Welcome PACC AGM & Conference 2022



Parent
And
Carer
Council

Annual Report 2021 – 2022

Information & Support, Influence & Change

The Shropshire Parent and Carer Council (PACC)

PACC is the parent carer forum for Shropshire. Our core aim is ensuring that the voice of parent carers informs and influences local, regional and national decision making related to Special Educational Needs and Disability policy and services.

PACC provides representation for families of children and young people aged 0-25 years, who identify themselves as SEND families in Shropshire. Our core funding is provided through an annual participation grant from the Department For Education, we have also secured funding this year from Shropshire Council, Shropshire CCG, Learning Disability England and the Pears Foundation Trust. PACC is a registered charity.

A key principle of PACC's work is that it is experience led and so all PACC's trustees and operational leads are themselves parent carers, who work closely with the Shropshire parent carer community to inform their work.

PACC's focus is on creating an environment that supports co-production, working in a solution focused way, to enable improved outcomes to be achieved for everyone.

An important element of PACC's work is supporting information provision to the Shropshire SEND community, ensuring that parent carers are able to make informed decisions and understand what support is available for SEND families.

The PACC Team

- Zara Bowden Chair, Communication & Engagement Lead and parent carer rep chair@paccshropshire.org.uk
- Sarah Thomas Participation Lead and parent carer rep enquiries@paccshropshire.org.uk
- Abi Taylor Development & Support Lead, PFA Navigator and parent carer rep abi@paccshropshire.org.uk
- Cathy Williams Administrative Support and parent carer rep cathy@paccshropshire.org.uk
- Denise Glover PFA Navigator and parent carer rep <u>Denise@paccshropshire.org.uk</u>
- Annie Taylor parent carer rep



Parent And Carer Council

Connecting with the Shropshire Parent Carer Community

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



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

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





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

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





Over 750 members on the Actio database, managed by PACC. Targeted mailouts are issued at least biweekly.

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



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

2000 people.

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



5 Parent Carer Engagement Groups established in schools, with 1 more being developed. PACC manage closed social media groups for these as well as facilitate face to face opportunities. Community Engagement -How do we connect with Parent Carers in Shropshire?





Over <u>2,300</u> followers across our social media platforms and closed groups.

Up to <u>10</u> posts a day are issued across our groups and pages.

'Community'

Actio Summer Activity
Programme for Children and
Young People with SEND







The creation of a Shropshire parent carer community that reduces isolation and strengthens the capacity of parents and carers to support their family;

As we learnt to live with Covid, and we started to come together as a community again PACC have continued to offer the chance for SEND families to meet up and benefit from peer support.

Actio Consortium

PACC continues to support the development of the Actio Consortium and the increase of inclusive, community-based activities for children and young people with SEND. We are in the second year of the managing the All In scheme on behalf of Shropshire Council and are very please with the increase in members from just over 200 families to over 700 families. Over the summer of 2021 PACC secured additional funding of £10k to be able to offer a summer programmed aimed at supporting families to re engage in community activities after lockdown. The summer programme was very well received

http://www.paccshropshire.org.uk/summer-activities-for-children-and-young-people-with-send

"Going to a new place can be really daunting for us, especially when we have been so out of practice of getting out about post lockdowns, but we all very quickly felt relaxed there and went on to laugh more than we have in a very long time "

Feedback from a family who participated in the Actio Summer programme 2021

'Community'



The creation of a Shropshire parent carer community that reduces isolation and strengthens the capacity of carers to support their family;

In addition to the work with Actio we have offered a number of other opportunities for parent carers to come together to receive support and guidance.

PACC In Touch Course – Planning for the Future

This 12-week course was aimed at parent carers of young people with a learning disability and / or Autism aged 13 - 25. It was delivered virtually to 13 parent carers

http://www.paccshropshire.org.uk/planning-for-the-future

'The course has been very useful, nice to be in contact and not feel so isolated'

Other activity included;

Mediation Workshop

http://www.paccshropshire.org.uk/mediation-workshop-for-parent-carers

Let's Go Out Film project

http://www.paccshropshire.org.uk/filming-project-opportunity

'Information'

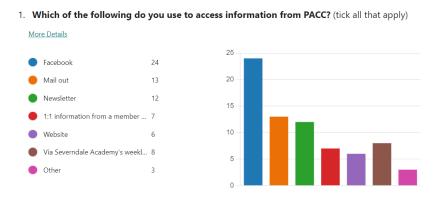


The provision of information to inform and empower parent carers about the services and issues that affect their families;

Having access to information is a key part of being able to participate in decision making and having a voice. It is important to PACC that we understand how to effectively share information with Shropshire SEND families, with this in mind we issued a survey in March 22 asking parent carers how they prefer to access information from PACC and how the information we share has helped.

