

Family Voice

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

Participate

Find out what's going on, Have a say, Make a difference



"We know what we are but not what we may be"

William Shakespeare (1564 - 1616)

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Face 2 Face
Parents supporting parents
of disabled children

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Parent
And
Carer
Council

Welcome from PACC

Welcome to our Spring Newsletter

Carers week is coming up in June and, with the Government currently running a 'Call for Evidence' to inform a review of the National Carers Strategy and PACC, funded by Shropshire Healthwatch, launching its most recent report looking at the impact on parent carers of supporting a child who is a multiple service user, we have decided to focus this newsletter on life as a 'parent carer'.

What does it mean to be a parent carer?

The term 'parent carer' is defined by the Children's Act 1989 as an adult 'who provides or intends to provide care for a disabled child for whom the person has parental responsibility'. It is a term that has recently been taken for their own by Parent Carer Forums and the National Network of Parent Carer Forums, to describe the community they support. The term highlights the fact that parenting a child with a disability or additional needs is different to parenting a child without a disability.

When you are a parent carer you find yourself taking on multiple roles; you become an administrator (managing the endless amount of paperwork generated by having a child with a disability or additional need), an appointments co-ordinator, a Physio, a Speech therapist, an Occupational therapist, an interpreter, an advocate, a

weight lifter (for example, so that you can move the boxes and boxes of continence pads that get left in your porch while you are out!), not to mention an expert in medical terminology that you never thought that you would be able to pronounce, let alone know what they mean. While parents of a child without additional needs might take on some of these roles for a short period of time, it is likely that for 'parent carers' they will be lifelong roles, that might change slightly, but do not go away.

In addition to the multiple roles taken on when parenting a child with additional needs, it is also different emotionally. From the earliest years of our life we all have a subconscious blueprint for life, clear expectations about what our life and our children's lives will be. We expect that we will learn to walk, talk, go to friends birthday parties, ride a bike, learn at school, get a job have a relationship, create our own home and eventually have children who will do the same.

When you have a child with a disability or additional need suddenly what you expect does not happen, and sometimes the simplest of things, that other families take for granted, are not possible for you and your family.

Adjusting to this new life can be an emotional experience, constantly being faced with a life which is not as you expected, and which is often not well understood by others, is a challenge that can leave

parent carers isolated and exhausted.



'Having your hands full' - what it means to be a parent carer activity from PACC Annual Conference 2016

The impact of being a parent carer is explored in our most recent report "You don't even know if you're aware of what's happening unless you are in it": the experiences of parent carers of disabled children as multi-service users. Katharine Slade shares the key findings and recommendations from this work later in this newsletter.

Support for parent carers

We know all this, yet the phrase 'parent carer' is not widely recognised and the picture that springs to most people's minds when you say you are a carer is of someone looking after an elderly relative. That is why it was so important when in 2014 the Children and Families Act recognised 'parent carers' by introducing the Parent Carer Needs Assessment, which incorporates the 'wellbeing' principle. This meant that for

Welcome from PACC

the first time parent carers could access an assessment that considers their wellbeing as individuals, and not just in relation to their continuing ability to care for their child.

There is more information about the Parent Carer's Needs Assessment later in this newsletter.

"We know what we are but not what we may be"

William Shakespeare

Possibly one of the biggest challenges we face as parent carers is preparing our children for the future and their lives as adults. Feedback from parent carers in our Mad, Sad, Glad update report in 2015, showed that worrying about the future was one of the main things that made them 'sad'.

In this edition of Participate we are really pleased to be able to share two parents carers experience of their children moving into adulthood, which involved big changes for all involved but has also delivered some good outcomes too. PACC believes that it is important that parent carers have opportunities to see just what is possible for young people with additional needs to achieve in adulthood, and we hope to share more examples of this with you over the coming months.

The Mental Capacity Act

One aspect of supporting our sons and daughters into adulthood is enabling them, whenever possible, to make or contribute to decisions about their own life. PACC recently worked with Shropshire Joint Training Team to offer an introduction to the Mental Capacity Act for parent carers. The MCA was introduced in 2005, it empowers people to make decisions for themselves wherever possible, and protects people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process. One of the key aspects of the MCA for families is that it recognises the value that family carers bring to the lives of people who might lack capacity in some areas of their lives, and requires that carers are involved in discussions about capacity and any subsequent decisions that are made in an individual's best interests. We have provided more information about the MCA and its importance for parent carers in this newsletter.



