



SHROPSHIRE Parent  
And Carer  
Council

# Annual Report Oct 2013 - Sept 2014



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## Welcome

Thank you for your interest in PACC, whether you are a parent/carer who someone who works with children with disabilities and additional needs and their families.

PACC has been supporting and encouraging parents/carers to be actively involved with the services that their family use since 2007. All of our members and our committee are Shropshire parents/carers who have a child with a disability or additional need, aged 0-25 years. As an independent, parent led organisation we have a real understanding of the challenges faced by families. Over the last twelve months we have had more opportunities than ever before to deliver our aims of:

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

We have to highlight the huge impact of our BIG Lottery Family Voice project. We are now one year into this three year project, run jointly with PODS (the parent carer forum for Telford & Wrekin). This year it has enabled us to promote ourselves more widely and to ensure that our Face2Face service and OASIS groups continue to thrive and flourish. More members and more people informed and supported means more people who can fully participate and share their views.



We have also been involved in the huge changes at national and local level due to the changes to Special Educational Needs and Disability (SEND) system, including:

- the move to Education, Health and Social Care Plans
- increased opportunities for parent carers to be involved in decision making and planning both at an individual and service level
- the move to a personalised approach across education, health and social care
- the requirement on Local Authorities and Clinical Commissioning Groups to ensure parents carers have access to impartial Information, Advice and Support Services.

These changes have been energising for those who have been pressing for change, exhausting for others, and something of both for most people! However, these are the first changes on this scale to have happened in Shropshire in which large numbers of parent carers have been listened to and have been able to contribute to decision making – and PACC has been delighted to take part.

Thank you to everyone who has invited PACC to participate in planning and delivery of services – we look forward to continuing to work with you – with respect and honesty! If your service would like to know more about how parent participation could contribute to your service development please do contact us.

Thanks are mainly due though to the parents and carers who make up the PACC membership. We are pleased that so many of you are now joining PACC and contributing to its success. Whether you are committee members, parent reps, Face2Face volunteers, people who give up your time to come to consultative events and to complete surveys, people who write for the newsletter ..... thank you all. Your energy, commitment and good humour in caring for your own families whilst taking part in making Shropshire a better place for all families is truly wonderful.



This report gives you a flavour of what we have been able to achieve in the last twelve months, but we do hope you would like to know more.

Please contact us for more information about PACC, or look on our website [www.paccshropshire.org.uk](http://www.paccshropshire.org.uk).

Also do please remember to sign up to receive our up-dates and newsletter.

Best wishes

**The PACC Committee**

## Highlights of 2014

**September 2013**

### **New Co-ordinator for Face2Face parent support**

Shana Weir appointed as our new Face2Face co-ordinator (shared with PODS in Telford & Wrekin).

**October 2013**

### **New look newsletter launched**

Changes to services, opportunities to get involved Family stories (ups and downs!)

**November 2013**

### **AGM and Open Meeting 2013**

Essential information for parent carers on Wills & Trusts and consultation activity on draft SEND Code of Practice.

**December 2013**

### **Craft Fayre and Carer Christmas Buffet**

Ran our first Christmas craft fayre and had provided some festive pampering for parent carers.

**January 2014**

### **Face 2 Face befriender Training**

Ran first combined Telford and Wrekin and Shropshire Face 2 Face training course.

**March 2014**

### **Website up-graded and new information leaflets**

It's not just about looking good -it's about making sure that everyone knows we're here and is clear about how we can help.

**May 2014**

**Annual Conference**

Biggest ever attendance with 80 plus parents and professionals in one room to discuss the SEND reforms.

**June 2014**

**Annual Information Day**

Now a regular highlight. This year 53 parents and carers came to find out what is available to their families, chat to people who provide the services they use, and to meet one another.

**OASIS Groups**

Started new OASIS Group in Oswestry, giving parent carers an opportunity to meet & share information and experiences.

**August 2014**

**PACC Membership tops 400**

Since then it has climbed to 444 - an increase of 107 in one year. The increase in our membership rate has grown by 50% this year.

