PACC
Championing your voice

Parent Carer Council
Shropshire

Exploring Support for Parent and Family Carers in the Shropshire SEND Community

July 2026

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What would help?

Executive Summary

During Carers Week 2026, PACC (Parent Carer Council Shropshire) brought together parent and family carers from across Shropshire to explore what supports their wellbeing and what changes are needed to improve life for families raising children and young people with Special Educational Needs and Disabilities (SEND).

This report draws together the experiences of 57 parent and family carers through conference discussions and an online survey. Families represented children and young people aged 0–25 years across mainstream, specialist, and post-16 settings, from across Shropshire.

The findings present a consistent and compelling picture. Parent carers described lives characterised by overwhelming caring responsibilities, constant uncertainty, lengthy waits for support, fragmented services, and the emotional burden of having to continually advocate for their children. Many spoke of feeling isolated, exhausted and unheard, while trying to balance employment, family life and caring responsibilities with little opportunity for rest or recovery.

Despite these challenges, families also identified clear solutions. They highlighted the importance of accessible peer support, opportunities to connect with others who understand their experiences, and practical information delivered at the right time. They called for practitioners who understand the realities of family life through lived experience, better communication, transparent information, coordinated services, and genuine co-production where parent carers are recognised as equal partners.

Across every discussion, one message was consistent: supporting parent carers is not an optional extra—it is fundamental to improving outcomes for children and young people with SEND. When parent carers are informed, listened to and emotionally supported, they are better able to advocate for their children, engage positively with services and sustain their caring role.

The report identifies four priority areas for action:

- Reducing isolation by strengthening community connections, peer support and accessible local opportunities.
- Building trust and understanding through lived experience training, trauma-informed practice and meaningful co-production.
- Empowering families with timely, accessible information, clear pathways and coordinated support from the earliest stages of their journey.
- Providing practical support through improved respite, holiday provision, wellbeing support, joined-up services and recognition of parent carers' own needs.

The report concludes that there is an urgent need for a coordinated Parent Carer Wellbeing Offer across Shropshire. It recommends greater recognition of Parent Carers' legal rights to assessment and support, investment in peer support and therapeutic services, improved communication across the SEND system, and a stronger culture of partnership between families and professionals.

Background

To mark Carers Week 2026 PACC’s annual conference focused on ‘exploring support for Parent and Family Carers in the Shropshire SEND community.’ During the day we explored key questions;

- What are the main things that **impact** parent/family carer **wellbeing**?
- How can we create a sense of **community** and belonging for Parent / Family Carers to address **isolation and loneliness**? What is currently working and what else needs to be done?
- How do we create **empathy and understanding**, so that Parent Carers feel listened to and understood? What is currently working and what else needs to be done?
- How do we ensure that Parent Carers feel **empowered** and know their rights? What is currently working and what else needs to be done?
- What should be offered as **practical support** for Parent Carers? What is currently working and what else needs to be done?

These questions also formed the basis for an online survey the responses to which also informs this report.

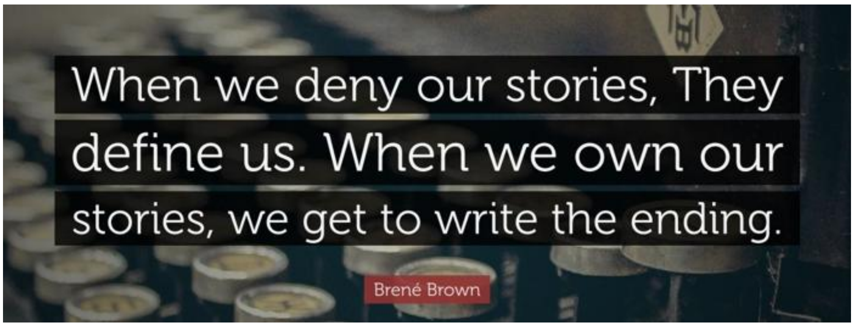
Practitioners from across the Shropshire SEND system were invited to attend the conference, but there was only representation from Social Care on the day.

The conference was opened by Rachel Wright, author, nurse and Parent Carer.

Rachel Wright

- Director- Born at the Right Time
- Burse
- Authort- The Skies I’m Under
- Podcast Host- The skies I’m Under
- Finalist- National Learning Disability and Autism Awards 2026
- Finalist- HSJ Best Education Programme- NHS 2023

Rachel's presentation, **'It's Hard because it's Hard – the life of a Parent Carer'** talked about the many aspects of being a Parent Carer, much of which is hidden. She spoke about the importance of Parent Carers understanding their own lives and the value of research that helps with the understanding of why it can be so challenging. She then focused on how even small things can make a big difference in making life less hard.



When we deny our stories, They define us. When we own our stories, we get to write the ending.

Brené Brown

Further reading;

Bridging the Gap Between families and Services www.bornattherighttime.com

Trauma and Parent Carers https://www.bps.org.uk/psychologist/trauma-and-parent-carers

System Generated Trauma https://cerebra.org.uk/systems-generated-trauma/

More Than a parent https://www.birmingham.ac.uk/about/college-of-social-sciences/policy-engagement/parent-carers

Conceptualizing burnout from the perspective of parents of children with complex care needs https://www.sciencedirect.com/science/article/pii/S2772628224000736#s0065

Research Says

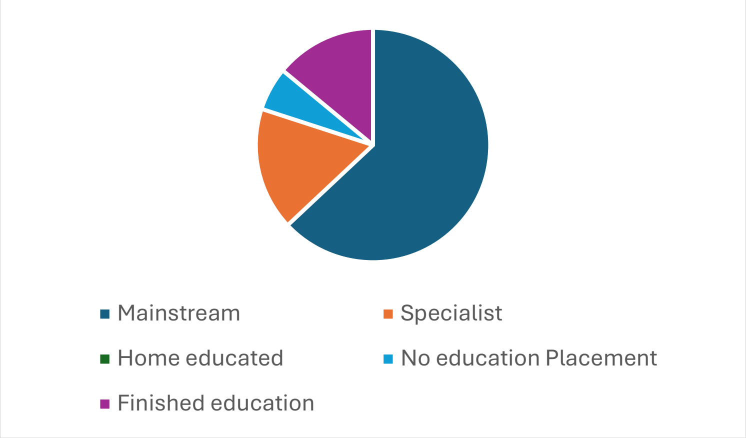
It **is** hard.
It isn't that you are doing it wrong.

Our brain naturally focuses on negatives.
Train it for the positives too.

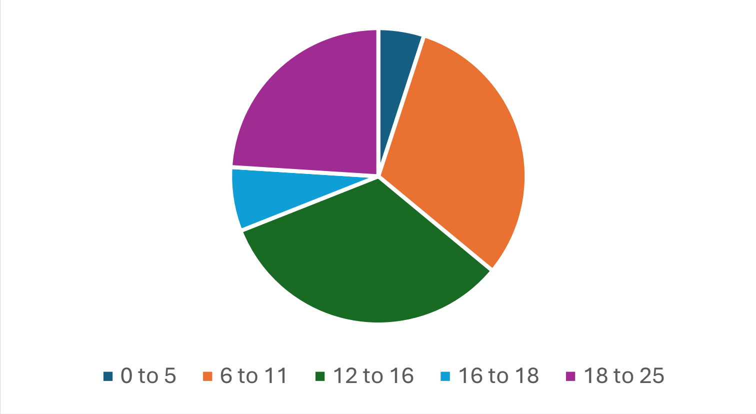
Discussion and Survey Responses

32 parent / family carers attended conference and further 25 parent / family carers responded to the online survey. 57 parent / family carers participated in total.

Education Setting representation

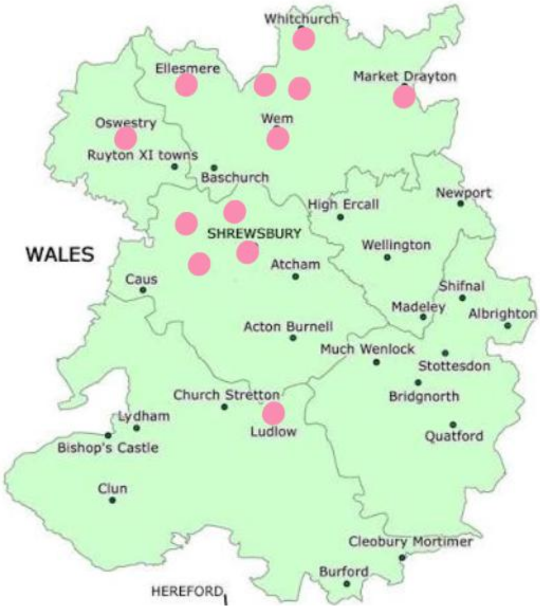


Age range of children and young people represented



Parent / Family Carers participated in this discussion from the following places in Shropshire;

- Shrewsbury
- Wem
- Bayston hill
- Whitchurch
- Baschurch
- Stanton upon Hine Heath
- Ludlow
- Ellesmere
- Market Drayton
- Yockleton
- Worthen
- Grinshill
- Oswestry


Whitchurch
Ellesmere
Market Drayton
Oswestry
Wem
Ruyton XI towns
Baschurch
Newport
High Ercall
SHREWSBURY
WALES
Wellington
Atcham
Caus
Shifnal
Madeley
Albrighton
Acton Burnell
Much Wenlock
Stottesdon
Church Stretton
Bridgnorth
Lydham
Ludlow
Quatford
Bishop's Castle
Clun
Cleobury Mortimer
Burford
HEREFORD


Group Work
What is the hardest bit right now?
(30 seconds only!!!)

