimed at me the damage to the home we live, the police showing up due to my child reaching out after attempting to take her life and then being sent straight back home to deal with alone, the no support whatsoever
It's a 24h job -
Feeling alone, worrying about my child managing basic tasks as an adult
Obesity as he cannot stop eating He says it is comfort eating but I am going to have to consider putting locks in kitchen but then he will resort to eating non foods eg paper tissue blue tack etc
No break, constantly on the go!
His autism. Limits him
Constant battle with authorities for the things he is entitled to causes nothing but stress

Being rejected by CAMHs without anyone actually seeing my child, my child's deregulation after school and their resistance to demands, watching them being bullied regularly.
Inability to attend school full time, inability to socialise with family or peers.
Managing his needs when out in public
Accessing support and provision outside school.
Communication
Activities, keeping him safe, lack of understanding
Overwhelm, uncertainty about what provision is best and how to access it and generally not feeling like my parenting experience is similar to others.
Controlling his behaviour, anxieties aggressive behaviour etc
Every aspect
Lack of sleep
Concerns about suitable secondary education provision
Ongoing barriers, drift and delay from Sen team. Caseworkers do not seem to understand education systems or neurodivergent conditions. Ongoing battle to have needs understood or met. Lack of mental health support for younger children. Lack of appropriate educational provision for autistic/ neurodivergent children that don't have learning needs
Lack of sleep lack of support so called professionals not doing their job correctly.
Limited support from LA, schools and social
Other people's ignorance, especially professionals without correct and current autism training.
Isolation. Lack of support.
everything
Not enough support for myself on how I can support my child's needs. Luckily I have education and care background so I can cope but I still feel alone and when directed to professionals concerns are not listened to or either waiting lists are too long so you're stuck waiting for appointments and then hoping you get support once appointments come through.
Managing their stress
Our disabilities
Lack of support
The transition from child to adult, the only change is age. The need remains the same but law dictates that at 16/18 they no longer need parental input.
Terrified of going out in public places does not want to meet any people at all, terrified of door being knocked, had to get rid of landline as scared if phone rings

leaving college after 5 years now unsure what next stage will be and struggling with ocd, unable to travel independently

Professionals don't help, or care about him. We are all he has and people make decisions about him without even knowing what he looks like let alone who he is as a person or what he has been through

Q40. Respondents were asked if there was any training or workshops that would help them in their caring role.

Help to make friends and control temper

Challenging behaviour , Sleep on how to achieve this

Sensory feeding which we are attending a workshop for next month

What is on offer to help parents care for a Send child

Toileting

Training for the services that are failing them

How to deal with EHCP process. Knowing your legal rights for your child. Communicating with schools.

I don't feel that training would help, I have been told I'm expected to do training and workshops despite being a medical professional with significant experience.

Autism and understanding

Specialist NVR

Unsure

None for parents but plenty for health and social care professionals. Specifically the Oliver McGowan training

How to navigate the CAMHs pathway

Don't know, I've completed the Fearless Triple P training, as well as Young People's Mental Health

Schools need the training

More local provision for school holiday restbite

Managing dysregulation and challenging behaviour. Preparing for the future. Navigating the SEND system.

The *Alternative Provision* make me feel not alone, they make me feel validated but they haven't yet taught me something I don't already know in terms of how I support the children - our difficulty is the above answer. Children with autism present differently in different settings. This is not understood and parental blame is completely draining and pointless wasting resource looking in the wrong area to support.

Anything to help with parenting children with autism and ADHD

We don't need anymore pointless workshops

Autism in girls, asking for reasonable adjustments in a mainstream secondary school.
Trading by the new *Provider* (*Provider* hereford) should be rolled out everywhere! Went on their training and it was amazing! I learned more from them than the gp or so called professionals have ever taught me!
Autism support.
Workshops already exist and educate well, more services needs to be targeted to individuals (even if that is through one off assessments and a targeted plan with families)
None. This shouldn't be a classroom tick box forced on parents to buy Herefordshire council time before providing support.
Transition guidance.
Getting a diagnosis would be great firstly. After that, support on how best to support your child
Free advocates to fight the system that arr available and have funding
I have done some training already
Something on the EHCP system and other support routes available.
Caring for an autistic child
How to help manage regulate my child's outbursts and meltdowns
Not needed but feel school staff would benefit from training related to understanding SEND
Done so many and repeated them 5 times
Occupational therapy drop ins as they're so selective who they see and sometimes there is no one else to seek help from for day to day living struggles.
strategies on how to help your child with different difficulties e.g self regulation , recognition of over and under stimulation
Anything possible
Support for older teens, so that they can understand their diagnosis in a positive way. Never been offered anything as Hereford health do not think that she is autistic, even with a private diagnosis. Response from one practitioner you only got a diagnosis as you paid for it. Which is not true as they need to follow the NICE guidelines which they did.
Autism and Communication support
None the people who are supposed to help need training and new techniques not me
How to move to adult life and independence - what is available .
I'm a single mum working full time and I get no help at all. I would like some independence training as he is very naive
None
Not sure