**September 2014**

**The year's figures show:**

844 parent carers received information directly from PACC on a regular basis (at least 3 times per year).

## A parent's journey

As a mother pregnant with my first child, as all mothers will understand, the possibilities are endless. Will my child one day fill my home with the laughter of their own little ones, will my child fall hopelessly in love as I did, and will my child one day change the world... These are all the questions and possible outcomes that we desire for our children. But not once did I ask myself will my baby make it into the world safely, will she survive her first night, or will this tiny creature that stole my heart break it.

Once your child comes into this world, everything changes. The world tilts and your priorities change forever. Especially when you are given that diagnosis. My world became so much bigger, learning all that I could about Hemiplegic Cerebral Palsy and Hydrocephalus. Watching the physiotherapist and taking notes on all the different ways she was helping my daughter. I even took up fitness, initially to help myself and manage my depression, but after a while I realised that I could transfer this knowledge into supporting my child even further. So I trained in various qualifications and set up my own Dance Fitness business, working in local gyms to pay the bills but then using my new skills to work with my daughter to develop her abilities and strengthen her body.

It wasn't until my youngest daughter came along, and with encouragement from our portage worker, that I started to realise that I had skills that could be offered to help other families. I was introduced to Sarah Thomas who talked me through the Face to Face scheme and asked if I would like to start coming to the oasis groups. I was soon attending the befriender training course where I travelled a very personal journey, truly realising the distance I had come. This gave me the confidence to then start working with the PACC committee and parent reps in attending strategic meetings, regional, and national events.

I started my parent rep work at a very crucial time and was lucky enough to be one of the first parent carers to sit at the table discussing the SEND Reforms in Shropshire. This area of work ignited a spark within me. I could make a real difference here. As a part of the working groups looking at all areas of the reforms, our shared stories, experiences, and opinions were influencing change that was happening now.

At an NNPCF (National Network of Parent Carer Forums) AGM in 2013, Sarah asked myself and another committee member if either of us would be interested in the Co-Chair role with PACC. I hesitated for too long, giving away my enthusiasm at such an opportunity. This time last year I was successfully elected alongside Anne Lanham.

Since then my world has changed significantly. I have become more involved with the reforms process in Shropshire and two months ago secured a contract working within children's services as the Local Offer Coordinator.

I could never have imagined my life going in this direction. Seven years ago I was working in mental health as an administrator in rehabilitation. Today I am a very proud mother of two, Co-Chair of a successful parent carer forum, running two businesses from home, and am now working in the heart of the reforms developing the Local Offer.

I have made friends along the way, and discovered a new family within PACC. This whole time learning more about myself and gaining in confidence and ability while managing to improve my daughter's prospects at every turn.

Thank you PACC for all that you have done for me and my family.

