Family Voice

For families who have a child with a disability or additional need aged 0-25 years

Participate

Information and Support, Influence and Change

Autumn/Winter 2016

In this issue;

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PACC unlocking doors together

SHROPSHIRE Parent And Carer Council

Welcome from PACC

Keeping the Faith……

I have been working in parent participation for the past eight years, sometimes in a voluntary capacity and sometimes in a paid role. It has been an amazing journey, I have met some wonderful people and learnt so much.

I have also had the opportunity to do something that I feel passionate about and which means so much to me personally, because first and foremost I am a parent carer to three sons who all have additional needs.

Other parent carers have asked me in the past, how do I work with a system that has at times caused so much distress to families like mine? In fact, on one occasion my job was likened to 'sleeping with the enemy'! Keeping my faith in the effectiveness of parent carer participation has not always been easy and sometimes I have to admit that the scale of the task can feel overwhelming.

One of the challenges of parent carer participation is to remove some of the emotion from the situations that you are faced with, and when you are doing something that is so important to you as an individual, that is not always easy to do.

Most parent carers have had to deal with being let down by 'the system' at some point in their lives, and this often results in a lot of distrust and anger towards 'the system', and sometimes the people that represent 'the system'. Getting involved in developing parent carer participation meant that I had to put aside any anger I felt towards 'the system' and believe that things could be better. Actually believing that things could be better wasn't that difficult, because as a parent carer I felt that I had to believe that we could do a better job at supporting young people with SEND, otherwise what hope was there for my three boys!

I was lucky that I got involved in parent carer participation at a time when there was a national focus on improving the SEND system and a general belief that developing parent carer participation was key to this. In 2010 the government issued a call for evidence about the SEND system and this was the first big piece of participation work that I was involved in.

Since then parent carer participation and the SEND Reforms have dominated my life. In the early years, when we were developing the Children and Families Act and contributing to the new SEND Code of Practice, it was easy to keep going. It felt like we made progress every day and there was so much possibility.

As time hass gone on and parent carer participation as become more established it has, on occasions, become more difficult to maintain that early enthusiasm and belief. The quick wins have been achieved and expectations righty raised, but there is still so much to be done.

It is particularly hard when, despite all of the work by a huge number of people, you continue to hear of families being let down and services not being delivered in a way that ensures the best outcomes for children and young people with SEND.

This summer I was reminded personally how painful it is to be let down by 'the system' and to be excluded from the decision making that has a fundamental impact on your family's life. I once more found myself struggling to put aside the anger and the fear for your child's future that being treated this way brings and I questioned if my work for the past eight years had had any worth?

Something had gone wrong with only one aspect of my son's care, but the emotion that this generated was overwhelming. The scab was knocked off an old wound, and I struggled and failed not to let that negative experience taint everything. For a while I lost sight of all the positive things that had been achieved, both for my own family and for families of children and young people with SEND generally, and all I could see was the failures.

I have been lucky and with support from my family and friends and the benefit of the experience gained through my

Welcome from PACC

work, I have been able to move on from that point. I have been able to take that voice that whispers into my ear that there is no point and stuff it back into its box, once more firmly shutting its lid. I was able to use the positive experiences that I have had and that others have shared with me, to drag myself out of that place where everything seemed too much, but it has made me realise how vulnerable our resilience is.

This experience has confirmed for me how important it is that as parent carers we share our good experiences with each other, as well as stories about how things can go wrong.

One conversation that also particularly helped me this summer was with a Shropshire professional, who through her actions reminded me that there are a lot of committed and hard working professionals who are doing their best to create a system that provides good outcomes for our families. During that conversation I started to remember why I do my job and why I believe in parent carer participation.

There is still much to do in the world of parent carer participation and the SEND Reforms and it is important that we are honest about that. However, it is just as important that we recognise that there has also been a lot of progress made.

PACC wants to represent the experience of families of children and young people with SEND in Shropshire, both good and bad, because there is something to be learnt from both.

It is important that we know where things are going wrong but it is just as important that we hear about where things are working too.

Sharing stories about the good things in our lives can help build resilience and can create hope for others.

I hope that you enjoy reading the personal stories shared in this edition of Participate and that you can take something from them that will help you on your journey.

If you have a personal story to share please contact

enquiries

@paccshropshire.org.uk or call us on 0845 601 2205.

Sarah Thomas
Participation Coordinator
& Parent Carer

PACC AGM and Open Meeting 2016

PACC AGM and Open Meeting 2016
Thursday 24th Nov from 9.30pm to 2.30pm
Shrewsbury Baptist Church, Claremont St, SY1 1QG
Lunch & Refreshments provided

The theme for this event will be exploring how parent carers can use person centred approaches to have effective conversations with professionals. The morning session will include an introduction to Shropshire Council’s approach to embedding a person centred approach in all SEND activity. This will be followed by afternoon workshops which will consider and ask for your feedback on how parental contribution to SEND referrals, assessments and reviews can be supported and best delivered.

The event will start with the PACC AGM providing a chance for you to hear more about the work that PACC does and our plans for the future.

Booking essential – get your ticket on https://www.eventbrite.co.uk/e/pacc-agm-open-meeting-2016-tickets-28498754542 or email PACC at enquiries@paccshropshire.org.uk or call on 0845 601 2205

The Review of the Disabled Children's Register in Shropshire

Legislation

When planning services for children with special educational needs or disabilities, both nationally and in a local area, it is key that commissioners are well informed about the size, distribution and needs of the SEND population.

Since 1989 the Children Act has required that each Local Authority maintain a disabled Children's Register.
Entry onto the register is voluntary and is at the discretion of individual families.

There is no legally defined purpose of the register but the summary below from 2008 is accepted as the usual interpretation;

"In order to plan and deliver effective services, local authorities require good information about the numbers and needs of disabled children, and about the support they receive. Such data are also needed by central government to support policy development and monitor progress in improving outcomes."

More recently, Part 3 of The Children and Families Act 2014 s22 states;

"A local authority in England must exercise its functions with a view to securing that it identifies;

(a) all the children and young people in its area who have or may have special educational needs, and
(b) all the children and young people in its area who have a disability."

Identification is a key local duty since it is the starting point for the delivery of all other duties and therefore the starting point for achieving positive outcomes for children and young people with SEND.

The new joint SEND Local Area Inspections carried out by Ofsted and CQC will specifically consider how local areas identify children and young people with SEND and how progress towards agreed outcomes is recorded, so the importance of holding good data is now even more important.

