

# The Shropshire Parent and Carer Council Annual Report 2014/15

*'Unlocking Doors Together'*



SHROPSHIRE  
Parent  
And  
Carer  
Council

Charity Number 1150180

Face 2 Face  
Parents supporting parents  
of disabled children



# Welcome

Welcome - whether you are a parent carer or someone who works with children with disabilities and additional needs and their families.

PACC is an independent, parent led organisation. All of our members and our committee are Shropshire parent carers who have a child with a disability or additional

need, aged 0-25 years. Since 2007 we have been supporting and encouraging parent carers to be actively involved with designing and reviewing the services that their family use and contributing to enabling children and young people with disabilities or additional needs to achieve better life outcomes.

If you would like more information about PACC

Phone us on 0845 601 2205

Email [enquiries@paccshropshire.org.uk](mailto:enquiries@paccshropshire.org.uk)

or go to our website [www.paccshropshire.org.uk](http://www.paccshropshire.org.uk)

And do remember to sign up to receive our up-dates and newsletter!

## Our Aims

- To create a community of Shropshire parent carers
- To provide information about issues that affect them
- To provide opportunities for our members to influence decisions that affect their families, and to contribute to developing services.



"Knowledgeable, interesting, informative, useful information. Very good speaker that gave me information that is timely to my own son's circumstances. I will keep the handouts and refer to them in future as required"

Feedback from PACC AGM & Open Meeting 2014

# Trustee's Report

It has been another busy year for PACC. Like all Parent Carer Forums, every year we apply for core funding of up to £15,000 from the Department for Education (DFE). This 'Strengthening Parent Carer Participation' grant is administered by Contact a Family. Our application includes our activities and aims for the next 12 months which continue to be: growing the PACC membership, increasing contact with parent carers, and ensuring that parent carers have a voice in shaping local services and national policy. We also have had to provide information on last year's activities and achievements and we were pleased to be able to report that our membership had grown considerably.

Even better news, parent carers tell us that they feel more informed and more confident about influencing local decision making because of involvement with PACC.

Our two administrators have once again played a key role in maintaining PACC as an effective organisation, reviewing our policies and

governance documents, updating the PACC membership database and monitoring our activities and outcomes. As we also receive funding from the Big Lottery we have to collect additional information to show that we are reaching all groups in the Shropshire parent carer community.

PACC's core work is developing parent carer participation in Shropshire and working with other organisations, both statutory and voluntary, that support families of children and young people with disabilities or additional needs in Shropshire. We aim to help these organisations to offer services that respond to local need.

In the statutory sector our main contact is with Shropshire Council. Here are some examples of how we have worked with them to improve services during the last year.

**Shropshire Information, Advice and Support Service** – This is a newly commissioned service replacing the previous service provided by

Telford CVS, via what was formerly known as the Parent Partnership Service. Due to new requirements in the Children and Families Act 2014 this service was put out to tender, with a new specification and a wider remit, covering education, health and social care, for the 0-25 age group. PACC worked with Shropshire Council to identify what parent carers want this new service to look like and were involved in assessing the bids received to deliver this new service. The contract to deliver the Shropshire IAS Service was awarded to a consortium of local voluntary organisation, led by Citizen's Advice Shropshire and PACC look forward to working in partnership with consortium members to continue to develop this new service.

**The Shropshire Local Offer Work Group** – The Shropshire Local Offer continues to grow and develop, with over 500 entries currently uploaded. Recently the Local Offer Co-ordinator met with our members to discuss how information is presented in the Local Offer and to explore its effectiveness.

# Trustee's Report Continued.....

**Disabled Children's Social Care Pathway** – This work is linked to the Local Offer, which requires transparent information about accessing services and eligibility criteria to be accessible to families. Feedback has suggested significant issues around transparency of decision making in the Shropshire Children's Social Care Service for children with disabilities or additional needs. We are exploring how we can work together to ensure a clear and understandable process for requesting support and for responding in a timely and appropriate manner.

**SEND Reforms – Joint Assessment and planning Group** – This group oversees the SEND reforms in Shropshire. Several other work groups (early years, post 16 and Local Offer for example), report to this 'multi agency' group which includes representatives from education, social care and health services.