I've been caring and fighting for him for the last 7yrs I don't feel any training/workshops now would be beneficial to me might be a tick box for the system but waste of county money unless a parent asks dont push
PDA
Some understanding sessions of his condition to gain much more of a deeper knowledge
Autism awareness, learning about different methods of communication
Meeting other parents of SEND children and training/ information regarding all available resources and support and how to access these services and best advocate for my child.
NVR which we are conducting now
None
None as they are patronising.
Better training for school/LA staff on autism and adhd.
I dint every training course available.
Send the professionals on autistic lead training.
Education on options of pathways you can go if you have certain concerns. My child was a lock down baby so I've never had close contact with a health visitor and I feel that has impacted my confidence on behind able to contact them as I don't know who I would contact.
Unsure, I'm not aware of any
None
None for parents but local authorities need the training
Preparing for adulthood, next steps, employment/ housing etc.
Too late now as left education. *Educational Setting* should never have got rid of educational outings as cannot manage in society due to extreme agoraphobia
Bring back educational outing at *Educational Setting* to help with managing socially
None. Unless you want to train your professionals to actually have some compassion they might benefit from extra training

Q42. Respondents were asked to share examples of things that *have* worked well for them or their child / young person in the last 12 months.

College
Educational setting
Now she is in an independent school things are changing slowly for the better
Excellent youth club for young adults with Down's Syndrome in Abergavenny.

My child has transitioned to a new nursery, both nurseries have been extremely supportive which has resulted in a very smooth transition for my child. He is moving to *Educational Setting* next September which again was a faultless process for us a family, done in a timely manner. No complaints on our experiences so far in our journey.

A charity called Empathy for special children- they are supportive. To child,siblings and parents and caregivers.

The 1:1 my son has at school is amazing

The dentist at goal street is fabulous

Now that my daughter is in *Educational Setting* she is attending more than she was last year . School have been fantastic and are really supportive.

School - good communication, have respite (short breaks) now after 7 years of waiting!

Accessing Hereford Parent Carers and associated groups and services

Additional needs swimming group, portage service helping it get specialist pushchair, securing ehcp

We attended the inclusive race at the Courtyard which was fantastic

Engagement from the Children and Family Support Officer and SENCO at school. Somatic rocking and talking things through with the kids if they are dysregulated.

Provider have just started therapy sessions with my son at *Provider*, this is the first time in years that he has been positive about attending such sessions. The use of a more open relaxed setting with the inclusion of animals is very positive.

Childrens community Nurses have been a godsend to myself and child .

Power chair using in a school setting OTs and wheelchair specialist working together from different regions of the uk.

Child Development Centre talk talk group was invaluable in their support of both my child and family

Provider swimming lessons - the instructors at the Ross pool are very inclusive and he trusts the adults teaching him. School - SENDCo and teaching staff know him well and challenge him but also show him kindness and understanding. The GP surgery is inclusive.

Where my daughter swims they provide discounted 1:1 sessions for children who cannot access normalLessons. At the cartshed the children can wear their own clothes and be themselves. My children are highly perceptive of judgement and respond well when there isn't any. Where people listen to their experience of the world to understand what they individually need. Because allAutistic people are different.

Visual timetables, wobble cushion at school, fidget toys

Music therapy at school has been amazing

excellent support from a school where key staff listen and respond to me and my child. a brilliant GP who we have managed to see several times. thoughtful responses from an Ed Psych

Child not in school as he can't attend mainstream but council won't pay for him to attend a special school, that have accepted him!

Change of education setting has been a positive move.