The Children and Families Act 2014 s27 additionally requires that local authorities assess and keep under review the sufficiency of social care provision (and educational/ training provision) for disabled children in their area.
Compliance with this and the other strategic duties will require local authorities to know their population of disabled children and young people, understand their social care needs and assess whether the level of social care services available is sufficient to meet those needs.

Review

Over the past few years, as PACC have worked with Shropshire Council and other statutory partners on the commissioning of services for children and young people with SEND, it has become clear that there were opportunities to improve data collection for this group of children and young people.
Following the submission of a report to Shropshire Council from PACC and the Council's own assessment on the need for improved data on SEND children and young people in Shropshire, the Local Authority contracted 'SN Consultancy' to review the local Disabled Children's Register and to make recommendations about future activity to ensure the local area is meeting its statutory duties.

The review took place over a 3-month period, June – August 2016. It included discussions with the PACC Steering Group, the delivery of a parent carer workshop, meetings with a range of service managers and voluntary sector organisations and the initiation of some work to gather the view of children and young people with SEND on the topic.

The Review of the Disabled Children's Register in Shropshire

The report has been completed and a summary of the findings and recommendations was presented to the 0-25 SEND Strategic Board in September 2016.

Parent Carer Participation

One of the biggest challenges faced by many local areas is to achieve a sufficient voluntary uptake, so that the amount of data held on the register is suitable to inform commissioning decisions.

As part of the review parent carers views on data collection were collected, both via a workshop and an online survey. 12 parent carers attended the workshop and 52 survey responses were received via the online survey. Parent carers with a range of experience and from throughout Shropshire provided feedback and there were some consistent messages in relation to the development of a register or database;

The key concerns raised by parent carers were about confidentiality and data protection and ensuring information was not passed onto third parties.

There was an overwhelmingly positive response to the idea and purpose of the register, but parent carers reported that they would want to feel confident the information was being well used.

At the Workshop there was a discussion about the possibility of an annual report being produced, providing details of what information had been collected and how it had been used.

There was also a strong message that there should be a focus on ensuring that families do not have to repeatedly share the same information with professionals / services.

In terms of incentivising joining, or agreeing for their child's name to be placed on a register, parent carers primarily felt the potential for improving local services would be a key incentive.

The potential for using the register to enable parent carers to receive information relevant to them, was also felt to be a potential major incentive for placing your child's details on the register.

A few respondents highlighted the benefits of particular incentivising processes (e.g. Disability card/ max card)

The majority of parent carers stated that the name 'The Disabled Children's Register' would not put them off placing their child's details on the register. There was an acknowledgment however that not all parent carers or young people would agree with this and a discussion about the value of capturing data about all young people identified as having SEND, not just those who identify with the term 'disabled'.

PACC has asked the Strategic Board to consider how the findings of the report can be shared with parents. PACC will also continue to represent parent carers in any further work that the council and its partners do to improve data collection and coordination.

PACC's aim is that Shropshire Council and Shropshire CCG take steps to improve the collection of data about children and young people with SEND, with a particular focus on developing a co-ordinated collection process across all services and using the data to inform all commissioning of SEND provision.

Nancy’s Early Years Journey

Nancy

Our daughter, Nancy, is 6 years old and has undiagnosed global developmental delay.
She is non-verbal and whilst she attempts Makaton signing, it is only really decipherable to her family and teachers and, even then, only really in context. She wears AFOs to assist her poor, but improving mobility.

She is incontinent and has the developmental age of a much younger child. All of this creates a complicated and often challenging life for us, especially with our two other young children who still need a lot of our attention.

However, Nancy is the happiest little girl you could meet, and those complications and challenges are ours, not hers. Nancy was born at 35 weeks weighing just 3lb 8oz. She is a twin, and whilst her brother was thriving in utero, she had stopped growing so I was induced due to concerns for her growth.

The Early Days

The next few weeks passed in such an anxious and exhausted blur that my memories of this time are pretty sketchy. Nancy was discharged after 17 days, some time after her twin, and the day I finally had all my family together under one roof was the happiest/most emotional/most terrifying day of my life – flying solo with what had been really quite a poorly baby. And her new-born twin. And her two year old sister.

Busy days (and nights!)

Opening the door to the “Special Needs World”

I started to attend the Friday group with Nancy in the Autumn of 2010 when she was aged just one. That was our first peek through the door of the Special Needs World and it was terrifying. Having kept our head down for the first year and busied ourselves with the very busy business of having three children under 3, and whilst I wasn’t quite in denial, I just really didn’t have the time to consider what her evident and noted developmental delays might mean.

The Friday group was such a window on the possible future for us and Nancy. There were so many children with obvious learning difficulties; physical disabilities and medical needs, of which Nancy was the youngest.

We went to the first one and then didn’t go again for a long time until the run-up to the Multi-Disciplinary Assessment when she was about 2½ (18 months later), and even then we only went because we had been strongly advised to do so in order to make the Multi-Disciplinary Assessment a simpler, quicker process because they could take into account observations they could make of Nancy at our attendance at the Friday morning group sessions.

Early Years Education

We were extremely fortunate to have been exposed to a wonderful not-for-profit mainstream playgroup that Nancy’s elder sister attended, and, from Autumn 2011, aged 2, Nancy’s twin brother had started attending.

The playgroup manager asked me directly one day after Christmas why I hadn’t put Nancy in for a session too. It seemed blindingly obvious to me, standing there with my non-verbal, non-mobile extremely vulnerable little girl, why I hadn’t put Nancy into Holy Trinity mainstream playgroup.

I was given what I can only describe as a ticking off by the manager, by now a good friend, who reminded me that Holy Trinity playgroup was accessible to <u>all</u> children. Once I’d dried my tears (she got accustomed to keeping a box of tissues to hand whenever we subsequently met to discuss Nancy’s progress!) she asked if that’s what I wanted. Of course it was. By then it was clear that it was unlikely that

Nancy's Early Years Journey

mainstream compulsory schooling would be right for Nancy, and this last academic year 2011/12 was the only time she would be at a setting with her big sister, who would start school that September, and generally the only opportunity she might have to be educated with her twin.

I said "yes", and, in very early course, (but not before the manager moved heaven and earth to make it happen with her 1:1 support!) I was told that Nancy could start at playgroup after Easter.

