



**PACC Conference May 2016**

**"Understanding our Lives" Research and Healthwatch Report Launch**

**PARENT CARER FEEDBACK**

**27 parent carer attenders/ 15 feedback forms returned**

<b>Has attending the event helped you to feel more connected to other parent carers?</b>	
No change	2
Improved	12
Improved a lot	1
n/a	0
<b>Has attending the event helped you to feel more able to support your family?</b>	
No change	7
Improved	7
Improved a lot	1
n/a	0
<b>Has attending the event increased your knowledge on services</b>	
No change	5
Improved	7
Improved a lot	3
n/a	0
<b>Has attending the event made you feel more confident or more aware of opportunities to participate in decisions that affect your family?</b>	
No change	5
Improved	6
Improved a lot	4

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n/a	0
<b>Rating of venue</b>	
Poor	0
Good	3
Very good	12
not answered	0
<b>Rating of Refreshments</b>	
Poor	0
Good	5
Very good	10
not answered	0
<b>Rating of Organisation of Event</b>	
Poor	0
Good	2
Very good	13
not answered	0

### Suggestions for improving

- Better internet access
- Invite elected members
- Professionals introduce themselves and what their role is
- Better internet connection !!
- Powerpoint handout would have been better printed larger so it could all be read clearly especially graphs (really needed to be A4 size to be useful)
- Cake and lunch - maybe this is saved until tea time but sadly I had to leave before the end. Otherwise great! (smiley face)

### Other comments

- Mike Thomas' presentation was really good and left an impression on both parents and especially "professionals"
- Excellent Day - difficult to improve
- It would be great to have regular carer get together's somehow - perhaps every 2 weeks?

## PROFESSIONAL FEEDBACK

**13 professionals attended/ 4 feedback forms returned**

<b>How far has this event improved your understanding of the issues that are faced by parent carers</b>	
No change	0
Improved	3
Improved a lot	1
n/a	0
<b>Has attending the event improved your opportunity to share and discuss issues that affect your work?</b>	
No change	0
Improved	3
Improved a lot	1
n/a	0
<b>Can you suggest PACC activities to improve partnership working between parent carers and service providers?</b>	
Focused events - eg post 16 providers/services (Julie Duncan, Shropshire Council)	
Awareness for decision makers, co-production, engagement group (Mark Donovan SCHAT)	
<b>Would you be interested in working with PACC to develop such activities*</b>	
YES	2
NO	1
n/a	1
<b>Rating of venue</b>	
Poor	0
Good	1
Very good	1
not answered	0
<b>Rating of Refreshments</b>	
Poor	0
Good	0
Very good	1
not answered	0

<b>Rating of Organisation of Event</b>	
Poor	0
Good	1
Very good	2
not answered	0

### **Suggestions for improving**

Better internet access needed

\*Professionals who are interested in working with PACC to develop joint activities

Julie Duncan (Shropshire Council)

Mark Donovan (Shropshire Community Health Trust)

## WHERE IS YOUR COMMUNITY?

Parent carers and professionals in separate groups. Each were asked to mark on an individual map where they live, where they socialise, where their child receives healthcare and where they go to school. The aim was to show a disparity between parent/carer lives and control group (professionals). However, the sample was too small and it would seem that the majority of parent/carer participants live in Shrewsbury. It was interesting to see the distances that some travel for healthcare and school, but then so did the control group (reasons unknown). No significant difference in social lives could be noted. The main point of interest was that two who are carers for young people post 16 both commented on their limited social lives.

<b>Parent/carers</b>			
<u>Base</u>	<u>Socialise</u>	<u>Health care</u>	<u>School</u>
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury
Shrewsbury	Lancashire	Lancashire	Lancashire
Shrewsbury	Shrewsbury	Telford	Telford
Oswestry	Shropshire wide	Shrewsbury	Shrewsbury
Shrewsbury	Shrewsbury	Shrewsbury	Pontesbury
Shrewsbury	Shrewsbury	Oswestry, Telford, West Midlands,	Shrewsbury
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury
Between Ellesmere and Oswestry	Shrewsbury, Oswestry	Shrewsbury, Oswestry	Between Ellesmere and Oswestry
Allbrighton	Shrewsbury	Birmingham	Telford
Shrewsbury	Shrewsbury	Telford	Telford
Shrewsbury	Molverley, Yorkshire, Stafford	Shrewsbury	Shrewsbury
Shrewsbury	Telford and Nantwich	Stoke on Trent	Oswestry
Pontesbury	Shrewsbury area, Wellington, Ludlow, and out of county	Shrewsbury	Shrewsbury
Market Drayton	None	Shrewsbury	None
Chirk	Shrewsbury	Shrewsbury	Shrewsbury