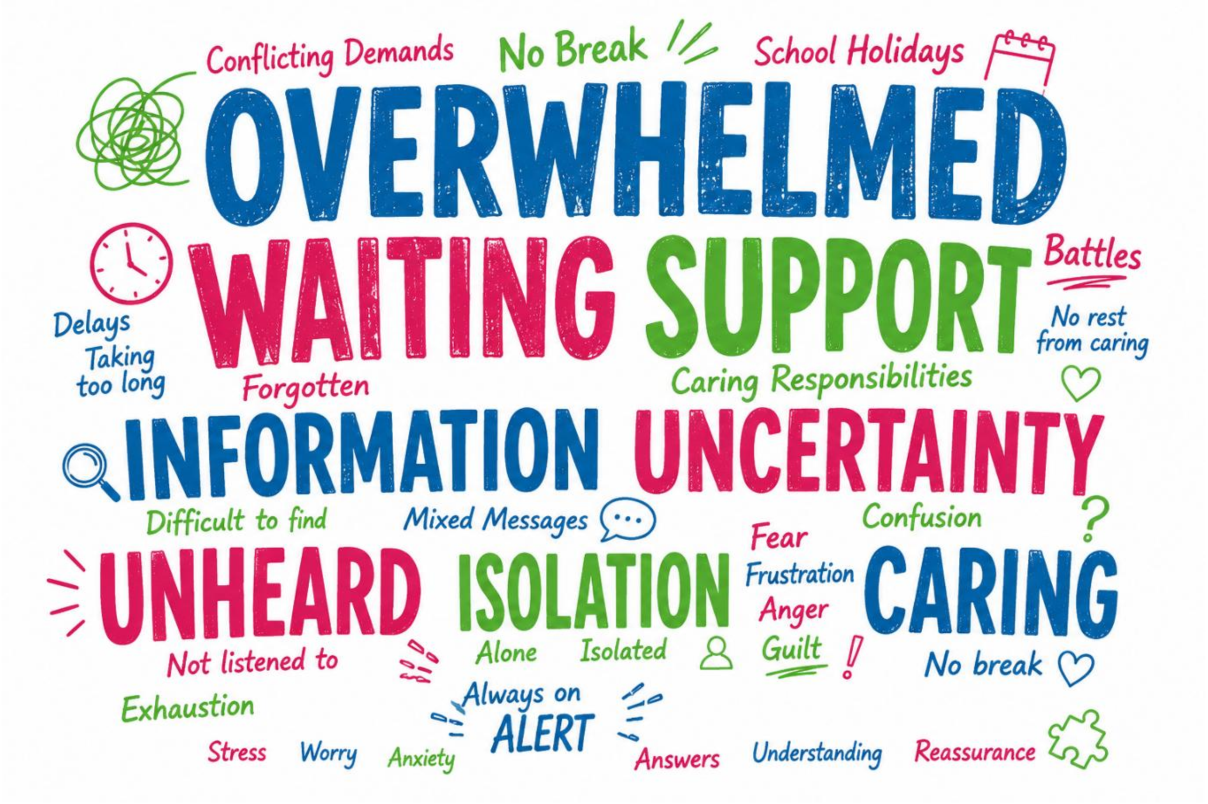

Born at the Right Time


Employment Law & HR Specialists

Summary and key finding of Conference Discussion and Survey Responses

(see Annex 1 for full transcript of discussions and survey responses)

What are the main things that impact parent/family carer wellbeing?



Key themes;

- Juggling many conflicting demands, feeling overwhelmed
- Difficulties in finding the information and support you need, everything is a battle
- Mixed messages – not knowing what is right, confusion and uncertainty
- Extreme emotions – fear, guilt, anger, frustration
- Everything taking so long – the impact of waiting and not knowing, feeling forgotten
- Always having to be on alert
- Not feeling heard
- No rest or break from caring – especially during school holidays
- Feeling alone and isolated

“My wellbeing is most affected by uncertainty and the lack of a clear, realistic pathway. It's frightening and exhausting not knowing what happens next in further education and beyond - not just some vague theoretical options some people may mention if you're lucky. I worry about how I'm supposed to balance work with caring responsibilities, how I'll manage the time and money to drive him to day provision and whether he will get the right support. Access to post 19 provision feels inconsistent and secretive, with some families able to access things that others never hear about. I'm left year by year, constantly fighting for, researching, and negotiating continued education, even though it's known that young people with SEND need more time to learn and develop.”

“Lack of rest, breaks, respite. Lack of support from friends and family. There is no "village" there is just you. Lack of normality in your own life yet trying to fit into a world built for so called normal people.”

“For me it’s filling in endless forms, all the chasing and follow up that has to happen when you don’t hear back. Having to fight the system for something that really should be basic. That alongside the caring responsibilities and just general day to day coping. Also, the juggling of your child who has SEN and their siblings needs. That family don’t really want to help as it’s too complex, so you never get time for yourself or with your partner. Oh, and trying to manage to fit in a full-time job!”

What would help?

1. **Addressing isolation and loneliness by creating a sense of community and belonging. How do we do this?**

Key themes;

- Making places accessible for everyone, space to be quiet as well as talk – remember Parent / Family Carers can be neurodivergent too
- Use accessible language to make people feel welcome
- Opportunities to meet at a range of times and places
- Different environments are needed for different groups
- Connect people from the start of their journey's
- More local support and services – remove travel barrier
- Reach out to those who find it difficult
- Support greater visibility of SEND
- Improved communication and information sharing
- Support for experience led groups

"Personally, I don't feel isolated anymore as have surrounded myself with people who are in the same boat but 2 years ago it was very different story. South Shropshire is seriously lacking support. There needs to be more openness around parenting Sen children because sadly nobody understands unless they live with it"

*"It's always reassuring to know that other people have shi*t days too"*

"I don't have a village when it comes to SEND – but I am trying to find it"

"Proper signposting i.e. for half term and summer holidays 1:1 funding to go to clubs. Theres not a lot of Information sessions in areas such as Shrewsbury. More tea/coffee mornings/afternoons in a week on different days and times to cater for working parents."

"Creating a sense of community and belonging for parent carers starts with having spaces where we don't have to explain ourselves from scratch. The things that work best right now are the peer-led groups and the bigger lived-experience events — those moments where you walk into a room and instantly feel understood. Hearing from others who've walked similar paths genuinely lifts something heavy off your shoulders. The annual conference is a perfect example: it reignites that spark, reminds you you're not alone, and gives you a kind of energy you can't get from anywhere else. But there's still a lot more that needs to be done. So many parent carers are isolated because time is a luxury we don't have. Any spare moment gets swallowed by the basics — food shopping, cleaning, paperwork — so even when you want to prioritise your mental health, it's the easiest thing to push aside. That's why community has to be made accessible, flexible, and built around real life, not ideal circumstances. We need more peer-led spaces that are properly supported, not relying on volunteers burning out. We need lived-experience events that happen more than once a year. We need meet-ups that don't require planning weeks ahead, and options that include children so carers who can't get childcare aren't automatically excluded. And for those of us doing this single-handedly, connection is even more important. When you don't have another parent to bounce ideas off or share the emotional load with, community becomes your lifeline. That's why support for single parent carers needs to be built in, not an afterthought. What works is simple: being around people who get it. What needs to happen is making those moments easier to access, more frequent, and properly supported so no one feels like they're carrying this journey alone."

2. Creating empathy and understanding – feeling listened to. How do we do this?

Key themes;

- The need for training for Practitioners and Managers from all services on the lives of SEND Families and its potential impact on wellbeing
- The need for Practitioners and managers to understand how the wider system works so they can signpost effectively
- All training to be delivered by or in partnership with those with lived experience
- A culture of active listening supported by transparent, honest and non-judgemental communication
- Support for Parent / Family Carers to understand and explore their own emotions and feelings
- Embedding coproduction so that lived experience is valued and recognised in all decision making
- Support for community-based, experience led groups

"Importance of listening and validation – Not being made to feel like a neurotic mother"

"Parent Carers are small fish in big sea – when we work and share our voice with PACC we become a bigger fish by being together"

"I think having more opportunities to meet with specialist practitioners and LA decision makers to build a connection with these people rather than as a one off could help to develop trust and a sense that they understand the realities of our lives."

"I just want to feel like someone is listening to me, not judging me or assuming I am failing as a parent because of how my child behaves, If I was failing, I wouldn't be asking for help."