Nancy, her sister and her twin brother outside Holy Trinity Playgroup, Shrewsbury

The Multi-Disciplinary Assessment and all the associated meetings and paperwork were taking place around the same time (Spring 2012), and consequently, we were able to state as our preference a split placement for Nancy – half at Holy Trinity and half at Severndale Assessment Nursery.

Nancy was offered a place at the Severndale Assessment Nursery in March 2015, to start in the September.

The professionals at the Child Development Centre were the first to raise the need for a Statement of Special Educational Needs, for Nancy to have the support she would need at Holy Trinity, and so that process was triggered by one of the CDC child development specialists in February 2012 and we received the Statement just after her 3rd birthday in the Autumn of 2012.

I was surprised at how long the Statementing process took. I was very aware that playgroup was absorbing the cost of Nancy's 1:1 whilst the Child Development Centre seemed to be taking a long time to produce reports following assessments that we'd been to. It was all resolved by the Autumn, though, and then Nancy's Statement was in place.

I think that had Nancy not had older siblings that had exposed us to a mainstream pre-school setting, and particularly a twin who attended the same setting, we probably wouldn't have entertained the idea of her having a split placement.

It was, as it happens, the best decision we could have made because she benefited in different ways, comparing her sessions at the Severndale Assessment Nursery with her mainstream sessions.

It was important to us that she spent that brief time with her siblings (there was a 3-month period before Nancy's big sister started school when they all had a session at Holy Trinity playgroup at the same time!) and she was nurtured with love and care by her key worker who would plan activities for her to do with Nancy, and who spent enough time with Nancy to know how to pique her interest in things and would work out ways to prolong her concentration on task.

At the same time, it was abundantly clear that Nancy was getting exceptional support from the Severndale Nursery. I can see that they intensively focus on the nursery children to optimise their potential – whether that is the potential to go into mainstream education, or to give them the best possible start at the main Severndale School.

Nancy's development increased dramatically in her two, pre-school years. The effect of this was that by the time the letter came to invite us to state our preference for compulsory schooling, we were confident that Nancy had maximised her potential at the Severndale Assessment Nursery, and it was clear to us that the right thing to do was for her to continue there.

Nancy is about to go into year 2 at Severndale School, which continues to nurture her, and could not be happier .

Francesca Cawood

More information about SEND in the Early Years can be found on https://www.shropshire.gov.uk/special-education-needs-and-disability-(send)/send-in-early-years/

The NNPCF visits BBC Breakfast in Manchester

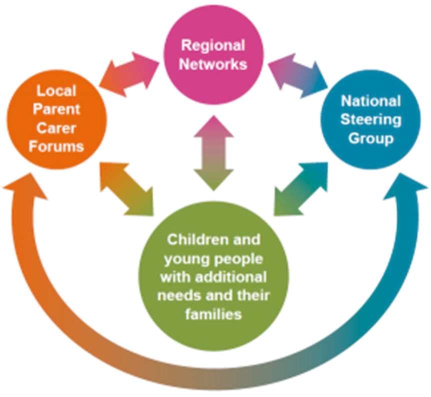
National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

The National Network of Parent Carer Forums represents local parent carer forums at a national level. All local parent carer forums, which are in receipt of a participation grant from the Department For education are members of the NNPCF.

The NNPCF national steering group is made up of representatives from each of the English regions. The regional representatives meet regularly with local forums at regional meetings, providing a pathway for local issues to be considered on a national level.

The NNPCF works closely with the DFE, the Department of Health and other Government departments to raise the profile of the issues impacting on parent carers and children and young people with SEND.



The function of the NNPCF is to develop cohesive good practice, effective participation and 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 participation continues to grow and strengthen.**
- **to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England.**
- **to strengthen the pan disability, parent carer led model of local forums and boost our collective voice.**

PACC is very proud to be a member of the NNPCF and has worked closely with the national steering group. Sarah Thomas, the PACC Participation Co-ordinator was a founder member of the NNPCF and represented the West Midlands region on the national steering group until 2015. Currently Zara Bowden, another long standing member of PACC is the NNPCF West Midlands rep.

Working with the NNPCF brings many opportunities and recently Zara was asked to represent parent carers on national television, to talk about the effectiveness of SEND Provision in schools.

My Visit to BBC Breakfast;

Having been a strong advocate on Shropshire local radio for parent carers, SEND services, and mental health issues, the idea of supporting our cause on a national programme was terrifying but also really exciting. Being on television is great fun, but the preparations were intense.

The NNPCF steering group had been given some details about the opportunity as and when they became available. Meanwhile we gathered our information on the subject matter; school leaders feeling that schools are failing to support SEND pupils, as per findings of a study by 'The Key'. This was all very short notice however, due to the sensitivity of the topic.

Once it was agreed that it was going ahead, and that I would be representing the NNPCF, I had to make very quick child-care arrangements (thanks to my mum and fiancé for their support and help) and head to Manchester. The train journey was a welcome opportunity for me to get my thoughts together about how I wanted to represent the NNPCF and make sure that I said what was important.

I arrived at the hotel, which was located a short walk from the BBC studios and offices in media city, and was promptly called by the liaison from 'The Key' who had made the arrangements with the BBC for me to be there. She ran through the expectations of the morning, explaining where I needed to go and when, as well as encouraging me to be as honest and open as I could. The evening while lonely was fun, I enjoyed a

The NNPCF visits BBC Breakfast in Manchester

meal at the hotel restaurant and got myself ready for the next day.

Zara on BBC Breakfast

In the morning I was ready and eager to get there and get the interview over with. My stomach was in knots, my hands were fidgety, and my mind was a whirl of things I wanted to say. The whole morning was a bit of a blur if I'm honest, but the walk to the studio was wonderful. Strolling slowly through media city at 7.30am was so peaceful, even with the big screen in the square reminding me of what I was about to do.

After being passed through security and escorted to the green room I took great pleasure in taking photos of myself next to photos of the celebrities that were hung on the wall and was eventually introduced to the teacher they had also asked to be interviewed. We sat chatting about the report we were there to respond to and what we felt needed to be discussed.

A whistle stop tour of hair and makeup, which I'd already painstakingly done myself, and a briefing on what was going to happen and we were in the "production zone". This wasn't my first television experience as I had been 'Gok'd' once before on This Morning last year, but this was much more intense. The production area was an open plan office with all the staff milling around working and looking generally busy. Three people introduced themselves as various producers and floor managers before we were given the dos and don'ts of live television broadcast, whilst being reminded it's just us in the room forget about the 2 million viewers at home (easier said than done I assure you).