As previously parent carers told us that Facebook is an important delivery mechanism for information, along with the PACC newsletter and direct mailouts.

This is reflected in the ongoing growth in our social media reach, through which we share a range of information on a daily basis across our open page and a number of topic specific groups. We also use Facebook to connect with the wider support network for Shropshire parent carers.



'Information'



The provision of information to inform and empower parent carers about the services and issues that affect their families;

With an increased staff team, we were very pleased to be able to reinstated our newsletter, which is now published on a monthly basis, along with regular direct mail outs to our contact database when we have specific information to share.

http://www.paccshropshire.org.uk/about-us/pacc-newsletters-and-reports

PACC has continued to share information relating to Covid 19 – particularly ensuring that families had details about the national and local vaccination offer.

http://www.paccshropshire.org.uk/flu-and-covid19-booster-vaccinations-in-shropshire

It is also important that we share information about the work that PACC is involved in and the development of local services

http://www.paccshropshire.org.uk/learning-disability-and-autism-champion-expression-of-interest-ndash-shropshire-telford-and-wrekin

http://www.paccshropshire.org.uk/north-midlands-autism-in-schools-pilot-newsletter

http://www.paccshropshire.org.uk/new-shropshire-adult-social-care-direct-payments-website-launched

'Participation'





The provision of opportunities for parents and carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families.

Participation is at the heart of PACC's work, promoting the importance and value of using the experience and knowledge of parent carers to coproduce services and support.

This year there has been an ongoing focus on ensuring Shropshire parent carers have a voice in the delivery of the Written Statement of Action workstreams, responding to the SEND inspection carried out in 2020. PACC provides parent carer representation on all workstreams. Towards the end of the year our thoughts turned to the upcoming reinspection, and we published a survey to gather parent carer feedback on progress in key areas.

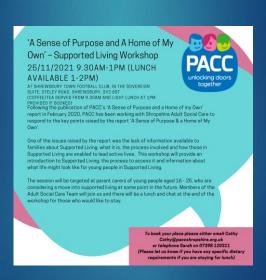
http://www.paccshropshire.org.uk/shropshire-send-inspection

http://www.paccshropshire.org.uk/speech-and-language-service-redesign

http://www.paccshropshire.org.uk/information-from-the-recentneurodevelopmental-pathway-workshop

http://www.paccshropshire.org.uk/follow-up-send-inspection-expected-for-shropshire

'Participation'



The provision of opportunities for parents and carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families.

Another key area of focus for PACC this year has been 'Preparation for Adulthood'. While this was not identified as a significant area of weakness in the Shropshire SEND Inspection, opportunities for improvement were noted and it is an area which families tell us is of particular importance to them. PFA is also central to the Shropshire SEND Strategy published April 21

http://www.paccshropshire.org.uk/shropshire-send-strategy-20-25-launched-today

After publishing our report 'A Sense of Purpose & A Home of My Own' detailing families experience and thoughts on PFA in Shropshire, PACC working with Shropshire Adult Social Care hosted a Supported Living conference in Nov 2021. The conference aim was:

'To respond to the findings of the 'A Sense of Purpose and Home of my Own Report', so that parent carers are more confident about what Supported Living is, the process and how to ensure that young people in supported living lead good lives.'

The conference was very well attended with 50 participants and feedback was positive with many parent carers saying they would like more opportunities to discuss this topic. The feedback from the facilitated discussions which were part of the events programme has informed PACC's PFA activity going forward, in particular the development of the PFA Navigator Project.

http://www.paccshropshire.org.uk/pacc-rsquo-s-work-with-adult-social-care

'Participation'



The provision of opportunities for parents and carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families.

