PACC Consultation Report

'Building the Shropshire Information, Advice and Support Service and Local Offer'

January 2014

PACC
unlocking doors together

SHROPSHIRE
Parent
And
Carer
Council

Face 2 Face
Parents supporting parents of disabled children

LOTTERY FUNDED

BACKGROUND

Parent and Carer Council Shropshire (PACC) delivered two activities to consult with parents/carers (p/cs) of children with disabilities and additional needs on the features they would expect to see in in an impartial Information Advice and Support Service (IAS).

1. A day workshop to which all PACC members and appropriate stakeholders were invited. This activity also gave parents/carers and stakeholders the opportunity to participate in the development of the web based Local Offer.
2. A paper and electronic survey of PACC members

WORKSHOP

Arrangements

This took place on Tuesday 21st October 2014 9.30 am – 2.30 pm. These times were based on advice from p/cs to fit in as well as possible with caring/family responsibilities. It was held in a meeting room at Shrewsbury Town Football Club which is fully accessible, has good, free parking and has good road links to the whole of Shropshire. Lunch and refreshments were provided.

There were three sessions:

9.30 – 11.45	Impartiality – led by Alex Hiam (contracted by PACC)
11.45 – 12.00	IAS services – led by Sarah Thomas (PACC)
12.30 – 2.30	Local Offer and Local Offer website led by Shropshire Council Local Offer contracted web team – Future Gov.

Participants

Participants - 26

- 14 parent/carers
- 12 stakeholders representing local statutory and voluntary services

The event had been publicised to all PACC members. PACC invites all parents/carers of children with disabilities and additional needs to become members and actively works to recruit members from across the whole of Shropshire using a variety of methods.

The ages of children whose parents/carers attended ranged from 4-19.The following areas were represented:

Shrewsbury	6
NW Shropshire	3
NE Shropshire	1
SW Shropshire	2
Telford & Wrekin	2

The two participants from Telford & Wrekin were from PODS, Telford & Wrekin's parent carer forum. They had been invited as observers but their views were invited as relevant to the general discussions in Sessions 1 and 2. They then left at Session 3 was not relevant to them.

Stakeholder organisations represented included: Shropshire Council Local Offer Co-ordination and SEN Team, Hope House, Taking Part, Action 4 Children, OSCA, Prospects, Prime Resolution, IAS (formerly PPS). These organisations all have a brief to deliver information and/or advice and/or support in various capacities.

Stakeholders had been asked to book and also to come to Session 3 only, so that consultation on impartiality would be with p/cs only. In spite of this some had not booked and all arrived for the start of the session. As one organisation had called to request that they attend the full day (which had been agreed) then we can be confident that the information about attendance was clear, but that it had not been thoroughly read or digested. For the sake of maintaining good relationships with these services it was agreed that their representatives would attend the full session.

Objectives

The objectives of the day were:

To increase knowledge of the Shropshire Local Offer and information, advice and support (IAS).

- Inform p/cs about the Local Offer and the team who will deliver it

Sessions 1 and 2

- Improve p/cs' understanding of the requirements of an impartial service
- Create a p/c centred model of an "impartial" service
- Create a p/c centred list of the type and range of information, advice and support that is needed.
- Gather p/cs' views to help shape the IAS service for Shropshire
- Gather p/cs' views about how they want to receive information

Session 3

- Gather feedback from parent/carers about trial Local Offer site.
- Gather p/cs' views about how they want to receive information

P/cs rated the event highly for raising their knowledge of the local offer and IAS. Feedback on the facilities and quality of presentations was also good.

This report presents findings from Sessions 1 & 2 delivered by PACC. Feedback on Session 3 was collected and collaged by the Local Offer team.

Parent Carer Centred Model of an "Impartial" Service

Activity 1

Following an ice-breaker exercise to help people to focus on the concept of impartiality participants were asked to suggest definitions/alternative words for the term. The responses have been grouped as follows:

Quality of information
- Unbiased
- Balanced
- Neutral
- Importance of clear transparent criteria to inform decision making

Equality / non-discriminatory practice/attitude
- Non-judgemental
- Responding to the individual and not the label
- Fair
- Don't make assumptions

Individualisation
- Individual content and delivery
- Be clear it is a targeted audience
- Respond to individual need and capacity
- No right or wrong answer

Transparency
- Honest – linked to personal experience and the impact this has on your views
- Not profit-based
- Not benefit-based
- Your role influences what you say
- Depends – are you talking as an individual or as an organisation?
- Unpressured
- Don't persuade
- Supporting the right to challenge

There was a discussion about the similarities / differences between an "impartial service" and a "client-centred service". The point was made that the current legislation concerning the "impartiality" of IAS services was based on feedback from parent carers, so it is important to gauge what they mean by impartiality rather than rely on academic definitions or on IAS practice.

Activity 2

The following scenario was read to participants.

"We want our son to go to a secondary school that is 8 miles away because he will get more help with his reading, but the local authority say he has to go to the school up the road. The other school says it is full. We don’t drive so even if he got a place at the other school, we don’t know how we could get him there. What can we do?”

They were then asked to comment on fictitious responses. Some of these responses were exaggerated examples of bad practice to help p/cs to highlight why they were unacceptable.

Feedback is given in Table 1.