"Recognising your own triggers when interacting with others"

"Attending my first local PACC meet up this week, I found all the ladies welcoming and very understanding of my situation. It was a 'breath of fresh air' to speak to people who have been there, done that already, and reassure me that there is help and support available. It has made a huge difference to how I am feeling about my future and the future for my daughter"

3. Empowerment and Understanding your Rights – what would help you feel empowered and to understand your rights

Key Themes;

- Having access to a person to discuss the information you need – can be face- to- face or online but needs to be the option for 1:1 discussion
- More support from the start of the Parent Carer journey, proactive support
- Regular workshops covering a range of topics on offer, in different places, at different times
- Create a co-ordinated peer support offer
- Creation of transparent and accessible information so that families and practitioners are clear about what should happen and when
- Information about SEND more visible in the community – especially education settings
- System is more joined up and co-ordinated
- Clear guides and pathway maps available
- Timely responses to questions and enquiries

"Early on I wanted practical information about what diagnosis meant and how to help my child"

"I wanted information as soon as possible"

"It is difficult to know what help and support is available. I find trying to look for help a bit mind boggling trying to navigate websites and different links. I also find when you do contact anyone it all seems very disjointed, one team can look at this, another at this etc"

"Empowerment starts with actually being able to access the right information at the right time. When you're in crisis, being told someone will call you back tomorrow — or next week — doesn't help. What is working at the moment is how quickly PACC respond, and how accessible they make their website. When you reach out, you get a call back fast, and that alone makes you feel less alone and more in control."

4. Practical Support – what does this look like. What has worked well?

Key Themes;

- Need to create a joined-up system
- Need to Co-ordinate information sharing
- More support is needed during school holidays – recognise the challenge of balancing work demands and caring as well as fulltime caring
- Need breakfast clubs and afterschool care for SEND families
- More Short Breaks are needed to give Parent / Family carers a break.
- Create a therapy offer for Parent / Family Carers to support wellbeing
- Create a programme of wellbeing activities for Parent / Family Carers
- Practitioners being readily available to speak to and ask questions

“Link together which things that already exist, e.g. the mental health bus already visits lots of areas of Shropshire, this service could be expanded to include other support services”

“More Holiday provision – a massive gap, complexities of looking after other children/siblings, 1:1 support in school but nothing in holidays”

“More help at home – need order, need to not feel overwhelmed, reduced parental load”

“Emotional support/counselling is missing for Parent / Family Carers”

“Need to embed self-care, people see time out as self-indulgent”

“Having a consistent point of contact with someone who knows what support/provision is available who is transparent and not governed by another agenda, political agendas or finances”

“Holiday clubs!!! Proper ones not 9-3 but ones that real working parents who do a 9-5 job can use. Ones that aren’t just based in Shrewsbury. We have nothing for SEN kids in Whitchurch in the holidays. I take unpaid leave to manage. It really affects our home budget and the only reason I have to do this is because my child has SEN. It’s disgraceful.”

“Love, love, love HLP. It is life changing. No longer the fear and dread approaching the school holidays!”

“Parent carers shouldn’t have to be the admin team, the case manager, the advocate, and the crisis-handler all at once. Services need to offer real hands-on support — someone who can step in and actually do the task, not just tell you how to do it. Especially for single parent carers, because there’s no one else to share the load with.”

Conclusion

It’s clear that Shropshire Parent / Family Carers are struggling and their wellbeing is being eroded. This is not happening to a few individuals but is experienced throughout the community and is something that is reflected not just in this piece of work, but in PACC’s daily contact with Shropshire Parent / Family Carers.   Not addressing this will inevitably result in poorer outcomes for children and young people with SEND in Shropshire and potential the wider family unit. A clear plan to support the wellbeing of Parent / Family Carers is essential both for the community and the system.

Key issues to be addressed are;

- **Increasing opportunities for Parent / Family Carers to connect with each other and to benefit from Peer Support.** The value of this is continually highlighted by Parent / Family Carers and was evidence in the feedback collected through the local Partnership for the Inclusion of Neurodiversity in School (PINS) project, where PACC worked with Primary Schools to create opportunities for Parent Carers to come together.

  It is important that these opportunities are organised and led by trusted, experience led organisations, offering Parent / Family Carers a space where they are confident that they will be welcomed and not judged.

  There are opportunities for the system to facilitate Parent / Family Carers coming together by sharing information about existing opportunities at the point of diagnosis. There is also potential for Family Hubs and the Best Start for Life offer to work with experience led organisations from the SEND Community to develop a network of Peer Support opportunities.

- **Improved recognition that Parent Carers have a right to an assessment of their needs under the Children and Families Act 2014.** Under it, local authorities must assess parent carers if:

‘it appears to the authority that the parent carer may have needs for support’, or they
‘receive a request from the parent carer to assess the parent carer’s needs for support.’

These assessments are called parent carer’s needs assessments, and they must also take into account ‘the well-being of the parent carer’, as well as the needs of the child. The ‘wellbeing duty’ means local authorities must consider a person’s:

- personal dignity and respect
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family, and personal relationships
- suitability of living accommodation
- contribution to society.

It is unclear how parent carer needs assessments are being delivered in Shropshire. It would be beneficial to understand the data around the number that have been completed and what support has been provided as a result of these assessment. This data should be used to inform the delivery of a clear support offer for Parent Carers alongside a Carers offer for those supporting individuals 18 plus.

It is particularly important to recognise that the ‘participation in work’ is specified under the ‘wellbeing duty’ since PACC is aware that this is a particular area of concern for Parent Carers. Many have shared experiences of having to reduce or give up their work roles due to being Parent Carers which impacts family financial security as well as Parent Carers mental health.

Feedback also highlighted the need to support the emotional wellbeing of Parent / Family Carers and how a specific therapeutic offer would be welcomed. The need for this is well supported by research, which evidences the level of trauma often experienced by Carers from the SEND community.

- **Build a more positive relationships between Parent / Family Carers and the local SEND system (0-25 years)**
  It is clear that currently too many Shropshire Parent / Family Carers do not feel sufficiently listened too or valued by the local SEND system. Their feedback highlights concern with poor and delayed communication creating anxiety and distress, frustration from receiving inaccurate information and feeling like they are blamed for needing help.

  There are several things that can be done to improve this relationship;

  Training; Practitioners must be supported to understand the impact of raising a child with SEND and be familiar with the research on this subject. Their interactions with Parent / Family Carers should be trauma informed and considerate of the mental wellbeing of individuals. Managers should create a culture shaped by understanding and empathy, where it is acknowledged that for many SEND families asking for help is a result of the impact of SEND on their lives and not poor parenting.

  Understanding the lived experience will also support the delivery of coproduction. Practitioners and managers should receive training to ensure that they understand what coproduction entails and how to deliver it at an individual, operational or strategic level. Seeing Parent / Family Carers as partners and not opponents will only strengthen the effectiveness of the system.

Creating a responsive and joined up system; Much of the frustration felt by Parent / Family Carers is due to a lack of responsiveness from the local system. This is evident in long waiting times for various assessments but is also present in everyday communications which families tell us too often become extended and exhausting, requiring them to constantly chase responses to even the most basic questions or enquiries. Good communication with Parent / Family Carers needs to be recognised as an essential aspect of an effective SEND system and must be prioritised.

Alongside this the system needs to be more joined up, sharing information instead of constantly expecting Parent / Family Carers to repeat their stories. Practitioners need to widen their knowledge and understanding beyond their own service and understand how their work area connects and interacts with others so they can contribute to the provision of effective joined up support.

Accessible and transparent information provision; The system should operate in an open and transparent way, including ensuring that SEND families can access information about their rights and how services are expected to operate. SEND families understand more than most that sometimes things don't go to plan and that resources are not unlimited, more open conversations would strengthen relationships and build trust.

Access to accurate information is also key to empowering Parent / Family Carers and enables them to effectively participate in decision making about the support their family receives. This ability to positively shape and contribute to what their and their child's lives look like is beneficial for their wellbeing and capacity to continue caring.

Learn from previous activity; The experience of PINS highlights the value and impact of focusing on relationship building, with teachers and senior leaders from schools receiving 'Understanding the Lives of Parent Carers' and 'The Coproduction Journey' training from PACC. This training, along with support to deliver coproduction activity with Parent Carers, changed relationships and enabled new more positive partnerships to be developed through improved understanding of a different way of working.

PINS Shropshire – Coproduction in Action Report
https://www.paccshropshire.org.uk/wp-content/uploads/2026/07/PINS-Shropshire-Coproduction-in-Action.pdf

PINS Shropshire – Coproduction in Action, A Parent Carer Resource
https://www.paccshropshire.org.uk/wp-content/uploads/2026/06/Coproduction-in-action-A-Parent-Carer-Resource-Shropshire-Primary-Schools-PINS-1.pdf

Next Steps

PACC will use this report to inform our discussion with the Shropshire SEND system and promote the need for improved support for Parent and Family Carers from the SEND Community, as a fundamental element of the work to improve outcomes for children and young people with SEND.

PACC will share this report with Shropshire Senior Leaders from Education, Health and Social Care, and local elected representatives and request a response to the concerns raised.