SHROPSHIRE
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Don't forget you

The theme for Carers Week this year is 'Building Carer Friendly Communities'. Carer Friendly Communities are defined as places where carers feel supported to look after their family or friends, and are recognised as individuals with needs of their own. The second part of this definition is one that perhaps we as carers often overlook, since as carers we focus on what we do for others and the needs of those we care for, sometimes to the detriment of our own needs. Maybe the first step in building carer friendly communities is being friendly to ourselves, recognising the impact that caring has on us as individuals and that if we don't care for ourselves we can't care for others. With that in mind we hope that you are all able to find a few minutes, sit down with a tea or coffee, and enjoy reading this newsletter.

Sarah Thomas

**PACC Participation
Co-ordinator**



Shropshire PACC Needs YOU

Why join PACC?

It's a good question – because many of you reading this newsletter aren't members of PACC and you still get sent a copy.

You can also go on to our website any time to find out about issues that affect parent carers in Shropshire and about opportunities to share your views.

You can even come along to all the events that we organise (information days, family activity days, conferences, training days, workshops, support groups) or contact us if you would like to be matched up with one of our volunteer befrienders.

At PACC we have always been very clear that PACC is here for all parent carers, whether you are members or not. We know, as parent carers ourselves, that you have enough things to think about without feeling forced to become a member.

The thing is – we need you!

We want to be able to carry on providing our newsletter, our website, and all our activities.

We do not get any funding from local government or health services, so we can honestly say that we are truly impartial. Other than a small grant that all parent carer forums get from national government we have to rely on grant funding to be able to carry on.

We can **only** get grants if we can show that:

- ⇒ More and more of you support our work
- ⇒ We are reaching out to all of you and encouraging you to take part
- ⇒ That you have found what we do useful
- ⇒ That we have enabled you to participate in decisions that affect your lives
- ⇒ That we are listening to you and finding out about what you need.

The simplest and easiest way of being able to do these is if you all decide to join us.

You will not only continue to get our newsletter, be able to use our website, and take part in our activities, but you will also be offered the chance to:

- * Get our monthly e-bulletin with up-dates about what is happening nationally and locally
- * Share your views and opinions with us and with the people who make the big decisions
- * Be part of a fast growing and effective organisation that puts your needs and the needs of your family at the heart of everything we do.

You may not be sure whether you are a member of PACC, because we send our newsletter out to all Severndale parent carers whether they have joined or not.

Basically, if you only get the newsletter then you are not a member. Members also get e-bulletins and other communications from us.

If you would like to join PACC please :

fill in the Membership Form enclosed with this newsletter and return it to us,

or you can go to our website

www.paccshropshire.org.uk

and click on the Join PACC icon.

Looking forward to hearing from you!

Anne Lanham
PACC Chair



National Carers Strategy

National Carers Strategy - Call for Evidence

The Government has announced that it wants to update the National Carers strategy, stating that;

"We think that we need a new strategy for carers that sets out how more can be done to support them. It needs to reflect their lives now, their health and financial concerns, and give them the support they need to live well while caring for a family member or friend."

The call for evidence is open until the 30th June 2016. You can share your thoughts on how to improve the support for carers by completing the online survey at <https://consultations.dh.gov.uk/carers/how-can-we-improve-support-for-carers>

If you would like to submit a separate response, or if you have any questions about this call for evidence, please contact Carers@dh.gsi.gov.uk

The survey particularly asks for your thoughts on;

- Challenges faced by Carers - the impact on physical and mental health, education and employment?
- How can carers be identified more effectively and why is this important?
- What are the best ways to provide information to carers?
- What is the most important form of formal support for carers and what is the best way to deliver it?

- What is needed to support working carers?
- What is needed to ensure that carers have a life outside of their caring role?

PACC is particularly keen to use the call for evidence to highlight the role of parent carers and the specific and different challenges faced when you have a child with a disability or additional needs.

PACC will be discussing how support for parent carers can be improved during May to inform our response to this call for evidence.

If you would like to contribute to our response, please email your comments to PACC at enquiries@paccshropshire.org.uk

or ring us on 0845 601 2205

Parent Carer's Needs Assessments

Information taken from Contact a Family's Factsheet

<http://www.cafamily.org.uk/know-your-rights/disabled-childrens-services/needs-assessments/>

The aim of a carer's assessment is to give you a chance to tell social services about the things that could make looking after your child easier for you. This may result in getting services or direct payments to meet your own assessed needs.

A carer's assessment focuses on you as a parent and your needs. Social services should discuss issues like the help you need, and whether there is anyone else who helps or if you are your child's only carer. The carer's assessment should also consider your wellbeing, including health and safety issues, and important commitments like relationships and employment.