Table 1
P/Cs comments on sample responses by a fictitious information service

Given Response			**P/Cs comments**	**Impartiality issues**
I'll send you some information about dyslexia	X		May not have dyslexia, have not asked for this	Quality, equality
I'll send you a prospectus for the school up the road – it's got quite a lot in it about how they support children with reading difficulties	X		Trying to persuade - either because they don't want to do any work or because they don't want to stir up problems with school admissions	Transparency
I'll send you a list of all the schools in Shropshire, transport arrangements how to complain, how to do an admissions appeal, how to help your child to read.	X	√	A few thought was better but information overload, needs to know more about context, whether need advice and support, help with paperwork, take it stage by stage.	Quality, equality
Can you tell me a bit more about why you think the other school would help him more with his reading?		√	Good - gives time to p/cs to explain context and find out what information would be appropriate	Quality, equality, individualisation
Would you like me to send you information you can read through about admissions appeals, or would you like me to talk it through with you on the phone first?		√	Good - sensitive way of finding out about additional communication needs	Equality, individualisation
Did you know you can get read the OFSTED reports for all schools on the internet?		√	Good - steers people towards impartial information	Quality, transparency
I can help you with an admissions appeal straight away (secretly thinking – that will help me hit my target for complex cases that I help with).	X		Triggered discussion about targets for information services - must be about quality not just quantity	Transparency
To be honest, the Local Authority usually know what is best for a child.	X		Not respecting p/cs' views - opportunities to take part in dialogue (advice and support is often needed)	Equality, Transparency
That other school is definitely full and unless your son has a statement you would just be wasting your time.	X	?	All felt that p/cs have the right to challenge a decision and should receive impartial IAS, but a few made the point that sometimes insider knowledge is useful as long as it isn't used to persuade.	Equality, Transparency

Activity 3

Sub-groups were asked to produced their own definitions, or work towards a definition, of impartiality based on the previous discussion.

The group was asked to divide into three groups of stakeholders and three groups of p/cs. In fact two groups of p/cs decided to work together so five sets of responses were gathered.

One group (P/C 1) provided a precise definition as follows which was well received by all the participants.

An impartial IAS Service should offer:

- A one stop shop for information and direction through the system.
- Support and guidance which is individual and unbiased
- Empowerment for parents/carers to navigate the system and make positive decisions (last four words added in ensuing discussion)
- Different ways to access the service according to preference.

Other groups provided loosely grouped criteria. Table 2 groups these responses under headings previously used (quality, equality, individualisation, transparency) and new groupings for issues that were raised under communication, delivery and arrangements.

There are some criteria/definitions which seem to duplicate but have been left as separate because slight differences in vocabulary are interesting and revealing.

Table 2

PC=Parents/carers SH=Stakeholders

		PC1	PC2	SH1	SH2	SH3
Quality	Structured					*
	Mandatory rights		*			
	Balanced		*			
	Comprehensive range		*			
	Criteria based		*			
	Accurate		*			
	Fact based		*			
	Realistic		*	*		
	Neutral					*
	Up-to-date				*	
Equality	Empowering	*	*	*		*
	Inclusive				*	
	Approachable			*	*	
	Welcoming				*	
	Sympathetic – empathetic				*	
	Empathy/positive		*			
	Supportive			*	*	*
	Encouraging				*	
Individualisation	Individual	*				
	Target audience		*			
	Child's age / SEND		*			
	Family/person centred/individualised				*	*
Transparency	Unbiased	*				*
	Unbiased / independent			*		
	Knowledge of law/informative			*		
	Knowledgeable				*	*
	Signposting knowledge			*	*	
	Experienced				*	*
	Transparency – direct and indirect benefits					*

Communication	No jargon		*			
	Unpick the jargon			*		
	User friendly / simple		*		*	
	Visual next to each fact / statement		*			
	Personal stories		*			
	Keywords		*			
Delivery	One stop shop	*				
	Navigation/follow journey/continuity	*	*		*	*
	Different ways to access service	*				
	Confidential			*		
	Free			*		
	Accessible			*		
	Open all hours				*	
	Flexible				*	
	Advocacy included				*	
Arrangements	Good links		*			
	Independent of local authority		*			
	Critical friends				*	
	User led				*	
	Connected				*	
	Insider knowledge				*	
	Does not need to reinvent wheel				*	
	Knowledge of market and users					*
	Impartial funding				*	

Notes

Attitude – stakeholders used the term sympathetic/empathetic implying that they might consider these to be the same. Parent carers used the term Empathy/Positive and did not use the word sympathetic at all. Further work on unpicking the differences between these terms with providers and users would be useful.

Communication – parent carers used the term "no jargon" whereas stakeholders used "unpick the jargon". This suggests that p/cs would like to be able to access information independently, whereas stakeholders see themselves as gatekeepers of knowledge. Practically it may prove to be impossible to remove all jargon but "jargon busters" and use of clear English are obvious options. It was clear tha p/cs felt that information needed to be as clear and jargon free as possible to empower p/cs who have the confidence and resources to take things forward independently. There was a recognition that some p/cs would need additional support and empowering others would allow scarce resources to be focused on this group.

Individualised – different interpretations of what this can mean in practice were used. Some focused on the individual child, others on the family or just used "person centred". The issue of providing information that is appropriate for the child/young person and for the wider family needs further discussion, as does a process for dealing with possible conflicts of interest within a family. There is no independent advocacy available for children/young people unless they are in the Looked After system.

Transparency – one group used unbiased/independent implying that they thought that independence is a requirement of an unbiased service.

Delivery – four groups used terms that implied that they would expect the service to offer something more than one-off involvement, but the terms navigation, continuity, and follow the journey were kept separate as they all implied slightly different things. Navigation could imply something that can be used independently, whilst "follow the journey" implies a more interactive approach in which families are led to appropriate information at each new stage (even a keyworker approach).

Arrangements – stakeholders in particular showed concern for where an IAS service sits. One stakeholder group suggested the need for an IAS service to be user-led but it was not clear what arrangement was intended (Board? Delivery? Voluntary or salaried?)

The following points arose from the discussion:

- You don't want a website to "blow sunshine at you".
- The right to challenge the system
- "Sometimes information/ advice/ support provision makes me feel guilty" (that I should be doing more).
- Whose best interest? Child? Parent? Organisation?

- You have to be careful – link between advice and impartiality. This related to directed advice (when a service makes a recommendation).

The two most chosen criteria suggested by both p/c groups and stakeholder groups were:

- Empowerment
- Navigation/follow the journey/continuity

These two criteria go hand-in-hand and if delivered successfully both improve p/cs quality of life and reduce stress on overstretched services. They do not, however, imply a hands-off approach or p/cs necessarily doing it for themselves. They require information to be accessible, navigable, and to be delivered pro-actively.

