

Introduction

The Shropshire Parent and Carer Council (PACC) has aimed to ensure the experiences and knowledge of local parent carers have shaped the development of the local SEND system, since the introduction of the Children's and Families in 2014. It has been a period of significant change and a lot of hard work by many, progress has been made in some areas, but there are still many challenges facing Shropshire SEND families.

As the Children and Families Act reached its 5 year anniversary and following the announcement of the SEND Review by the Government, PACC has been reflecting on the implementation and impact of the SEND Reforms in Shropshire.

PACC is in constant contact with Shropshire parent carers and while our capacity and activity has fluctuated over the years, we have always prioritised remaining in touch with the everyday experience of the community we represent. Over the past 5 years we have talked to parent carers from Shropshire about many aspects of the local SEND system and shared their feedback in a number of reports, which are available on our website www.paccshropshire.org.uk

Understanding families experience is at the heart of our work with local decision makers and informs our ongoing discussions with managers and practitioners about how SEND services are developed and delivered in Shropshire.

This report is based on the observations and experiences of those involved in PACC, on wider discussions with Shropshire parent carers and feedback received via recent surveys.

PACC would like to thank all the parent carers who contributed to the surveys and discussions that informed this report, along with the Shropshire SEND practitioners and managers who work with PACC to improve outcomes for children and young people with SEND and their families.



What Does Good Look Like To Shropshire SEND Families?



A good education where young people with SEND thrive and are happy, is central to a good life for families in Shropshire. Families tell us that education needs to be **person centred, responsive** and available **close to home**.

The **right support** needs to be available for all aspects of young people's lives, delivered by individuals who are **well trained and informed** about SEND systems and know how to **work positively with SEND** families.

Good quality and accessible information should be on offer, **providing transparency** about decision making, clarity about what services and support is available and details about how that can be accessed.

Families will not have to 'fight' for support and their input will be **valued and listened to**.

All these elements will come together to enable children and young people with SEND to live **confident and happy lives**. They will have **friends** and be able to enjoy spending time together **doing activities they like in the community**, where they will be **welcomed and valued**.

As they become young adults, they will gain **independence** and be able to live in their **own home** and **live self-directed lives** wherever possible. This will include the opportunity to **work** in an area that reflects their interests, develops their **potential** and provides a **sense of achievement**

What is it like now?

Education and Preparation for Adulthood

Shropshire parent carers identified a positive educational experience as a key element of a good life, but their experiences are notably inconsistent. Some Shropshire educational settings clearly work hard to welcome children and young people with SEND, but parent carer's experiences in some schools is very poor, with a lack of differentiation, adjustments, compassion and understanding reported.

PACC has worked closely with the Shropshire SEN Team for the past 5 years, focusing on supporting schools to deliver a positive environment for SEND students in local schools and colleges. Autism Education Trust Level 1 training has been offered to all education settings in Shropshire by the SEN Team, along with training to implement personal centred approaches when supporting young people with SEND, but not all schools have not accessed this.

"He is at the end of primary school, and newly diagnosed. Primary school do not seem to have a plan of support for him, almost as if it is nothing to do with them and secondary school can pick up the support he needs" (Response to Shropshire SEND Strategy Survey – May 2019)

For young people with autism and associated difficulties there has been a particularly limited offer of appropriate educational settings. PACC facilitated parent carer input to the development of alternative provision in Shropshire (see <http://www.paccshropshire.org.uk/cd-content/uploads/files/Participation%20Report%20-%20Developing%20SEND%20provision%20final%281%29.pdf>) and a number of Hubs attached to mainstream schools are under development. It is hoped that this additional provision will enable young people with social and communication difficulties to access a suitable mainstream education closer to home.

"not sure provision is the right one for his needs. He is bullied daily physically. He never wants to go but due to being slightly above criteria for special school he has nowhere he can go instead. There is no in between school or primary with an asd hub in north Shrewsbury sy1 area."