We want to thank all the Parent and Family Carers who found the time and energy in their busy lives to either attend the conference or respond to the survey. Your words speak for those members of our community who are too overwhelmed, frustrated, angry, tired or sad to share their experiences. Coming together in this way is another example of the important support we give each other on this unexpected journey.

Annex 1

What are the main things that impact parent/family carer well being?

Feedback from Conference

- *Small village single parent – isolation*
- *Good transport*
- *Secrecy*
- *Who you ask*
- *Capacity to find information*
- *Some people manage to access things that others can't – who you know makes a difference*
- *Accessing events with other commitments*
- *Trusting and gullible of what specialists have said. When going private/ independent then you get a different message.*
- *Guilt*
- *Time for support and need to go private*
- *Parents expected to work to deadlines, but specialists don't*

Online Survey Responses

The fighting of getting any support, not being listened to, the feel of parent fault from professionals and the anxiety of how are they (Child) going to be in a certain situation, having to pre plan everything

Professionals not taking on board what you're saying

No rest

School not listening or taking on board thing we say or taking it on board but not actioning what they say

Feeling like you constantly battling for your child to get help, especially from an uncooperative school. Worrying they are missing out on life experiences. And forever wondering if you're doing the right thing

My wellbeing is most affected by uncertainty and the lack of a clear, realistic pathway. It's frightening and exhausting not knowing what happens next in further education and beyond - not just some vague theoretical options some people may mention if you're lucky. I worry about how I'm supposed to balance work with caring responsibilities, how I'll manage the time and money to drive him to day provision and whether he will get the right support. Access to post 19 provision feels inconsistent and secretive, with some families able to access things that others never hear about. I'm left year by year, constantly fighting for, researching, and negotiating continued education, even though it's known that young people with SEND need more time to learn and develop.

Lack of sleep and fighting for everything it's exhausting

Not being able to access support unless in crisis.

Lack of support, bureaucracy around obtaining and keeping any support. How demeaned you are made to feel by the processes.

Full time carer for child with complex medical and cognitive needs – lots of paperwork on top of physical care role – lots of chasing Shropshire Council and not getting anywhere – lots of fighting for basic support. Child cannot manage any of his medical care autonomously due to his cognitive disability, yet we have a constant battle to prove this need. There are no breaks – it's a 24/7 job night and day – even when he's at school or respite, I'm usually either needed on the phone in some way or I'm going in to pick him up because he's not well or I'm going in to support staff with equipment failures etc. I'm also spending hours and hours completing paperwork on top of all this. It feels never ending and exhausting.

(Child's) Anxiety about Leaving me and going to school.

Negativity from school as they have a lack of understanding in The Hub. That NO Shropshire services i.e. Camhs and Local Authority know where to signpost parents to get the 1:1 funding they need for their child to go to half term and summer holidays. The constant stress of specialist schools not having space for SEN kids. The parent constantly having to chase up *schools, local authority etc updates on alternative provisions to the point parents such as myself have to chase them up to get things sorted quickly.*

No time to self, cannot be ill or meet my own needs, no respite,

For me it’s filling in endless forms, all the chasing and follow up that has to happen when you don’t hear back. Having to fight the system for something that really should be basic. That alongside the caring responsibilities and just general day to day coping. Also, the juggling of your child who has SEN and their siblings needs. That family don’t really want to help as it’s too complex, so you never get time for yourself or with your partner. Oh, and trying to manage to fit in a full-time job!

Not feeling supported by local councils, feeling like you have to 'prove' or educate in order to be heard. Feeling like education is more important than mental health. Pressure to send a child to school who's struggling. The changes the government are making to home educators, parents should be able to know what's right for their child and that should be the priority, with support if needed. Schools are not inclusive, where our daughter can participate in certain events or activities, because schools don't have the support to do it. The list goes on. It's a full-time unpaid job , chasing school, doctors, appointments do activities outside of school because they missed out on inside school activities again the list goes on.

Constant worry about child's wellbeing and mental health. Lack of appropriate services, waiting times for what is available and lack of clarity about how to get support. Fear for the future.

No joined up working between services meaning parents have to share all the information over and over again. Lack of understanding about ND, even from specialist professionals. Poor support via social care. Being made to feel inferior for living in a rural area.

Ability to get timely appointments, diagnoses, and treatments for loved one. The consistency and reliability of the support system in education for loved one. Having support from other parent carers who 'get it' about the role of parent caring. Being able to find support and information swiftly and without huge effort/being directed to up-to-date support and information *easily. The ability to grow a support network in the context of the extensive role of caring in a Parent Carer's life. (make a positive difference)*

Managing 3 different sets of needs, 3 different levels of support, often with long delays. Getting letters which don't specify which child they are for, and what the appointment is about. Having to advocate and push for every bit of support, but then the schools not proving what is needed. Relying on me to notice, activate, push, not drop the ball, refer into unknown services with unknown wait times. Exhaustion from working full time, caring for 3 children and a husband.

Lack of rest, breaks, respite. Lack of support from friends and family. There is no "village" there is just you. Lack of normality in your own life yet trying to fit into a world built for so called normal people.

Fighting the system for the right support. Transitions Living with the uncertainty of 'what next'. Waiting for things to happen/ be put in place Lack of day-to-day practical support and inflexibility of support on offer - having to 'fit in' with what's available rather than it being individualised to meet day to day and changing demands and needs

Trying to find out what is available and fighting for your child due to unrealistic expectations.

Poor service from schools/local council causing endless chasing, complaining, etc is draining. Concern for the future of our son when we are not here.

Parent carers' wellbeing and mental health are heavily impacted because the system requires them to constantly repeat the same information and start again with every service, with no continuity or joined-up support. There is a constant fear that one wrong word or misunderstood comment could block access to help, and families are rarely told what the criteria actually are, leaving them feeling let down and blamed for things they were never informed about. This pressure leaves no time or space for processing, talking things through, or having any meaningful self-care, especially when short breaks aren't available to many families. For single parent carers, the impact is even greater because there is no second parent to share the *mental load, decision-making, or emotional strain. And when you have two children with SEN, their needs, profiles, and journeys are never the same — meaning you are effectively navigating two separate systems, with different professionals, pathways, and challenges, all at the same time.*

Not having enough sleep, no respite, your child needing round-the-clock care for safety and financial difficulties also add significantly to our low mental health.

Lack of support, slow response times (support, diagnosis)

What would help?

1. **Addressing isolation and loneliness by creating a sense of community and belonging. How do we do this?**

Conference Feedback

Accessibility for all – are there quiet spaces, can we park nearby?

Digital has a role to play. Face to face is more enjoyable – can we do hybrid?

The word conference sounds very formal.

Recognise that PC may be nervous

Having weekend activities

Need somewhere to just breathe

"I don't have a village when it comes to SEND – but I am trying to find it"

"It's always reassuring to know that other people have shi*t days too"

Lots of people are hidden at the start of the journey. Pre-diagnosis and the early years are hard

Having an open space to ask questions without judgement

Remembering to consider PC's own neurodivergence

Making sure that practitioners/schools/SENCOs know the right information to share

Having better and more local community services you can refer yourself to

Is there a SEND offer within young farmers?

Having a directory of voluntary organisations that PC could access

Knowing which venues are SEND friendly and where our allies are is important

Peer support within schools to help make diversity positive

Increase provision in all areas of Shropshire

Employers being supportive and educated in SEND

Addressing isolation and loneliness

Have a dark room

Importance of networks – little and often

Support for dads – emotional support – Best time of the week is going to the pub with other parents on a Thursday

Understanding that some parents can't get out

More courses like the Healthy Parent Carer course run by PACC

More community networking e.g. Buddies bowling

***"Hair, prayer and publicans"** - this was a scheme that ran a number of years ago where information on support for PC was available on beer mats, via hairdressers etc*

Survey responses;

Support groups, events for parent carers chill time

I attend PACC's sessions which have supported me loads and made me feel a part of something, but it's difficult if your small person wants all your attention to not feel alone. Carry on with this support PACC as it makes so much difference

Sound bath session was great to promote relaxation. Miss in person Autism West Midlands information sessions. PACC sessions for parents and their children under 7 in the holidays

I'm still new to the SEND world but I have no idea where to look for help

Attending events run by PACC mean that I get to meet parents in a similar situation. It's been a lifeline and you get to develop friendships with people who truly understand.

Personally, I don't feel isolated anymore as have surrounded myself with people who are in the same boat but 2 years ago it was very different story. South Shropshire is seriously lacking support. There needs to be more openness around parenting Sen children because sadly nobody understands unless they live with it

I must admit I am not completely sure what is currently out there with regards to isolation and loneliness however I have seen some things being advertised which seem to be more based in Shrewsbury, Bridgenorth, Ludlow, as a resident of Whitchurch it would be great if occasionally there was something here. Apologies if there is though and I haven't seen it.

PACC are amazing don't feel so alone.

Informal meet ups

More teams meeting or catch-up dates.