Support from *Provider* - able to attend sessions
The diagnosis was very quick and detailed once appointment was provided. support and provision at *Educational Setting* was incredible.
Nothing
Changed from nhs dentist to private
Private support
My daughter needs to go to a special school bur her current school say they think they can meet her needs but are not and my daughter tells me this
Educational Setting SENCO is very supportive.
Fab OT assessment with some great advice
OT were great and accommodating. School SENDco is amazing. Portage are brilliant.
The courtyard, inclusive/relaxed activity
My child receives DLA which has enabled us to put them in out of school activities, swimming horse riding rugby which is helping massively with keeping them active and focussed, we have been able to afford things we need extra of such as bedding, clothing as my child has toileting issues
The OGroup has been amazing and have seen improvements
We've been extremely fortunate to have found a nursery willing to take on my child and offer a 1:1 support before even having a EHCP. The NHS physio team have been fantastic with my child and the weekly group physio service is wonderful. Our council support worker has gone above and beyond to ensure any lacks in support have now been covered for my child.
Struggled to find anything last year when she left college, so nine months with nothing to do.
Moving to a specialist independent school has been life changing and mental health has improved. Horse riding has been a huge benefit too
Early help. But it's a shame it is only for 6 months. As it just starts to make a difference and then they have to finish and if we are referred again it is someone different so we have to start over again.
Their school *Educational Setting* is the only good everything in Herefordshire has been poor or worse
Aspire Living - he loves to go there for board games - youth group and Drama
His support teacher that he has had since year 7-11
P/a s help
Transitioning over from junior to senior has been a major success with patrol care moving with the children from the junior end for the first year allowing them to Transition
Adapting our parenting style to try and reduce perceived demands and help them regulate.
Education Setting are brilliant, they've listened to *Child* and adapt appropriately to his needs. Working so hard at getting him to attend school

Ring out into full time education in a specialist school has been a life saver for us as a family.
Accessing some 1:1 swimming sessions using the short breaks scheme. It provides 15 sessions a year which is not enough but it does help.
Portage team are amazing
SEND specialised education nursery placement, early help support (self referral made), portage support
Educational Setting and *Staff* (portage) have been so appreciated and supportive.
We now have CAMHS/NVR training. Children with disabilities working with us and putting things in place. One person in particular has worked very hard.
His school *Educational Setting* has been wonderful.
My own knowledge and understand of SEND law and allowed me to better advocate for my child
EOTAS (but Herefordshire need to develop a provider list as I have had to do this all myself with no support)
Both nursery settings have been proactive at supporting my child and his needs and trying to support myself to get the help and support they need.
Our son has moved to a mainstream school in *County* which has an excellent SEND provision and where staff appear to be more aware of issues around autism. The support we received from *Provider* and Social Inclusion was excellent as neither CAMHS nor the school were anything other than obstructive and they helped us hugely in obtaining an EHCP.
Educational Setting
We adopted a cat, that has increased his sense of independence and self confidence
Provider leisure centre have been brilliant throughout child's life being able to attend swimming lessons and activities with others
Talking therapies team good but you are only given so many appts but the problem doesn't go away need OCD provider in herefordshire for support adulthood
Nothing

Q43. Respondents were asked to share examples of when things *haven't* worked as well for them or their child / young person in the last 12 months.

Poor support in transition to secondary school. Lack of social groups to support young autistic children. A long and difficult process of getting an EHCP.
SEN team
Additional support is no longer provided as her funding couldn't transfer to school. Despite all previous experiences, she is expected to have no issues now, so not additional support is provided.
Provider. *Staff* wasn't very good