Parents of disabled children (called parent carers in the legislation), young people and young carers have strengthened rights to an assessment of their needs

under the Children and Families Act 2014. The Children and Families Act amended the Children Act 1989 (sections 17ZD, 17ZE12 and 17ZF). Under it, local authorities must assess parent carers if:

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

“You Don’t Even Know If You’re Aware of What’s Happening Unless You Are in It” – PACC Research Project

Kat Slade is a PACC Trustee and has a son who has autism and severe learning disabilities. She has a background in research and journalism, and has a particular interest in health and disability.

Kat has recently completed a 12 month research project for PACC and funded by Healthwatch Shropshire on “The experiences of parent carers of disabled children as multi-service users”.

Most children with disabilities or additional needs are users of multiple services, such as health, social care and education, regardless of the type and severity of their condition. Parent carers of these children advocate and co-ordinate services for them.

The aim of the research project was to discover the reality of being a parent carer of a multi-service user within Shropshire by exploring:

- the barriers parent carers face when dealing with multiple services
- specific impact of multiple-service use on family health and emotional wellbeing
- parental perceptions of how well the multiple agency services are working together.

Healthwatch Shropshire’s research grant scheme priority for 2014 –15 was ‘Exploring The Reality’ and this project has been supported by Healthwatch Shropshire grant funding.

Stage 1 - interviewed 8 mothers of children with disabilities living within Shropshire. Three themes emerged from these interviews.

- The child in context - inclusion and exclusion; acceptance and normalisation of disability
- Managing outcomes—co-operation and conflict with service providers; communication and empathy
- The impact on the parent carer - maternal identity and emotional impact.

Stage 2 used two of these themes, ‘Managing Outcomes’ and ‘Impact on the Parent Carer’, to develop a questionnaire. This was distributed to 864 people (PACC membership and parent carers at Severndale Specialist Academy) and 60 questionnaires were returned.

These showed children currently using an average of 6.9 services each. The range ran from 1 service used to as many as 24.

The questionnaires also showed that in the past they have used on average approximately 10 services at

one time (ranging from 1 to 28 services used). Children had a range of disabilities and needs. Those who had a social worker had on average more areas of disability than those that did not.

The most used services were the GP, Royal Shrewsbury Hospital, Paediatrician, Child Development Centre, Health Visitor and Speech and Language Therapist. Parent Carers made suggestions for improving support, communication and meetings.

Findings

Many parent carers were happy with the services they received, but whilst it is important to acknowledge these positive experiences it is necessary to concentrate on the negative comments in order to make recommendations for improvement.

Parent carers often viewed themselves as experts on their child, but striving to obtain services also had a direct and indirect impact on their self-image.

Many felt professionals lacked empathy and did not understand their lives. Times of transition were highlighted as particularly stressful for child and parent carer.

One of the more distressing aspects of the accounts is the number of times parents feel that they are not believed by the professionals. They want professionals to “witness”

their child's behaviour; they feel they have to "convince" professionals that they need help and that they are judged. Often they state they are not "listened to" and at times felt patronised.

It is important that it is understood that the intent of this research is not to demonise professionals, many of whom are working hard in difficult circumstances, but to raise awareness of the central role that parent carers play in the lives of their disabled children and the potential cost of that role to them as individuals.

Recommendations

Parent-professional partnership

Professionals should attend workshops to:

- learn first-hand about parental experiences, the potential emotional impact of caring for and supporting a disabled child, and how being a parent carer is different to the 'normal' parent role.
- receive training around help-giving styles, so that parent carers feel valued and understood and on an equal footing with professionals.

Parent carers should also be given the opportunity to understand the potential impact of having and supporting a disabled child and to explore their own emotional responses.

Co-ordination of Services and Communication

- Explore ways of improving co-ordination, focusing on reducing the parent carers' burden of information sharing and provision.
- All professionals undergo training in person centred planning and the use of person centred planning tools, which are an effective way to share key information.

Transition

Professionals should recognise and value the key role of parent carers as advocates for their children. This will be underpinned by the recommendations made above.

Role of the GP

- GPs should actively support and engage with families of children with disabilities from the earliest point, with a focus on increasing awareness of the positive role that they can play in co-ordinating services and signposting families to support.
- Ensure that any young person with a Learning Disability is flagged on the GP data register, so that annual health checks are offered from the age of 14 and the GP is actively engaged in the transition process.
- Parent-led training for GPs and practice staff to improve understanding of specific problems around being a parent

carer of a child with disabilities or additional needs.

Vision

'Parent carers and professionals working together to establish a common framework for partnership. The balance of power should be shifted from the caregiver (the professional) and the care receiver (service user) to a three-way partnership between parents, young person and professionals, where all parties are equally valued'.

PACC would like to thank all those parent carers who contributed to this research and Healthwatch Shropshire for their funding and support.

The full report will be available on the PACC website in the near future.