This group initially designed the Shropshire process for Education Health and Care Plans (EHCPs) but now that the new system is in place it will monitor how

it is working and aims to continue to improve the system for families. PACC would be keen to hear from parent carers who have experienced the transfer to an EHCP, or who have applied for an EHCP from scratch, to hear about their experiences.

## **Adult Learning Disabilities Partnership**

– Very recently PACC have established links with adult services. We had a positive meeting early this year with Stephen Chandler, the Director of Adult Services, resulting in an invite for a PACC Rep to join the Adult Learning Disabilities Partnership Board, which we were very pleased to accept.

**Transition** – PACC is working with Shropshire Council to ensure that new requirements around transition are met. Shropshire Council is also exploring a lifelong service for people with disabilities, joining up children and adult services. Two committee members took part in a workshop to explore what this might look like, followed by a parent carer workshop which looked

at families' experiences of transition. PACC produced a short report which was shared with Shropshire Council's senior management team.

PACC also works with **statutory health organisations** including the Shropshire Community Health NHS Trust which delivers all community health services such as Speech and Language, Occupational Therapy, Physiotherapy and CAMHS amongst others. Recently we have particularly been focusing on working with them to improve families' experiences of CAMHS in relation to diagnosing Autism and associated conditions. PACC also recently met with the Shropshire Commissioner for Children and Women's Health and a representative of the Shropshire Clinical Commissioning Group to discuss the role of health staff in the EHCP process and the need for more focus on the health of young people with disabilities or additional needs in planning and funding local health services.



# Trustee's Report Continued.....

PACC published its 'Health and Wellbeing For All' report, in response to the Shropshire Health and Wellbeing Strategy, in January 2015. While PACC has had some positive contact with the Shropshire statutory health organisations, we feel this relationship needs to be further developed to ensure a higher level of parent carer participation in local strategic health decision making.

Shropshire also has an active **Voluntary and Community Sector**, with many organisations supporting families of children and young people with disabilities or additional needs. PACC is a member of the Shropshire Voluntary and Community

Assembly (VCSA) and up until recently chaired the VCSA's 0-25 Summit. PACC highlights the challenges faced by parent carers and their families, the implications of recent legislation, and aims to strengthen the role of the voluntary sector in providing support.

One of our closest voluntary sector partners is the **Autism West Midlands (AWM) Shropshire Project**.

Currently we jointly offer 2 monthly coffee mornings in Shrewsbury and Bridgnorth, and are planning another in Oswestry. We recently worked together on the parent questionnaire for the Shropshire Autism Needs Analysis which received over 300 responses.

This year we have also developed our partnership with **Shropshire Healthwatch**. We were extremely pleased to secure a Healthwatch research grant to explore the impact of supporting children and young people who are multiple service users, on parent carers.

**Supporting and Informing Parent Carers** - Since all committee members are parent carers we know that supporting a child or young person with a disability or additional need can be challenging at times. Providing opportunities to meet for mutual support is an essential part of our work as we believe that this is an important first step towards participation. PACC offers monthly OASIS support groups and a Face2Face Befriending

scheme led by Shana Weare, the PACC Face2Face Co-ordinator.

While PACC is not here primarily to provide information, we know that well informed parent carers feel less frustrated and demoralised. They are often more resilient and able to participate in decision making both for their families and on behalf of the wider community. The PACC website, Twitter and Facebook pages are all regularly updated and our termly Participate Newsletter goes out to 1000 people including PACC members and Severndale School families. A copy is also sent to all Shropshire schools, GP surgeries and professionals on our mailing list. In addition to this PACC send an e-bulletin to our members every 2-3 weeks, providing information on consultations and activities on offer.

We hope that has provided a good overview of the work that PACC is doing. If you have any questions about any of the above or about PACC please do get in touch by sending an email to [enquiries@paccshropshire.org.uk](mailto:enquiries@paccshropshire.org.uk)

# Highlights of 2014-2015

**October 2014**

Four parent carers train to become **parent reps**.