Findings

There was a consensus amongst p/c participants about what they mean by impartiality. They are clear about the difference between impartiality and client-centred, and did not seem to expect that an IAS service should automatically take their side. They do expect a service to be transparent about its interests and to be able to signpost them to sources of client centred advice and support where required.

Empowerment and Navigation were highlighted as essential aspects of an impartial service and the two criteria go hand-in-hand. If delivered successfully both improve p/cs quality of life and reduce stress on overstretched services. They do not, however, imply a hands-off approach or p/cs necessarily doing it for themselves. They require information to be accessible, navigable, and to be delivered pro-actively.

P/cs would expect an impartial service to work to standards of quality, equality, individualisation, transparency, communication and delivery. They are less concerned about arrangements for delivering this service that stakeholders might expect - as long as these standards are guaranteed and upheld.

A parent carer centred information, advice and support service

All participants were asked to consider the terms information, advice and support and to suggest terms which would help to differentiate and define them.

Information
- Facts/guide/current
- Relevant
- Statutory
- Commentary
- Evidence
- Intelligence
- Personal experience?
- Comprehensive

Advice
- Steering
- Options
- Specialist
- Legal
- Guidance
- Empathetic
- Person Centred
- Relevant
- Practical
- Impartial

Support
- Individualised
- Practical
- Community
- Case Studies – sharing
- Values personal choice
- Not necessarily a support group
- Not feeling alone
- Personalised Q&A service – "Ask Jeeves"
- Pro-active – a dialogue
- Not wrapping people up in "cotton wool".

With these terms in mind the group were asked as individuals to circulate around the room considering the Information, Advice and Support needs of families in a variety of circumstances. Each case study was pinned onto a large sheet of paper and individuals wrote their suggestions onto sticky notes (colour coded to show whether defined as information, advice or support). All contributions were anonymous and beneficiary and stakeholder contributions were not differentiated.

Carl is aged 4. His mother, Maria, is pregnant but has no other children. Carl has a visual impairment. He can just about see books with the correct magnification, but he has a rare genetic condition which means that his sight is going to get worse in the future. He is due to start mainstream primary school next term. The sensory inclusion service has said that he will get support. Maria is very worried about how he will cope as he is very clingy. They don't know how she will help him to learn at home and is worried about having to pay for special equipment.

Information
- Other options for learning at home
- Referring to outside agencies
- Learning options
- Grants

Advice
- Grants/funding
- Genetics
- Direct payments
- Referral to relevant services

Support
- Support SENCO
- TAC meeting of professionals
- Respite
- School based support

Leo is aged 10. He lives with his parents, Dan and Sophie, and his younger sister. He was diagnosed with ADHD when he was 8. He has had a statement since he was 9. Although this has helped him to settle in the classroom he says he is picked on in the playground, and his parents don't feel that this has been tackled. Leo is about to move up to the local secondary school. With all the recent changes to special educational needs procedures Dan and Sophie don't really understand whether he will still have a statement in his next school. The school isn't far away and Leo wants to walk there on his own, like the other children do, but they are concerned that he could be picked on.

Information

- Transition info
- Info how to tackle school about bullying
- Bullying policy at school
- ADHD info and how it affects children at school
- Who deals with SEN child at school
- Ask the school about, if the do a transition club in the holidays to make new friends.
- Who could possibly walk to school with him?
- Transition process
- Anti-bullying policies
- Statement process
- EHCP process and transition onto it
- Journey to school – options
- Who is the SENCO
- Info needed on transition SEN
- More info on statement and the legal requirements
- What is the bullying policy in school
- SEN – new changes legislation
- Transport options
- How 11+ school transitions work
- Contact IAS Service for help (*formerly PPS?)*
- Legislation
- Transitional info/review
- Info on statements
- Transition review
- Legal – re statement transfer to EHCP
- Transition advice
- What is the bullying procedure

Advice

- Advice on how to tackle journey to school
- Tackling anxiety at school
- How to work with SENCO and school to resolve issues
- Sleep issues
- Behavioural issues
- Tell the parents to contact the new school, ask them what they have in process
- Advice from school and SENCO how to help transition

- Advice form PPS, PACC etc to guide/advise
- How to support child being bullied
- SENCO – if unhappy/unaware of SEN support who to ask

Support

- Counselling for child and parents
- Out of school activities for SEN children to allay anxiety
- Help with building friendships/buddy systems at school
- Support at unstructured times
- If the school has a buddy scheme working
- Counsellor at school for child
- Support form siblings at school and on journey if viable
- Emotional support
- School counsellor to help with emotional difficulties
- Liaise with form tutor and head of year and school
- Support from Parent Partnership
- Support from a friend
- Support to access SEN info and to access SEN info for child and parents. Is sister being affected?
- School counsellors support available?

Note – this case study was covered most comprehensively. All suggestions are included here but could be grouped. Interestingly it is the area where participants showed the greatest practical knowledge and were offering solutions as well as questions (eg ask for school anti-bullying policy)

Harriet is 15. She has a severe learning disability. She lives with her father, Greg. Her mother died when she was 11. She has attended a special school but the plan is now to start on a catering course at a local FE college. Harriet and Greg spend every evening together and neither of them get the chance to make friends or socialise. Greg is very worried about being apart from Harriet, particularly as he feels that she is very sexually naïve and trusting but does seem to respond when boys are around. He is concerned about how much supervision she will get when she is at college.

