



SHROPSHIRE Parent  
And  
Carer  
Council

# Shropshire Short Breaks 2013

Parent and Carer Council  
Shropshire



## Shropshire Short Breaks

On the 1<sup>st</sup> May 2014 PACC and Shropshire Council jointly hosted a conference for parent carers and professionals to consider the future development of Shropshire short breaks.



Good quality Short Breaks for children and young people with disabilities or additional needs have been proven to be a key to maintaining the resilience of families and the development of young people with special needs. The term Short Breaks refers to any period of leisure time that a young person spends away from their home or family and includes clubs, activities, 1:1 support, family based shared care and overnight stays in a residential setting.

Short Breaks continue to be a priority funding areas for the Government who recently commented;

*"Short break services remain a key priority for this Government and Ministers are very much aware of the invaluable support they provide to children and young people, as well as to their parents and carers. That is why, between 2011-12 and 2014-15, Government has made available £800 million to local authorities for short breaks, through*

In Shropshire a wide ranging Short Breaks programme has developed over the last few years. The 'All In' programme is aimed at supporting young people who have difficulties in accessing mainstream activities without extra help but does not offer 1:1 support. 'All In' also has developed a number of services that offer family activities, enabling parents, siblings and young people with a disability or additional need to have fun together. Those young people or families who need a higher level of support access this through assessments carried out by the Disabled Children's Team.

It is always appropriate to continually review services and to consider how improvements can be made. With an increasing focus on the provision of person centred services that offer choice to the individual and their families it seemed the right time to consider how Shropshire Short Breaks might contribute to this approach. In particular to consider what difference are Short Breaks making to Shropshire families of children with disabilities or additional needs?

The conference was held at Central Baptist Church in Shrewsbury Town centre and was well attended by parent carers with experience of a range of disabilities or additional needs and representatives from Shropshire Council Children Services.

The day was opened by Kath Edwards, Head of Safeguarding and Sarah Wilkins, Service Manager Safeguarding Group, who both stressed the value in those who plan, fund and provide services working in partnership with the families who use them. Services need to be efficient and delivering what is needed so that they are effective and offer value for money.

During the morning session there were three presentations given exploring different aspect of Short Breaks. The opening presentation was given by Katharine Slade, who is a mother of a child with autism and severe learning difficulties and a PACC member and who has recently completed a psychology degree. Katharine shared some of her research around 'parental experience of Short breaks' with the conference and talked about;

- The issues that impact on accessing short break provision for an individual, such as challenging behaviour and continence
- The emotion cost to parent carers of accessing Short breaks
- The need for parents to have choice and control around short breaks.

The second presentation was from Dermot Dolan, Ambassador Club Co-ordinator for Whizz-Kidz. Dermot in particular spoke about the role of the Ambassadors Club in developing the independence and leadership skills of the young people who attend the clubs.

The final presentation was by 'Taking Part Shropshire' which provides independent services to people with learning difficulties.

They aim to support these young people to:

- Have a voice with more choice
- Be more independent
- Understand their rights
- To be included and treated equally