**October 2014**

Parent/carers meet with local organisations and local authority to discuss what is required of an impartial **Information and Advice Service**.

**December 2014**

Our AGM and Open event provides valuable up-dates on changes to **social care legislation**, much needed when so much is going on.

**February 2015**

Fifty eight parent carers benefit from attending a PACC/ Spectrum training event on **behaviour management**.

**May 2015**

What helps a family to help itself to flourish? Thirty six of you came to our **conference on "Living Positively with Disability"** to share ideas and laughter.

**June 2015**

Our annual **Information Event** attracts 50 people, with a focus on providing face to face information on a Friday, and family fun on Saturday.

## PACC Membership

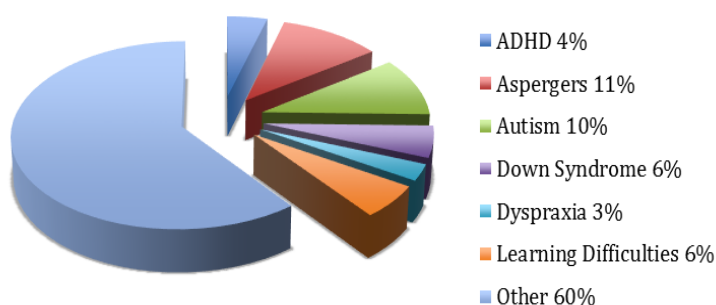
We currently have 489 members of the Parent and Carer Council. All members are parent carers and are living in Shropshire. Between December 2014 and November 2015, we have had 38 new parent carer members.

46% of children registered with PACC attend mainstream school, 22% attend specialist school, 1% are home education and we do not have this information for 31% of children.

Ages of children registered are up to 5 years 5%, 6-12 years 54%, 13-19 years 35% and over 20 years 6%

NB: We do not currently hold a full set of information for all our members resulting in some categories having a large 'other' or 'unknown' component.

### Disability or additional need



### Breakdown of disability



# Peer to Peer Support for Families

At PACC we understand how much we may need to talk, and to talk to someone who shares our concerns and experiences.

In the last year:

- 5 trained volunteers with our Face2Face service provided one to one support to parent carers across the whole of Shropshire.
- 76 parents carers came to one of our five OASIS Group meetings (day-time, evening, school based and autism specific).
- 108 parent carers have reported increased resilience and ability to cope after attending PACC events

In 2011 we asked parent carers what made them "Mad, Sad and Glad" – you can see our report on our website. In 2015 we asked everyone who came to our Annual Conference the same questions. It is interesting to see the changes in the responses and what issues have remained the same

**Isolation** was an important theme in the 2011 survey, but did not feature in 2015.

New in 2015 – **concern for other families** featured strongly as a theme which made people "sad". Comments included:

- Other parents still having to fight for

rights for their children

- People out there who are unaware of support
- Sad that so many people don't know what is out there
- Seeing the stress and anxiety some of my friends are experiencing through transition.

This shows an important trend – that parents carers are now getting the opportunity to share concerns and work with and for one another.

"I recently did the Face2Face befrienders course and found this really helpful in thinking about how I and we as a family are developing our resilience."

# Informing Parent Carers

The better informed parents carers are, the more confident they are and the more able to make informed choices for their community. PACC has an important role in making sure that parent carers know what is available, know where to go for information and advice, and know about developments

and changes that are going to affect their families.

We asked our members, "Has information provided by PACC from the newsletter, updates or events improved your knowledge of services or legislation?"

**96% of respondents told us YES!**

In the last year:

- 830 parents /carers received 3 editions of our newsletter
- There were 4613 visits to our website
- We have 283 likes on Facebook and 518 followers on Twitter.

# Co-producing with Parents

Co-production requires opportunities for parent carers and professionals to work together right from the start of a process, to develop a shared understanding of issues and to jointly develop solutions.

We asked our members, "Do you feel that PACC provides you with the opportunity to

participate in joint decision making in relation to service provision?"

**89% of respondents told us YES!**

"(I was) very encouraged how parents/carers have been invited to be involved in this process rather than us just being presented with a

fait accompli website. It makes parents/carers feel much more comfortable that the LA and local service providers are working hand in hand with them, rather than both parties being on opposite sides of the fence."