PACC is keen to work with local professionals to how the learning from the project can be used to improve parent carer / professional relationships and would be happy to hear from any service provider who is interested in discussing this further.

Joint Training and the Mental Capacity Act

"An Investment in Knowledge pays the best Interest"

Benjamin Franklin

Shropshire Joint Training Team

Shropshire Council provide a programme of health and social care training for those that work in the sector, for service users, and for family carers.

The programme is mainly aimed at issues relating to adults who have additional needs, and covers topics such as; Autism Awareness, Welfare Benefits Reform, Introduction to Epilepsy, the Care Act 2014, Learning Disability Awareness, Makaton workshops, and Mental Health and Aspergers.

The full range of courses available can be viewed on <https://www.shropshire.gov.uk/social-care-and-health-training/joint-training/>

Or you can request that information is sent to by ringing 01743 254731

Service users, family carers and unpaid volunteers living in Shropshire (not Telford and Wrekin) can attend Joint Training courses **free of charge.**



The Mental Capacity Act 2005

Recently PACC worked with the Post 16 team and the Joint Training Team to provide training to parent carers on the Mental Capacity Act. The training was delivered by Mary Johnson who is the MCA Learning and Development Officer.

The Mental Capacity Act came into force in 2005, covers England and Wales and applies to everyone from the age of 16. It includes a clear test of capacity and outlines what is best practice when supporting somebody who may lack capacity. The Act applies in all health and social care settings, including GP and hospital appointments, social care assessments and care review meetings.

What does 'Capacity' mean?

It means being able to make a decision for yourself. To do this someone must be able to;

- Understand the information given to them
- Retain that information long enough to make a decision
- Use the information to make a decision
- Communicate their decision

Just because a person is deemed to lack capacity for one decision it does not mean that they lack capacity in all decision making.

Principles of the Act

There are 5 principles which underpin the Act.

- Start by assuming that someone can make a decision for themselves
- Do everything you can to enable someone to make their own decisions
- Do not conclude someone lacks capacity just because they make an unwise decision
- If the person lacks capacity, you must act in their best interests and
- You must aim to choose the least restrictive option

Why is the Mental Capacity Act Important to Parent Carers?

Making our own decisions is part of growing up and preparing for adulthood, as such it is important that family carers ensure that disabled individuals are supported to do this whenever possible. Where it is decided that an individual is not able to make a particular decision for themselves, it should have been evidenced that the people supporting that individual have done everything possible to enable them to participate in the decision making.

This includes providing information in a way that the individual is most likely to understand, communicating with them at a time and in an environment where they feel

Joint Training and the Mental Capacity Act continued



comfortable and ensuring that they are presented information without bias. This is called 'supported decision making'.

When decisions are being made on behalf of someone they should be made in their 'best interests'.

The MCA states that, when doing this, health and social care staff should consult with other relevant people including family carers and "those that take an interest in the person's welfare".

'Hft' is a national charity that supports people with learning disabilities to live life the way they choose. They have produced a number of short films about using the Mental Capacity Act, including one about involving family carers.

You can view these films on their website <http://www.hft.org.uk/mcaguide> or you can request a copy of a DVD with the films and an accompanying guide to be sent to you in the post;

please send an A4 self-addressed envelope with postage £1.65 first class or £1.48 second class to:

Using the Mental Capacity Act
Hft Family Carer Support Service
5/6 Brook Office Park
Folly Brook Road
Emersons Green
Bristol
BS16 7FL

There is also a Code of Practice for the MCA that provides detailed guidance on how health and social care professionals should implement the Act.

This includes case studies that might be useful for parent carers when considering how the MCA applies to their family. This is available on <https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

A further free information briefing for Shropshire parent carers about the Mental Capacity Act is

being offered in June. The briefing aims to provide parent carers with up to date information on the Mental Capacity Act 2005. This will include;

- **The key messages & implications of the Mental Capacity Act 2005**
- **How Capacity to make a decision should be assessed**
- **The process of making Best Interest decisions**

It will take place on Wednesday 22nd June 2016, 6.00-8.00pm, at Derwen College at Craven Arms, Shrewsbury Road, Craven Arms, Shropshire, SY7 9Q

To book a place on either briefing, please contact Catherine Jones by email cathe-rine.jones@shropshire.gov.uk or phone 01743 254304 and include delegate names.

PACC's Face 2 Face Befriending Service

Our Face 2 Face Befriending scheme offers peer-to-peer support to Parent Carers across Shropshire. We are a team of parents ourselves who all have a child/ young person with additional needs or disabilities, so our personal experience spans across many different special needs and also the age of our children.