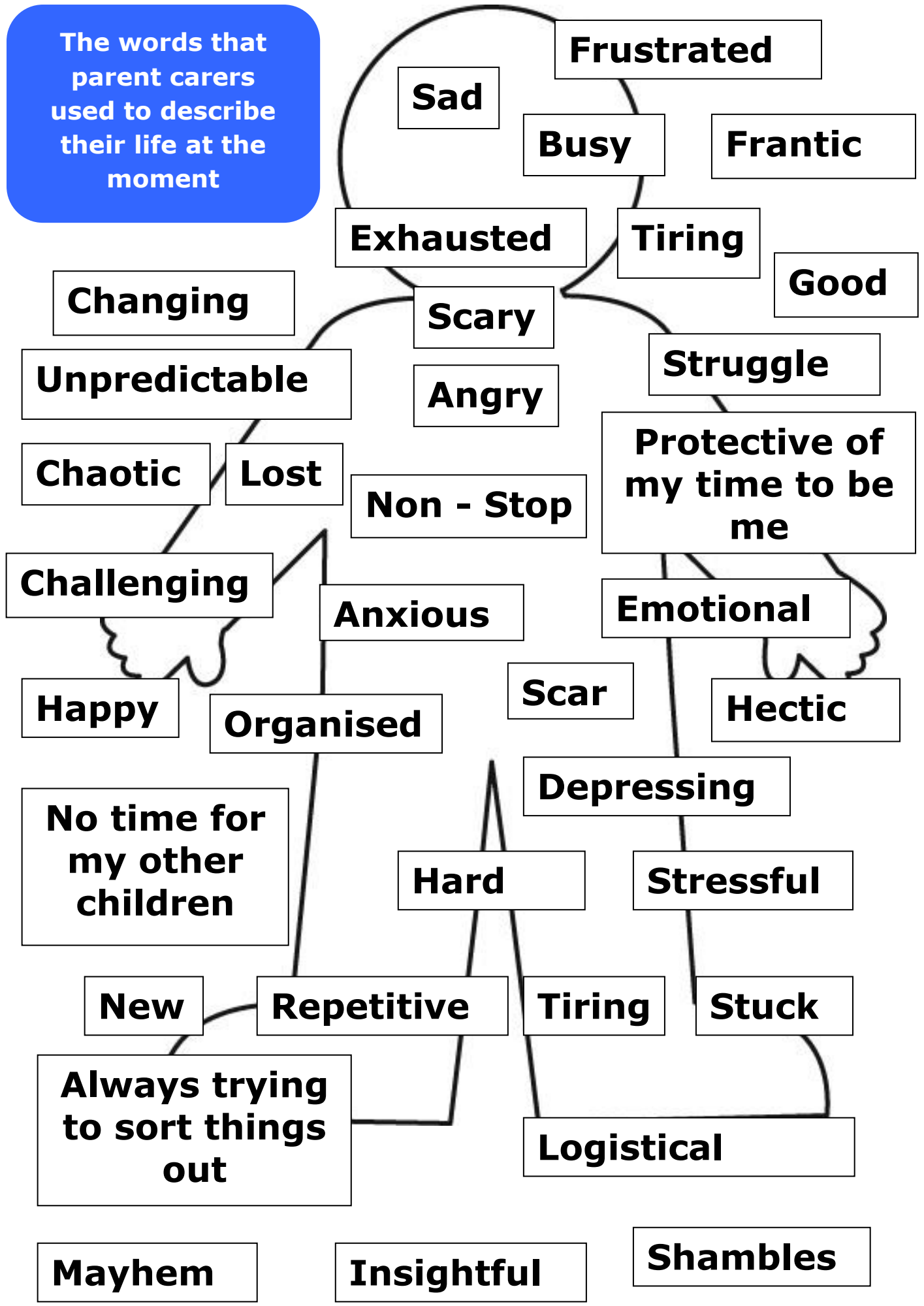
## Discussion Activities

Following the presentations parent carers and Shropshire Council representatives took part in a number of discussions activities. These discussions asked parent carers to consider the following four questions;

1. What are the words you would use to describe your and your child's life at the moment?
2. What are the words you would like to be able to use to describe your and your child's life in the future?
3. Thinking about the words that you identified this morning what needs to happen to move from the words you would use now to the using the words that you want to be able to use? Think about the barriers that exist to your lives being like that, what do you, your child and services need to do differently to make this change happen?
4. How can Short Breaks help with this?



The words that parent carers used to describe their life at the moment



The words that parent carers want to use to describe their life in the future?

**Contentment**

**Assured**

**Supported**

To feel that my son is safe in the community & being cared for properly

**Hope**

**Aware**

**In Control**

Just to make sure he is fine

**Predictable**

**Encourage**

**Fulfilled**

**Sustainable**

**Happy**

**Confident**

**Predictable**

A Sense of purpose

**Hopeful**

**Prepared**

To feel I made the right decisions

To know that my children will be happy and will have a good life

**Included**

**Unrestricted**

**Peace**

Not to feel so scared for him all of the

Confidence that my daughter will be happy, supported and 'cared' for in later life

**Calm**

To know his life experiences are good, fair and enjoyable

**Smooth**

**Quality Childcare**

**Connected**

**Liberated**

## Words to describe my Child's life – Now and in the Future

CONDITION	AGE	WORDS NOW	WORDS FUTURE
Complex Needs			
Cerebral Palsy / Hydrocephalus	4	Adventure New Exciting Tough Challenging Fun Frustrating Upsetting	Safe Confident Included Loved Excited Sustainable Achieving Satisfying Encouraged Happy Fun filled Growing Developing
Learning Difficulties	6	Confused	Settled / Happy
Downs Syndrome	7	Fun	Happy / Safe
Cerebral Palsy / ASD  Tube fed	11	Frustrated Happy Controlling Smiling Support Family	Happy Settled Growing Up Active Choices Independence Smiling
Chromosome abnormality / SLD / ASD  ADHD /	12	Limited Complicated Fun Difficult Vulnerable	Productive Planned Self Directed Sociable Fun
Downs Syndrome	13		Independent as possible Enjoying Life Friends Active
Downs Syndrome	14	Chaotic Unpredictable Friendly No Change	Supported to be independent Family Work
Rubinstein-Taybi Syndrome	16	Frustrated	Happy Content
Cerebral Palsy /Epilepsy  /wheelchair user	18	Joyful Stressful Frustrating Tiring Bureaucratic	Settled Content Happy Achieving Joyful Varied Stimulated love Filled

