



SHROPSHIRE
Parent
And
Carer
Council

Shropshire's 'State of SEND' 2022

If the Local area SEND Inspection revisit happens tomorrow, what are the SEND community saying about services they access and their experiences in Shropshire today?

Information & Support, Influence & Change



Our **SEND Reinspection Survey** was designed to give us an updated reflection of family's experiences of Shropshire's SEND services and systems. We asked 10 questions, these focused on the Written Statement of Action Themes.

125 people responded to the survey.



**Community Engagement -
How do we connect with
Parent Carers in Shropshire?**



Over **750** members on the Actio database, managed by PACC. Targeted mailouts are issued at least bi-weekly.



**Community Engagement -
How do we connect with
Parent Carers in Shropshire?**



We work across Shropshire with multiple agencies, groups, organisations, and services to connect with Parent Carers of children and young people with SEND

**Community Engagement -
How do we connect with
Parent Carers in Shropshire?**



We work with local community groups, inc:
 Severndale Parents Voice
 Friends of Severndale
 Empathy
 Parents Supporting Parents support group
 Shropshire Downs Syndrome Group
 NAMPSS - Neurological And Mental health Parent Support Shropshire
 To connect with more families in the SEND community.



PACC's Reach

**Community Engagement -
How do we connect with
Parent Carers in Shropshire?**



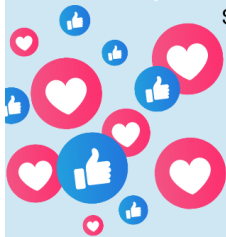
Monthly newsletter shared with Actio database, via social media, to all Shropshire schools, and via the SEND Local Offer distribution list of over **2000** people.

**Community Engagement -
How do we connect with
Parent Carers in Shropshire?**



5 Parent Carer Engagement Groups established in schools, with 1 more being developed. PACC manage closed social media groups for these as well as facilitate face to face opportunities.

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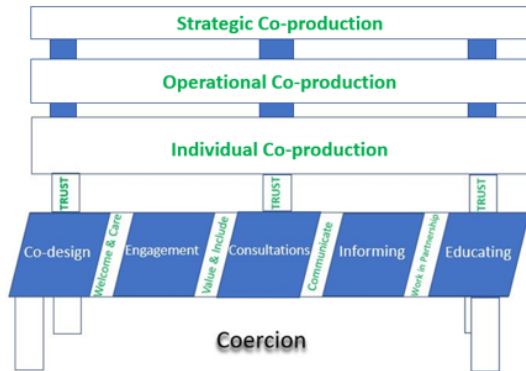


Over **2,300** followers across our social media platforms and closed groups.

Up to **10** posts a day are issued across our groups and pages.

PACC's Reach

Co-production The Shropshire Bench



The elements of co-production used in our bench are taken from the TLAP Ladder of Co-production <https://www.thinklocalactpersonal.org.uk/Latest/Co-production-The-ladder-of-co-production/>

The elements of co-production are supported by core principles identified by the Genuine Partnership 'Voices Project', which are; Welcome & Care, Value & Include, Communicate and Work In Partnership <https://genuinepartnerships.co.uk/>

Coproduction is delivered by several tools, all of which themselves should be implemented in a co-produced way. Describing this as a bench rather than a ladder illustrates the collaborative nature of co-production, involving multiple aspects of participation, that combine to deliver true co-production. The bench also illustrates that co-production is a shared and supportive experience.

Individual Co-production - person centred working with the individual with support needs to plan how they will live their life. What can they do what, assets they have and where extra support is required to help them to achieve their aspirations.

Operational Co-production - working with the community to inform individual service development, improvement and review. Includes the use of group participation activities and parent carer representation in planning meetings.

Strategic Co-production - joint working with independent, experience led organisations, who represent individual communities via a team of trained and co-ordinate representatives. Personal experiences used a collective thematic representation of wider community experiences, influencing system wide planning, including agreeing priorities and budgetary management.

Shropshire SEND Co- production Model



What did Shropshire Parent Carers Say?

Do you feel that EHCP's in Shropshire are effective in delivering good outcomes for children and young people?

[More Details](#)

● Yes	28
● No	81
● Not Applicable	15



What do parent carers think about the quality of EHCPs in Shropshire?