Zara Bowden

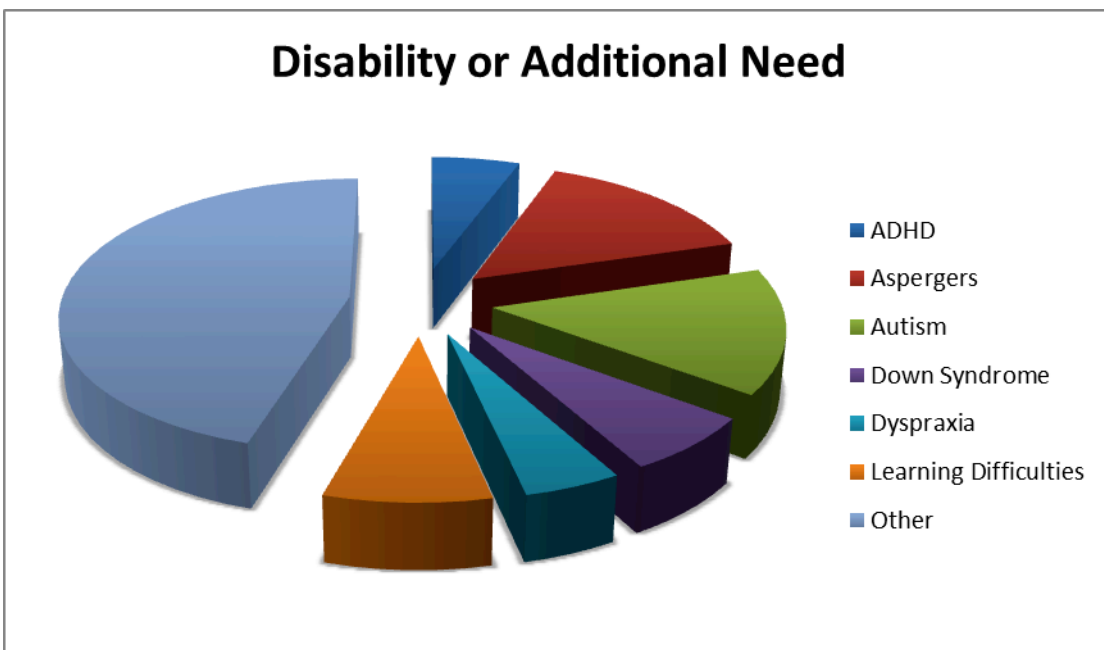
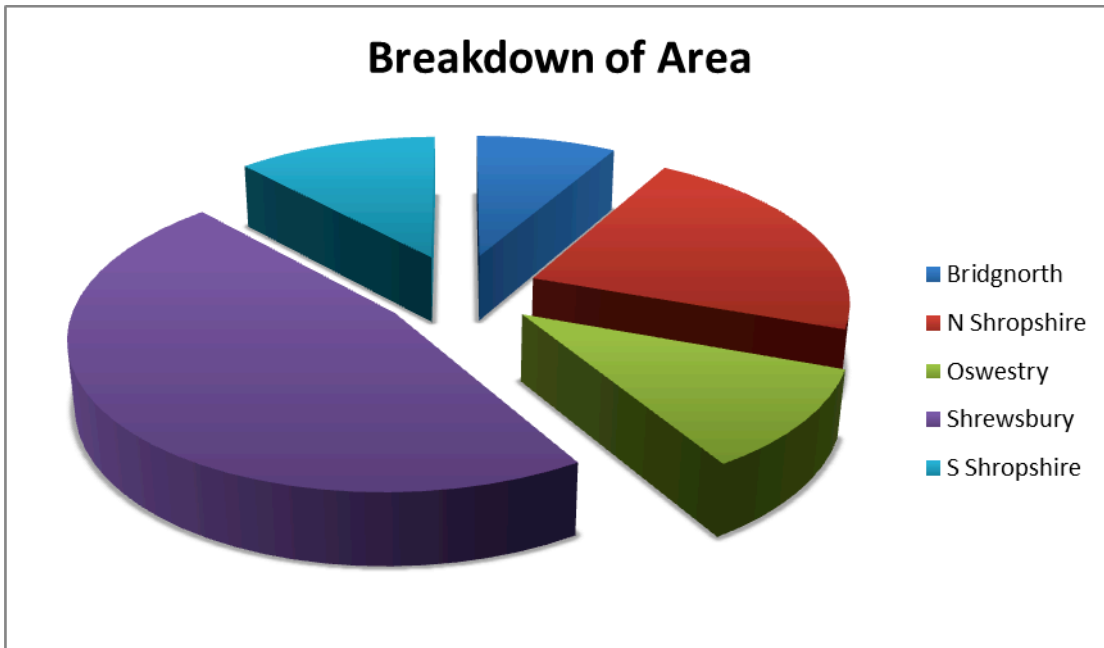