post  
16

Shrewsbury	Wellington (very little)	Shrewsbury	None	Post 16
Much Wenlock	Shrewsbury and Oswestry	Shrewsbury	Shrewsbury	
Market Drayton	Market Drayton	Market Drayton	Shrewsbury	
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury	
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury	
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury	
Shrewsbury	Shrewsbury	Shrewsbury	Pontesbury	
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury	

<b>Professionals</b>			
<u>Base</u>	<u>Socialise</u>	<u>Health care</u>	<u>School</u>
Newtown	Shrewsbury	Shrewsbury	Shrewsbury
Telford	Shrewsbury, Market Drayton, Telford, West Midlands	Staffordshire	Telford
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury
Church Stretton	Shrewsbury	Shrewsbury	Church Stretton
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury
Shrewsbury	Shrewsbury	Shrewsbury	Telford
Shrewsbury	Shrewsbury	Shrewsbury	Shrewsbury

## PROFESSIONALS' ACTIVITY REPORT

It had been planned that professionals should complete the same activities as parent/carers in a discrete group. Other than those who completed the "Where is your community" activity (see above) this did not happen. There was a strong desire by some in the room to respond to the launch of the Healthwatch Report. Instead the following activities took place:

- Comments made by some members of the group about barriers to developing co-ordinated services were noted.
- All participants were invited to anonymously contribute their own individual message to PACC, and an individual recommendation for one simple practical change that would improve co-ordination of services.

### Comments – are there barriers to developing co-ordinated services?

The following comments were made by individuals and do not necessarily reflect a consensus.

- Shropshire Council's Early Help is providing a family based holistic assessment.
- Parent/carers say that there is no-one to support them, but there are many people, sometimes too many.
- The potential of the Local Offer should be acknowledged, especially now that it is working well and up-to-date.
- Web-sites need to be sensitive to parent carer needs.
- Professionals need consistency to develop effective working, but protocols keep changing.
- Need to be clear and practical rather than visionary about what can be changed.
- Often there needs to be a lot of professionals all working within their own "silo" because they offer a specialism. Can't go back to generic working.
- Each organisation has its own particular IT system which it relies on, so cannot close these down. To make these IT systems work together effectively would mean that someone would have to be responsible for inputting additional data. Early Help does this but it is a discrete system so does not involve a huge amount of extra data.
- Managing transitions is a challenge.
- Every type of agency is working to different time scales about when someone becomes an adult.
- Parent carers say they tire of "repeating" their story, but you need to turn this on its head. Would you trust a professional who hadn't heard your version of events, who just said, "don't bother – I've read it all." This process is part of the way that they develop relationships.
- The potential of social media should be explored. Closed forums are an issue.

- One participant expressed the fear that public services are facing unprecedented challenges. The test is to model sustainable public services. There may need to be a focus on particular groups. The major shake-up of police IT systems was raised.
- An example of another authority's successful approach to reducing costs by focusing on target groups (CAMHS services) was raised, whilst another point of view was that preventative work across the wider population was required. This was not resolved.
- Need to remember that parents/carers may not necessarily be asking for something that are going to be in the child's best interests in the long term. Particularly difficult as young people achieve adulthood and their rights and expressions of need may conflict with parent/carers.
- The idea of giving a quiz to elected members is not a good one. It is designed to undermine them and not to work positively with them. Oh look – you don't know anything so you need our training.

#### Messages to PACC

- How is positive feedback disseminated to professionals? Also need to know what they do well.
- Wider representation would be good. Need to get the messages out there – but balanced.
- Have a positive approach – not a negative one.
- Tell us when we get it right.
- You mother We care. (not sure if I have read this correctly)
- An open forum for discussion is better than a closed door.
- We can work together in localities to help families feel that they have a role in their community.
- Professionals want to work with parents – let's build relationships.
- Please give the feedback to professionals/services to enable them to improve their service – positive and negative
- There are lots of challenges families face – more than having a child with a disability. Professionals do care and do understand and many will have experienced difficult challenges in their lives.
- Thanks for the feedback – please work with us to design and improve services.