Mainstream school has left her traumatised
Asked to leave a send session because of a child crying which set another child on a rampage
College transport- daughter spends more than 3 hours per day on the bus- sometimes it is just cancelled without warning.
The school is reluctant to help my son toilet train
Camhs, Sen team, education the list is endless
Mainstream school gave my child so much trauma. She now finds it difficult to trust adults.
CAMHS- poor at present we have completed around 5 medication reviews but due to poor staffing, no continuity of care and having to repete myself a lot! Some patronising behavior from professional who do not understand the challenges experienced by carers in order to preserve safety of children with behavioural difficulties, use of tick box exercise and clearly more interested in audit trails that provision of quality person centred care. School provision is good, so long as it remains accessible. Rural location and no provision or ability for my child to attend any extra curricular activities and support life skills due to home address.
CAHMS refusing initial referrals, inappropriate referral to early support.
The fight to get the ehcp/school place (initially being refused ehcp needs assessment and having to appeal)
As stated before, we applied for my daughter to go to *Educational Setting* and were assessed and accepted however she was denied a place and we were told her needs could be met in Hereford. However 7 weeks down the line nothing has been implemented to achieve those goals
Trying to get an ADHD assessment for our youngest.
The pace of the lessons within my son's educational setting is not adjusted for those with additional needs and my son finds most lessons move too fast for him, the handouts are also not adjusted to meet the needs of those with additional needs making it impossible for my son to read some of the information presented. The educational setting are training ELSA's, but as those selected for the training are TAs who have already given my son a feeling that they do not like him, he is unwilling to work with them once their training is complete. My son engaged in an intial meeting with WEST at school and felt they did not listen to him when he tried to express that he was being bullied, he therefore refused to attend further meetings saying they were pointless if he wasn't going to be listened to. My son has also participated in two 1-to-1 sessions with our Family Support Worker, the first was just a 'getting to know you' session and the second worked was intended to work on his school anxiety but he again felt he wasn't listened to when he tried to explain that some of the coping techniques being explained wouldn't work in class.
Secondary school bullying not being addressed and Sen being punished as school staff do no understand or have the knowledge to support Sen children. They have to fit into a system that is so out of date and that they don't fit into.
Better communication when transition from child to adult services.
DFG -disabled facilities grant. My daughter is too big for me to give quality care without the adaptions of a wet room and wheelchair access. It's becoming increasingly difficult to maintain dignity and personal care.
GP making referrals to wrong pediatrics team
There was a lot of change at his school and the school weren't recognising the impact this had on him until we flagged up his challenging behaviour at home. *Leisure Provider* tried to be inclusive but weren't

successful at meeting his needs - he was often left to practise a repetitive skill independently whilst other children played - and we ended up withdrawing him from the group due to many meltdowns. Third party provision at his school was poor with staff that did not seem qualified to offer quality teaching to neurodivergent children. We were advised by a paediatrician in December that we would wait 3 months for a referral, after 3 months I chased this up and was told that standard in Herefordshire was 9 months, when I chased this again, I was told 13 months and advised to contact the services myself to check waiting times - communication whilst waiting for assessment has been non-existent.

None flexibility, uniforms, large groups, intruder drills, not feeling safe, not feeling heard, having to hide themselves and their diagnosis.

Accessing support from CAMHS. Medical tests and not knowing who will do the referral.

being refused a needs assessment with no rationale and having to wait months and months for our appeal. waiting, waiting and waiting for a diagnosis. seeing one locum paediatrician after another each with a different idea.

School dividing her from her friends in Year 10, resulting in her becoming overwhelmed and anxious.

As above. Also nobody in schools or hereford council return your calls or emails. The council simply shut you down and ignore you! They won't discuss anything or even answer to meeting requests. They are appalling. They are rude and lack compassion. They are bullies and don't care if children suffer!

No CAMHS support whatsoever. No access to appointments for months on end. No access to specialist dietician or SALT locally. No access to specialist dentist, and treatment / sedation being refused to treat oral health.

SALT limited support/input/missed review timelines, child has had numerous transitions due to lack of school places when specialist setting required (refused from mainstream), OT refused targeted services due to child's limited communication ability, physio long waitlist from point of referral, social care exceeding timelines, sen team unresponsive and failing to complete actions on time

Long wait times.

Having to wait three years to get a CHAMS appointment/assessment was very difficult

I had to rewrite the report from the paediatrician as all information was incorrect. He also laughed at me to my face. I have felt humiliated.

Moving into an adapted bungalow with no wet room, taking months from OT assessment to the council granting the DFG and 3 months later still no wet room, daughter has not been able to shower in 5 months, she tried to bath but was unable to get out so we had to call an ambulance with lifting gear to get her out, had at least 20 safeguarding put in by my request to professionals and social services ring to ask if they could send links by email to see if that could help my daughter.

Educational system is massive issues

Detentions, quiet space, buddy support, communication book

Anxiety at *Educational Setting* was treated as a behavioural issue, and the school responded to EBSA by threatening fines; when our daughter did get to school on time, her teacher greeted her with "So, you've decided to come today, then?"; she was completely excluded from the end of Y6 play after missing a couple of rehearsals due to EBSA. A terrible end to primary, and it caused a lot of school-based trauma that will take a long time to unpick.