(Response to 'If the SEND Inspection was Today Survey – October 2019)

Shropshire also offers limited choice in terms of specialist school settings. Severndale Academy is the main special school in the county, with 400 plus pupils, with a wide range of needs. A number of parents have highlighted this lack of choice as an issue and a significant number of young people have long journeys to and from school. This means that young people are educated away from their local community and are unable to access after school activities easily.

"The provision of school is unfair as Severndale has the monopoly of being a service provider..."

(Response to 'If the SEND Inspection was Today Survey – October 2019)

Issues relating to anxiety and mental health issues resulting from SEND, seem to particularly challenge the local education system. Where poor experiences are reported, this often relates to educational settings not being able to understand/meet the emotional needs of SEND pupils and this becomes a barrier to a positive educational experience. In some cases, this may be because there is a lack of flexibility in a school's approach and a lack of willingness to make reasonable adjustments. There is however

also still limited joint working between schools and therapeutic support services for SEND pupils in Shropshire meaning that schools are often not well equipped to respond to these needs.

“So what needs to change? A more holistic approach to helping children and young people with ASD. A system where agencies talk to each other, are able to try proven therapies, measure impact and take appropriate further action. A system that enables my daughter to focus on her strengths rather than worry about her differences. A system where we don't have to fight for every level of support. A system in which she can thrive.”

(Response to Shropshire SEND Strategy Survey – May 2019)

There is also an inconsistent experience of the local EHCP process, with families at the start of their journey more likely to report a positive experience, feeling that they are listened to and involved in the process.

“We are at the beginning of our SEN journey and so far all our experiences are excellent. Our concerns we listened to, investigated and outcomes explained with clear plans for the future.”

(Response to Shropshire SEND Strategy Survey – May 2019)

PACC has promoted the importance of ensuring that the voice of young people and parent carers is at the heart of the EHCP process and have championed the use of person-centred tools and the need to work in partnership with families. There is some evidence that this approach is making a difference, but its implementation is totally dependent on the willingness of individual schools and colleges to work in this way. PACC supported the introduction of a Graduated Support Pathway, to facilitate quicker access to support in schools. Families have been positive about this approach and Shropshire has had a notably low level of tribunals in recent years, which we believe is due to a focus by the SEN team on responding quickly to identified need and working in partnership with families.

A higher level of poorer experiences are reported to PACC during the Post 16 years and the transition period however, with parent carers often feeling poorly informed about the options available.

“(Young persons name) this year has moved from Post 16 to Post 19 Education ----. Other than IASS we have received no help or support ----. His Current Course wasn't agreed until March, we had to apply ourselves & by the time Interviews had taken place it was too late to arrange any taster days - so other than looking around the first time (Young person's name) experienced College was at his enrolment We never received an updated EHCP until after he had started his new Course.....We found this last year extremely stressful full of uncertaintya complete nightmare”

(Response to 'If the SEND Inspection was Today Survey – October 2019)

“Training & social care provision difficult to arrange, (provision just isn't out there to arrange). Suitable work experience not available. Choice-based housing bewildering, no suitable transition programme in place.”

(Response to Shropshire SEND Strategy Survey – May 2019)

The creation of the Transition Team with Adult Social Care has been a positive move and some families report more positive experiences of preparation for adulthood. The recently established annual Transition Event has been well received.

“He is well supported by (adult) social care - he regularly goes to Derwen short breaks where he is able to experience what it is like in a supported living placement & receives weekly support travel training ... This means he is well on the way to meeting his aspirations of living independently”

(Response to ‘If the SEND Inspection was Today Survey – October 2019)

“Continue with transition event, perhaps 2 per year Have open sessions perhaps like IASS have with representatives from education, social care and health Events around 14+ to support knowledge and implementation of PFA”

(Response to Shropshire SEND Strategy Survey – May 2019)

One of the concerns most frequently raised with PACC is the lack of Post 16 provision for young people with SEND. There is a particular concern that there are insufficient opportunities for young people with SEND to develop the key life skills that will enable them to achieve the Preparing For Adulthood outcomes. There is also a particular challenge about the offer for young people who are more profoundly disabled and where the educational value of developing life skills, such as living away from home, communicating needs and self-care is not always recognised by the system. This has resulted in a very limited offer for this group, since the social care offer is also not well developed for these young people. PACC feels that this is an area of work that still needs significant improvement, despite the acknowledged increase in joint working between education and social care services.