Proper signposting i.e. for half term and summer holidays 1:1 funding to go to clubs. Theres not a lot of Information sessions in areas such as Shrewsbury. More tea/coffee mornings/afternoons in a week on different days and times to cater for working parents.

Activities or events for carers with activities/entertainment/space for a crèche or similar for our young people so I can relax and concentrate on just being, on getting information on sharing any difficulties with others who understand and can offer accurate advice or knowledge or share ideas that can help.

My child's condition is quite specific so as awful as this sounds, I'm only really interested in connecting with others in the same situation. I don't *want general SEN groups etc as often our needs are different to others and tbh some of the silliest comments re my child’s condition I’ve had have come from other SEN parents who don’t know about my child’s condition. There are local charities and I connect with them. More support for them would be good.*

It's lovely to have activities for children in school holidays, but it's not always easy to make connections with other parents. May be a regular no pressure gathering for parents and carers. I had intended to start something offering my services, but due to having no support, struggling to get a local venue that would cost too much and the increasing struggles of my children I had to stop doing it. I had so many ideas to try to help so many, but really felt it important also to be with others to help it happen.

I attended a sound bath this week with PACC. Being in a room doing something relaxing with a group of people who have similar experiences to me really gave me a lift.

What is not working is all services centralised to Shrewsbury to save money, leading to lack of services in rural areas leading to isolation.

The Mobilise forum is already helping me enormously after just a few days; people who really understand, friendly faces, supportive words...and helpful resources. I haven't seen much activity in the 'Shropshire' section of the forum but perhaps it is a fairly new service. Maybe more publicising of this resource could help to connect more people in Shropshire. I am not a social media user, and this is a lovely supportive community I recommend :) I plan to take up the coaching service soon to support me in how to make the most of a carer's assessment.

PACC cafe at school worked well. Otherwise, I don't have capacity for anything else at the moment, nor the energy to find out what is out there. If I have to organise stuff for me it doesn't happen. I'm on the bottom of the pile.

Work by area- who is in each geographical location and might like to meet up? Whose children have similar interests? Who is available at the same time? Maybe some kind of "speed dating" but for parent carer friends is *needed Lift sharing - i am a nervous driver after a serious crash. I would love to go to horse riding with my child but am too nervous to drive to that location. Could someone give us a lift? Good way to make friends Match us up - who has come to you for help with Direct payments for example and who has just set it up? Put them in touch to chat and help out. Put more on non-staff members with experience and knowledge, use that to lighten the load for staff*

Maybe some sort of befriending/ matching / upon diagnosis, first contact with SEND systems?? This might already happen though. I wonder how parents first hear / get in touch with others in a similar position other than 'word of mouth' Events specifically for new PACC / parent joiners / potential joiners? Online and face to face forums. Think PACC does an amazing job of creating a supportive community for parents and through Buddies and Holiday activities etc the young people.

More fitness and wellbeing classes like yoga and nights out and intelligent conversation.

I think the Buddies network is brilliant for this. And the offshoots, e.g. Wem. Maybe more people in the organising "role" to take the pressure off.

Creating a sense of community and belonging for parent carers starts with having spaces where we don't have to explain ourselves from scratch. The things that work best right now are the peer-led groups and the bigger lived-experience events — those moments where you walk into a room and instantly feel understood. Hearing from others who've walked similar paths genuinely lifts something heavy off your shoulders. The annual conference is a perfect example: it reignites that spark, reminds you you're not alone, and gives you a kind of energy you can't get from anywhere else. But there's still a lot more that needs to be done. So many parent carers are isolated because time is a luxury we don't have. Any spare moment gets swallowed by the basics — food shopping, cleaning, paperwork — so even when you want to prioritise your mental health, it's the easiest thing to push aside. That's why community has to be made accessible, flexible, and built around real life, not ideal circumstances. We need more peer-led spaces that are properly supported, not relying on volunteers burning out. We need *lived-experience events that happen more than once a year. We need meet-ups that don't require planning weeks ahead, and options that include children so carers who can't get childcare aren't automatically excluded. And for those of us doing this single-handedly, connection is even more important. When you don't have another parent to bounce ideas off or share the emotional load with, community becomes your lifeline. That's why support for single parent carers needs to be built in, not an afterthought. What works is simple: being around people who get it. What needs to happen is making those moments easier to access, more frequent, and properly supported so no one feels like they're carrying this journey alone.*

The Kids charity run online coffee and catch-up sessions which is great when you can attend. Isolation is huge. As part of carers week, I applied for an Attingham park ticket. Celia said I could take a friend - I don't have any! I haven't been able to get out so it's hard to suggest what could help. The Actio sessions at the cavalier centre have been good. Ava gets to get out the house. I can have a little walk if they're hacking and I have chatted to another parent in a similar situation. I'd love to take A to more of these, but we can't afford it. So, I guess sessions where the kids are occupied at the same time parents can chat.

Online groups, meet ups after working hours (not just daytime) family sessions for all impacted

2. Creating empathy and understanding – feeling listened to. How do we do this?

Conference Feedback

Empathy and understanding (training for practitioners) – feeling listened to

Managers need a better understanding of life for families in Shropshire – there is the feeling that this used to happen but now the decision makers don't meet the people

There needs to be a recognition that practitioners can be burnt out too and they can't be empathetic when they are burned out

Have those with lived experience at events and conferences

Needs to be more understanding of the life of parent carers

*Importance of listening and validation – **"Not being made to feel like a neurotic mother"***

Emphasis on working together - open door policy with an emphasis on time to listen and offering time rather than me needing to ask for the time

People being responsive when you contact them

Someone providing reassurance, so PC don't jump to worst case scenario and crisis

Importance of leadership – empathetic leaders = empathetic culture

Share good stories, promote compassion and empathy

Using governing body to challenge culture in schools

Share research – more than a parent

Recognising your own triggers when interacting with others

Challenge of co-parenting and people not understanding

Understanding the bigger context that PC are living in

A good relationship is so much easier for everyone. Need to recognise the positives.

Training Practitioners

Go into schools to educate practitioners

Practitioners need to understand the diversity of needs

Not to train staff using power points

More training needed for nursery and primary school SENCOs

More practitioners need lived experiences and should be going into more settings to experience this

Stop relying on parenting courses

Communication to be non-confrontational and respecting privacy

Understanding of the impact on parent carers

Sometimes PCs don't help themselves by getting on with everything

PCs small fish in big sea ***– "when we work and share our voice with PACC we become a bigger fish by being together"***

Support for PCs peering support during term time – feeling connected at a time that you want to be connected. Connection in the way you want it. Different for different people – online, pub, in-person groups

Perception of joining a group

Environmental considerations such as sounds and lighting

Survey Responses:

Practitioners to actually listen to parents more training for them looking for the subtle signs

PACC always make me feel this

Surveys and emails for opinions are great like this

I'm still new to the SEND world but I have no idea where to look for help

I think having more opportunities to meet with specialist practitioners and LA decision makers to build a connection with these people rather than as a one off could help to develop trust and a sense that they understand the realities of our lives.

A system that 'gets' the exhaustion and frustration of parenting Sen children. I have said in the past it is almost as bad dealing with system as it is parenting the children

I just want to feel like someone is listening to me, not judging me or assuming I am failing as a parent because of how my child behaves, If I was failing, I wouldn't be asking for help.

Things such as PACC, knowledge and awareness is empowering.

Shropshire Council have no empathy of our situation and because they don't have lived experience, they'll never know how hard it is. There is a distinct lack of compassion and a serious lack of communication from the council - we currently have a stage 2 complaint open with social care but they've not met the extended 65 deadline so now we are in limbo.

Weekly updates or groups to be involved in.

We are generally listened to with Empathy, but you have to of walked in our shoes to understand the impact that caring has on a carer, how it changes the dynamics of the family, the tiredness, the repetition. Groups are great but need to be focussed for each diagnosis as each has its own areas of need for a carer. They are only monthly and often get cancelled at short notice and some are reliant purely on funding and can close permanently,

We're so lucky as our child's school is amazing. I know if I go to them with concerns, they'll act on them and even if they can't help will show empathy. Other parts of the system aren't so good, and you have to go ready for a bit of a fight or discussion to get what you'd like. Helen Morgan and her office staff however are amazing. She has helped us, we've felt listened to and I'm seriously impressed by her and her team.

When someone has been through what you're going through they get it. Courses do not make people get it on this level.

Those who make decisions need to commit to really understanding our lives, not just caring about what we cost.

Services do not promote ND staff, and there is still a tendency to try to 'fix' young people to make them more neurotypical which is very outdated. The double empathy problem is very real for ND families and leads to misunderstanding often for everyone.