*Feedback by parent/carer on PACC IAS consultation event*

# Parent Carer Participation

We are always looking for more parent carers to join our Participation Steering Group, as parent carer reps. One of the most important parts of PACC's work is participation in meetings with the organisations who design, review and deliver services used by PACC members. It is crucial that we have the capacity to ensure that parent carers are in the room when decisions are being made about the services our families rely on.

Due to PACC's success in establishing itself as an effective parent carer Forum we are receiving an increasing number of requests for

representation and it is key for PACC's ongoing development that we can respond positively to these. Parent participation is a significant step up. Although it requires commitment from parents/carers it brings a real opportunity to use their unique skills and expertise to become actively involved in service planning and decision making.

PACC currently has 6 parent carer representatives. These parent carers are able to commit to representing parent carer views on local strategy groups. It is challenging but interesting work and all

parent reps receive training and ongoing support. Initially new parent reps will be partnered by experienced reps when attending meetings. It is a great opportunity to develop new skills and your confidence by doing something that will really make a difference to families of children with special educational needs and disabilities. **PACC cannot be truly effective without your support, join us in unlocking doors together.**



# PACC Participation Forum



This forum meets monthly to discuss issues and concerns affecting our members. All members are welcome to attend the forum. Details of future meetings are published in our newsletter and on our website.

**Zara Bowden (Chair of Participation Forum)**

## Management and Funding

PACC is a registered charity. It is managed by the PACC Management Committee, which meets at least every 2 months and keeps in touch in between times by email and phone. Membership of the committee is only open to parent carers, although other people are invited to the meetings from time to time to advise or consult with. The PACC Management Committee is a diverse group and brings a wide range of experience and knowledge to the work of PACC.

This year PACC refreshed its governance to ensure its structure is consistent with its constitution. From now on all the PACC Management Committee members act as PACC

trustees and will meet regularly at least every two months to oversee governance and policy. Following each Committee meeting there will be a Participation Forum, which will be an open meeting for all members to discuss current issues and activities.

Participation activity is planned and implemented by the Participation Co-ordinator. This role is the main point of contact between PACC and statutory partners, such as Shropshire Council and Shropshire Clinical Commissioning Group, and the local voluntary sector. The Participation

Co-ordinator also monitors the PACC phone line and email address and is the initial

point of contact for most parent carer contact. In 2015 PACC's Participation Co-ordinator moved to a new post with a different organisation and so far, due to administrative and personal issues affecting recruitment, this role has not yet been filled. This work is currently being covered by temporary staff. PACC is currently able to employ a part-time administrator and also outsources administrative support. PACC does not charge parents carers for any of its activities or services. It currently does not charge stakeholders for any of its activities or services (other than expenses for parent reps) but this may have to be reviewed in the future.

# Management and Funding Continued .....

PACC receives grants which have consolidated its position and built its capacity.

- Department For Education – annual grant managed by Contact a Family
- BIG Lottery – 3 year funding

- programme October 2013 – Sept 2016
- Healthwatch Research Grant – 1 year grant April 2015 – March 2016

These grants came with requirements to improve the capacity, range and quality of what we deliver. In 2015 PACC

has been able to report that it is on target to deliver these requirements. We are actively seeking funding to ensure sustainability once these grant periods are ended. PACC's annual accounts are available on the Charity Commission website.

## Volunteers

Over the last year PACC volunteers contributed 800 hours of their time.

We are a voluntary organisation. We employ a Participation Co-ordinator, an administrator and some outside support with administration but most of our activities are delivered by parent carer volunteers who give up their time and much needed energy.

Currently 9 parent carers support PACC on a voluntary basis by being part of our Management Committee or delivering activity. In

total they contribute nearly 500 hours by planning and delivering events and groups and representing PACC at strategic meetings.

5 volunteers are active as Face2Face befrienders to support other parent carers by phone, email and face-to-face. They are also involved with running OASIS groups and in-school groups. Over the last year they have contributed 325 hours to PACC.