For some young people Derwen College is recognised as a centre of excellence providing good quality Post 16 provision but it is also clear that this does not meet the needs of all young people and for those for whom Derwen isn’t a suitable option, choice is limited.

“Derwen college is an amazing place, good training for the future and good friendships are being formed. The future should have similar opportunities for friendships with peers.”

(Response to Shropshire SEND Strategy Survey – May 2019)

Quality Support, Accessible Information and Participation

Feedback from families often highlights the level of confusion within in the system, with families struggling to find accurate and clear information and too often receiving conflicting advice. This was a significant theme in the work PACC did looking at the development of Learning Disability and Autism Services and was highlighted as an issue by both parent carers and practitioners;

Developing Pathways for Neurodevelopmental Conditions Workshops Report- <http://www.paccshropshire.org.uk/cd-content/uploads/files/EHWS%20SEND%20Workshops%20Report%281%29.pdf>

And was reflected in more recent feedback;

“We feel like we are in a continual cycle of chasing for support and advice, with no real idea of who we can turn to for help. There doesn't not feel like there is any consistency or communication between departments so parents spend endless hours phoning and emailing different teams to get answers and help.”

(Response to Shropshire SEND Strategy Survey – May 2019)

“What will help? More Information on family days for disability families. More information of what is out there for our children in the future”

(Response to Shropshire SEND Strategy Survey – May 2019)

Shropshire Council have recognised the importance of improving communication with families and we are pleased to see an increased focus on improving the Local Offer. PACC provides parent carer representation on the Local Offer development group and there has been a definite move to respond positively to feedback from parent carers and young people about this resource. PACC also chaired a Communication and Participation Workstream that has developed a SEND Communication and Participation Strategy. This document highlights the need for there to be a consistent and positive response from **all** services to sharing information via the Local Offer and to providing participation opportunities. PACC hopes that this strategy will be fully implemented following sign off from the SEND Strategic Board.

“When the stress, anxiety, isolation and loneliness of parents are helped with , a full explanation of everyone you can use to support you (diagram of places to go) our children are being emotionally and practically looked after re prescriptions given to doctors authority to prescribe medication, have a system that's easy and the parents don't have to fight for every little bit of help ..the most frustrating and difficult diagnosis process, use charities to understand how the parents and families feel ...communicate communicate, communicate!!”

(Response to Shropshire SEND Strategy Survey – May 2019)

Feedback from parent carers recognise the importance of parent carer participation and ensuring that services are informed by the knowledge and experience of those who use them.

“Keep listening to young people and their families. Keep looking at the services in place and assessing their impact on individuals.”

(Response to Shropshire SEND Strategy Survey – May 2019)

Over the past few years PACC has developed a positive relationship with Shropshire Council and there is a clear commitment to ensuring that services are designed and developed in partnership with parent carers. On occasions this has included the provision of funding for PACC to maintain its high level of activity, however in the main there is a decision by PACC to not rely on funding from the Local Authority, to maintain our independence and to strengthen our role as a ‘critical friend’.

PACC has representation on the SEND Strategic Board and the four workstreams that will report to the Board. Our long-standing working relationship with senior managers and elected members enable us to have meaningful discussions about issues and to influence decision making. There is clear evidence of the parent carer voice influence local decision making in relation to the planning, design and delivery of SEND services, see the following reports;

Co-producing the Shropshire SEND Strategy - <http://www.paccshropshire.org.uk/cd-content/uploads/files/SEND%20Strategy%20Vision%20Day%202019.pdf~RF2dcfdcd.TMP>

Developing SEND Provision in Shropshire - <http://www.paccshropshire.org.uk/cd-content/uploads/files/Participation%20Report%20-%20Developing%20SEND%20provision%20final%281%29.pdf>

Both of these pieces of work have led directly to changes in Services and show how in some areas the parent carer voice is influencing decision making in Shropshire. We are particularly positive about the development of the new Shropshire SEND Strategy, which very much reflects the voice of families, is outcomes focused and offers a real opportunity to improve joint working.