#### Practical recommendations

- Development of keyworker. Once professional that coordinates/communicates with others to prevent repetition and aid communication.



- Children with disabilities have Health Passports – personal hand held book – “This is me”. All info about child so parents don’t have to keep repeating their stories.
- Services should consider the needs of all the family. Share info wherever possible.
- Better communication in the world.
- Multi-agency awareness building on the experience of parent/carers and young people.
- Better relationship building opportunities amongst different professionals across Shropshire ie networking opportunities.
- Share space – co-location. Joint training. Accessible and Family Friendly. Statutory and Voluntary.
- Encourage joined up approach to care holistic
- Improve – be able to see parents more quickly through a drop-in system around the county
- A multi-agency approach – different professionals have difference areas of expertise.
- Focus on providing more integrated and coordinated delivery of services.

## WHAT DOES THE FUTURE LOOK LIKE?

The following comments arose out of a discussion around a selection of images presented as “Life’s Journey” (eg a foggy road, a maze, a rosy path through a wood, children playing on a beach etc). We asked parent carers to tell us which image they felt most closely represented their life’s journey with a particular focus on thinking about the future and why. The discussion also touch on what could help to improve their ‘Life’s Journey’

- I don’t want to just be told go and sort it out, I want help and guidance.
- Fog – scary and frightening
- What is the point trying to plan because everything changes.
- It is all about hope – how do we get hope, flexible, options, choice, so we can imagine the possibilities, helpful to know what is possible, but I also know the challenge of making what’s possible happen.
- Believe that you can change things.
- Difficult to imagine a future – it took away any hope
- Actually you discover your child is a child and they happen to have a disability
- Good stories help- but we as parent carers have to find them and ensure that my child can achieve what I believe they can

- I feel it is on my shoulders to find my daughter's future.
  - It is a maze – I can see lots of good things out there but I don't know how to get to them.
  - Professionals to have positive case studies to share.
  - Depends on how your day has been.
  - Fog – too hard to project through everything school / work / where he will live. Health issue are huge and I take each day as it comes. The fog is OK at the moment because it would be too emotional to think too far ahead
  - Roller coaster – just as I think they are settled down everything changes. Journey full of challenges. Don't expect that to change. Had to fight for tea visits when he went to a new respite home.
  - Severdale need to look at the future planning for our children –
  - The children on the beach – older children will continue to care for my disabled child. Hoping we will overcome the challenges and my child will keep that sense of belonging.
  - Children are given encouragement – they need examples of what they can do.
  - What we want: clear vision, know what is going to happen and when
  - I want a path like other children have
  - Fog – no idea what the future looks like
  - Need to change people's expectations – professionals and parents.
  - Not told about others achievements – need to celebrate more – the little things.
  - Community and friends are so important
  - Need to hear lots of positive starting to believe what is possible
  - It is important for our kids to see a grown up version of themselves.
  - Focus now is client base – too much focus on child wishes which might not be achievable
  - Future is too difficult to deal with.
  - It is about the people you meet and the stories you hear
  - Don't hear enough positive stories about the future
  - We were told all the worst case scenarios at diagnosis
- 
- If you are dependent on services and suddenly aren't their it puts you off thinking about the future
  - Fog – try not to look too far ahead because it gets scary
  - I can't see where I am going
  - Winding Road – so much you have to find out for yourself
  - Balloons get heavy and your arms get tired

- Maze and fog I am confused – not knowing where the beginning or end is. Never ends
- On the beach – carefree – would like my life to be like this. We all want this. Impossible to get family together. Want to be with friends and family but I feel isolated even within my own house
- Professionals don't share what other young people have done
- Only person who helped was other parent. The other parent had answers – but the professional didn't.
- Social worker / key work needed
- Need to know what services are there.
- Know what our roles are in their adult life for our children

## TO THE ELECTED REPRESENTATIVES

Suggestions were invited for one message for elected representatives, and for questions for a proposed quiz to give them.

Professionals did not contribute to this (see account of activity above) although a senior professional in Children's Services voiced her opposition to the idea of the quiz as she said it was designed to undermine them and would not contribute to positive working.

Should PACC decide to go ahead with the messages and the quiz (with the understanding that it is intended to promote positive relationships) then there are useful suggestions here but they would need to be worked on to form the basis of a quiz that had the right tone.