PACC is very grateful to all these volunteers who give up their time and

much needed energy. We are always keen to hear from any parent carer who would like to volunteer with PACC in one of these roles, or to support with administrative tasks.

“Thank you for your hard work and thoughtfulness in organising the day and I will use the ‘My Joy of’ Book. All excellent and worth finding time in a busy day for.”

*Parent Carer feedback on PACC Conference on family resilience May 2015*

# Challenges

## **We want more members**

It is estimated that there are 7000 plus children and young people with disabilities and additional needs across Shropshire. We want PACC to reach out to ALL their families. We will continue to promote PACC widely and aim to increase our membership to 600 in the next 12 months.

## **So much more to find out**

Our annual survey of members highlighted a wide range of concerns. Transition again headed the list, but with education a close second. This probably reflects the huge changes to the resourcing and delivery

of special needs education in the last two years. PACC will continue to raise concerns about what will be available for our children as they grow up and to work with services to ensure that parents and carers participate in planning for the future.

## **We can't always be there**

We know that sometimes people just need someone to talk to, which is why we set up the Face2Face project and OASIS groups. Sometimes though people need someone to talk to "there and then". We are happy to talk on the phone, but can't always

be there. We will continue to work alongside other services to develop information, advice and support services in Shropshire. We will also keep our own records to contribute to service planning.

## **Funding**

PACC's largest grant ends in 2016 (BIG Lottery). Given the expected membership by that time then it will no longer be feasible for volunteers to undertake all the administration and promotion. It will be important for PACC to develop effective partnership with other organisations and to explore all possible funding opportunities



**Katie Clarke presenting at the PACC Conference 2015**

# The Management Committee



## **Anne Lanham (PACC Chair)**

I am a full time mother to 2 children. My daughter has a rare chromosome disorder and attends Condover College Day opportunities programme, having previously attended Severndale . Over the last 20 years, my family has accessed many of the services available to disabled children and young people in Shropshire. I joined PACC as I felt that my experiences would be invaluable in helping to ensure that those services meet the needs of all our children in the best way possible. I represent PACC in areas including Short Breaks, Palliative Care, Transport and Transition.



## **Sarah Thomas (Secretary)**

I have 3 boys. My eldest son, Jake, is diagnosed with ADHD and Aspergers, my middle son, Owen, has a rare chromosome abnormality resulting in physical and learning disabilities, and Eliot the youngest struggles with ASD, dyspraxia and dyscalculia. I believe that parent carers must be equal partners in any decision making about their child and family and they have a huge amount of knowledge and experience to contribute to building a better support system.



## **Julie Davenport**

As a Nursery Nurse and Nurse I have experience of working in Health and Education. I have two daughters, one in a special school and the other in mainstream. I joined PACC to lobby for positive changes in Education and Health Services for disabled children in Shropshire



## **Annette Whitaker**

With a background in health and education, Annette is mum to three adopted children. Two have needs including ADHD, learning difficulties, global developmental delay, developmental coordination disorder, attachment issues and Autistic Spectrum Disorder. Her third has had surgery for scoliosis.



## **Kat Slade**

My son, who is 18, has autism, severe learning difficulties, and epilepsy. He currently attends Overley Hall School in Wellington, on a 52 week residential placement, where he has been for five years. I feel very strongly that parents who make this hugely difficult decision to send their children to a residential school need supporting. Previously a journalist, I have recently completed a Masters in Health Psychology at Aston University, and my particular interest is health issues around being a parent carer. I also lecture at University College Birmingham.



# The Management Committee



## **Gail Hogan**

I have 3 children and my youngest has had corrective surgery for a congenital heart defect and has ongoing input from the cardiology team at Birmingham Children's Hospital. She has Down's Syndrome; she experienced a number of the difficulties associated with her diagnosis but she is growing up beautifully. I am secretary of Shropshire Down's Syndrome Support Group. I have finished working as a Registered Manager of a Children's Home (having worked with looked after children for 15 years) to study an MA in Social Work at Wolverhampton.

## **Sarah Lou Holme**

Due to changes to personal circumstances or to PACC's governance then the following people stood down from the PACC Committee during the last year. We thank them for everything that they have contributed to PACC as committee members and look forward to continuing to work with them as PACC members.