Attending my first local PACC meet up this week, I found all the ladies welcoming and very understanding of my situation. It was a 'breath of fresh air' to speak to people who have been there, done that already, and reassure me that there is help and support available. It has made a huge difference to how I am feeling about my future and the future for my daughter. I would say, publicise more! I struggled to get to the Family Drop-

In at Raven House last year because the fliers seemed to be out of date for the time of the group and it was difficult to find the right information. Accurate, up to date information, in the right places will really help and part of that is making it easier to find information through Shropshire Council. It is BEWILDERING just how many different offerings there are and how they overlap and whether they are just giving information about help, or are actually giving practical help! And it can be hard to find stuff on the Council website - you have to know what you are looking for, or spend a long time just 'digging' until you come across something that helps. It seems as though there are lots of pages that are repeating the same information (when I last went 'digging'!). I can't recall where I found out about PACC; it might have been through a Family Services course I attended earlier this year, or through the website...I don't think I was told about it at Raven House last year. What I would find really helpful is a flow chart, giving pathways to follow according to circumstances and need, so that the information is presented at suitable stages along the journey. Ruth and Louise at PACC gave me plenty of information, and spoke about which bits to pursue first, second etc. But if this is in a flow chart, a visible guide, I would find that great. For example, there are things that that have to be in place before it's possible to access other things, like having PIP before being able to access certain other benefits...it is, as I said, bewildering, and that is off-putting for someone who does not have a great deal of spare time, and who, until now, had no idea that there is support available for me, as the carer! And flow charts showing help available for caring for young children, then young adults, and what is relevant at different ages and stages...

PACC cafe worked well, though there was a lot of 'professional' talking and not much listening at the last one

Shout louder about how staff are all parent carers themselves because I don't think everyone is aware and this is absolutely key! Just think - staff have chosen to help you support your child in a rare break from their own when they could instead choose to do literally anything else! Or even at the same time as looking after their own if their own child is attending an event

Navigator System. A friendly face and voice. Supportive events.

Even send settings or staff most do t have lived experience.

I think PACC do an awful lot, and we are lucky to live in Shropshire with such a supportive network.

Creating real empathy and understanding for parent carers starts with people dropping the judgement. It's so easy for others to look back with hindsight and say what they would've done, but that doesn't help anyone. A lot of the time, what looks "fine" on the surface isn't fine at all. A cry for help doesn't always look like someone breaking down in tears — especially for neurodiverse parents who mask, minimise, or stay quiet because they're scared of the repercussions of being fully honest. If people stopped taking everything at face value and actually listened, parent carers would feel understood a lot more. What is working right now are the moments where lived experience is front and centre. When you hear from someone who's been through it, or you sit in a room with people who just get it, empathy happens naturally. It's real, it's human, and it cuts through all the assumptions. But honestly, we need way more of that. Extended families and support networks are often completely in the dark — not because they don't care, but because no one has ever explained it properly. Education around this is so far behind. We don't need more PowerPoints or generic training sessions. We need lived-experience seminars where people can hear the truth directly from parent carers, young people, and adults with lived experience. That's what actually changes understanding. If we want parent carers to feel listened to, we have to stop assuming, stop judging, and start learning from the people who live this every day. That's where empathy really comes from.

I think staff are great at this - Abi at PACC, Dawn and Katy at Kids and Celia at the council. Drop in calls are helpful.

Quick check ins, decision tree style charts to check what other options there are, not just round in the same circles

3. Empowerment and Understanding your Rights – what would help you feel empowered and to understand your rights

Conference Feedback

Having tool kits and guides for PC

PC feel overwhelmed by paperwork so workshops would help

Benefits advice would be helpful

Help to understand what is not normal

Help filling in paperwork

Knowing other parents to talk to

Talking to PACC navigators

1:1 digital is ok (groups can be more difficult)

"Early on I wanted practical information about what diagnosis meant and how to help my child"

"I wanted information as soon as possible"

Information needs to be clear – No acronyms

Getting into primary schools is key

0-5 things to know – what is the pathway, what is the process, not to feel lonely, to be believed

GPs need better training

Knowing where to get information from – even if you do know it's still hard to navigate

Social workers to be better informed about what services are out there so this can be passed on to families.

Put on a trade show for all families with EHCPs (maybe held at Shrewsbury Town FC) to share information

Access to knowledge and services needs to be equal

Increase the PACC navigator role, for example to go in to schools

There is a role for schools to play as a first point of call for information provision – this could be a National Mandatory scheme (where an EHCP is not required to access the information)

Accessibility to information

Accessible websites

Jargon free information

Use of peer support, those with lived experience

Being given options before a decision needs to be made

Appropriate support when needed, not one size fits all

Use of appropriate terminology

Look at how we are communicating

Co Production at all levels

Practitioners to have appropriate skill sets

Including children and young people in conversation where appropriate

Not relying on parenting courses

Open and honest communication

Provisions meeting needs

Being honest and giving options

Support in place when needed

Not waiting for plans/reports

Trauma based therapy for burnout

Not everyone has the time or capacity to help

The need for a map of what is available at different times and what needs doing at different ages.

Survey responses:

Training, info in public view like the ask Angela posters

Professionals are getting better but I feel that actions talk better than words

Surveys, newsletters to keep up to date is great thank you

I'm still new to the SEND world but I have no idea where to look for help

Again, a transparent pathway of what is available without being told you won't be able to access something due to cost.

Easier access to support instead of hearing from other parents

It is difficult to know what help and support is available. I find trying to look for help a bit mind boggling trying to navigate websites and different links. I also find when you do contact anyone it all seems very disjointed, one team can look at this, another at this etc

Emails, forums, local availability is a big issue in Shropshire it's a huge county.

Better signposting - council staff who know their jobs and do their jobs well and actually answer the phone to parent carers and support us and understand our needs.

I don't I feel like I have very little support and is quite lonely

You give us email newsletters etc. Maybe printed information too and posted, regarding new rights and updated help.

Information is key, carers cannot always attend meetings, conferences, due to lack of care availability for our young people, 10am to 2pm during term time is more accessible to many as our young people are in education, parents need to know the information, email notes out, or recorded video links would really help, so we can watch them at a time that we can manage around our caring responsibilities.

The charity I'm linked into informs me of things relevant to my child's condition. They have provided education advocates for EHCP annual reviews etc. they work amazingly with our school and we're the ones to *note our child’s EHCP which the council edited had put SALT under health and not education, so they didn’t have a statutory responsibility for it.*

IASS have helped. It's hard to know you rights when no one tells you and there changing laws. Someone who works in law or is very clued up, Perhaps a help line or regular events, Perhaps even after gatherings or socials.

Navigator role is fantastic, more access to people who help map our journeys would help.

Sharing the fact sheets and promoting use of PACC, SENDIASS and IPSEA is really useful. It would be helpful if professionals knew so they weren’t telling patent carers the wrong info!

*See last answer...build it into the same flow chart, or one alongside it, tailored for the legal side of things. I had no idea that there are legal definitions of a cared for person and a carer, until this week! Mobilise is working to help inform me and give me confidence to move ahead with seeking practical and financial support. Make it more widely known about - maybe an email 'flyer' to encourage everyone already on the carer register (I have just signed up this week and it is great to get details) or promote it *everywhere* that Shropshire Council has a presence...because anyone, anywhere, might be a parent carer, or other unpaid carer, or know someone who is. Is it listed on the Shropshire Council website homepage?*

Email works well.

Help us avoid unnecessary and unhelpful meetings. E.g. PFA meetings arranged by Severndale have been such a waste of time with no new info. Maybe every week on Facebook post a FAQ or a Did you know......? With some useful facts/rights/info

I think events organised empower parents in part through feeling they are not alone and are part of a wider community - a feeling of solidarity to stand up for their rights. Not sure how to ensure ‘harder to reach’ parents are part of this

Booklets and webinars on your rights.

Again, PACC do a wonderful job with this. More information/signposting from health professionals on diagnosis.

Empowerment starts with actually being able to access the right information at the right time. When you're in crisis, being told someone will call you back tomorrow — or next week — doesn't help. What is working at the moment is how quickly PACC respond, and how accessible they make their website. When you reach out, you get a call back fast, and that alone makes you feel less alone and more in control. But across the board, there needs to be immediate support for parents when things are falling apart. Not 24 hours later. Not after the weekend. In the moment. Because when you're overwhelmed, that's when you're most likely to miss something important or not know what your rights actually are. Tight timeframes also make everything harder. When you're rushed to respond, you don't always have the headspace to read the fine print or understand the legal side properly. It's so easy to accidentally agree to something you shouldn't or miss a deadline you didn't even know mattered. That doesn't mean parents don't care — it means the system is set up in a way that makes it almost impossible to get it right. To really empower parent carers, we need clearer information, quicker responses, and support that shows up when it's needed, not after the fact. And we need services to recognise that parents can only use their rights if they're given the time, space, and guidance to actually understand them.

I think the biggest thing is having to wait for support or action and not knowing when it will be or when it is due, it does not happen. There are great resources out there - Kids and SENDIASS have been particularly helpful. However, it's more the EHCP process or CAMHS. If there can be more transparency about where your child is in the process or what the LA is waiting for etc, that would be helpful. With a child with autism who likes to know everything, it can be so hard for them and then it's heartbreaking knowing the support they desperately need is not coming. We had BeeU Crisis support which was really helpful.