All of our Befrienders have completed a 10-week training course that's endorsed by Scope the national charity which is specifically tailored around providing emotional and practical support to Parent Carers.

We offer 1-2-1 Befriending sessions in your home or somewhere you feel comfortable where

you can be assured of confidentiality and the support of someone who really understands and won't judge you. As well as our 1-2-1 support we also offer support at the PACC OASIS parent groups that are run monthly across Shropshire.

If you would like more information about the Befriending Scheme then please get in touch with Shashana Weare – Face 2 Face Co-Ordinator
Telephone - 07557 130 091 or
Email - f2ftelford-shropshire@podstelford.org

Face 2 Face
Parents supporting parents
of disabled children

Leaving Home - Charlotte's Story

My name is Jill Cleveley and I am Mum to 3 daughters; Beth who is 18, Georgi who is 20 and my eldest daughter Charlotte who is 22 and has Learning Difficulties and no speech.



Charlotte is an extremely happy young lady who thrives on being sociable and seems to laugh all day long (even when it may be inappropriate) Charlotte attended Severndale Nursery at the age of 2 ½ and left Severndale School 3 years ago when she was 20 years old. In that time, Charlotte met some wonderful teachers and teaching assistants.

When Charlotte reached the age of 14, I can vividly remember the feeling of uncertainty. All we had all known was Severndale and I couldn't imagine Charlotte ever going anywhere else!! I started researching all of Charlotte's options for further education and life after Severndale School but in February 2009, when Charlotte was 15 years old, we started noticing that Charlotte was acting differently and noticed that she didn't really seem herself. After 15 months

of visits to many professionals, Charlotte was diagnosed with a brain tumour in May 2010. Although we knew that something was very wrong, we really were not ready for this news!! 5 days after diagnosis, Charlotte underwent a 12 hour operation to have the tumour removed, which was successful and Charlotte spent the next few weeks recovering.

After the operation, Charlotte had a couple of complications which meant that she had difficulty swallowing thin fluids and now has to have her fluids thickened. Throughout this whole period of time, Charlotte was amazingly happy.

Whilst Charlotte was poorly, we seemed to put Charlotte's future plans on hold and although we had a couple of ideas where we felt Charlotte would be happy in further education, we were not certain.

When Charlotte had recovered, we visited Conover College which is only down the road from where we live and we were fairly sure that this option would be great for Charlotte, however when we visited, although the staff seemed lovely, it didn't seem quite right for Charlotte. It was small and quiet and Charlotte really thrives with lots of people around her. We then visited Derwen College and really did fall in love with it. As soon as we drove on to the campus, It seemed to have a lovely feel. All the students were milling around independently and they all seemed happy and the staff all seemed extremely friendly. We were shown the living accommodation where

Charlotte could stay for 37 weeks of the year and we were really daunted to find out that there would only be one member of staff in the accommodation overnight and Charlotte would have to pull a cord to wake them up. Needless to say, we were extremely concerned that Charlotte may not be able to cope!!

After looking after Charlotte for many years, we couldn't possibly imagine how anyone else could provide for Charlotte, understand her needs etc. especially after her illness. She was so vulnerable in so many ways and we just wanted to protect her. We have always said that we wanted Charlotte to be as independent as possible and attending Derwen seemed to be the best opportunity for Charlotte, although it was the proving to be the hardest decision we have ever made.

Once we had made the decision that Derwen was the right choice for Charlotte, Severndale made several trips to Derwen with Charlotte so that she could get to know the campus and the staff. We had lots of contact with Derwen staff and met with the college nurses, physiotherapists and speech therapists to discuss Charlotte's needs. The difficulty with the process, was that although we wanted Charlotte to attend Derwen college, we still needed to get the funding agreed from Social Care and Education. This process took many months which increased our anxiety as we couldn't help Charlotte plan until the funding was agreed.

When it came to the day for Charlotte to start Derwen, we packed her cases in the car

Leaving Home - Charlotte's Story

and took lots of pictures and photos for her new bedroom. Charlotte was really excited and although we knew it was the right choice, it didn't feel right knowing that we were going to drop her off for someone else to look after her. We spent some time meeting all of the support staff in her house and some of her new house mates



(there were 12 girls sharing in her house). We unpacked her bags with her and decorated her bedroom with her belongings and then the time came we had to say our goodbyes!! The photo shows how excited Charlotte was to be staying there, thankfully there are no

photos to show how we were feeling!!! It was the quietest drive home ever!!!

After a few months, we were able to drive away from Derwen without any tears and suddenly came to realize that it was us that were upset about leaving Charlotte at Derwen and Charlotte herself was having an absolute ball with her friends and wasn't upset at all!!!