We were taken into the studio where things suddenly felt very real, we had to be silent and move in the exact places we were directed so as not to disturb any segments. I can't tell you how daunting and tiny the studio actually is. It's unbelievably small compared to what you might expect yet it feels so intimidating.

The interview itself flew by, and although nervous to begin with once I relaxed it was a walk in the park (though I never stopped shaking and repeated the word fortunate way too often!).

In the Studio

It was the bit after the interview that really sticks with me though, as both Charlie and Naga were blown away by the passion I feel for parent carer participation and the role parent carer forums can play in supporting local strategic development of SEND services. It's really encouraging to see people's reactions when they feel your desire to make change and they truly believe you can do it.

In the production office, we received a round of applause as we came out of the studio and were told by the production manager that the office fell silent during the comments I made about the importance of getting things right for our children.

I cannot stress how proud I am to have represented you, the parent carers that make up the NNPCF. I am astounded by the commitment you show to your forums, your local areas, but most importantly to your children and families

It's because of your skills, your drive, and your hard work that we have such a powerful and meaningful voice. Yes it can be hard at times to be heard in the crowd, but do you know what? This year I feel like we have achieved brilliant things. I only hope that you feel I represented you well.

Let's continue to do what we do best! Let's Participate!

**Zara Bowden
NNPCF steering group member &
PACC Shropshire Participation Chair**

You can find out more about the NPCF on their website www.nnpcf.org.uk

Further information about The Key's SEND report June 2016 can be found at

http://www.bbc.co.uk/news/education-36425290

News From the Shropshire SEN Team

PACC works closely with the Shropshire Council SEN Team to review and monitor the new local SEND system. Input from parent carers has been central to the development of the new Shropshire Education, Health and Care Plan process and other SEN systems and will continue to play an important role in monitoring the effectiveness of these process.

The Shropshire SEN Team oversee the delivery of support for children and young people with special educational needs locally, working with schools, colleges, health and social care services, as well as families. We are pleased to announce that 'News from the Shropshire SEN Team' will be a regular feature in future editions of Participate, ensuring that you are kept up to date on local SEN developments. In addition to this the SEN Team will also be issuing a Shropshire Parent Carer SEN Newsletter, which will provide further updates.

All children and young people will be happy, healthy, safe and reach their full potential, supported by their families, friends and the wider community

Welcome to Shropshire SEN News

Developing Specialist Provision

In Shropshire we believe that all children have a right to a mainstream education. We think that it is important for children to have the opportunity to be a part of their local community and we work with all of our settings to support this to happen. However, for a small number of children and young people it may be necessary to access a more specialist learning environment. If this is the case then we will work with parent/carers to find the most suitable placement possible. This means that we continually evaluate the provision that we have available so that we can be sure that we have provision in place to meet the changing needs of Shropshire children and young people.

Over the last year Woodlands School has developed the Acorns Centre. This specialist provision is co-located with Holy Trinity C of E primary school in Oswestry. It supports children who have an Education, Health & Care Plan within Key Stage 2. Children who access this provision may have challenging behaviour associated with a Social, Emotional or Mental Health (SEMH) needs. Acorns is also able to support children with additional needs, including learning difficulties and Autism. This is achieved because the provision is small, only catering for a maximum of 12 children at any one time, with a well-qualified and experienced staff team.

The Woodlands Centre

Children at Acorns are able to be supported through the transition into the secondary stage of their education and this can include any of the following: Mainstream high school; Woodlands specialist provision; an alternate specialist provision as appropriate.

In addition to the current Acorns provision in Oswestry, Woodlands School are working with the Local Authority to provide a similar provision in the south of the county. The intention is that specialist provision remains local and that children will not have to travel long distances to school.

You can find out more about this provision at www.woodlandscentre.org

Shropshire Council are also supportive of a free school bid that has recently been submitted by Shrewsbury Academy Trust. If this is successful it will provide a specialist environment, located in Shrewsbury, for children with moderate to severe learning difficulties who are not able to access a mainstream curriculum.

We are working with PACC to ensure that this proposal is developed with the input of parent carers and more information about this will be provided in the near future if the initial bid is successful.

Two other projects include a specialist hub in South Shropshire and local early years provision. We are looking to implement a range of training in order to support early years settings across Shropshire to meet the needs of children with SEND within their local community. We will provide more information about these initiatives in the near future.

News From the Shropshire SEN Team

Assessment for an EHCP

Shropshire continues to have a greater percentage of children and young people with Statements/EHCP's than the National average.

All schools % with statement/ EHCP	2013	2014	2015
National	2.8	2.8	2.8
Shrops	4.0	4.1	3.8

EHCP's and the Early Years

From 2014 Shropshire Council has been working with the child development centre (CDC) to provide a more integrated approach to assessment for younger children aged 0 to 5. For many children this means that a multi-disciplinary assessment will also be an assessment for an Education Health Care Plan (EHCP). This has proved a great opportunity for parents and professionals to work together at an early stage to discuss aspirations and identify appropriate outcomes. As a result of this we have seen an increase in the number of EHCPs being issued for children aged 0 to 5.

Over the last year requests for an assessment for children with social, emotional and mental health needs (including those with an autistic spectrum condition, ASC) have continued to feature prominently.

How are we performing?

Prior to 2014 the Local Authority had 26 weeks to issue a Statement of SEN once it had received the initial request. In September 2014 with the implementation of the Children and Families Act this timescale was reduced to 20 weeks. Whilst we had a difficult start and initially were only managing to hit this target for 33% of the EHCPs that were issued between September 2014 and January 2016 we have recently managed to improve this and from January 2016 we have been able to complete 85% of new assessments on time.

Transition from a Statement to an EHCP

We have until April 2018 to transfer Statements of SEN to EHCPs. The local authority are working hard to complete this work on time. This year the priority year groups are Years 2, 5, 9 and 11. All children in these year groups with the exception of those attending Severndale School should have a transition review this year unless they already have an EHCP. If you are unsure please look at the timetable on the local offer. You will also be able to find out more about this process by following this link. www.shropshire.gov.uk/local-offer

If your child attends Severndale Specialist School please contact the school directly for more information about when the transfer review for your child will take place.

All About Me, All About Us; Person Centred Approaches in Shropshire

Having monitored your responses to the 'all about me/us' sections of the EHCP we have identified a number of priorities that we need to implement to secure better outcomes for Shropshire children with SEND.