Some Comments on Education, Health, and Care Plans in Shropshire

- ▶ They are good but taking far too long to get done
- ▶ Too slow, inaccurate and staff don't listen when preparing plan
- ▶ Too vague and out of date before they are received
- ▶ School aren't very supportive of this option
- ▶ After completing all paperwork, including paperwork that should have been completed by early help (because they were too busy to engage) and left me to complete this alone, we sent an application off in February, which when I chased up was informed they had not received it.
- ▶ Difficult to understand. Unsure how much of the EHCP is adhered to by the school. extremely difficult process that an average parent, already struggling with their child's needs, should not have to fight to receive
- ▶ They should be run as a live document at all times, not only updated when a child changes setting, for example. Otherwise they are confusing and misleading.
- ▶ Often EHCPs are very education focused and the quality of other inputs either totally absent or very limited due to lack of knowledge by those chairing review.



EHCPs – Key Themes

▶ **Timescales**

Feedback raised concerns that statutory timescales were not being met, in particular in relation to Annual Reviews. Examples were given where this had a particularly negative impact on preparation for adulthood.

▶ **Support**

Parent carers told us that they would like more support through the EHCP process and that EHCPs too often don't translate into positive support in schools.

▶ **Barriers**

Parent carers often found the EHCP process in Shropshire complicated, unclear and stressful. Many stated that they had repeatedly been told by their child's school not to apply for an EHCP because they wouldn't be successful.

▶ **Quality**

Concerns were raised about EHCPs not fully reflecting a child's needs and being too academically focused. There were particular concerns that Shropshire EHCPs are not effectively preparing young people for adulthood, with an insufficient focus on basic health care and developing social skills.

If applicable, have you had a positive experience of Autism/ ADHD assessment and support during the last 2 years in Shropshire?

[More Details](#)

● Yes	15
● No	69
● Not Applicable	41



What do Parent Carers think about Autism and ADHD Assessment and Support in Shropshire?

Comments about Autism & ADHD, Assessment & Support in Shropshire

- ▶ Unacceptably long waiting time. Difficulties getting to see the right professionals to be considered for assessment in the first place
- ▶ He can not attend school due to severe anxiety and his mental health is so bad he threatens suicide daily. The only help we have had is from school. We have found that every step of my sons Autism journey has been a fight.
- ▶ The reason that she was so anxious was that camhs forced her to wait 4 years for assessment and withheld any appropriate support from her until that was complete. Therefore she is now irreparably anxious, unable to attend school or interact with any therapists thanks to this lack of care provided. If it was not for us removing her from school and going to extreme lengths to keep her safe at home, who knows, we may not even have a daughter any more due to your horrendous, unlawful and inhumane "processes".
- ▶ Terrible support. All geared up for high functioning autism, nobody can help my child who has complex needs, non verbal, learning disabled and autism.
- ▶ Once you have a diagnosis, you are discharged from the BeeU service with no support
- ▶ There was no attempt to explore if the support was right or could be improved. When i asked if we should look at moving him to a specialist setting as soon as possible the consultant stated 'he was glad that was a decision that we had to make and not him'. There seems to be a total lack of understanding of how to build positive relationships with parent carers.
- ▶ Medication is difficult to get in an emergency. Assessment is impossible.



Autism & ADHD Assessment and Support – Key Themes

▶ **Timescales**

Parent Carers repeatedly highlight the excessive wait times for assessment and support.

▶ **Communication**

Poor communication and transparency about timescales, criteria and the assessment process is a key theme in feedback from families

▶ **Lack of Support**

Families are waiting for long periods of time without any additional support and there is a lack of post diagnostic support

▶ **Impact on mental health**

Long waits and the lack of support is causing the mental health of CYP and their families to deteriorate and increasing the numbers of families reaching crisis point

If applicable, have you had a positive experience of speech and language support and assessment in the last 2 years in Shropshire?

[More Details](#)

● Yes	18
● No	41
● Not Applicable	66



What do Parent Carers think about Speech & Language Support in Shropshire?