Information

- Youth clubs
- Where to find carers support
- Different courses at different settings for daughter
- Support groups for dad and daughter
- Respite

- Female mentor?
- SEN Youth Clubs
- College support – may need help to adapt to college lifestyle
- Suitable social activities
- Suitable courses
- Appropriate support available
- Options re courses / colleges
- Clubs for Dad

Advice

- How to encourage independence
- Youth clubs/respite
- Options for colleges/courses
- Carers' rights
- Who to go to/what to do if in trouble
- Which college is most suitable?
- Which course is most suitable to Harriet
- Training opportunity to help her with sexuality issues
- (training?) opportunity for him to help her learn
- Youth clubs
- Single dads' clubs

Support

- Support at college
- Local youth clubs
- Respite
- Independence/living/social skills
- Support him with giving her independence
- Support her with transition to college
- Parent support
- Transition support
- Moving on
- Support groups for SEN
- Family activity groups
- Individual counselling
- Mentoring
- Female support guidance as lost mother – female led groups – girlie shopping – beauty – female mentor

Samantha is aged 18 and has Cerebral Palsy. Samantha has just finished her A levels and is planning to go to university. Her parents, Charles and Fran, are very proud of her achievements, particularly as nobody in the family has ever been to university. She had an amanuensis for her exams as she has difficulties with co-ordination. She uses a wheelchair for much of the time. Samantha has always received Disability Living Allowance and the family has also had other benefits such as Carers Allowance and a mobility car. She has been offered a place at a university 200 miles away and she is very keen to go there. Her parents are worried that she will be very isolated and don't know how much support she will get. They are concerned that it will be difficult for her to travel home to see them, and they cannot afford the train fares to visit her. She wants to study business and they do not think that this is a good option for her because they think it will be difficult for her to get a job in business afterwards. They are also worried about money as they do not know how her moving away will affect the benefits that the family receives.

Information

- Allowances (including DSA)
- Student Finance England
- University support – learning support

Advice

- Support for Samantha
- Respect daughter's decision
- Family mediation
- Options for different courses/colleges
- Sufficient support/taxis
- Local youth clubs
- Respite

Support

- University
- Community
- Disabled support
- University societies for disabled students
- Student union
- Local support networks

Bradley is now 24. Bradley has Downs Syndrome. He went to a residential college to study horticulture for 3 years, which he loved. His mother, Louisa, found it difficult without him at first but then got used to having some independence back and has now built up a good social life for herself. She is in her mid-50s and is keen to carry on going to a couple of sports clubs that she has joined to keep herself fit. She also works full-time at a solicitor's office. Bradley has finished his time at college and says that he would like to come home to live with his mother. There is a small day centre in a nearby town that he could attend, although it is under threat of closure. He says that he could help at home, particularly in the garden.

Information

- Carers Advice Service
- Assess Bradley for personal budget and needs
- Does Louise have to have him back?
- Find out options for Bradley
- Benefits / personal budget / travel
- Advocate

Advice

- Carers support

Support

- Possible respite provision
- Bradley – support for transition and community network
- Louisa – help not to feel guilty (support groups)

Findings

Coverage of case studies was unequal. This may be because of time or practicalities of getting around the room, but interestingly the case study that had the largest response, Leo’s case, was one that is possibly one that the majority of parents recognised as closest to their own experiences. This case also highlighted the need for an information service to keep abreast of changes to legislation and rights policy so that they can pro-actively keep people informed.

The range of information required was wide and included:

- Statutory rights and legislation (with up-dates)
- National organisations
- Finance and benefits
- Local statutory and voluntary services
- Education provision
- Professionals who will work with you and your child
- Community and social opportunities
- Advice and support services.
- “Fixed” and short-term information required in all areas.

All participants had a very clear understanding of differences between information, advice and support. There did seem to be overlap between information, advice and support with some suggestions cropping up twice under different headings for the same case, but discussion showed that p/cs had a very clear idea about the distinction between them all.

For example: Harriet’s case showed reference to “Clubs” at all levels.

- Information – location, contact details, what they do
- Advice – discussions about options for going to clubs, help to decide what would be appropriate or helpful, working out other arrangements that would be needed (such as transport or respite)
- Support – building confidence to go, practically supporting to attend (initially or long-term)

Sometimes suggestions under “advice” looked like support – eg “carers support” but in these instances the advice would consist of signposting someone to a particular support service.

However, there was a real lack of knowledge around options for teenagers/ young people and their families which was of concern, indicated by the very general and tenuous suggestions made for these cases. One parent/carer has told PACC that she just wants to have an idea of what her child’s future will be like and at the moment there is not enough information to enable people to look forward.

In particular Bradley’s case led to the poignant comment “Does she have to have him home” which read like a genuine and heartfelt personal concern as much as a contribution to the debate. A subsequent discussion amongst PACC representatives about how an information service would deal with a question like this led us to consider an appropriate response. The simple answer “No – there is no legal requirement for you to care for someone beyond the age of 18” could be devastating unless delivered appropriately and with appropriate advice and support offered. A model answer would be, “Once your son is 18 there is no legal requirement for you to care for him, but may parents tell us that is a very difficult decision and people need time to think through how that affects them. Would it help to talk it over with someone?”

The term advice was interpreted as both directed advice and non-directed advice. There is confusion about the term. Also the term advocacy was used without any clarity about how this sits next to an IAS service.

P/cs will “dip in and out” of requiring IAS as their child grows up. The range of issues, and level of information, advice and support will vary at different times. It cannot be expected that resilience will continue to grow, or that support needs will be consistent, because changing circumstances bring changing challenges. PACC suggests that an information service can handle this by building a relationship with its cohort of users, so the service is not just something that they go to with a problem. The benefits of this is that p/cs will feel ownership of the service, contribute to its development, and share experiences to build its reputation.

This exercise also illustrated the range of activity that needs to be delivered. The lives of families of children with SEN and Disabilities are often complex and the information, advice and support they need is extensive and covers a significant number of areas. While one organisation may be able to facilitate p/cs access to this information, advice and support it is highly unlikely that one organisation will have the range of knowledge, understanding and capacity to deliver everything that is needed.

INFORMATION, ADVICE AND SUPPORT SURVEY 2014

Arrangements and participants

The Information, advice and support survey was sent out to all 397 PACC members in the autumn of 2014. It was sent as a paper document and with an invitation to take part in a survey monkey survey online. It was posted on the PACC website and Facebook page.

By 7 November 2014 35 responses had been received – a response rate of 9%.

Responses were anonymous.

Findings

Please tell us where you currently go for information about your child's disability or additional need?