Shropshire local authority recognises the importance of embedding person centred approaches into all areas of practice. Person-centred approaches empower people to create positive change. They are about involving young people, children and their parent/carers in decision making, and ensuring that they are truly listened to and are kept at the heart of all decision-making.

Shropshire Council are working in partnership with Shropshire PACC and external training providers to deliver training for schools, parents/carers and other practitioners to promote a cultural change across all services and settings. There is a launch event on 15th November at the Shrewsbury Town Stadium followed by subsequent training events to be held regionally. Further information can be found on the local offer. **http://shropshire.gov.uk/local-offer/**

Local Area SEND Inspections - Be Involved

These new local area inspections will look at the effectiveness of local SEND systems. The SEN Team is working across education, health and social care to prepare for inspection and is using this as an opportunity to review processes, to ensure that we are doing the best we can to make a positive difference to the lives of children and young people with SEND. A key part of the inspection is that parent carers are available to provide feedback on their experiences of support. Please see the letter below introducing the inspections and how parent carers will be able to get involved.

Dear Parent Carer

Local Area SEND Inspection

I am writing to you to let you know about the Ofsted and Care Quality Commission (CQC) inspection of local area services for special educational needs and disabilities (SEND).

The Children and Families Act 2014 introduced a new SEND system. At the heart of this system was a commitment to improving outcomes for children and young people with SEND and ensuring that children, young people and their families are fully involved in decision making processes. Over the next five years Ofsted and CQC are carrying out inspections to evaluate the effectiveness of local areas in fulfilling their responsibilities in relation to children and young people with SEND. We do not know when Shropshire will be inspected but I wanted to make you aware of this process and the opportunity it will provide for your involvement.

As part of the inspection process the inspectors will want to talk to children and young people and their parents and carers. They will also identify providers that they wish to visit, including nurseries, schools and colleges. The inspection team will focus on the following key areas;

- How effectively the local area identifies children and young people who have SEND.
- How effectively the local area meets the needs and improves the outcomes of children and young people with SEND.

In addition, inspectors will look at how education, health and social care services work together in the best interests of children and young people. They will look at how effectively assessments and reviews are coordinated in order to reduce the risk of unnecessarily repetition, especially at each stage of the young person’s transition towards adulthood.

Inspectors will want to meet parents and carers who are representative of the local area and may ask to meet parents/carers as part of a visit to a setting, school or college. The inspectors may also want to talk to learners with SEND to seek their views on the support they receive. They may review case studies, inspection reports and evidence of outcomes.

We will notify schools, colleges and other services, during the five days before the inspection starts and request that they in turn notify all young people and the parents/carers of children with SEND. We will also notify all young people with an EHCP who do not attend a school setting. PACC as the Local Parent Carer Forum, will also be notified of the inspection and we will work with the Forum to ensure that parent carers are fully involved in the inspection.

Following the inspection, Ofsted and CQC will publish a report in the form of an outcome letter that will be sent to the local authority in its lead role for the local area. This report will outline a summary of their findings, including key strengths and areas requiring further development.

Further details of the inspection framework and handbook are available at: https://www.gov.uk/government/publications/local-area-send-inspection-framework

Yours sincerely

Julia Dean Service Manager SEND julia.dean@shropshire.gov.uk

Shropshire Council

Other SEND Updates

Health News

Transforming Care Partnership

Shropshire Footprint

PACC recently met with Helen Bailey, the lead for the local **Transforming Care Partnership**, to discuss how Shropshire parent carers can be involved in this work. TCP 's are developing plans to change services in a way that will make a real difference to the lives of children, young people and adults with a learning disability and/or autism, who display behaviour that challenges, including those with a mental health condition. Plans include things like improving community services so that people can live near their family and friends, and making sure that the right staff with the right skills are in place to support and care for people with a learning disability and/or autism

The PACC report that consider the impact on families of supporting children and young people who are multiple service users has been shared with the Shropshire TCP and Sarah Thomas will be presenting the key findings to the Integrated Clincal Care Steering Group in October.

If you would like to know more about the Transforming Care Programme visit https://www.england.nhs.uk/learningdisabilities/care/

In August 2016 NHS Telford and Wrekin CCG, NHS Shropshire CCG, Telford and Wrekin Council, and Shropshire Council together issued a collaborative commissioning arrangement to purchase a new **Emotional Health and Wellbeing Service** (formerly CAMHS Tier 2&3)

The aim is to secure a service that is available 24 hours a day, 7 days a week in order to promote resilience, prevent mental health crises and respond quickly to the presenting needs of children and young people in relation to mental health. The new service is expected to start in May 2017.

For more information on the local CAMHS Transformation Plan visit

http://www.shropshiretogether.org.uk/supporting-the-emotional-health-wellbeing-of-our-children-young-people/

Social Care News

PACC representatives Sarah Thomas and Sarah Cox have been part of the task and finish group developing the business plan for the **recommissioning of assessed social care services** for young people with disabilities up to the age of 18 in Shropshire. These services include overnight short breaks, provision of 1:1 support for accessing the community and specialist afterschool clubs and holiday care.

PACC's main input has been working with Shropshire Council to ensure that the business plan reflects the feedback from parent carers, about how they would like to see these services delivered and what outcomes they should achieve.

The business plan is awaiting final approval and then an Invitation to Tender will be published. It is expected that the new contracts will be in place from January 2018. If the provider of existing services change following this process there will be a significant hand over period to ensure that families are supported through this change.

Service priorities identified by parent carers for assessed Short Breaks

- Services support young people towards preparing for adulthood
- Services are flexible & respond to individual need
- Services provide consistency in staffing & communicate well with families
- Services offer an effective induction for new families

SEN Transport News

PACC has been contacted by the National Network of Parent Carer Forums and asked for feedback on parent carers experience of SEN Transport provision in our local area. Nationally there are reports of the provision of transport being a significant area of challenge for families. Please share your experience with PACC at enquiries@paccshropshire.org.uk

Laura and Maisie's EHCP Journey

Maisie with Laura

My daughter Maisie is 11 years old and was formally diagnosed with Autism, Sensory Processing Disorder and an anxiety disorder in March 2016. Maisie is in mainstream education and has just transitioned to secondary school, which hasn't been easy for her, but because she is receiving the right support it is going ok.