We are concerned however about the lack of opportunity for parent carer participation and co-production in the local health sector. There is no clear pathway for parent carer engagement and PACC has no relationship with the Shropshire Clinical Commissioning Board. We have had links with individual managers and commissioners within local health services, but our experience is that discussion have, in most cases failed to have any real influence or to deliver the required change. PACC has been requesting an opportunity to contribute to local work on the Transforming Care Agenda for several years but have made no progress in being involved in this programme of work locally, despite a clear national directive that their should be a greater focus on children and young people in Transforming Care work in local areas and that families should have a voice in how this programme is delivered.

PACC has worked to create opportunities for parent carers to share their experience and views on local health services, see;

Developing Pathways for Neurodevelopmental Conditions - <http://www.paccshropshire.org.uk/cd-content/uploads/files/EHWS%20SEND%20Workshops%20Report%281%29.pdf>

Exploring the Reality - <http://www.paccshropshire.org.uk/cd-content/uploads/files/PACC%20Exploring%20the%20Reality%20Report.pdf>

It has been disappointing however, that despite sharing the learning from these events there has been no clear response to the issues raised or opportunities offered by the CCG to work with PACC further to improve families' experiences or outcomes. PACC is in particular seriously concerned that there have been little or no opportunities for us to work with the Midland Partnership Foundation Trust to support the design and delivery of the Neurodevelopmental Pathways. This service area is the area on which we receive the most feedback from parent carers and it is overwhelmingly negative. There have been long standing issues with waiting times, but we also hear repeatedly that families experience of this service is poor.

"It's awful. My son has been waiting to see CAMHs for over two years. We've requested and requested and requested, even telling them about when he has threatened to hurt himself but to no avail. The length of backlog is unacceptable and needs sorting. At the moment you are going to end up shutting the gate after the horse has bolted".

(Response to Shropshire SEND Strategy Survey – May 2019)

"If anything the support has made my daughters difficulties much much worst and exasperated her mental health. Her mental health deteriorated to such an extent her self harm is prolific and she recently took an overdose."

“After having a seriously depressed teenager for 18 months, he is now in the right programme, and is on the way back to having a reasonable level of self-esteem. But he has been damaged by the way Shropshire failed to adequately meet his needs for over a year!”

“Receives medication to help with ADHD diagnosis. However needs behavioural and emotional mentoring to work effectively with on going long term support than quarterly check ups because he is often changeling in behaviour and been addicted to over age product.”

“My child was assessed at 3 years and the assessment team didn't want to give an ASD diagnosis at that time as he was so young and had further to develop. It was promised that his diagnosis would come to a conclusion at a later date. However 4 years on, my child is now 7 years old, we are still waiting for that conclusion. I had to ask and persuade the paediatrician to re refer to what is now BEE U for a final conclusion to his diagnosis. She did so when my child was 5 years. I received a letter stating a 9 month waiting list before we would hear anything. Before my child's last visit to the paediatrician after the 9 month wait, I contacted BEE U to discuss possible appointment times. I was laughed at and told that he was on the list but couldn't possibly tell me when he would receive any information regarding next steps or appointment date. I was promised some literature through the post, this had been the second time I'd been promised this and as yet it still hasn't arrived more than a year on. We saw the paediatrician who could only apologise for our wait with BEE U. Apparently we are lucky to be in the system at all. At that point my child was 6 years and was discharged from her care. We are still waiting for a response from BEE U for the literature I was promised or appointment. Just appalling service.”

(Responses to ‘If the SEND Inspection was Today Survey – October 2019)

Families have also highlight an ongoing issue around a lack of co-ordination between services and the impact that has on families.

“What would help? - An administration tool that manages all our appointments and paperwork, a one stop shop about my child. Especially as I am sick of toing and froing to change appointments so my daughter can actually attend school! If they could all see what was happening, then they could take that into consideration!”