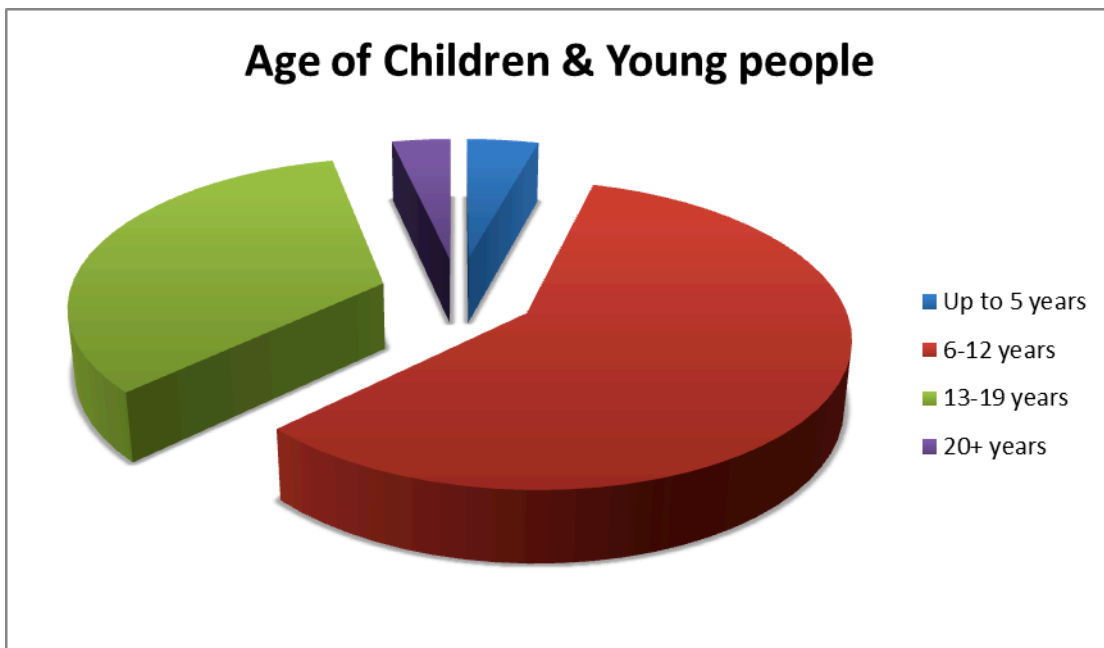
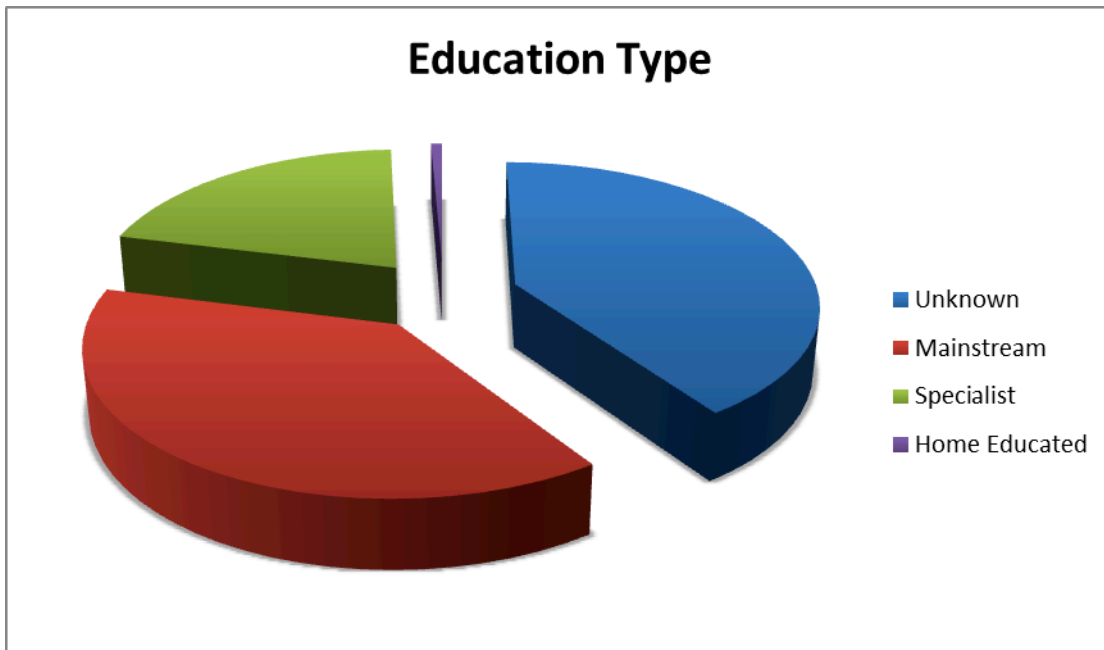
## PACC Membership

We currently have 451 members of the Parent and Carer Council. All members are parent carers and are living in Shropshire. Between December 2013 and November 2014, we have had 110 new parent carer members.