This year we have also worked with Shropshire parent carers to progress our work on developing a 'Coproduction Framework' for Shropshire. At this event we talked about why parent carers having a voice is so important and how we know when that is happening. We introduced the Shropshire Co-production Bench and asked;

- How do we evidence that co-production is happening?
- How do we measure how well it is being done?

In June we launched our fourth 'Mad Sad Glad' Survey to capture what it is like to be a parent carer in Shropshire. The experiences shared in this survey will inform our work with commissioners to improve parent carer support in locally. There were some powerful messages about parent carers feeling undervalued and the negative impact of continually trying to navigate a complex and disjointed system on their wellbeing and health. Feedback also highlighted the importance of peer support and the value of being able to connect with 'people who understand'.

http://www.paccshropshire.org.uk/mad-sad-glad-survey-launched



'Participation'



The provision of opportunities for parents and carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families.

Other Participation Activity

Shropshire SEND Local Offer - PACC is part of the Local Offer working group and co-produces the Shropshire SEND Newsletter

https://shropshire.gov.uk/the-send-local-offer/education/education-services/special-educational-needs-sen-team/sen-newsletters/

- Preparation for Adulthood (PFA) There are currently four workstreams under PFA which cover; Employment & Volunteering, Accommodation, Information & Advice, Community & Leisure
- PACC provides representation on all of these workstreams and the PFA Strategic Group which oversees them. PACC works closely with the Shropshire PFA team and Adult Social Care to support this work.
- Learning Disability & Autism Programme and Delivery Boards
- STOMP / STAMP Steering Group
- Learning Disability & Autism Accommodation Group
- Covid Vaccination Uptake Group
- Learning Disability Partnership Board
- Autism Partnership Board
- Carers Partnership Board
- Direct Payments Board (Adult Social Care)
- SEND Partnership Board
- SEND Strategic Board

Chair's Report

Last year I closed the chairs report with the statement:

"...you are the ones making the real difference. Without your feedback, experiences, and critical eyes, we would have very little to share with the LA and CCG on your behalf. You are the heart and soul of PACC. "

Well, this year we have most certainly felt your influence in our work stronger than ever. Our Parent Carer community have contributed to, and influenced, 11 participation opportunities, 2 learning events, and we provided 11 key communications to update and inform families of our ongoing activities alongside our usual updates and news articles.

We coproduced a bespoke program of activity for children and young people that provided activities and opportunities for those up to the age of 25 as part of our work within the Actio Consortium, and a filming and production opportunity in partnership with The Hive.

Parent Carers shared their experiences and aspirations for speech language and communication services, neurodevelopmental pathway, adult social care services, and most importantly fed into our Mad Sad Glad survey.

As always, we are humbled by the honesty with which you engage with us. Our Mad Sad Glad survey demonstrated the challenges you face, and the sadness these bring to our communities lives every day. We were devastated to hear of some of the things that make families Sad and frustrated to hear that little impact is being felt by the work we participate in as a strategic partner in the SEND system. The themes we picked up running though the Mad section of the survey did not come as a surprise to us, but we were again frustrated that families are still feeling let down and unsupported, particularly around the neurodevelopmental pathway and mental health support for their children.

So, while we hear about, and provide opportunities for you to share, your experiences, what do we do with them?

As always every experience shared with us informs conversations, we have with local area services or commissioners. It helps us coproduce changes and solutions that, we hope, better reflect the needs of the community. And we have a greater understanding of the needs of the SEND community and Parent Carers as a result.

Already, following the publication of our Mad Sad Glad Report, the Shropshire Carers Service has been instructed to explore and coproduce a clear and improved carers service offer for Parent Carers of children and young people with SEND, under the oversight of the Joint Commissioning working group. The Integrated Care System asked us to deliver a 'key points' presentation via a recorded message shared with them to bring the key themes to their attention. The Director for People and Assistant Director for Education and Achievement at Shropshire Council have ensured all Senior Leaders and Service Manages across education and social care were made aware of the report and our recommendations. We feel it has made an impact in the right ways, but it was certainly a difficult read for many. However, families also shared what made them Glad, and some of these comments have inspired us in PACC, as well as strategic leads in the SEND system, to strive to be better still and aspire to have a greater impact on your lives.