- *Name of information provider*
- *What was good about the way this information was provided?*
- *What was not so good about the way this information was provided?*
- *What could be done to improve the way that this information was provided to you?*

The results are provided in Table 3 on the following pages.

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Pacc	Professional, impartial, confidential	Service is centred around Shrewsbury	OASIS meetings/events could be in the South of the county
	Relevant information Local view on national issues	-	-
	Very good, concise advice, straight to the point	-	Maybe specific times when Helpline could be manned
	Excellent, easy read information on what is happening in England	Nothing	More of the same please
	Accurate and current	-	-
	Easy website layout Information is up to date	-	-
	Easily accessible by phone, web or newsletter	-	-
	Supportive	-	-
	Lots of emails and information online	Meetings in an evening	When you are a carer alone, an evening is often unsuitable
	Facebook page Handouts	-	-
	Usually there is someone who can help	Some can be just opinion	
	Clear to understand		
	Small group setting local to me	Not long enough to discuss fully. Not as often as I would like	More often

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Pacc	Regular information and updates	Think its great! Very clear and factual	Bit more regular. Little and often rather thank getting lots of information at once
	Practical advice, easy to accesss and understand	No obvious negatives	-
	Paccs magazines, books and attending meetings	Gave me some idea of where to start	All in one place and offered at the time of diagnosis ie groups and agencies that can help and support you and your child as you come to terms with diagnosis and forward into a happy fulfilling future.
	Clear and from a parents perspective	-	-
Pacc (OASIS Group)	1:1 support Other parents in similar situations Issues we could discuss together Very good clear, up to date knowledge/empathy/ support Excellent guidance	I am a visual learner so handouts would be great (possibly written) working with the necessary confidentiality issues	

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Family Information Service	Some staff are informative and knowledgeable	Lack of impartiality	Service should be independent of Shropshire Council
	Family pack – lots of good information	-	-
	Phone call – sent out information clearly written and able to answer questions. Follow up calls	Some lack of knowledge about certain conditions and limited written details	Larger stock of information handout covering more divers issues, medical info.
	Rainbow pack – some of the signposting is accurate	Some telephone numbers and websites are out of date	Needs to be regularly updated

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
National Autistic Society	Online Available 24/7		
	Well informed and easy to understand	Site not that easy to navigate	
	Plenty of information – easily accessible	Not always accurate	More tailor made Site not that easy to navigate
	Easily accessible by phone, web or newsletter		

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Severndale School		No information about 'Future' which is relevant even though I went to a parents forum and transition event	Much more depth of information about what will happen at 'Futures' & what opportunities will be available. Face to face events and written info/email would be useful.
	Professional backed up with good information	Limited to telephone and knowing who to ask	Knowing who to ask
	Information on new opportunities given by severndale nursery	Not much information	Signpost to other sources
	The head of nursery is an experienced worker who seemed knowledgeable	Given only once the need arose	Given as general information to help parent or reduce the impact of need

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Parent Partnership	Once they got in touch they were sympathetic and gave information available at the time	Could only give information on educational matters at that time	Information could be downloaded off the site to read later
	Very good at helping with schools and meetings	-	-
	Phone, email – very informative, very helpful and understanding	Too much information all at once	Not so much information in one go. More relevant on topic

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Autism West Midlands	Tailored information to the age group of your child	Had to wait a little before available to speak to you – short staffed at times	Accessible website
	Email format	Can be slower than other providers	-
	Well informed and easy to understand	Not always tailor made	
	Easily accessible by phone, web or newsletter	-	-
	Easily accessible	-	-
	Understanding	Lack of funds means limited access	Funding – more trained staff
	Useful, well presented and relevant. Consistently high quality	-	-
	One on one meeting Helpful and understanding	Fleeting, no structure to when/how Long time sometimes to receive help	Regular meetings
	Friendly, knowledgeable staff	-	Ensure contact prior to multi-agency assessment

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
All In	Lots of information Easy to navigate	-	-
	Tells you what's available to widen child's experience	You have to understand how the system works	Needs to make sure that parents new to the area know about facilities and help available.
	Regular updates	-	-
Mainstream school	-	Not explained as to what it would mean to find out more information. Very last minute	More time to arrange meetings. Not through schools – they don't pay attention to anything that is not educational
	School SENCO provided out of school activity information	-	-
	Some staff excellent and supportive at annual statement review	Most written information is given during the meeting so no opportunity to read and absorb.	Better preparation, more child focused rather than school focused
	They are helpful and interested in my child's individual needs	They don't know all the answers and are busy	Link the school into the new loop of SEND
Student Finance	Nothing!	General line Wait 30-50 minutes Different advice from different advisors	Dedicated disabled student telephone number and advisors
MIND Children's health	Very Professional Very kind/caring Very useful advice	Telephone only Only limited numbers of sessions (3)	Face to face Local

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
Social Care	Absolutely nothing	Passed from one to another 12 times. Un-responsive and inappropriate. Social workers don't do DV.	Follow statutory guidance Care about the children Treat residents as humans
	Helpful	No central information point	Answer queries quicker. Access for all services for the same information
	-	The advice was generic and not geared to the request. No local knowledge	The provision of a nominated Social Worker (Adults team) thus giving continuity
	Face to face	Limited to local opportunity	Backed up with written material
Internet	Plenty of information Easily available	Not always accurate	
	Quick to access	Often only lists negatives	Public perception of disability changed
	Vast amounts of information	Some information not from a proven source	Give me approved sites
	Can usually find reliable answers	Long and tedious, end up reading legislation	Handy summaries of key bits of legislation
	Information on new opportunities	Need to have an idea myself first No one to ask questions	Signpost to where to ask for more information
	Can find almost anything	Not always relevant	-
Disabled Students Association	Lots of information Helpful staff on the phone	Hard to find exact answers	