### Breakdown of membership



Over the last year, we have been gathering more information about our members' children including age and education type. We have only been able to gather this information from approximately half of our members so far.



## Peer to peer support for families

92 parent carers have reported increased resilience and ability to cope after attending PACC events.

In the last year:

- 12 parents carers received one to one support from the 4 trained volunteer befrienders with our Face2Face service
- 226 parents carers came to one of our five OASIS Group meetings (day-time, evening, school based and autism specific).

Thanks to our BIG Lottery Reaching Communities Grant PACC we have been able to extend Face 2 Face support to Telford and Wrekin and have been able to employ a Face 2 Face coordinator who covers both areas. This means that we are now able to ensure that we have the capacity to train and support our volunteers and to make sure that everyone who could benefit from the service can benefit from it.

Data and feedback from our events show that meeting with others parent carers help increase resilience and ability to cope. Parent carers really value the opportunity to meet with others who have similar experiences.

I know how hard and lonely it can sometimes feel to be a parent carer, having someone friendly and non judgmental can make a massive difference in how we feel and can cope.

**Face 2 Face Befriender**

- It is nice to know someone is there for me, before I just felt like no one really understood.
- I would recommend the befriending scheme to anyone, it's comforting to know I could contact you again if I felt like I needed support again.
- I'm very grateful to volunteer befrienders for all their hard work and time they commit to it.

**Feedback from parent carers who have been supported by Face 2 Face**

Before I joined this group it felt very lonely being a parent of a Sen child. The support and advice everyone in the group gives is invaluable.

**A parent carer who attends a PACC OASIS Group**

## Informing parent carers

In October 2014 we asked our members, "Has information provided by PACC from the newsletter, updates or events improved your knowledge of services or legislation?"

**94% of respondents told us YES!**

The better informed parents are, the more confident they are and the more able to make informed choices for their children.

PACC isn't a dedicated information service but we have an important role to play in making sure that parents/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.

In the last twelve months we've arranged these events, attended by exactly 100 parent carers:

- Annual information day for parents and carers (run jointly with PODS from Telford & Wrekin)
- PACC Christmas Fair
- Wills and Trusts – presentation by a solicitor
- Behaviour Management

We also know that our members value our termly newsletter, email up-dates, social media and our newly developed website.

In the last year:

- 844 parents / carers had our newsletter
- There were 3,122 visits to our website
- We have 195 likes on Facebook and 331 followers on Twitter.

## Consulting with parents/carers

In October 2014 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?"

94% of respondents told us **YES!**

We also asked, "Do you feel that PACC provides you with the opportunity to have your "voice heard" which helps shape service provisions?"

91% of respondents told us **YES!**

Consultation requires two way communication. Professionals may consult with parents on existing services, seek their opinions on how services can be improved or how good practice could be replicated elsewhere. In the last 12 months PACC has put on events where over 105 parents/carers met up with one another and with service providers to share their views on:

- New SEND Code of Practice
- Shropshire's Education, Health and Social Care Plans
- Parent Centred Planning and one page profiles
- The Local Offer and Information, Advice and Support Services.

As it isn't always easy or possible for parents/carers to get to events we also give people the opportunity to take part by sending out paper surveys and setting up on-line surveys, such as:

- Helping design the Shropshire Local Offer
- Building the Shropshire Information, Advice and Support Service (IAS)
- PACC Newsletter survey

*"Real eye opener, has made me think about how I represent my child. Really positive experiences. I feel more prepared. Thank you."*

*Parent carer who attended the day on Parent Centred Planning Day*

## Parent/carer participation

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 parents/carers are able to commit to representing parent/carer views on local strategy groups. It is challenging but interesting work and PACC offers training and support to make sure that parent reps get the most out of their experience and can really contribute.