As always, I reflect on a year of activity that has kept our Strategic Leads busy, maintained your voice within key conversations ensuring your experiences influence change locally, and a year that has challenged us immensely. Our team of leads, volunteers, our wider community partners, and the SEND Parent Carer community have made a difference this year. I must thank you all from the bottom of my heart for your honesty, your support, and your trust to allow us to represent you in the work that we do. But it would be remis of me not to recognise that a significant proportion of the work we do is delivered on a voluntary basis, by Parent Carers who themselves are experiencing challenging times personally and navigating the same system you do. Without their unwavering commitment and passion, PACC simply could not exist.

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The year ahead has already started with a lot of activity and opportunity, as well as a lot of challenge. We look forward to sharing with you next year how we have continued to champion your voice and be representative of the community.

Zara Bowden



Financial Report

- The audited accounts for 2020/21 are available on the Charity Commission website https://register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/5026729
- The accounts for 2021/22 have been completed and our grant monitoring submitted to all funders as required. The audited accounts for this period will be completed in time for the Charity commission submission deadline of 31st January 2023.

In the period April 21 – March 2022 PACC secured the following funding;

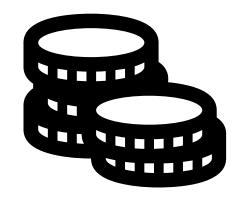
Dept For Education – Core funding of £17500

Shropshire CCG - £4950 to support parent carer representation in WSOA work

Learning Disability and Autism Program - £10,000 for delivery of peer support activity

Actio - £13,000 database management, promotion and participation

Pear Foundation - £10,000 to support re engagement in community-based activities after lockdown



Thank You For your Support

'Unlocking Doors Together'



New Trustee Elections

Andy Edwards

I am a 46-year-old father to 7 children ranging in age from 22 years to 4 months old.

Due to a works injury just over 10 years ago I was physically injured meaning despite years of trying I was unable to work.

Whilst we are lucky that we have a family setting it is not what most people would call normal whatever normal is?

My first understanding of a child with additional needs was having a brother with ADHD as a teen, more recently my connection is down to my cheeky cute 5yr old Son who is a pupil at Severndale. Academy and has a diagnosis of ASD & severe learning disabilities.

Like most parent carers I think we do what we can to support our children regardless of age, whenever they need it whilst trying not to go mad trying to access the services we are all told are available to us.

My interest in becoming a PACC trustee is down to the personal support and advice I have received from the PACC as well as the memories of the mind-numbing amount of red tape and repetition it takes to get support from the correct teams and believing there has to be a better way via PACC & Co Producing.

I personally have had to fight and do far too much self-researching to get the help and support for my Son and Family and have experienced the stress and frustration in getting the basics such as OT and Social Services allocated.

If I am appointed as a Trustee, I would be willing to not only attend required meetings but to undertake any additional workshops or work to aid and improve my understanding of the work of the PACC to ensure I repay the trust put in me.

New Trustee Elections

Ruth Minshall

I'm Ruth, 48, and parent to a very special 11 year old named Jacob. I've been a single Mum since Jacob was 9 months old. At aged 3, Jacob was officially diagnosed with Autistic Spectrum Disorder and Severe Learning Disability in Communication and Social Interaction. It's just been me and him and we've been on our journey together. I was a previous Parent Rep for PACC but as Jacob grew older I needed to devote more of my time and energy to him. Unfortunately along the way, it became apparent that Jacob had very complex needs including ADHD, Severe Anxiety, erratic sleep patterns and behaviour that challenges to name but a few.... We have worked with various health and social care services over the years and Jacob was previously schooled at Severndale. It has given me first hand experience of the support services available and I hope to be able to contribute with my experience to help inform future planning to support other Parent Carers. Jacob and I have had some significant changes in the last 18 months and he is now a very happy (on the whole) and well supported young person at Overley Hall School on a residential placement. He copes far better with the World around him with minimising transitions and wrap around consistent support. However after a period of quite difficult adjustment personally, I now have time to work with PACC again and look forward to the opportunity.