Name of information provider	What is good about the service?	What is not so good about the service?	What could be done to improve the service?
LEA	-	Lack of understanding towards individuals	Understand that all individuals are different
	Friendly knowledgeable staff. Do return calls (SEN & Inclusion team)	Process driven	Increased resource would help more children and better
CDC	Professionals dropped in	Relatively quick response but sometimes time limited	Specific time slots where FAQ's could be done
Derwen College	Particular to your child	Takes ages to get through on the phone and during college hours	Out of hours helpline
Other parents	Honest feedback I can rely on	Sometimes is after I needed it	Parents information isn't easily located from other sources
Telford & Wrekin Council	Email format	-	-
Contact a Family	Easily accessible by phone and email	Not specific enough to local area	-
Syndrome Specific website	Targeted to my child's disability	Not updated very often	Updated more often
GP	Face to face	Only occasionally contact	See more frequently
Downs Syndrome National	Regular newsletters/articles and helpline if needed	Lots of national stuff that seems a very long way and not relevant sometimes	-
	Lots of information Helpful staff on	Hard to find exact answers	-

	the end of the phone		
Carter Centre for Brain research	Relevant to us	US based	-

Name of information provider	What is good about the service?	What is not so good about the service	What could be done to improve the service?
Blended diet UK	Open all hours Knowledgeable and experienced	-	-
Scoliosis Parent Support	Open all hours Knowledgeable and experienced	-	-
ASBAH – now called Shine	Regular updates and activities	Not very local Usually 1 hour away	Would be good if my child knew someone locally with the same condition.
Mums Net	Lots of examples of similar issues and responsive support	Very few real answers	Nothing. Is fine as it is for the purpose it serves. Maybe a background worker mopping up difficult legal queries
Colleagues in professional setting (childrens services)	They know the system	Can be embarrassing and blurs the home/work boundary	-
Medical Team	Trusted as it is from Medical professionals	Its verbal so easy to get mixed up and forget things	Provide information in written form, on web so that it is updated regularly

What are the main barriers to obtaining information about hour child's disability or additional need?

Top 3 barriers to obtaining information highlighted by parent carers

- Not knowing where to go and what to ask
- Not having the time/due to working
- Insistence on agencies following text book and unwilling to consider different ways to do things – not being person centred

Other barriers

- Being a single parent
- Lack of knowledge
- Not much known about the condition in the UK
- No one knows my child well enough to give me answers
- Not knowing who to contact in Council due to changes
- Rare condition so no knowledge
- School very poor at communicating with parents
- Lack of signposting
- Lack of accountability
- Lack of information sharing
- Staff changes
- No central access point
- Not having the energy
- Doesn't fit standard guidance

How would you like to receive information, advice and support in the future?

Top 3 ways to receive information highlighted by parent carers

- Email (tailored to your needs and central email list were highlighted)
- Website (interactive based on your circumstances/one stop shop website)
- Post

Other ways to receive information in order of priority

- Phone
- Regular meetings with same person/1:1 support
- Written info
- Leaflets/text/independent body
- Facebook
- Home school book
- Open days
- Parents groups
- Central email list
- Age appropriate
- One stop shop

Do you feel that any information that you have received has been impartial?

- 66% told us that they felt that the information that they had received was impartial
- 31% told us that they did not feel that the information that they have received was impartial.
- 3% told us that they were not sure whether the information that they have received was impartial.

In your opinion what makes a service impartial

The top 3 themes were:

- Not driven by finances/no vested interest
- All information given, not just selected information
- Providing information in the best interests of the child and family

All feedback
"Consider all options for the child and family not the professional"
"Not driven solely by finances"
"Information given regardless of cost implication to LA"
"Central hub with leaflets"
"A service that does not directly benefit from how you use that service"
"A service can only be impartial if it is not the funding body"
"The service should not have its own vested interest"
"A variety of information, not just the council"
"Not making do with things that are only in the county"
"Can advise on all aspects without bias"
"People running the service do not gain financially and do not try to influence decision making as a result of information given"
"Stand alone excellent provision with relevant curriculum"
"Not tied to the government"
"Where the priority is you as a carer and not other business concerns"
"Decisions should be made by a group of people, not one person who may have their own agenda"
"Free from National/local government and free from commercial support"
"Giving information on all services regardless of cost and accessibility
"Fair and balanced. Pan disability, specific when needed"
"Objectivity"
"Funding"
"Being clear about information ie; how you access, named contact, what the process is"
"Service provider can not be employed/seconded from an organization seeking budget reductions around SEND children"
"Moderation/arbitration mechanism built into specification"
"All agencies should share information and work together towards the best interests of the child"
"One that has no vested interest in how the budget is allocated and spent"
"Not selective"

"Not biased to one opinion. Look at all options available, gives accurate information on latest laws, where to go for help, gives all possible agencies a chance to discuss their views. Not tied in to one provider, that may in turn lead to biased support"
"Financially independent. Should have no regard to cost to LA when they are giving advice. Should only have regard for the law and the needs and well being of the young person"
"Takes individual circumstances and sign posts you to services best suited, rather than having a vested interest in one service provider over another"
"All inclusive, non judgmental"

Please tell us what you feel makes a good Information, Advice and Support Service.

The top 3 themes were:

- Up to date accurate and accessible information
- Supports access to a wide range of information, advice and support and doesn't just pass people on but empowers p/cs to make decisions
- An empathetic service that understands what it is like to be a parent of a child with Sen or a disability.