A clearer understanding of all support available at the point you are at now and being able to check back on this at different points in your journey

4. **Practical Support – what does this look like. What has worked well?**

Conference Discussions

Make use of college students – e.g. those on childcare courses could gain work experience by linking in with the SEND community

Create one stop shops for information

Link together which things that already exist, eg the mental health bus already visits lots of areas of Shropshire, this service could be expanded to include other support services

Bring back the play bus and the youth bus to bring services to rural communities

PACC PFA guide is helpful

Peer support at activities – like All In and Healthy Lives – works well

PACC Navigator service works well

BeeU MH team signposting to private/right to choose when appropriate

More Holiday provision – a massive gap, complexities of looking after other children/siblings, 1:1 support in school but nothing in holidays

More help at home – need order, need to not feel overwhelmed, reduced parental load

Places where our children can socialize in their own way

Support to broaden my child's world

Specific therapy offers for Parent carers, general offer/CBT is not always suitable

Emotional support/counselling is missing for Parent / Family Carers

*Need to embed self-care, **“people see time out as self-indulgent”***

Need something more than anxiety or depression support

Prioritise emotional support for Parent / Family Carers

Flexibility on respite models Council have trialled PA taking young person to Airbnb for respite.

Flexibility with direct payments – using them for Pas to support young person in work.

Use of young people as Pas

Stepping stone to independence through access to residential colleges where they learn independence.

Effective delivery of the system; Meeting statutory timescales, Practitioners listening, having appropriate contact details, accurate and correct information recorded.

Building meaningful relationships through consistency in teams

Co-production understood by practitioners and supported by managers

Increase funding to voluntary sector to create more independent support services for young people

Communication is good between families and service providers

Good communication would help myth busting, especially within social care

Co-production – this is not widely understood within the council. Is not just cooperation, is about listening to the community.

Planning for the future, particularly around transitions, getting to know staff

If information provision (local offer) was better, then finding support would be easier – councils assume parents know what different services are, but they often don’t. Parents rely on google.

More information into school at a young age so that you know at an earlier age what is happening.

Having a key person who is informed but able to signpost and who know the system

Celebrating successes to increase visibility of SEND community

Survey responses:

PACC does a fantastic job and helping parents navigate this difficult time, more amazing people like yourselves, do community events get your name out there to reach more parent carers who may need support

Support for a family as a whole and Support for working mums as you miss out due to work

Clear information on what support should be offered for different pathways

I’m still new to the SEND world but I have no idea where to look for help

Having a consistent point of contact with someone who knows what support/provision is available who is transparent and not governed by another agenda, political agendas or finances

Respite . More holiday clubs (instead of cutting them) for Sen especially in south Shropshire

I would like to know what I can access, what I might be able to claim, where to get help and for what e.g. if I need support with how to handle mobile phone issues. I think something like a parent carer Citizen advice service'.

Easier access to respite care

Teams meeting .. catch up dates .. groups sessions

Offers to see people 1:1 to give specific help to parents. Maybe parents who match with their experiences, to another parent who could be a buddy which both can help each other?

Crèche/caring area with activities/sports or crafts so carers can attend, as before emailed notes and information, pre-recorded video links of information, lists of already available support and resources, difficult to ask *when you don't know what is already available to ask for, suggestions of help available, groups, for carers and our cared for*

Holiday clubs!!! Proper ones not 9-3 but ones that real working parents who do a 9-5 job can use. Ones that aren't just based in Shrewsbury. We have nothing for SEN kids in Whitchurch in the holidays. I take unpaid leave to manage. It really affects our home budget and the only reason I have to do this is because my child has SEN. It's disgraceful.

Local support

Proper respite, trained support staff, people with a can do attitude rather than saying 'it's always been like that' or 'that's just how it is'.

I haven't engaged with PACC long enough to have a view on this yet. I think the Carer Week offerings were great, and perhaps having them more often, to give more opportunity to take part, would be helpful. Parent Caring can be unpredictable.

Not sure. Capacity is very low for working or what is out there. Holiday club at SYA works for one of the three.

Love, love, love HLP. It is life changing. No longer the fear and dread approaching the school holidays! Would love a few more music sessions as my child especially enjoyed Sensory Music with Lynne, singalongs with Sal and Eve. Also, yoga. I think you need to check with medieval madness when their SEN sessions are as last time the PACC one was the day after theirs. We were going anyway as my child loves soft play! But I imagine most people wouldn't go to both. But maybe that's the only date they offered you

From what I see and hear everything PACC does is really valued: Healthy lives programme is fab Buddies works well Navigator system Specific events As above I wonder about the 'harder to reach' parents who perhaps have less of a voice in the system … From conversations with other parents about mental health - counselling/ therapy offer specifically for parent carers. Individual: family: group.

Maybe a buddy (1:1) system for parents on diagnosis.

Practical support for parent carers has to be more than a shoulder to cry on. That's lovely, but it doesn't actually take anything off your plate. What makes the biggest difference is when someone steps in and does a real task for you — writes the email, makes the phone call, chases the service, fills in the form, or speaks to the professional on your behalf. Taking even one thing off a carer's list can completely change how heavy the day feels. Right now, what works is when you find that one person — a friend, a worker, another parent carer — who says, "Give it here, I'll sort it." That kind of practical help is worth more than any amount of "you're doing amazing". It's action, not sympathy. But we need far more of that built into the system. Parent carers shouldn't have to be the admin team, the case manager, the advocate, and the crisis-handler all at once. Services need to offer real hands-on support — someone who can step in and actually do the task, not just tell you how to do it. Especially for single parent carers, because there's no one else to share the load with.

There are a few websites but too many to know which are the best ones so you can get lost down a rabbit hole. The OT support call was useful. Maybe more opportunity for calls like that 1:1 focussed support? It's hard to get respite - our children need to feel safe and they may not with other people. More opportunities for teens to get together in a safe space where parents can grab a coffee whilst being there.

Own wellbeing/mental health sessions, family support sessions, sibling sessions. Check-ins

Other Comments from Survey response

Keep doing what you are doing your helping so many people and without you guys we would all struggle 🙂

I would like to thank PACC because with put them I would feel very alone plus wouldn't of known lots of information I needed for Noah and the family

More alternative therapies such as yoga, meditation etc

Give parents hope instead of creating more hassle for already exhausted parents

What training offers are available to parent carers. I have asked various people in Shropshire Council about NVR training and still don't have any answer or any idea where I might be able to access this. This could be paid or free training courses. I apologise if everything I have raised is available to me via your website, as I've said above it has been a tricky time at home and I haven't looked that much into things such as PACC but I have opened your website and I'm going to look now :-))

Consultation and more local offers

Just more support in general.. I've had to take a career break and feel very isolated in my position.

Step by step guide to how to access support from diagnosis

I think I've mentioned everything already

Supporting rural areas not just Shrewsbury. I've a bee in my bonnet about it, as I'm tired of professionals telling me they 'just don't come out that far' and that I have to take my ND to them for support.

Keep things up to date if possible, please. I am very grateful for all the information given to me by PACC, and while I don't know how unique my situation is (my daughter's conditions), I feel that some of the experiences shared relate to times when getting support, practical and financial, seemed to be much more straightforward, and perhaps easier. I appreciate that budgets shrink and thresholds change, and my experience of seeking support will be different; I think understanding these things from a 'PACC-customer' perspective could help to 'keep it real' for 'newbies' in the Parent Caring community space :) Nevertheless, PACC has changed my situation hugely, in under a week! Thank you! :D

Understanding that there is often a lack of capacity. Signposting is all very well, but it stays as a list of things to do on an ever-expanding list when the priority is firefighting and just trying to keep on top of the basic daily stuff.

I think some parents get overwhelmed by newsletters packed with information and do better with smaller bursts of information. Little and often can be more helpful and easier to understand. And you read it all in one go then.

It’s such a diverse range of parents with young people with hugely differing needs it’s hard to have ‘a one size fits all’ offer. A range of flexible support needs to be available at the time a parent needs it.

Just thank you again for everything you do.