### One message

- Parent/carers were asked to compose messages to give to locally elected representatives.
- Listen to the children
- Could you hold a survey specifically on SEND
- Experience of SEN in (????)!!
- Missing a layer of services MS – special!
- Hidden disabilities are real!
- Mental health for children!
- Ensure people in power can help you find answers
- Awareness of disability
- Impact on our lives and our children's
- Designing services from "our" perspective
- Aspiration not cost focused
- Do they see them as future voters?
- Sit and do the paperwork – see the complexity
- Listen to us
- Represent us
- Be understanding – be aware of our "normal", take our concerns seriously
- We are not as scary as we look
- Would you be willing to share our experiences, visit us and see how we live our lives?
- We have positive stories – you need to know about it and promote it
- Understanding their responsibility to our community – and take action when required
- They need to be involved
- How do our children enrich our community?
- How do our children influence how parent carers enrich their community – inspired job changes etc

- Also, professionals learn from our children

### Suggested quiz questions

- Multiple Choice??
- How many children have SEND?
- How many and can you name our special schools?
- Do you understand that there is a difference between conditions eg MLD, Autism, Quadra and Hemi-plegic etc)
- Do you know about the SEND Local Offer
- Could you visit us – conference or parent group
- Do you know what services there are for SEND
- Do you know what benefits we are entitled to and how we get them (struggle)
- Do you understand the issue with crisis care for both children and PCs in Shropshire (health and Social Care)
- Do you understand the dynamics of disabled and SEN families?
- How many forms a PC fills in for ....?
- Do you know these statistics – how many appointments, how many services, they access, how many parents can't work or work reduced hours due to limitations set by carers allowance, access to social care, support to find work that fits our dynamics?
- How many parents have mental health issues/health needs of their own?
- How many children/young people with SEND have mental health issues?
- How many families suffer from sleep deprivation?
- How many vehicles are providing SEN travel?
- Are they aware of the increase in demand/decrease in service?
- Are we an important constituent group?
- Do we matter?

## LOCAL MEDIA

Parent carers were presented with three tasks which were based on collating news stories relating to disability in the Shropshire Star throughout April 2016.

Task 1: A summary of the types of news stories were presented, showing that the highest number of stories related to fundraising. The question asked was "Does this coverage reflect the lives and aspirations of people with disabilities and their families? What other types of story should be covered?"

- Positive stories about children with disabilities
- How many people disabilities in Shropshire
- Stories about disability awareness – particularly ASD
- Good example – Employable Me – on TV – what they can do rather than not do
- Places you can go which are particularly welcoming and have special facilities
- Promotion of places with specific facilities for disabled eg Supermarket trollies
- Positive stories from Specialist Schools, Willows, Bradbury
- Always having to fundraise – disabled people as charitable cases (sad face)
- Promotion of services – eg Autism West Midlands
- Makes disability all about money – 50% of articles
- Up to individuals/organisations to contact papers

Task 2: Three sample articles relating to disability were presented:

- a story about a little boy with ASD who visits fire stations and fundraises for fire services
- a story about community fundraising for a seriously ill little boy who requires a lot of home adaptations
- a story about Alton Towers dedicating a lodge for use by families of children who are disadvantaged or end of life

The question asked was: What impressions does each of these articles give you about the lives of people with disabilities and their families? Can you suggest any improvements?

- The aaah factor
- People think there is more provision than there is
- That there are no statutory provision
- No link to groups eg local autism groups like the BBC does at the end of their programmes
- Alton Towers story "Poorly children" – poor use of language (poorly means cough/colds). Why only "disadvantaged" children?
- Fire Service story - Implies that parent of disabled child has time to take their child all over the country – makes us feel inadequate as a parent by not doing something like this.

- Why do you have to be disadvantaged or at end of life to have an accessible holiday at Alton Towers?
- Disabled people as “victims”.

Task 3: Two sample articles relating to activities for all the family were presented:

- Ideas are wanted to get more people active
- Family Fun event in the park

The question asked was: Do these articles encourage people with disabilities and additional needs and their families to take part in community events and activities?

Can you suggest any improvements?

- No mention of activity being wheelchair accessible
- Photos all happy smiley neuro-typical looking people
- Only mentions less active (by choice or old age?) not really disability
- Photos don't look inclusive
- Season of events – so could promote future events as accessible to all
- No-one hiring mobile “changing places” unit.