Over the last year parent/carer reps have sat on the following groups.

### Hosted by Shropshire Council

- 0-25 Children and Young People Strategic Board
- Short Breaks Steering Group
- Autism Steering Group
- Task and Finish Group for the Personalisation Pilot

### Health Service

- Children's Palliative Care Group
- Paediatric Continence Group
- Shropshire Patient Group
- Health and Wellbeing Stakeholder Alliance Network
- Women and Children's focus group - Future Configuration of Hospital Services
- Care and Health Issues Group

### Voluntary Sector

- The Children's Summit
- The Pan Disability Forum
- The National Network of Parent Carer Forums (NNPCF)

### PACC has also been involved in the following areas of work.

- Review of the Shropshire and Telford and Wrekin Autism Information Pack
- Ongoing discussions with SEN School Transport Service
- Ongoing discussions with Shropshire Healthwatch

For information about these groups and how we are involved:

- go to our website [www.paccshropshire](http://www.paccshropshire)
- click on about PACC / current work areas.

## What difference did we make?

In the last twelve months parents and carers have told us that because of their involvement with PACC they are feeling:

- More resilient and able to cope
- More informed about legislation and the issues that affect their families
- More able to influence decision making.

Our community of parents/carers has worked together with local services to influence change and ensure that developing services take account of parent/carers views.

Examples include:

- Working with the Paediatric Continence Steering Group we ensured that the Continence policy clearly stated that decisions about products and quantities should be based on individual needs assessment, with no blanket approach.
- The invitation for tender for Shropshire Short Breaks 2013/14 reflected the parent carer led outcomes identified in the PACC Short Breaks report.
- The new education, health and care plan process in Shropshire recognises the value of information provided by parent carers about their child's needs and strengths, reflecting the input of PACC representatives into this work.
- The Shropshire Local Offer has been co-produced with Shropshire parent carers and the voice of parent carers has been central to this important piece of work.



## Volunteers

Over the last year PACC volunteers contributed 600 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.

There are nine parent/carers who form our committee to oversee all PACC's activities. By attending meetings they contribute a total of 250 hours a year, plus the time they spend preparing for meetings and representing PACC.

Four 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 140 hours to PACC.

Six volunteers have been trained as parent reps, to represent the views of the PACC membership on strategic groups. Over the last year they have contributed 210 hours.

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.



*"With PACC I want to improve the system and make service providers understand the different and complex needs of our children. It is also important to think about the parent/carer during confusing, difficult and emotional processes."*

*Nick O'Leary - member of PACC Committee*



## Management and funding

PACC is a registered charity. It is managed by the PACC Committee, which meets 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. We are looking to extend our management committee and to increase the frequency of committee meetings to once a month. The PACC committee is a diverse group and brings a wide range of experience and knowledge to the work of PACC.

PACC is currently able to employ a part-time administrator and also outsources administrative support. The level of funded administrative support has increased over the last 12 months due to additional funding being secured. This has meant that PACC has been able to increase its contact with members and create and manage an extensive membership database. The PACC website is also managed and kept up to date by this post.

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. As part of the role the PACC Participation co-ordinator also chairs the Shropshire Voluntary and Community Sector Assembly '0-25 years Forum'. This group brings together all the local voluntary sector organisations which have an interest in supporting children and young people aged 0-25 and their families. 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.

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.

In 2013 it received two substantial 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
- Shropshire council – 6 months Face 2 Face funding April 2013 – Sept 2013

These grants came with requirements to improve the capacity, range and quality of what we deliver. In 2014 PACC has been able to report that it is on target to deliver these requirements. We will be actively seeking funding to ensure sustainability once these grant periods are ended.

## Challenges

### **We want more members**

Nobody knows for sure how many parents/carers of children with disabilities and additional needs there are in Shropshire, but there are estimated to be 5000 plus when you consider all young people with Statements or on School Action or School Action Plus alone. We want PACC to reach out to ALL of them. 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 and future planning topped the list. PACC continues 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 two main grants end in 2016 (Department for Education and 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.