Maisie's need for routine and her reliance on rituals are a major challenge for her, but they are also what helps her cope with environments that she finds difficult, such as school. When talking about her rituals she tells us that she has a 'black bubble' in her head which tells her to do things which will help her feel better. Sometimes that will be having to do so many jumps on the trampoline or score a number of baskets in her basketball hoop, to help her de stress. Maisie's sensory issues means that she is upset by such things as loud or repetitive noises and 'bad' weather. Dark clouds in the sky means that Maisie will become very anxious and she will fixate on the weather, worrying if it is going to rain, or will it become windy? Her level of anxiety then becomes a real barrier to her learning, because she is unable to process information. Being in a constant state of anxiety has impacted negatively on Maisie's level of comprehension, her ability to concentrate and short term memory.

Her primary school had been very supportive, providing her with TA support and managing her anxiety by time-out and interventions such as 'Cool Kids' groups. The problem was that it was starting to feel that she was spending more time out of the classroom than in it, and it was difficult to see what progress was being made. When Maisie was finally formally diagnosed the report from CAMHS suggested that I discussed with her school about whether or not to request an EHCP assessment.

With only a few months left in primary education, her school was not keen to start this process, but I felt that following the report from CAMHs that it was now clear that Maisie's needs were quite extensive and I was particularly worried about her ability to cope at secondary school. I had spoken to the SENCO at the secondary school that Maisie would be attending and they had made it clear that they would not be able to provide the same level of support provided to Maisie at primary school, without additional funding.

With this in mind I contacted the 'Information, Advice and Support Service Shropshire' (IASS) for support. They allocated me an Independent Supporter and I submitted a parental request for an EHCP assessment. At this stage I informed the primary school that I had made this request and my Independent Supporter also contacted the school to talk to them about what was happening. Following the discussion with IS the school did support the request for the EHCP assessment and together we provided information about Maisie to the SEN Team.

The first thing that I had to do as part of the request for assessment, was to complete the 'All About Me and All About Us' forms, sharing information about Maisie and our family; what was important to us, what worked, what didn't work and what hopes we had for the future. At this point I was particularly grateful that I had contacted IASS and had been allocated an Independent Supporter, writing everything down was so daunting.

We had lived with Maisie's 'difference' for 11 years, she had been born with an eye condition that had mean she needed surgery as a baby, so things had not gone exactly right from the start, but that had been 'fixed'. As she got older we thought of her as perfect, but a little bit eccentric, wanting to be

Laura and Maisie's EHCP Journey

naked around the house, wearing a woolly hat in the summer and when her younger brother came along, not being able to cope with being in the same room when he was crying.

I look back now and I wonder how I couldn't see it but I refused to believe that anything was wrong. Even when Maisie went to school and the teacher asked to speak to me and Autism was first mentioned I didn't want to believe it. The word Autism scared me – Maisie wasn't like the children with Autism that you see on TV – so she couldn't have Autism could she? Maisie was our first child, she had become 'our normal' and I didn't realise how much we had shut ourselves off from the outside world so that she could cope.

Having to write everything down in one place highlighted the scale of what we had been living with and that was a struggle and at times painful. I was also worried that I would miss something, that I wouldn't say the right thing and although I wanted to complete the All About Me, All About Us myself, being able to talk it through with the Independent Supporter was really helpful. Actually in the end I found documenting everything quite therapeutic, it made me realise just how much Maisie needed support and that we were doing the right thing for her by asking for help.

Maisie having fun

After investing so much time and emotion in requesting an assessment it was a massive blow when, after 6 weeks, we received a response from Shropshire Council saying that they had decided that Maisie would not be assessed for an EHCP. This was because they felt that the level of support needed could be provided by the school, as it had been up to this point.

The letter from Shropshire Council included information about the mediation process which you can use if you don't agree with decisions. I rang the mediation service straight away and arranged for their representative to visit. The mediator was supportive and reassuring but it did mean going over things again, so that he could understand our case. It was great, however, to not feel like I was having to deal with this alone and he arranged a meeting with the SEN Team and invited IASS to join us.

After the mediator visited I contacted the SEN Team to inform them that I was going to go through the mediation process and at this point was offered a meeting with a senior case officer.
They asked me to come in and talk to them and I am really pleased that I said yes, even though nobody was available to come with me and I had to go by myself.
The case officer really listened to me and put me at my ease, she took lots of notes and at the end of the meeting agreed to invite the school back to panel to provide further information.
It seems that the initial information provided hadn't made it clear just how much support Maisie was receiving and that it was significantly above the level of support received by other children her age. Schools do receive some funding in their annual budget to support children with SEN, but they hadn't made it clear that they were using much more of this funding than would be expected on supporting Maisie. Within the week we were notified that Maisie would be assessed for an EHCP.

We didn't have time to relax however because we were straight into assessments. It was the end of term so things were a bit chaotic and routine was out of the window, which is never good for Maisie. Add in numerous visits to different professionals, so that up to date assessment reports

Laura and Maisie's EHCP Journey

wasn't the easiest of times. One of the positive aspects of the timing however was that because Maisie was transitioning to secondary school the reports, particularly the one from the Educational Psychologist, didn't just focus on how Maisie's difficulties had presented to date but how they might present in the future in a new environment. Finally, in the last week of the holidays we received Maisie's draft EHCP and this meant that Maisie was able to start secondary school with the right support in place.

We are still finalising the draft EHCP because there were a few things that needed to change. I was able to continue to have support from IASS and they went through the draft EHCP with me, making sure it was accurate and specific. I have also continued to talk to the SEN Team and having this open communication has really been helpful and reassuring.

Overall I am very happy with Maisie's EHCP, I feel more confident that she will continue to get the support that she needs and reassured that there is an agreement detailing what everyone involved in her care is trying to achieve. I am looking forward to the first review when we can all look back over the plan and see what progress has been made.

I found as a parent, one of the hardest parts of contributing to the EHCP process was sharing my hopes and aspirations for Maisie's future. I had to keep coming back to that because thinking about the future is hard when you have a child with SEND, however since completing the EHCP the future does feel brighter and I feel more positive about looking forward.

Our EHCP journey hasn't been straightforward and at times it has been hard to keep going with it, especially while continuing to manage the rest of family life alongside the process. There are a lot of people out there that can help however and I think it is really important that families use the support that is available, I am certainly glad that I did because I feel that I couldn't have done it on my own.