**Esther Scriven, Nick O'Leary, Jeannette Griffiths,**



**The PACC Conference  
Mad, Sad, Glad wall**

***"Knowing that you are not alone"***

***Response to the question  
What makes you Glad about  
being a parent carer of a child  
with a disability or additional  
need in Shropshire?***



# Trustees' report on the Financial Statements for the year ending 31 March 2015

## **Shropshire Parent and Carer Council (PACC)**

### **Charity Number**

1150180

### **Principal Address**

Shropshire Parent and  
Carer Council

PO Box 4774

Shrewsbury

SY1 9EX

### **Trustees**

Anne Lanham

Sarah Thomas

Julie Davenport

Annette Whitaker

Kat Slade

Gail Hogan

Sarah-Lou Holme

### **Accountant**

Crundell & Co  
Accountancy Limited

5 Winterton Way

Shrewsbury

SY3 5PA

### **Trustees' Report**

The trustees present their annual report and financial statements of the charity for the year ended 31 March 2015. The financial statements have been prepared in accordance with the

Charities Act 1993 and the Statement of Recommended Practice: Accounting and Reporting by Charities published in 2005.

### **Structure, Governance and Management**

The charity is registered with the Charity Commission and is run in accordance with the constitution adopted on 3 December 2011 and as amended on 16 November 2012.

### **Objectives and Activities**

The objectives of the Charity are to relieve the needs of children with disabilities and additional needs, their parents, carers and families, particularly but not exclusively by (a) the creation of a Shropshire parent carer community that reduces isolation and strengthens the capacity of parents and carers to support their families, (b) by the provision of information to inform and empower parent carers about the services and issues that affect their families, (c) by the provision of opportunities for parent

carers to influence the decisions that affect their families and to contribute to developing services that meet the needs of their families. The trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives and in planning future activities. The Charity carries out these objectives by running parent groups, workshops, training, providing parent carer representation and offering emotional support.

### **Reserves Policy**

The Trustees aim to maintain free reserves at a low level sufficient to supplement the day to day running of the Charity. The restricted funds are made up of grants and are spent according to the grant requirements which assist the Charity in meeting its objectives. Any money left over at the year end is kept in reserves to be spent in the following year.

# The National Picture



## The National Network of Parent Carer Forums - "Our Strength is our Shared Experience"

PACC is a member of the National Network of Parent Carer Forums (NNPCF) and our representatives regularly meets with other Parent Carer representatives at West Midland Regional Network meetings.

The NNPCF is funded by the Department For Education to enable the voice of parent carers to influence and contribute to national decision making. Each local area receives funding to support a pan disability forum, led by parent carers of children and

young people, aged 0-25 years. These Forums are all members of the NNPCF and at last count had a cumulative reach of 67,000 parent carers.

The NNPCF national steering group is made up of elected members from the Regional Networks. The function of the NNPCF is to develop good practice and effective participation, using a solution focused approach at all levels, locally, regionally and nationally. The aims of the NNPCF are;

- To ensure that good practice, knowledge and shared expertise about parent carer participation continues to grow and strengthen.
- To develop a cohesive and coherent structure and develop the effectiveness of parent carer forums across England.
- To strengthen the pan disability, parent led model of local forums and to grow the collective voice of parent carers.

Further information is available at [www.nnpcf.org.uk](http://www.nnpcf.org.uk)

**Contact a Family** provides support for local Parent Carer Forums and the NNPCF, through their Department For Education funded 'Strengthening Parent Carer Participation Programme'. The CAF 'Strengthening Parent Carer participation' team works closely with the DFE and other national partners providing feedback from parent carers on the development of parent carer participation in local areas.

For more information see <http://www.cafamily.org.uk/what-we-do/parent-carer-participation/>

**contact a family**  
for families with disabled children



**Shropshire Parent and Carer Council**  
**PO Box 4774**  
**Shrewsbury**  
**SY1 9EX**

**Email [enquiries@paccshropshire.org.uk](mailto:enquiries@paccshropshire.org.uk)**

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