## The PACC Committee



### **Anne Lanham (Co-chair)**

Anne is a full time mother to two children, Anne has a daughter with a rare chromosome disorder which means that she requires a high level of care and medical intervention. Anne's son is diagnosed with Aspergers.



### **Zara Bowden (Co-chair)**

Zara combines working as Shropshire's Local Offer Co-ordinator with raising her two daughters. Her eldest has medical and physical limitations.



### **Sarah Thomas (Secretary and Participation Co-ordinator)**

Sarah is employed by PACC on a part time basis and has three boys with SEN and disabilities, including ADHD, Asperger's, Dyspraxia and severe learning and communication difficulties due to a rare chromosome abnormality.



### **Esther Scriven**

Esther is training as a Social Worker and is mother to three sons, two of whom have additional needs. Her eldest has Asperger's, dyspraxia and epilepsy, and he youngest has Atypical autism and ADHD.



### **Julie Davenport**

Julie has two daughters, one in special education and one in mainstream. As a mother, and as qualified nurse and nursery nurse, she has particular interests in Autistic Spectrum Disorder and diabetes care.



### **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.



**Sharon Earney**

Sharon has four sons and as a mother has experience of ADHD, Asperger's, learning difficulties, epilepsy, and severe speech delay. She is currently at college and hopes to go to university to study Special Needs and inclusion.



**Nick O'Leary**

Nick is the father of an autistic son. He volunteers with PACC to share and learn from other parent/carers and to gain a better understanding of how the system works.



**Jeannette Griffiths**

Jeannette is a full time mother to four young children. Her eldest son has Aspergers Syndrome, Dyspraxia and ADHD traits and her younger son has Atypical Autism. She has considerable experience of befriending and running support groups.

**Richard Cooke (Treasurer) and Heather Cooke**

Richard and Heather have two sons, one of which is diagnosed with Autism and attends a special school. Due to changes in personal circumstances both Richard and Heather stood down from the PACC committee early in 2014.

**"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has".**

**Margaret Meade**

## Trustees Report

### Shropshire Parent and Carer Council

#### Financial Statements

For The Year Ended 31 March 2014

#### Shropshire Parent and Carer Council (PACC) Reference and Administrative Details

<b>Charity Name</b>	Shropshire Parent and Carer Council
<b>Other names</b>	PACC
<b>Charity Number</b>	1150180

#### Principal Address

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

#### Trustees

Mrs Julie Davenport  
Mrs Alexis Carolyn Evans  
Mrs Anne Lanham  
Mrs Annette Whitaker  
Mrs Esther Margaret Scriven  
Mrs Heather Cooke  
Mrs Jeannette Kay Griffiths  
Mr Richard Cooke  
Mrs Sandra Barrett

#### Accountant

Crundell & Co Accountancy Limited  
5 Winterton Way  
Shrewsbury  
SY3 5PA

## **Trustees' Report of Shropshire Parent and Carer Council (PACC) on the Accounts for the Year Ended 31 March 2014**

The trustees present their annual report and financial statements of the charity for the year ended 31 March 2014. 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.

### **Trustee selection methods**

The Trustees are appointed by the committee. The committee actively seeks out Trustees from suitably experienced members of the wider community.

### **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 parents/carers about the services and issues that affect their families, (c) by 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.

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.

### **Achievements and Performance in the year**

Over the past twelve months we have had more opportunities than ever before to deliver our aims.

We have to highlight the huge impact of our BIG Lottery Family Voice project. We are now one year into this three year project, run jointly with PODS (the parent carer forum for Telford & Wrekin). This year it has enabled us to promote ourselves more widely and to ensure that our Face2Face service and OASIS groups continue to thrive and flourish. More members and more people informed and supported means more people who can fully participate and share their views. In 2013 we also received a grant from the Department of Education. These grants are going to be able to help us improve the capacity, range and quality of what we deliver.

The highlights of this year were the appointment of Shana Weare as our new Face 2 Face coordinator; the new look newsletter launch in October; our first craft fayre

and parent carer Christmas buffet; a significant increase in our membership and a website and promotional literature upgrade in March.

### **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.

### **ACCOUNTS 2013 -2014**

**See separate document.**