Comments on Speech & Language Support in Shropshire

- ▶ They initially assessed my son during lockdown, then forgot about him. Quickly tried to rectify the situation, even though there are still issues he was taken off their books
- ▶ When we've accessed speech and language they've been incredibly helpful, welcoming, professional, and friendly
- ▶ Support is not there; my daughter has received no physio or SALT input. How can that be positive when she is non-verbal with mobility issues?
- ▶ My son has had constant input and support from speech and language, and we are very pleased in particular with the support.
- ▶ The SSLIC team are invaluable, as are the under 5's speech and language team.
- ▶ Our son had a virtual assessment during the first lockdown. We found the online workshop that was recommended was not suitable for his needs.
- ▶ Excellent advice, however, like everything, not enough professionals, so it can be limited.



Speech and Language Support – Key Themes

- ▶ **Inappropriate discharge**

Some families felt that they were discharged when they still needed help

- ▶ **Support**

There was some positive feedback about the quality of support but many families felt that they had received insufficient support and more direct SALT support was needed. Where some support was provided parent carers often felt it was not provided frequently enough.

- ▶ **Waiting times**

Excessive waiting times were highlighted which result in missed development opportunities

Do you feel that school-based support for SEND children and the approach to inclusion is good in Shropshire?

[More Details](#)

 Insights

 Yes	32
 No	87



What do Parent Carers think about School based Support and Inclusion in Shropshire?

Comments on School-based Support & Inclusion in Shropshire

- ▶ Unfortunately no support for children with or without diagnosis. Even with detailed reports from occupational therapy of how to support my son, his school has failed to follow them.
- ▶ Our experience has been that school would rather parent blame than fully explore the needs of the child/children, when a need has eventually been recognised school have used that as an excuse to not act and not support
- ▶ Children are isolated from peers, no awareness promoted in schools.
- ▶ At my child's school there has been good holistic support from all members of staff. The ECGP has been used affectively. My child has felt fully included in all activities and work has generally well differentiated.
- ▶ We have a great working relationship with the school team. We are regularly updated etc. our child has a brilliant teaching assistant providing 1:1 support and is very well supported in school. The school runs many groups and activities to promote inclusion and build confidence in the children. All school plays include songs with Makaton signing.
- ▶ School based support is very good academically, it follows progressive and positive patterns. School based support on social skills is more half hearted, it is intended but not followed through due to time, budget, not directly relevant to curriculum, not well understood that this group requires additional support (eg TAs to access school trips/after school clubs/playground social support).
- ▶ Attitude from some schools/professionals seems to be, 'ah yes, that person is not useful, they've always been like it, nothing we can do'.
- ▶ More training, listening to parents and understanding needed
- ▶ One size does not fit all, inclusion should not be at the cost of the child's mental health
- ▶ Every school I know send pupils home to calm down etc rather than putting right what is wrong in the setting
- ▶ Poor communication with parents has been an ongoing issue.



School Based Support and Inclusion – Key Themes

► Support

This was the area where feedback suggest the greatest variation in experience, highlighting how the quality of support and level of inclusion is dependent on individual school culture. In some cases, poor experiences of school-based support was felt to be because of the difficulties schools faced in accessing support from other agencies

► Training

Responses highlighted a perceived lack of training for school staff resulting in a poor or inconsistent understanding of SEND.

. Do you feel that preparation for adulthood for young people with SEND is good in Shropshire?

[More Details](#)

 Insights

 Yes	4
 No	68
 Not Applicable	52



What do Parent Carers think about Preparation for Adulthood in Shropshire?

Some Comments on Preparation For Adulthood in Shropshire

- ▶ Doesn't start early enough
- ▶ Not enough done in school in teaching independence and life skills
- ▶ Couldn't answer above question as I don't really know what Shropshire do in terms of PfA even though this is applicable to my child
- ▶ As soon as my ASD son turned 18 all services discharged us leaving us alone
- ▶ very confused about PFA and how this fits into /adds to quality of EHCP- quality of ending of EHCP is poor and no transition plan from education to next stage in adult life. Letter sent impersonal. Not discussed at review. Decided by LA case officer later. No signposting to next steps, activity planning or little support. Parents and young people just left to get on with it
- ▶ Everything is focused on curriculum when for SEND children it should be life skills and being the best they can
- ▶ Insufficient choices leaving school. Schools need to do more skills development.
- ▶ Focus tends to be on education instead of learning skills, providing new experiences and activity plans including social inclusion.
- ▶ We just want to get our son the right support at the right time to help him and us to manage every day .
- ▶ If able to access local authority information easily, PAAC information, have an active social worker for child, have good SENCO who communicates well then preparation for adulthood is a smoother path. Basically there is good provision but accessing it may be difficult for some



Preparation for Adulthood – Key Themes

- ▶ **Lack of opportunities to learn the right skills**

Parent carers repeatedly highlighted a lack of opportunities for their young people to learn the skills they need for adulthood, with the focus being predominately on academic progression.