Long wait for autism assessment (still waiting) little communication. Finding out by chance that my daughter doesn't have a paediatrician again but not told in writing, just when I phoned CDC

Hospital are not accommodating of special needs for things like blood tests or the waiting area. SEN team at the LA are poor. OT need to offer a longer period of intervention. Children's Continenence team are poor and understaffed.
I am awaiting an autism assessment through the CDC. I have phoned for help and support to simply be told there is a 2 year waiting list and we cannot be seen quicker. No empathy, no advice on where we can assess support for help whilst we are awaiting our appointment
School not following EHCP and little understanding of support needs
Community paed was a bit dismissive and feel a review ahead of suggested date was needed. No diagnosis
The health visitor service has been very poor. No communication when *Staff* went off sick, had to chase to get my child a new HV. New HV not conducting correct milestones and not taking into account parents wishes. Now on our 3rd HV.
My child is struggling at school, support isn't meeting my child's needs, and EHCP is needed but SENco says my child will not get one due to being academic.
See above.
NHS not very supportive and lack of education psych, ot, physio, salt assessments
Constant failures by camhs crisis team no help or support from anywhere
The review process for ECHP is not the best and the time the review happens and its confirmed is to far apart.
CAHMS is totally useless and not fit for purpose
He can't do things by himself.
Being on a classroom with kids that bully them daily.
N/A
Struggling in mainstream school unable to cater for his needs. Battling for camhs to see him for an adhd assessment time and time again before finally being accepted 4 years later.
As already described. Lack of joint up care, lack of communication. No therapy services during transition from mainstream in Herefordshire to specialist in Gloucestershire. Little oversight by Herefordshire of a specialist school in another LA
No speech and language therapy, no current diagnosis but is in progress
Slow and infrequent physio/ orthotic support.
Time to get things in place with the above teams.
No leisure activities or after school.provisions for my SEN child
Everything has to be so parent led. Feel I can't trust the professionals (Sen team) as not told the truth
Not having any care services or PA to deliver our social care package.
Isolation in a school setting, detention and exclusion for SEN related behaviours

SENCO giving false advice. Camhs being poor at appointments. Professionals with limited skills and expertise. Lack of TAs. Absolute lack of communication from teachers.

SEMH services as change in staff and not consistent and coming in to the settings to support my child or the settings.

His school treated his autism completely inappropriately and still failed to act when he stopped attending school through burnout. Trying to obtain an EHCP was the most dispiriting experience of my life and has caused considerable lasting damage to our child. The department would frequently not reply to messages or voicemails for weeks at a time. Statutory deadlines were missed, the EHCP was refused but we were not given the opportunity to appeal because we were repeatedly refused the relevant paperwork. Eventually, despite no new information being available, the decision was reversed. This extra delay was cruel, unacceptable and has never been explained to us. Over two years after initial assessment we remain on the diagnosis pathway although our child is obviously autistic. We are now being asked if we want to remain on the waiting list (why wouldn't we?) and after that and then being told not to phone, email or write to the team, they have the temerity to send both letter 'with kindness and compassion' which feels like a sick joke.

Educational Settings

Lack of dental care, can't get a NHS dentist

Education Setting needed more quiet areas for autism to get away from hustle and bustle

Camhs disregarding parents and child's pleas for help because of vindictive and biased teachers that don't actually understand your child, paediatricians dropping us without even seeing him despite open queries about his tics and mental health issues

Mainstream schools are not being held accountable for failing to meet the needs of SEN Children. No duty of care!!!

Q44. Respondents were asked what they feel should be the **top priority for improvement** for children and young people with SEND in Herefordshire.

Reduce barriers and time delays

More specialist support staff in school.

Better support after ASD diagnosis

SEN team

Better access to see paediatricians with shorter waiting times.

More social groups

The right school setting

Investment in inclusive universal/targeted services is very much needed.

Listen to parents!

More funding for staff training and development

More staff for SEN team so EHCPs can be completed in a timely manner and have meaning
Listening to them and their family about what is required, instead of making them jump through hoops
Occupational therapy / life skills / independence skills & speech therapy
Sen team and appropriate education options
Access to a decent CAMHS service. More educational psychologists and OTs working in schools. Training teachers.
All families should have the opportunity to have a family social worker. This way you will always have support.
- NHS waiting times and staff retention. - taking into account not all SEN children live in Hereford or the towns and significant outreach is needed and transportation for rural children to access local services.
Education - the service is appalling.
Conducting EHCPNA when child clearly meets the criteria, CDC wait times vastly reduced - early intervention from SALT etc. Waited over 12months to see SALT.
Reduce the amount of single occupancy journeys to and from education. This would free up more money for other essential areas
Better access to services / increased availability of services
A means of getting the support a child needs within their educational setting without having an EHCP
Having enough spaces for these children that need them and in the right setting.
Accessible respite and longterm care provision in the school holidays. DFG waiting time.
Health visitor support for early concerns and early intervention for children with developmental issues. More support for parents of premature babies after they leave neonatal care and the development issues they should be aware of
Improved communication and explanation of processes and accurate waiting times.
Listening to the parents. We are the unpaid experts who are exhausted. Sleepless nights worrying about our children when we see their huge potential and ability being cast aside and written off. You need a montessori approach in Herefordshire! It works...
Training, understanding and open communication with the parents
CAMHS and being able to support adopted children. Support for children at school.
rapid response to changes in needs
Listening to families and children about their specific needs.
Staff that care, that are trained and special school provisions given without deliberately forcing parents to go tribunal, in the hope of breaking them! Stop telling us you care about kids being in school and accessing education, when you don't care if they are sat for months at home, because you won't simply give them the specialised school setting they need. Close camhs and get a new service in. Camhs are literally null and void and do nothing! They rarely even accept referrals.