All feedback

"One place to go to find what you need"
"Staff are well versed in the law, are resourceful and capable of creative and out of the box thinking and act quickly"
"Non biased, all providers in an area are known, local and further afield options that are best suited to the individual. Takes all parties views in to account, not looking at cost cutting, offering best support to a person and needs on a personal basis, taking each case on its own merit"
"One where you are not transferred from one place to another with no end result. Makes a stressful situation even more stressful through lack of assistance"
"Up to date information, accurate information, easy to find, easy to navigate, covers all disabilities not just one or two eg autism, links to national specialist groups/websites, Information on local support, groups, help etc"
"Provides information, advice or support on a full range of issues eg help managing condition in schools, advice on benefits and finance matters, support groups, equipment/aids/adaptations, entering school, leaving

school, transition to adulthood, accessibility, rights and where is accessible”
“Friendly knowledgeable staff with ability to influence service delivery and policy”
“People with experience and professional skills so can make difficult information accessible to those who can not source/interpret if for themselves”
“Speedy response to information requests/prompt follow up”
“Personal one to one support on phone/in person so you feel listened to”
“Regular updates and information sharing”
“One that is impartial and offers courses, helpline and advertises where everyone can see it eg GP surgerys, Camhs”
“Clarity and brevity”
“Friendly, plain English and readily available”
“Accurate, concise, clear, contact points, approachable”
“Impartial, truthful and independent”
“Understanding and knowledge of all disabilities and a feeling that you matter”
“Tailored to the needs of the people/children who use the service, even the ones on the outskirts”
“Accurate, up to date information, good quality information, helpful, non judgmental staff, empathetic and understanding of living with a child with disabilities/additional needs, good at listening/remembering and non discriminating”
“Clear, well-informed, accessible, varied”
“Clear to understand, helpful staff, easy to contact, understand what you are going through, know what they are saying not what they think you want to hear”
“Sharing information – both with letters and IEP’s, regular face to face meeting not currently available at Severndale 6th form”
“Personal, relevant, practical”
“One that understands, listens, provides support and practical solutions. One that can be accessed regularly. One that really knows the correct and relevant information that helps put it into practice”
“Being confident and correct in the information they give or are willing to find out”
“Accessible and up-to date. Easy to understand”
“Accessible, links to other areas that may be of use, understandable, not patronizing, clear aims and objectives, costs, availability etc and comparison to other local authorities”
“Impartial, confidential, professional and user friendly”

“A confidential, holistic information point, be that a website, leaflet etc.
Needs to respond timely
Honesty, flexible (some evening/weekend slots to telephone for advice etc) caring, friendly, accurate up to date information”
“Clear and to the point with understandable outcomes”
“Parents views of service, names contact person with photo and brief description of their role/service”
“Information being shared by someone who has an understanding of SEND needs for their child and parents/carers”
“Publicity – let people know, CDC professionals, schools, nurseries, GP’s, hospitals alongside reports etc”
“Easy to access signposting information”
“Relevant advice”
“The ability to build up a relationship with a worker, rather than the current system, where whoever takes the file of the drawer deals with that issue and next time you have to start all over again with a different person”
“Willingness to look for information that will help, signposting”

Findings

The survey shows that people are using several sources for information. Some of these are clearly information providers, whilst others are seen to be sources of trusted information because of other services that they provide.

There were good responses about the service provided by PACC - we are clearly seen as an information provider since that is where the comments have focused on – this is a challenge since this isn’t our main role and we don’t have the capacity to do this in a comprehensive way. Although this reflects to some extent the fact that this survey was distributed by PACC, it may actually be an illustration of how little proactive information giving to families there is in general.

It is re-assuring that the majority of p/cs feel that their experience of information provision has been impartial. Their criteria for what makes an impartial service confirm that consultation with p/cs and stakeholders at the Local Offer and IAS Day and repeat the need for reliable standards of quality, equality, individualised services, transparency, and clear communication. This survey did highlight more concern from p/cs about delivery and arrangements than the workshop did however, and does suggest that this area needs to be considered carefully to build trust and reputation.

The main area for improvements are:

- Being able to contact someone for information and advice at weekends and evening
- Increased availability needed in other areas of the county
- More face 2 face support

Recommendations For Commissioning the Shropshire IASS

Parent Carer definition of IASS -

An impartial IAS Service should offer:

- A "one stop shop" for information and direction through the system.
- Support and guidance which is individual and unbiased
- Empowerment for parents/carers to navigate the system and make positive decisions
- Different ways to access the service according to preference.

P/cs have stated that they want a "one-stop" shop. A "one-stop shop" does imply that people come to the service, but it is also important to reach out to people who may not be aware that the service is available. P/cs also highlighted that they don't always know what they need to know and need the delivery of information, advice and support to be proactive as well as reactive.

Family Information Service has a good track record of delivering information sessions in community settings such as libraries, job centres etc. This has proved to be effective in identifying people who could benefit and building community links and could be a suitable model for IASS.

We recommend:

- **replicating this approach for parents and carers of children with SEN and disabilities.**
- **further exploration of methods of proactively reaching parent carers and building trust with this highly dispersed community**

Consultations touched on the need to provide information in different ways and in different settings and this needs further investigation. The need for having someone to talk to "face-to-face" was also mentioned but again identifying appropriate settings for this was not covered. We would expect that p/cs would differ widely in how they wanted to access information, advice and support and this would even vary for individuals depending on the issue and their circumstances at the time.

The full range of IAS services is likely to include:

- Web-based portal to information

- Telephone/text/email portal to information
- Telephone/email/face-to-face advice
- Telephone/email/group setting/one-to-one setting for support
- Face-to-face in various settings for advocacy type support
- Telephone calls/emails "on behalf of"

We recommend:

- **consultation with p/cs and stakeholders on delivering this range of provision effectively and cost-effectively.**
- **collaborative work to clarity what Shropshire Council and CCG should commission to effectively deliver their duty around creating an IAS service – is it mainly a signposting service – a front door that facilitates and supports families to access the information, advice and support they need? Is it a facilitation role rather than an actual delivery role?**
- **review options for using and increasing capacity of existing services, rather than creating new ones, to enable them to deliver specialist information to p/cs and to develop capacity and collaboration.**
- **choice of a different name for newly commissioned service to avoid confusion because Parent Partnership Service has now changed its name to IAS. Parent Partnership (IASS) have an important role to play in the provision of information, advice and support to p/cs but it is clear from the feedback that there needs to be different service that is the first point of contact for p/cs, that links to more specialist provision of the sort that PPS (IASS) currently provide.**

Clarity about Levels of Service

Within the Information/Advice services there are clear distinctions between information, advice and support (and advocacy). Consultation activities have shown that p/cs have a good understanding of these distinctions and would expect clarity of provision.