Charlotte is now in her 3rd and final year at Derwen and we are awaiting a decision from Adult Social Care as to whether Charlotte can stay at Derwen for a further 2 years on a Living & Working Programme where she will be able to continue to learn independent living skills and also continue her work experience in a local supermarket.

The one thing that we have learnt, is to never presume that Charlotte can't do something and instead always presume that she can – if the right support is found, Charlotte is much more capable than we thought. She has absolutely

thrived at the college, has made friends of her own age, has become much more independent and has a social life of her own (just like her two sisters). She goes to the disco twice a week, goes bowling with her friends and has many many outings and really enjoys her work experience in a local supermarket.

All of the staff have been fantastic and have been able to manage all of Charlotte's needs. They have always contacted us with any queries but the main thing is that we have always had confidence that all of the staff are able to support Charlotte.

Charlotte will need support for the rest of her life but we believe that her time at Derwen is equipping her with all of the skills needed to be as independent as possible in her future life. There is no doubt that the decision to let Charlotte go to Derwen was extremely difficult, but 3 years down the line, when we look at how much more independent Charlotte is, we are absolutely certain that this was the right decision.

Big Free Fun Day 2016

This event being held at Meole Brace school on **Saturday June 25th, from 1-5pm.**

The event is free and open to everyone and all activities are free and include: The Animal Man, climbing wall, magic show, Technique, Enguinity, colouring horses, fire engine, army band, guide dogs, scrappies and so much more!!

Follow on Twitter on @mbsstudents

If you have any enquiries please email hill.r@meole.co.uk

Some of the activities:

- Fran O'Boyle - story teller
- Smoothie Bike
- Face Painting
- Learn By Design incl. Soap Science 4 You
- Band and Bugles of Shropshire Army Cadet Force
- Technique (Planetarium, lego models & Kinex)
- Cycle Experience
- RAF Museum Cosford
- Shropshire Wildlife Trust
- Corner Exotics
- Climbing Wall
- Enguinity.

All activities are FREE!!!!

Additional Parking available at :
The Priory School, Longden Road, Shrewsbury SY3 9EE
Please note all children must be accompanied by an adult.
If you have any enquiries, please email hill.r@meole.co.uk

Meole Brace School

A colorful logo for 'Big Free Fun Day 2016' with the text 'BIG FREE FUN DAY' in large, bold, multi-colored letters and '2016' in a smaller font below it.

Leaving Home –Simon's Story



I won't lie, the transition to adult services was unnecessarily difficult, but we couldn't have predicted the outcome.

I am mum to Simon, a happy 19 year old with cerebral palsy, microcephaly, severe learning difficulties, epilepsy and gastrostomy fed. However, Simon loves people, socialising and being part of a lively environment.

He loved his respite in children's services (and so did we!). We had a few expected and unexpected difficulties to overcome when he moved to respite in adult services and we began to feel a little unsure

about the future.

We had decided that in view of Simon's love for socialising we would apply for residential college but wondered whether his health would pose problems. He has severe reflux and can easily aspirate leading to sudden chest infections/pneumonia. Also, if he did have a 52 week placement when would we be able to see him? However, if he was only resident in term time we would still have the same difficulties in holiday time.

I knew that if we didn't give residential a try we would never know if it could work for Simon - shouldn't we aim for the surroundings we knew he would love and try to make it work even if that meant some changes would be necessary. We pressed ahead and applied for a residential placement but in reality, at the back of our minds, we thought it was more likely that Simon would become a day learner and live back at home with us.

It is now 7 months since Simon left home and we couldn't be more delighted with how things have turned out – and we are as sure as we can be that Simon feels the same way. College and residential staff

have all got to know Simon extremely well. He loves their attention and the banter between staff. They have learnt how to care for him when he shows signs of becoming unwell and their quick responses have probably helped keep him out of hospital. They contact us when they feel it has become necessary and we have encouraged this contact.

As time has gone on we feel more and more relaxed about him living away from home. The strange thing is we are not missing him as much as we thought we would because he is happy, well cared for and we can see him when we choose. We can visit him whenever we want and can bring him home for a stay when we choose – it's up to us. This is far from how we expected things to turn out. You can still be very involved in your young person's care, as we are, just not carrying it out on a day to day basis. We are working as a team with the staff at college and medical professionals to give Simon a happy, healthy life.

Sarah Cox



STOP PRESS - Notice For Severndale Families

If you are not a PACC member but have been getting the newsletter because you have a child at Severndale - don't forget that you will need to join PACC if you want to carry on receiving it once your child has left.

If you are a PACC member and your child has just left Severndale, please let us know to make sure you receive a newsletter via the post.

If you are a PACC member and your child starts at Severndale, please let us know to make sure that we don't send you two copies.