Access to more information to outline what services are readily available to support. CAMHS has to be top priority for those that are under their care, the current support is lackluster and waiting times are extreme.
Services to work closer together and parent/carer involvement
Provide support and assessments in a quicker time frame.
Waiting lists. Better support & recognition for schools who are providing services that NHS and social care can't or won't. or
Making sure people are dealt with as people and not numbers. Having compassion for what people are going through
They need to be treated like every other child, it is their legal right to access anything that other children can, we as parents should not have to fight for the smallest things.
In-between children forced to give mainstream ago because of primary ate funding for middle private sen schools. If provided middle sen schools they would be used. It's ridiculous
Making sure they're sticking to their EHCP
CDC start listening and doing there jobs properly
More staff
Better training for teachers around mental health needs, with an emphasis on a support-based approach, not a punitive/dismissive one.
To be heard
Waiting lists and professionals need up to date training on autism and not the old fashioned view of what an autistic child looks like. So many professionals don't understand masking and think a child can't be autistic if they aren't banging their head against the wall and can make eye contact
SHORTER WAITING TIMES FOR ASSESSMENTS/DIAGNOSIS
Funding spent directly on support/resources
to be taken seriously
Getting funding and help for my sons nursery
What provisions there are after your child is born. We were told nothing and had to seek all this information out and push for services like physio and speech. Referrals lost and having to wait extra time and seek and pay private in-between. What process needs to be in place before trying to find nursery placements for SEN children. It's been a very stressful experience and could have been made so much simpler.
Communication , more local group opportunities
Parking for appointments
School support, I think schools need more training and advice on people with SEND.
Better staff training in Health.

Mental health support for autistic children and annual ed psych assessments. Access to services to help improve communication, sensory difficulties etc
Education inclusion
Have a ECHP that is SMART and the local settings follow and have the resources to fulfill them .
CAHMS needs drastic improvement Support for young adults finding employment. I have a 25 old autistic son as well and despite him finding jobs and him having a good work ethic and excellent time keeping he has been asked to leave two jobs because of his autism even though both companies were aware of his diagnosis from the start. Unemployment services just leave him to get on with finding work on his own. He is now very depressed. He needs help to find work and then a service to check up with him and his employer to support.
Communication and more Sharing of information
More places to hang out. With similar people.
The EHCP department at Herefordshire council is shocking and needs a complete rejig/training
Getting schools more au fait with SEND regulations, and increasing staff with SEND training
Peer support groups, school placements
Help and support for diagnosis with CAMHS
Early intervention. More specialist provision. Specialist support in mainstream schools. Better access to SEN activities especially in more rural areas.
Speech and language therapy availability, more group sessions for children with SEND, organised activities for SEND such as outings, swimming sessions etc all adapted to their needs
A wider range of provision. I feel that my child is neither mainstream ready, nor entirely appropriate for special school, and so I feel that her options are few and oversubscribed.
A magic wand but all
It all needs improving
EHCP draft was terribly poor.
Training for Sen team on autism that is delivered and led by autistic voices. Training on masking, female presentations and neuro affirming practice. For parents views to be listened too, currently if a professional dismisses the concern, eg school information towards an autism assessment then the case is declined. More needs to be done to ensure parents are listened to and valid
Care services need improving
SEN inbetween provision - not suitable to school or a specialist Sen school
Appropriately trained staff. More placements a available for alternative more accessible education settings.
Sen teams poor communication
Lowering waiting lists and support to settings.

Reduce autism diagnosis waiting times.

Funds and proper training

Acceptance and understanding

College geared for autism which could run up to 25 different courses so they can carry on learning after, different courses with life skills too

Guidance on where to go after college finishes

Mental health services, diagnostic services, community care services

SEN Team!