Laura Bates

Changes to Hospital Services

PACC recently meet with members of the Future Fit communications team to discuss how parent carers can ensure that their voice is heard in the redesign of local hospital services. They have provided the following information about Future Fit and how to get involved.

"As you may be aware NHS Future Fit plans to launch its public consultation into the reconfiguration of hospital services this December. Before you get involved, it's really important that you understand the reasons for this. There are already some very good health services serving patients in Shropshire, Telford and Wrekin and mid Wales. They have developed over many years to try to best meet the needs and expectations of the population served.

In spite of this, the changing needs of the population now and in the future, coupled with the quality standards that we should aspire to for our population and the challenging economic environment, mean it has becomes clear that the time has come to look again at how we design services, so we can meet the needs of our population and provide excellent healthcare services for the next 20 years.

Over the past three years, since the Call to Action event, NHS Future Fit has been busy engaging with, and listening to, many different groups and communities across the local population. This is why we want as many people as possible to have their say, so get involved. You can do this in the following ways;

Facebook – like our facebook page 'NHS Future Fit'

Twitter – visit @nhsfuturefit

Join our mailing list at: http://nhsfuturefit.org/get-involved
You can also register to be on our mailing list by emailing: nhsfuturefit@nhs.net or calling

Tel: 0300 3000 903."

Shropshire's Local Offer Update

Local Offer Growth and Development

Shropshire Council are pleased to announce our SEND Local Offer is changing. We are in a position where we can make some exciting changes to the way the SEND Local Offer works.

What does this mean for you?

While the content will remain much the same the URL will change and it will look different. We will have a landing page that has three distinct areas Parent Carers, Young People, and Practitioners. Each area will then be broken down further to make it easy to find the relevant information.

The three key features will remain the same:

- **Events Calendar** also accessing the Shropshire Council calendar.
- **Service Directory** linking with the FIS directory bringing universal and specialist services together with improved search features.
- **Information Pages** will have improved navigation for ease of use.

We are really excited that this change has brought us an opportunity to take your feedback and comments alongside data gathered from user journey mapping, web analytics, and search data to make some significant improvements to the website. We hope to have this up and running by Christmas. The existing web links will continue to work until the new site is ready to launch, so you should see a very simple and clean swap between the old and new service.

Zara Bowden
Local Offer Coordinator
Search: 'Local Offer Shropshire'
Email: local.offer@shropshire.gov.uk

Call: 03456789021 asking for 'Local Offer'

The Local Offer is your One Stop Shop for services and information relating to Special Educational Needs and Disability.

Ruckley Home Farm - Supported Living

Are you looking for long-term supported living Accommodation for a young adult with learning difficulties?

As a family, we have been privileged to live in a safe and beautiful countryside setting in the heart of Shropshire. This has enabled us to pursue a long held dream and embark upon a project to create a secure environment for young adults with learning disabilities similar to our daughter Isabella, where independence and support come together.

We are delighted to now see this come to fruition and we are looking forward to sharing this dream with other like-minded families. If this is something that may be of interest to you please take a look at our website and feel free to contact us on the email and phone number below. We are interested in meeting anyone taking their next steps as a young adult.

Information and contact: www.ruckleyhfarm.co.uk
01694 731 361 / info@ruckleyhfarm.co.uk

A new project offering supported living accomodation for young adults with learning difficulties in the heart of Shropshire.

For further information please contact:
info@ruckleyhfarm.co.uk
01694 731361
or visit our web site: www.ruckleyhfarm.co.uk

Shropshire IASS

Information Advice & Support Service

Do you live in Shropshire?

Are you a parent/carer of a child or young person up to 25 years old? Do they have a Special Educational Need or Disability (SEND) or a related health or social care needs?

SHROPSHIRE IASS CAN HELP YOU!

Free and impartial information, advice and support about:

Special Educational Needs or Disability (SEND) and related health or social care needs

The Local Offer and Personal Budgets

Welfare benefits, finance, independent living, employment, debt and money management

Working in Partnership

citizens advice Shropshire

01743 280019

www.cabshropshire.org.uk

cabshropshire

CABShropshire

independent support

Is your son / daughter being assessed for an Education Health and Care Plan?

Is your son/daughter having their Statement of SEN transferred to an EHC Plan?

The Independent Support Service is here to help you!

Independent Supporters can:

- Help you understand the process of being assessed for an **Education Health & Care Plan**
- Check through draft Education Health & Care Plans
- Help with gathering information for an EHCP
- Be a friendly face and a listening ear
- Help complete All About Me documents and put your views forward

For more information contact us on:

Phone: 01743 280019

Email: iassadmin@shcab.cabnet.org.uk

Or visit us at the Citizens Advice

Available at Shrewsbury, Ludlow, and Oswestry. Please check opening times first.

Face 2 Face Update - Mike Thomas

Face 2 Face
Parents supporting parents
of disabled children

On the 30th September 2016 PACC's relationship with PODs through The Family Voice came to a close with the end of lottery funding for the project. Both PODS and PACC will now pursue different options in this area of work and the options will be routed in the different needs that rural and urban areas have.

For six years I have been the trainer on the Face 2 Face scheme, initially in Shropshire and over the last three years across Shropshire and Telford. I would like to take this opportunity to thank all the people who have been active supporters of the project, because without them it could not have been a success and the befrienders would not have been recruited, so that we could offer this service to families who have needed it.

While delivering the Befriender training it has been a privilege listening to the many personal stories that have been told, and being asked to hold in trust the powerful emotions generated by the process of telling. Many tears have been shed and much cake and chocolate has been eaten along the way. This is alongside the funny stories told, the "you would not believe it moments" shared and the joy at our young people's achievements and successes.

At the core of Face to Face though is the idea that it really is only other parents and carers who know what it's like, and they will not judge you when the going gets tough and rough, as it surely will, for they may have experienced similar.

"Because I wish someone had been there for me"

As the trainer for all the sessions I have been struck by the common process that all the groups have followed as we explore differences between being a friend and being a befriender. Equally, whereas at the start of Befriending training there is often a good deal of noise, by the end the value of silence and listening is understood, alongside the real recognition that it is other people's journey, not yours to be redone; the recognition of the crucial importance of supporting others to make the decision that is right for them, even when it may not have been one you would have made yourself.

The people who put themselves forward to be befrienders were courageous and brave and my outside impression was that there was a benefit to them in the space and given by the course to think and review what has happened to them and how different their lives are from what they imagined. They were able to see their own strengths and acknowledge their achievements and feel good about themselves.