Shropshire's Local Offer for SEN and Disability



Shropshire's Local Offer for SEND - a Parent Carer Tool Kit

As parents we always want the best in life for our children, as parent carers this often seems a bigger challenge. This is usually because of the diverse and complex nature of our children's needs and the impact this has on our families. It isn't as simple as it once was to ask a question and get a straight answer, sometimes it feels like you have to climb a mountain to get the information that you need...

What if there was a single place where you can look to tell you about local events that could be suitable for you and your family?

What if you could look in one place to find out about a range of services to help your child become as independent in life as they can be, or where you can learn about a service that you have been recommended to use?

How about being able to share your thoughts and experiences about services with other parent carers to help them make informed decisions too?

Or even where you can get answers to your questions like what should a one page profile look like? What does early help mean? And how can I get a carers assessment?

Have you heard of the Local Offer for SEN & Disability?



We all know the importance and value of information for families. The Local Offer for SEN & Disability is now available as an additional specialist information tool kit for parent carers and professionals and has had an exciting update. For parent carers access to information is really important to help us understand where we have been, what we are involved in, and where we are going in the future. Being aware of the range of services and resources that we could use daily, weekly, at home or elsewhere can be empowering. As they say 'knowledge is power' and having that knowledge can offer us reassurance, answer questions, or even be the start of a really meaningful conversation about our child's future. The Local Offer aims to meet the needs of parent carers through a range of dedicated tools. These tools are split into three areas:

Services

Our service directory offers a wide range of services from therapy services, social care services including overnight residential care and short breaks, support and advice services, and a wide range of schools and colleges, training and vocational options as well as a lot more. There are recently added sections for transport services, money matters, and post 16 education and training options.

All services that are held here should include information

about how you can contact them, how you get access to using them (do you need a referral? how do you get this?), what they do specifically to support children, young people, and their families where there is an SEN or Disability. This should all be easy to understand and link back to other sources of information if appropriate.

As parent carers you can comment about the experiences you have had with services to help other parent carers be more informed when looking at this information. There is guidance provided on how to make comments in the 'About Local Offer' Information Pages.

Events

A calendar of events has been added to make it easier for families to find out about what activities and events are happening in their area. This is easy to use and can be broken down by date, week, month, or category to help you find what you are looking for quickly.

Information

The information pages are packed with information, resources, and tools that parent carers can use to help them in everyday life. Information pages are separated into specific areas of need and categories to help you find the information you are looking for more easily.

We know how hard it can be to find the right information at the right time. The Local Offer hopes to be a tool kit that offers you a single place to go

Shropshire's Local Offer for SEND - Continued

to, where you can ask any kind of question that relates to SEN & Disability and be provided with the right information when you need it most, there and then.



How can you help?

We understand the importance of having the correct and most up to date information available and you can help to ensure that the Shropshire Local Offer provides this. You can influence the range of services and information we provide by telling us what we may be missing, tell us about great services you have used

or share information you have found that could help others. Or you can become a Local Offer Champion and support us in promoting the Local Offer more widely.

You can do this by emailing Local.Offer@shropshire.gov.uk with the subject 'Local Offer Community'

Take a look at what the Local Offer can do by visiting www.shropshire.gov.uk/local-offer and click the big purple Local Offer logo!

If you want more help and advice and the internet is not for you, please call Shropshire Council customer service team on 0345 678 9008 and asking

for the Local Offer or you can come along to one of our Local Offer drop in sessions. Details of these will be posted in the events calendar once dates and venues are confirmed.



Zara Bowden
Local Offer Coordinator,
PACC Committee Member,
& Parent Carer.

Face 2 Face Befrienders Update

We'd like to congratulate our most recent team of Parent Carer volunteers who have just completed the 10 week Face 2 Face Befriender training. Kate Everitt, Sarah Farrington, Peter Bosher, Moira Hoath, Bev Rumble and Marie Welch. We'd also like to say thanks to Mike Thomas who has been delivering the training for us. The Befrienders wanted to share their feelings and thoughts about the 10 week course and what it has meant to them.



'I've learnt a lot about myself, it's given me more confidence'

'It's been a great opportunity to reflect on all of the different emotions and experiences we have faced as a family'

'I feel I've learnt how to 'listen' properly'

'The training has given me a chance to get off of the bus (parent carers life) and encouraged me to take time to look around'

'If Befriending is anything like the feeling I've felt within the group whilst training then it's going to be good and I'm looking forward to it'

Shropshire Information Advice & Support Service Update



Information, advice and support about Special Educational Needs, disability and related health and social care issues.

Whether you are a parent carer, a child or a young person, referring to the IASS service couldn't be easier- just pick up the phone.