- ▶ **Lack of support and information**

Families don't know what is available post 16 and pathways aren't clear. This is a particularly challenging time for families and they don't feel well prepared to support their young person PFA journey.

- ▶ **Lack of planning ahead by the system**

Parent carers tell us that they feel that progress is only made when they drive it. Some families have had positive experiences, but in many cases it has been dependent on their capacity to make things happen. This reflects feedback on the PFA Annual review process.

System Change at a Strategic and Operational Level

The Shropshire SEND Inspection in 2020 identified two further areas of weakness;


- ▶ Inconsistent strategic leadership and weak strategic planning across the area, most notably in the Clinical Commissioning Group (Health), including the ineffective use of data to accurately commission and plan services
- ▶ The lack of inclusion of health services' input into the area's SEND action plan

These are areas where PACC as the Shropshire Parent Carer Forum are able to provide observations on progress as part of our ongoing work as a strategic partner in the Shropshire SEND system.

PACC's Views:

PACC is in the unique position of being part of the system journey as the strategic coproduction partner while also hearing the reality of what families are living on a daily basis and using that feedback to inform, influence and sometimes challenge perceptions and decision making. It is a fine line to walk, ensuring that we support the principles of partnership working, while making sure that we remain independent and focused on representing the voice of the SEND Community. With this in mind PACC has the following reflections on the progress made in terms of strategic leadership and strategic planning across the Shropshire SEND system since its inspection in 2020.

PACC can see an improvement in the strategic direction within the Shropshire SEND system, with a greater recognition of the importance of the SEND strategy and a growing value placed on person centred and holistic care. We can see the commitment of staff and teams to making a positive difference for families and their determination to make improvements, listening to families while adapting and making change happen.



After a difficult period, including the impact of Covid 19 and staff changes in key positions, there is now some clear progress being made in strategic planning and leadership. The review of the SEND governance structure is positive, and the accelerated plan provides clear direction and oversight across identified areas of significant weakness. Co-production has a higher profile and there is a strong commitment to working with children and young people with SEND and their families, at individual, operational and strategic levels.

During the inspection in 2020 PACC particularly highlighted concerns about what we felt was a lack of engagement in the SEND agenda by the CCG, along with a lack of coproduction, particularly at a strategic level. This concern was supported by the Inspection Report. Since the inspection we have seen an increased involvement by health leaders in the SEND system and the related decision making, along with increased opportunities for PACC to be involved in health operationally and to some extent strategic planning. We still have significant concerns however that the new ICS is not fully sighted on their duties towards the Shropshire SEND community and this is resulting in ongoing failings of local health services to respond to the needs of children and young people with SEND and their families.


The improvements in the SEND Governance structure is not reflected in the ICS and this has meant it has been impossible to escalate concerns effectively. SEND in health is still in the main, isolated from the rest of the system, reducing impact and meaning that the needs of families are not being fully met. There are ongoing issues around accessing data from the local health system, which is continuing to negatively impact on strategic planning and it is not clear how SEND fits in wider health system priorities in Shropshire.


While PACC is more involved in health work we are not confident that coproduction is embedded across the local health system, including at the most senior level. This lack of coproduction has recently been highlighted by this issue being included in the Learning Disability and/or Autism Programme Board risk register. PACC has struggled to effectively engage in the development of the ICS involvement strategy, where a lack of understanding of co-production in the SEND system and the role of parent carers has been a barrier to progress.

All of the above means that the reality for many SEND families is that they have seen little change in the effectiveness of support, and there are a few areas where the lack of impact is now at the point of damaging families and breaking trust in the system. This is clearly reflected in the responses to the PACC survey shared above.