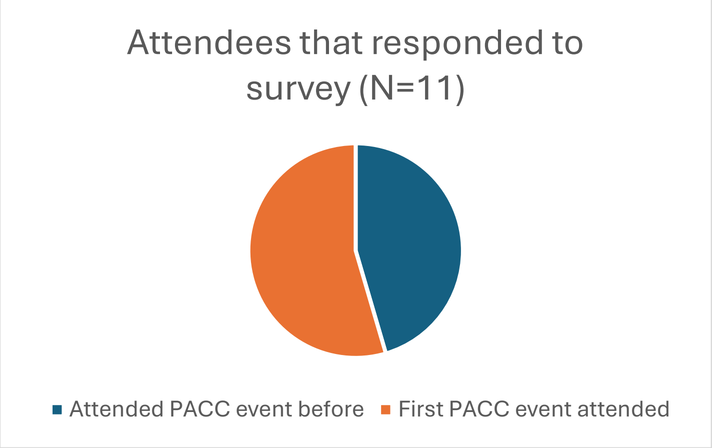
For me, real empathy and understanding starts with people actually knowing what parent carers have been through, not what they assume we’ve been through. A lot of my own experiences with safeguarding failures have left me feeling judged before anyone even listened. When you’re a single parent, that hits even harder because there’s no one else to back you up or say, “That’s not what happened.” You’re carrying the whole story alone, and if a professional gets it wrong, you’re the one who pays for it. What would help is people taking the time to understand the full picture instead of making snap decisions. So many of the let-downs I’ve had from services came from assumptions — things written down wrong, things not followed up, or people deciding what my situation was without ever asking me. If they actually listened, if they looked at the context, if they understood what it’s like to manage everything on your own, the whole experience would feel completely different. What does work is when people hear real stories. When someone listens to lived experience, you can see their whole perspective shift. That’s why we need more lived-experience sessions for professionals, schools, and even extended family. Not PowerPoints — real people talking honestly about what safeguarding mistakes feel like, what single parent carers carry, and how damaging it is when services get it wrong. If we want parent carers to feel understood, we need less assumption, less judgement, and more willingness to actually hear what our lives look like. That’s where empathy starts.

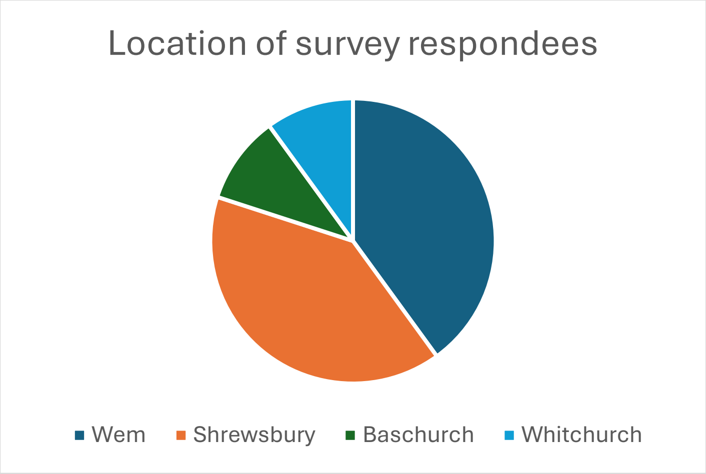
It’s very hard to support us. We need financial support but are restricted - we can’t have normal jobs. We need a bit of time to ourselves for our own mental health knowing our children are safe but that is restricted. We need practical advice but either don’t know where to turn, the wait is too long or it isn’t possible to access.

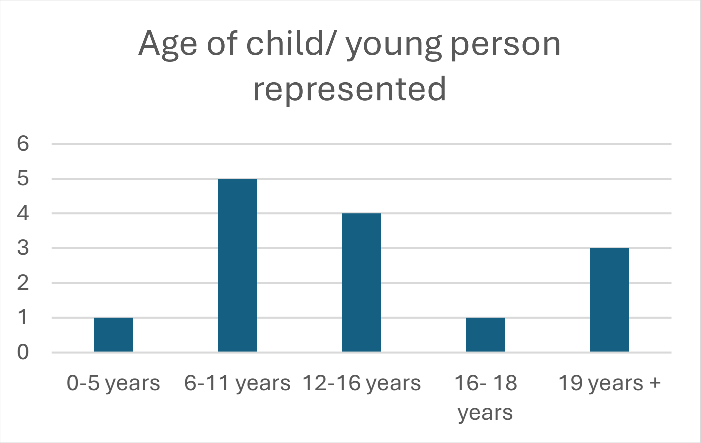
Just clearer pathways, we have been on our path for 3 years with our daughter, been through early help (multiple times), BeeU, school and we *haven’t really heard much about PACC. We have now a private diagnosis after waiting for so long and feeling like we were just going around in circles*

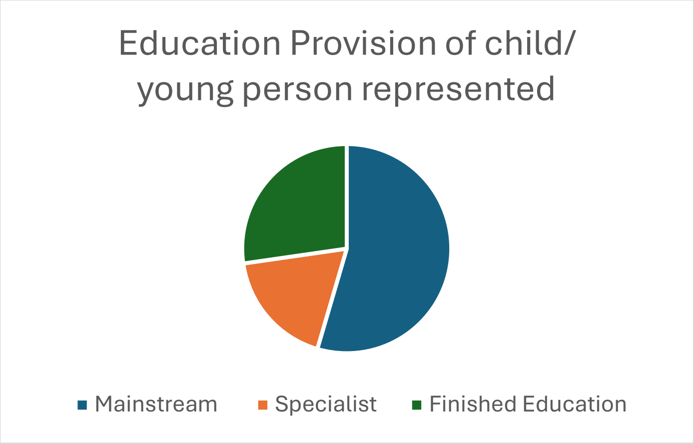
Annex 2

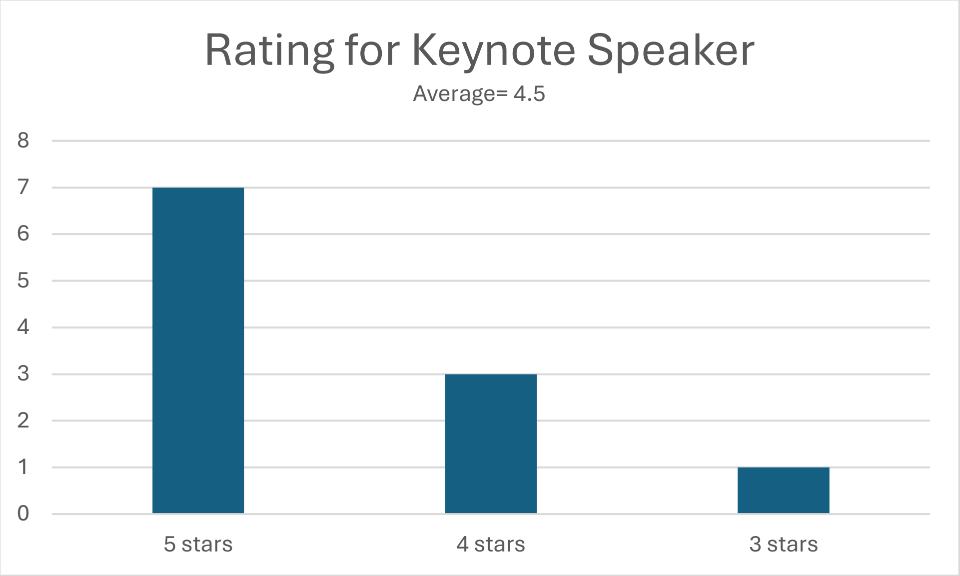
Conference Evaluation Data











Feedback on Keynote Speaker – Rachel Wright

“Amazing, so raw but inspiring. Really gave me the drive to go away and take targeted action of what needs to be done s for the kids.”

“Rachels talk was fully inspiring i felt heard i laughed I love the humour that was used in what can be a challenging time bringing up our children. I really truly loved it and have recommended the podcast and books to several other SEN parents”

“Spent to long dwelling on early life etc. Her explanation and tips of experiences in recent times was excellent. "BURNON!!!"

“Open and honest struggles through daily life.”

“Great but C only lasted 30 mins as it was too triggering. She felt unwell and went home.”

"Engaging speaker. Thought provoking talk. Balanced not blaming thinking about the relationship in/ between parents and professional systems"

"She was truly inspirational, funny, talented, honest and just all round an amazing woman! Truly feel blessed to have listened to her"

"Rachel was inspiring and funny. Took a refreshing view to being a parent carer. Faced the realities head on but in a way that I left feeling positive about my life and empowered."

How could the day been improved?

"- quieter music at lunch time people and also the food was not labelled there was a group of us vegetarians who had no idea what was suitable for us where as the gluten free was clearly plated up and labelled, couldn't hear one another talk"

"More small group discussions, lower volume music when talking to other parents"

"Would have been good to have some input to the day from Shropshire Council and/or providers of services"

"All good"

"Were there staff from social services there? (I dont know the answer)."

"Shropshire council child/adult services information question and answer session."

“To much down time. Thought the musical section could have been condensed. 2 or 3 technical speakers would have been good. Music playing at lunch time impacted ability to speak meaningfully to other parents and carers.”

“I felt the lunch break was too long, I loved that it gave us time to chat but would have rather a 10 minute break after Rachel, then the music, then a shorter lunch I thought it was such a brilliant day”

“Absolutely loved the music section but due to my Audhd I found the lunchtime accompaniment overwhelming.”

Other comments about the day

“Thank you to you all for the amazing work you do, the accuracy of information, swift availability for support and actual genuine empathy to help.”

“What a well thought out, parent focused day. I loved the joy of the music the speaker and the activities I loved the comradery that came out of it”

“The energy and enthusiasm of all those at PACC is massively appreciated. You are all amazing.”

“Always good for parents, carers and professionals to get together for an informative discussion.”

“Great, I just felt overwhelmed by outside factors”

“Really lovely day great to meet people in same situations as us but feel as if more Sencos and staff could do with being at these types of events to listen and understand what parents are going through and how to support us all more”