We suggest the following model for discussion, using p/cs who are trying to choose a school for their children as an example.

Information	Gather information from p/cs about types of school they are considering any any associated issues. Provide information in appropriate formats. Refer to sources of objective criteria. Signpost to appropriate advice and support

	service (if not able to provide in-house)
Non-directed advice	Would explore p/cs options, helping them to highlight their criteria for a successful school placement. Help them to assess each school against their criteria based on given information.
Directed advice	Recommend a particular school based on p/cs criteria and objective criteria. In this situation an advice service would rarely offer this type of advice and it is more usually found in legal or financial settings where people have given their consent to be directed.
Support	Help parent to contact school, attend meetings if requested, help to gather face-to-face information, attend school visits if requested, provide emotional support.
Advocacy	Presents p/cs case on their behalf, or helps them to present their case. Many advice services fulfil this role although they do not always call it advocacy. Advocacy is not necessarily adversarial (although it sometimes perceived as such), but empowers people to take part in a dialogue on equal terms.

In the model proposed earlier no one organisation would be expected to deliver all of the above. The newly commissioned service would focus on supporting to understand and access the appropriate level of service from a menu of specialist providers.

We recommend:

- **further research (including quality standards in the field) and discussion about how these levels of services are currently delivered**
- **clear identification of what is meant by terms IAS in local context**
- **clear identification of what is currently on offer and how services can be co-ordinated to offer a "one-stop" portal**

Training

The activities clearly evidence that p/cs place a high value on people who have a good understanding of what it is like to be a parent of a child or young person with SEN or disability. They repeatedly highlighted the need for empathetic approach, delivered by individual who were knowledge about a wide range of SEN and disability issues.

We recommend that all information providers should have training in:

- **The lived experience of being a p/c – delivered by p/cs**
- **The national and local context around SEN and disability**
- **Listening skills – empathy rather than sympathy**
- **Selecting appropriate approach**
- **Identification of whether and what level of additional advice and support should be offered by service or another service.**

Quality

Quality and range of information was a clear requirement of an impartial service.

We recommend:

- **More quality information for p/cs of older teenagers and young people**
- **Processes and standards that are based on externally recognised quality mark to build trust and reliability**
- **Monitoring of the quality of the interaction with p/cs by the IASS and the outcomes delivered**

Experience shows though that it is difficult to getting feedback on quality of information services, which would build user trust, because:

- Users rarely respond to requests for feedback
- It is difficult to unpick the difference between satisfaction with the delivery of information and satisfaction with the outcome. For example – to be told that there is no service available is good quality information delivery if the information is accurate and appropriate support is offered to supplement it. This may be perceived by the user as poor information because they are disappointed.

We recommend:

- **developing a process at the time of delivery for a plenary discussion at the end of contact: (you asked for this information, we have provided xxxxxxxx or will be sending you XXXXXX, or we have suggested that you contact XXXXXXX, is there anything else we can help you with?)**

- **appropriate record keeping would then enable monitoring of satisfaction of information requests as well as numbers of contacts.**
- **asking P/cs if they would be happy to take part in feeding back on the service, either on-line, on paper, or in a phone survey.**
- **working with parent carer forums to deliver surveys on quality of information services.**

Standards and Evaluation

It is important that the commissioning process provides clear standards for the delivery of an effective IAS service that will enable positive relationships to be built with p/cs and meaningful evaluation to take place

We recommend:

- **criteria and groupings used to define service standards and to measure the impartiality of an IAS service are based on these consultation activities (in so far as they are compatible with quality standards) - quality, equality, individualisation, transparency, communication, delivery and arrangements.**

Pro-active delivery

Parents/carers describe having to be pro-active in searching for information at each stage of their child's development. This can be very challenging and contributes to the extra responsibilities and duties that they have.

We recommend:

- **a central point of contact**
- **using a notification/subscription service (like the Council already uses) to send out staged, relevant and up-to-date information**
- **that the IAS Service includes a range of activity that involves taking information, advice and support to parent carers and not just relying on p/cs to come to the service when they have a particular problem.**

Reputation and relationship

Parents and Carers welcomed the opportunity to contribute to the developing IAS Service. This is a good moment to build trust and relationships with families and to redefine the relationship between 'professionals' and parent carers. The feedback highlights the need for a proactive partnership approach to the delivery of information, advice and support and the commissioning of the IAS service should reflect this.

We recommend;

- **That there is clear evidence in the commissioning of the IAS service that p/cs views have been listen to and have influenced the design of the new service**
- **P/c involvement on a steering group for new IAS service**
- **Outreach based on FIS model – including the delivery of events and invited speakers which responds to regular issues raised by parent carers in Shropshire.**

Note

Helplines Partnership provide training and quality standards.

www.helplines.org.uk

Local Offer

While this activity didn't really discuss the Local offer (that was a separately run activity with separate feedback) it is clear that the Local Offer is a key tool for the IAS service. The FIS Directory currently provides much of the information required of a Local Offer, although historically information for p/cs of children with disabilities and additional needs has existed alongside universal information and perhaps the specialist understanding of issues facing p/cs has not been present. Findings showed that people are increasingly using the internet for self directed research and often require more than just information.

We recommend:

- **Ensuring that the Local Offer goes further than simply providing information. Bringing the Local Offer website alive and giving added value by including top tips from parents/carers, case studies and FAQs.**

- **Using the Local Offer to empower parents to effectively use the information provided e.g. Actively flagging up to p/cs information about critical and effective use of the internet for research and information (Contact a Family produce useful and accessible information for example.)**

Finally PACC would like to make it clear that our intended role in IASS is to ensure that parent carers are involved in the design, commissioning, delivery and review of this service. PACC will not be bidding to deliver this new service. While PACC inevitably is seen as a provider of information, advice and support to parent carers it is not our main objective, which is to strengthen parent carer participation in the decision making which impacts on their lives. There will be activity that PACC can deliver to support the new service and it will be important to resource the engagement of parent carers in this process but this is separate to the delivery of the service itself.

November 2014