PACC would particularly highlight the following areas of concern;

- ▶ The Neurodiversity Pathway is not working, and we continue to have a significant waiting list with many families waiting beyond the expected 18 week limit. At the point of writing this there is still no recovery plan in place to address this and despite frequent requests there is an ongoing lack of clarity around the assessment process, which is preventing other work in this area progressing. This is also increasing pressure on other services as they are put in a position where they have to address the failings of this service as young people and families descend into crisis.
- ▶ While work has been done to improve the quality of EHCPs they are still not used well or actioned in a way that create value for families and connect the system for their child. Annual Reviews, particularly those focusing on PFA are not effective and are not on the whole supporting a good experience of transition.

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- ▶ Preparation for Adulthood in general is limited and fails to prepare young people to thrive as independently as they can. Families still too often find themselves facing the cliff edge of leaving an education system and framework with little support and with their young person having gained few skills to start their adult life. There are some elements of positive work being done to address this but there is a lack of strategic oversight, leadership and join up for PFA activity.
 - ▶ Early Help is not SEND focused or friendly and creates unnecessary challenge for families. There is a need to re-evaluate the approach taken and make significant change to improve families' experiences. This is resulting in an overwhelming demand for specialist services via the Disabled Children's Team.

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- ▶ Speech Language and Communication Services have limited capacity to meet the increasing demand for specialist interventions. Children and young people are waiting in considerable excess of the recommended 18 weeks for therapy services and are often receiving no support to improve their communication in settings without a Speech Therapy Service Assessment being delivered first. This could improve with the rollout of Talk Boost training, but few schools are taking up the training offer. This offer is also under resourced, limiting access for the target audience.
 - ▶ Permanent and Fixed Term Exclusions do still happen for children and young people with SEND, despite Shropshire Councils efforts to support schools to respond to needs effectively and mitigate the need for any form of exclusion at the earliest opportunity. Education settings often have conflicting approaches to behaviour and SEND which contribute towards the continuing challenge. Though we have seen significant improvement in some areas, families still report experiences of exclusion to be unnecessarily difficult and avoidable.

Summary

The SEND Survey tells us that while there are pockets of good practice in Shropshire, and some positive examples of services working well for families, there is still a lot to be done in terms of:

- Training and Awareness
- Communication
- Information Provision
- Range and Value of Offers
- Outcomes
- Quality Assurance and Delivery
- Commissioning for Needs
- Clear Pathways
- Connectivity of Services
- Joint Approach to Delivery
- Person Centred Approaches

Families make it clear that when a service works well, it can be extremely valuable and have a positive impact.

Families however are unclear on how to access the right help at the right time, and what focus it should have. There is a clear lack of cohesiveness across services in using the EHCP, or other plans, as a vehicle to drive holistic approaches to delivering a broad range of outcomes for a child/ young person that go beyond academic achievements.

Families highlight the need for clear, concise, and accessible information that is consistent across the system and known by the practitioners they engage with.



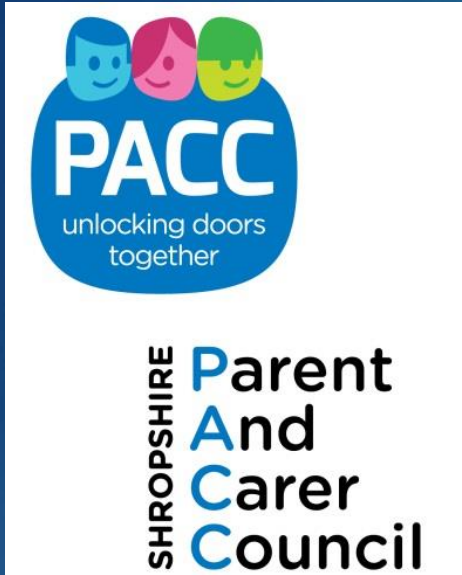


So what next?

The development of a whole system Action Plan is essential to address the significant gaps in Shropshire's SEND system and to deliver positive outcomes for SEND families.

The adoption and application of a shared coproduction framework is essential to improve communication, transparency, and engagement across Education, Health, and Social Care.

Improved use of data and intelligence to improve workforce development, system offers, and commissioning is urgently needed



“Making SEND everybody’s
business!”

Zara Bowden & Sarah Thomas

PACC Shropshire Community Champions and
Coproduction Representatives