Not everyone went on to be a befriender, but I hope and believe that everyone gained from the course and am proud to be associated with the work done.

Good luck to all of you
Mike Thomas
Face 2 Face Trainer

What Next?

From the 1st October 2016 PACC will change its focus from the providing one to one emotional support via befrienders, to the provision of group support through our newly developed 'Knowing You, Knowing Me' course.

This change has been promoted by the challenges we face as a small organisation, supporting a minority community, spread over a large geographical area. We have struggled to recruit enough befrienders to deliver the service throughout Shropshire and because of this we have decided to take a different approach to supporting parent carers In exploring their emotional response to caring for a child with a disability or additional needs.

'Knowing Me Knowing You' has been developed by PACC and Mike Thomas and reflects the learning we have gained from Face 2 Face.

The aim of the course is to provide parent carers with the space and time to consider how they feel about taking on an unexpected role, and how those feeling might influence their relationships with others. It also looks at 'toolkits' for managing the SEND system and communicating with the people who might be able to provide support.

We will be announcing dates for our next 'Knowing Me Knowing You' course in the near future.

If we are able to secure ongoing funding we hope to offer the course throughout Shropshire, bringing parent carers together in their local communities.

Sleep Tight Workshop

Does your child have problems sleeping?

Sleep Tight Talk - November 8th 2016
9.30am—12.30pm
Plowden Room, Craven Arms Community Centre

If your special needs child has problems settling at night or sleeping, then you will be interested in this talk on how to settle your child. Covering all aspects of sleep from its importance, sleep cycles, average sleep needs to advice around settling, sleepy foods, how to deal with night wakenings and developing a good routine, this talk will have lots of helpful tips for sleep deprived parents and their children.

Based on the Sleep Tight training developed by the Children's Sleep Charity, Kat Slade has run one workshop earlier this year in Shrewsbury, and PACC are keen to extend this service to the wider community within Shropshire.

For further details, or if you wish to attend please contact Kat Slade on enquiries@paccshropshire.org.uk or 0845-6012205.

North Shropshire Special Olympics

North Shropshire Special Olympics (NSSO) offer an all year round training and competition sports programme for people with intellectual and / or learning disabilities.

NSSO is part of Great Britain Special Olympics and we are part of the Olympic family. We concentrate on community sport at all levels for people of all abilities.

NSSO was formed in 1989 by Val Hannover. Today the club provides training with qualified coaches and a team of volunteers that offer weekly sessions in table tennis, badminton, swimming, boccia, basketball and athletics.

The group host various sports competitions throughout the sporting calendar as well as attending regional and national competitions. Various athletes from NSSO have represented the West Midlands region and also represented Great Britain at the European Championships and World Games.

For more information about either volunteering or becoming an athlete please contact Brian Johnson, NSSO Chairman on 01691 657370 or email environmental-brian34@gmail.com

Find out more about Special Olympics Great Britain on their website

http://www.specialolympicsgb.org.uk/

Special Olympics
Great Britain

SPECIAL OLYMPICS
GB NATIONAL GAMES
SHEFFIELD 2017

SEND Community Games 2016

In partnership with Derwen College, PACC hosted it’s first SEND Community Games & Information Event on Saturday 24th September.

Our VIP sporting guest was Gold Medallist , Danielle Brown, who exhibited her Archery skills and met with families. She also brought along her gold medals from the Beijing and London Olympics, which was very exciting!

Participants could choose to have a go at archery, golf, cycling, football, tennis, rugby, craft and drama activities, as well as spending time in the sensory tent and the information zone and on the bouncy castles. It was a great opportunity for families to get to know providers, to try out activities and to find out more about local services.

Everyone who took part received an individual medal and certificate.

As part of an ongoing partnership with Derwen College, PACC hope to run this as a regular event throughout Shropshire. Watch this space for further news!

Below are a few of the photographs of our SEND Community Games Superstars.

SEND Community Games 2016

PACC
unlocking doors together

SHROPSHIRE
Parent
And
Carer
Council

BIG LOTTERY FUND
LOTTERY FUNDED

dc DerwenCollege

"It was a lovely atmosphere, and being at Derwen we could relax and not feel on show.
It was great to see our kids, and their parents letting their hair down."

"The medals were a lovely touch as my oldest son (8) was so excited to get his first ever medal, that he's even taken it to school to show everyone! "

Thank you to our SEND Games Supporters

Danielle Brown
Energize
Friends of Severndale School
Kidz Coaching Network
Ignition
Empathy
Lanyon Bowdler
Shropshire IASS
The Pioneer Centre
Shropshire Cerebral Palsy Society
Oswestry All Saints FC
Aunty Agatha's Little Big Sensory Shop
A4U
Griffiths Hire Shops
North Shropshire Special Olympics
Quest 88
Shropshire Local Offer

"This was a great day. A family day out with opportunity to try lots of new sports."

"It was so nice for us to be given the opportunity to go out as a family as finding activities for us all to enjoy with no worrying about how my son reacts or the worry of getting judged was a nice change."

Dates For Your Diary

Oswestry PACC/AWM coffee morning

Thursday 10th November 10-12pm
Thursday 8th December 10-12pm

The Whole Life Centre, Cabin Lane,
Oswestry, SY11 2LQ

Shrewsbury PACC/AWM joint coffee morning

Tuesday 15th November 10-11.30am
Tuesday 20th December 10-11.30am

Palmers Coffee Shop, Central Baptist Church,
Claremont Street, Shrewsbury, SY1 1QG

Market Drayton PACC/AWM coffee morning

Tuesday 8th November 10-12pm
Tuesday 13th December 10-12pm

Coffee Shop, Festival Drayton Centre,
Frogmore Road, Market Drayton, TF9 3AX

Bridgenoth PACC / AWM coffee morning

Friday 24th November 10-12pm
Friday 16th December 10-12pm

Cartway United Reformed Methodist Church,
Cartway WV16 4BG

PACC Board Meetings

PACC Board Meetings are held monthly at the Shrewsbury Baptist Church. Each month these are followed by an open participation meeting between 1pm and 2pm, to which any parent carer is welcome to attend. These meetings are an opportunity to meet with the PACC Board members and to ask questions or provide feedback. On occasions there will be a speaker invited to these meetings to provide a specific focus to discussions.

Dates for upcoming PACC Board Meetings;

13th October 2016
17th November 2016
15th December 2016