(Response to Shropshire SEND Strategy Survey – May 2019)

This was an issue also covered in more detail in PACC's report 'Exploring the Reality' <http://www.paccshropshire.org.uk/cd-content/uploads/files/PACC%20Exploring%20the%20Reality%20Report.pdf>

More SEND training for schools and other services was identified by families as a priority and PACC would like to see a planned, ongoing programme of training that would ensure that families would receive consistent guidance and advice from the start of their journey and so would be met with an understanding of how raising a child with SEND impacts family life. We need all services to understand how best to support SEND families and to know what support is on offer or at least be able to effectively signpost families.

“A greater support network, so parents know exactly who to turn to for help or advice. I personally felt very alone and overwhelmed throughout the whole EHCP process. I turned to several professionals and

support outlets (I) for guidance but didn't feel suitably equipped or knowledgeable enough to ensure that my daughters needs were being met in the best way possible."

(Response to Shropshire SEND Strategy Survey – May 2019)

PACC does recognise that as an organisation we have our own challenges, with the main challenge being our current reduced capacity and our need to recruit more parent carer representatives, since there are often more requests for parent carer representation than we can respond to. During the period we received additional funding from the Big Lottery, PACC was able to maintain a higher profile in our local community and we were able to deliver a higher level of communication with Shropshire parent carers. We issued a comprehensive newsletter, 'Participate', on a termly basis, working with the SEN Team and other services to provide information to parent carers (See example at <http://www.paccshropshire.org.uk/cd-content/uploads/files/spring%2018%20v2.pdf>).

Since the funding from the Big Lottery came to an end we have struggled to maintain this level of communication and while we still maintain contact with the parent carer community via a very active social media programme, we recognise that we need to re-establish other ways of listening to and informing parent carers about our work. Over the past 12 months PACC has explored alternative ways of supporting parent carer participation in Shropshire and have looked to work increasingly in partnership with other organisation, to deliver shared aims. We are particularly pleased to be part of the newly formed Actio Consortium, which we believe will help PACC to reach more parent carers and to continue embedding co-production in Shropshire.

Summary

There is clearly a mixed picture in Shropshire in terms of the quality of support and experience for SEND families. There are some areas within the Shropshire SEND system where positive progress is being made and there is a high level of commitment to co-production, person-centred approaches and improving life outcomes for children and young people with SEND and their families. Families that are entering the Shropshire SEND system now, are in many cases having a better experience than those who went before, but some families are still left feeling that they are being let down and failed by key services. Some services such as the SEN Team are fully committed to co-production with parent carers and young people and are open to feedback and working in partnership with families, however other areas of the system remain impenetrable.

Based on the observations captured in this report PACC would like to see the following treated as priority actions for Shropshire's SEND Leaders;

- Improving communication and links between Shropshire CCG and PACC, so that parent carers are able to contribute and inform local health decision making and provide a focus on ensuring that the health needs of children and young people with SEND are addressed.
- Responding to and addressing the concerns raised by families about the Shropshire neurodevelopmental pathway, specifically around Autism / ADHD diagnosis and post diagnosis support. This should include improved co-production, transparency and joint working with other services.

- Improving Post 16 pathways and planning; specifically providing accessible information for families to enable them to make informed decisions about preparation for adulthood and improved joint working between education and social care for those young people with complex needs.
- Continuing to develop a positive and active relationship with SEND families, that informs and builds resilience.



SHROPSHIRE
Parent
And
Carer
Council

Meet the SEND Inspection Team

Have your say;
Tuesday 28th Jan 12-1pm at
Unison Club, SY2 6ND. Nr
Shirehall, access via Shirehall
carpark.

Are you a parent carer of a child/young person aged 0-25 with SEND who lives in the shropshire local authority area?

PACC are pleased to announce a meeting with the inspectors has been arranged for parent carers to come and share your experiences of SEND in shropshire.

This is not a place where they can resolve individual issues, but your experiences will help us understand where systemic challenges are and where changes can be made to improve the lives of SEND families in Shropshire.

Tea and coffee will be available, and PACC reps will stay for another hour to talk with parent carers afterwards. Please contact PACC directly if you wish to share your thoughts but cannot attend.

Please express your interest by emailing enquiries@paccshropshire.org.uk so we can ensure we have catered for enough people.