PMLD	18	All Change!	Safe Stimulated
ADHD / Learning Difficulties	19	On edge making plans	Get on With Life Reach Potential
Other			
Profound Hearing Loss	13	Loving Frustrating kind Fun	Secure Happy Strong Friendship Love
Autism			
Autistic	7	Limited Fun Unpredictable Happy Angry Loved Scary	Happy Confident Secure Not Limited Varied Included Enriched Supported To be part of The Decision Making process
Severe Autism / Sensory issues / learning delay	9	Isolated Limited	Choice (Where I live, what I do) Being Seen for Myself
Autism and Social Anxiety Disorder	10	Forgotten	Happy
Autism / Dyspraxia	12	Sad	Happy Safe
Autism	12	Isolated Outcast	Included Participant
ASD & Profound Hearing Loss	14	Conflict Funny Loving Hard work	Love Secure Happy Friendships Children
Aspergers	15	Frustrating	Independence
Autism	16	Controlled (by other people)	Secure Able to Express Choices
Autism / Epilepsy / Dyspraxia	17	Stressed uncertain Dependant	Promise Happy Hope Challenging Enjoyable Independent
Not given	Not given	Frustrated Violent Challenging Behaviour Bored	Friends To be able to do things Independently



## **Table 1. Questions 3 & 4**

**Thinking about the words that you identified this morning what needs to happen to move from the words you would use now to the using the words that you want to be able to use? Think about the barriers that exist to your lives being like that, what do you, your child and services need to do differently to make this change happen?**

What needs to happen to achieve the future we want;

- Opportunities are provided for young people to develop life skills
- Identify what outcomes young people should achieve by participating in any Short Breaks
- Sometimes a mixture of disabilities can be positive - can help young people to reach potential - but sometimes need activities targeted at particular disabilities
- Adults need to learn about disability and accept YP with disabilities into the community
- Need to aim for achievement, with goals and outcomes over a long period of time. Think about how what you do now will improve YP's future
- Need continuity in the adults who provide the support - both to YP and families
- Understand the individual needs of YP
- Provide support for all groups who are 'in need' - YP in mainstream, schools can have a high level of needs it is just a different type of need to those in specialist settings
- A 'can do' attitude
- Help YP to make friends
- Services need to be more flexible - talk to each other.
- LA's need to talk to each other to - i.e. T&W and Shropshire - put families first

### **How can Short Breaks help with this?**

- Have more local groups or provide support so that YP can access groups in their local community
- Reduce red tape - it is improving - but too much form filling still
- Ensure that all professionals involved in delivering SB have a better understanding of needs and the impact of disability
- Be more supportive - acknowledge that the challenges that families face are beyond that of meeting a normal child's needs - nobody wants to be in this situation

- More targeted work and small numbers that will help develop the skills and abilities of YP – we recognise that this could be more expensive but consider the long term gains

### **Table 2 Questions 3 & 4**

**Thinking about the words that you identified this morning what needs to happen to move from the words you would use now to the using the words that you want to be able to use? Think about the barriers that exist to your lives being like that, what do you, your child and services need to do differently to make this change happen?**

Barriers;

- Lack of family support
- Tiredness
- Lack of a predictable programme – can't plan
- Sensory difficulties (lights/noise)
- Unique and varied needs
- Lack of age appropriate activities

Remedies;

- Services are reliable and consistent
- A predictable offer of activities so we and the children know what to expect and we are able to plan
- Services to have planned outcomes
- Vocational activities – supported work experience / young people involved in planning / more social enterprise
- Increase number of volunteers – possibly by linking into company sponsorship

### **How can Short Breaks help with this?**

- Smaller Groups and suitable venues for young people with sensory issues
- Targeted activities for young people with sensory issues
- Train carers better – they need experience, desire and to be people that care
- Offer age appropriate activities
- Be creative and explore ideas – build in planning time
- Offer a variety of activities (a menu approach)
- Include parents in planning
- Allow flexibility to change activities
- Work with parents to find new links and new providers in the community
- Ensure time for families to plan

- Improve communication – fair access to appropriate levels of support and adequate notification of activities
- Have a range of activities for individuals / families / sibs
- The Special Olympics could provide a focus for sports activities