The majority of parents that we support have referred themselves to the service. Just call 01743 280019 between 9am and 4pm. You will be asked details about the case and about the young person, and you will then be allocated an IASS Officer.

Independent Information, Advice and Support is available for children and young people, with Special Educational Needs or Disability, aged 0 to 25 years old.

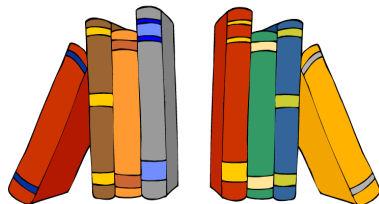
Do you know a child or young person with SEND who would find some information, advice and support around their education or related health and social care needs useful? Since September 2014 IASS offers a service directly to children and young people. At IASS we often meet young people who have a preference of course or college that they wish to attend but they haven't the confidence to be heard. IASS helps them to find their voice and have their views heard. We try to meet children and young people in their education setting but can arrange to meet them at home if necessary.

Are you on our mailing list?

Receive up to date information straight by email. If you would like to receive our newsletter by email just let us know by

email
iass@shcab.cabnet.org.uk.

What's new?



Find Shelf Help in your local library

Available at your local library is **Reading Well**, an excellent collection of books aimed at young people. The books cover mental health issues and are aimed specifically at young people aged between 13 to 19. These books also give parents an insight into some of the difficulties that their children are facing.

The collection includes some famous titles such as *Geeks, Freaks and Aspergers*. *Touch and Go Joe* gives an insightful look at the effects of OCD on one young man. *The Curious Incident of the Dog in the Night-Time* is a very interesting piece of fiction about a young man with Aspergers.

Young ideas needed!



Could your son or daughter help design IASS publicity and information leaflets? We need the views of children and young people about our "young people image". What should our Young People web page look like? If you know someone, aged up to 25, who would be willing to help please call us on 01743 280019. We really are friendly,

honest! Our partners Taking Part and OSCA are leading on working with young people and are thoroughly trained and experienced in working with young people. They offer an advocacy service to young people.

Personal Budgets.

Is your child being assessed for an Education, Health and Care Plan? Did you know that if the Local Authority agrees to issue an Educational, Health and Care Plan you can ask for some of the provision to be provided by a Personal Budget? If you want to know more give IASS a call on 01743 280019 and ask for our Personal Budget leaflet, or ask to speak with an IASS Officer.

Money Management.



Did you know that your new IASS service can now help you to complete DLA and PIP forms? We can do a benefit check and give advice about debt and money management. Just give us a call and we will organise this support for you.

Don't forget! If you need to meet with an IASS Officer, perhaps to go through paperwork, we often attend coffee mornings and support groups. We also host a SEND support group at the Lantern, usually on the third Thursday of the month. Check out our new Facebook page for details,
www.facebook.com/IASSShropshire/.

Dates For Your Diary



Pop along and have a cuppa and a chat, where you will always receive a friendly welcome and be surrounded by other parent carers. Our OASIS groups (apart from the Spectrum group) are for parent carers who have children with any additional need or disability.

Bridgnorth PACC/AWM coffee morning

Cartway United Reformed Methodist Church, Cartway WV16 4BG
10.30am – 12.30pm **Fri 26th May, Fri 24th June and Fri 22nd July**

Spectrum Meeting - ASD Group

Lecture Room, St Nicholas Hall, Shrewsbury United Reformed Church
8pm – 10pm **Thur 5th May, Thur 2nd June and Thur 7th July**

Oswestry PACC/AWM coffee morning

The Whole Life Centre, Cabin Lane SY11 2LG
10am -12noon **Thur 12th May, Thur 16th June and Thur 14th July**

Shrewsbury PACC/AWM coffee morning

Shrewsbury Central Baptist Church, Claremont Street SY1 1QG
10am-11.30am **Tue 17th May, Tue 21st June and Tue 19th July**

Market Drayton PACC/AWM coffee morning

The Coffee Shop, Festival Centre, Frogmore Road TF9 3AX
10am-12noon **Tue 10th May, Tue 14th June and Tue 12th July**

Autism West Midlands Training Course

AWM are now taking bookings for **Rising to the Challenge** a 6 session course that runs from June to October (with a summer break) at the Lantern Shrewsbury. Morning and evening sessions are available.

Dates:
Wednesday evenings - 22 &
29 June, 6 July and 14, 21, 28

Sept 6.30 pm to 9.30pm

Thursday mornings - 23 & 30
June, 7 July and 15, 22, 29
Sept 9.30 am to 12.30pm

To book a place please
email :

Shrophire@autismwestmidlands.org.uk

or phone 01743 210962