### **Table 3. Questions 3 & 4**

**Thinking about the words that you identified this morning what needs to happen to move from the words you would use now to the using the words that you want to be able to use? Think about the barriers that exist to your lives being like that, what do you, your child and services need to do differently to make this change happen?**

Barriers;

- YP need to be more independent and confident – they need to be able to build relationships
- YP need to be able to communicate better
- Services need to aim to develop independence, confidence and communication skills not just provide activities to pass time
- Feedback from families need to be valued and responded to
- There needs to be clear communication – instructions about what is happening and what families need to do to access services
- YP need to be supported to develop social skills, understand boundaries and know how to interact with people
- YP need opportunities to practice life skills
- Look to the future – develop skills that will make YP employable
- YP need to learn how to behave appropriately
- Opportunities to learn new skills need to continue after 19
- Our children need to be prepared for the future
- Help our children to be involved in planning their activity - adapt to meet the individual level of ability
- Targeted work needs to be done on issues such as attachment issues
- What about those who have significant needs but are not eligible for services?
- Parent carers need the right advice and support
- Parent carers need support to overcome fear / pain / guilt etc
- Families need continuity in the support they receive from professionals not for it to keep being provided by different people
- Families need emotional as well as practical support

## How can Short Breaks help with this?

- Ensure that short breaks services have appropriate expectations of YP – this doesn't just mean that they shouldn't be too high it also means that they shouldn't be too low
- Use activities to develop planning and listening skills
- Make sure that providers know how to support YP with disabilities effectively – clear instructions and boundaries for each activity – support with visual aids
- Provide activities that develop life skills – cookery club that includes planning menu's, going shopping, preparing meal for parents and friends to come to = pride and achievement
- Have activities that specifically target needs – e.g. friendship groups
- Have more small group activities to help develop confidence and interaction
- Music group – maybe percussion – can Shropshire Music Service offer anything
- Drama Group – work towards a performance and use to raise profile of disabled YP in the community or to raise funds
- Establish groups that are long term – 6 wk blocks of activity don't work for our children, they need time to adjust, settle in, become confident etc
- Improve the quality of staff who deliver Short Breaks
- More opportunities for parents to feedback on individual services
- Consider grouping activities by age, disability etc – don't lump everyone in together
- Offer activities that are based in families local communities – will help them feel less isolated
- Provide normal teenage activities – trips to cinema or bowling with friends
- When providers plan an activity programme ask them to identify what the children should achieve by participating – part of Short Breaks is about doing something different but it is also about growing up and developing new skills that will help you in the future

#### **Table 4. Questions 3 & 4**

**Thinking about the words that you identified this morning what needs to happen to move from the words you would use now to the using the words that you want to be able to use? Think about the barriers that exist to your lives being like that, what do you, your child and services need to do differently to make this change happen?**

What needs to change;

- Need greater continuity of staff – both in terms of providers but also those professional who support the family
- Providers listening to parents and social workers about what is needed especially when delivering health and behavioural management – they need to understand what is important on an individual basis
- Increased resources – more health contribution to Short Breaks
- Health need to understand the importance of Short Break in delivering health outcomes
- More 'Phil Cowells' – i.e. people who link children and adult services
- Any change to be better planned and prepared for
- Improved reliability of services
- Teach life skills proactively – how to make decisions, improve communication and reasoning skills
- Services and systems need to be person centred – respond to the needs of families
- Parents not being overprotective – need to allow children to grow up / take managed risks / - letting go a bit more before their children are 18
- More YP involved in planning services

#### **How can Short Breaks help with this?**

- Support YP to express their views
- Present 'educational' Short Breaks in an attractive way – learn and have fun
- Emphasis the benefits / outcome of activities
- Disguise 'education' – give it the 'wow factor'
- Help YP to develop life skills – using money and practical skills – cooking, sewing, cleaning!
- Ensure that staff are safe, well training and understand
- Offer stimulating activities

## Summary

When looking at the responses to questions 1 & 2 there were some clear themes present.

When considering the words that parents would use to describe their own lives, the words chosen illustrated how challenging it is to be a parent carer. There are obviously a number of different causes for this since caring for a child with a disability or additional needs can be emotional and difficult at times, no matter how effective support services are. It is important however that the services that support parent carers and their families understand and recognise this, along with the fact that sometimes the way services are planned and delivered can add to this challenge.

When considering their child's life the words used by parents of young people on the autistic spectrum, consistently suggested an over whelming sense of exclusion. The parents of children with complex needs and learning disabilities talked about life being complicated and frustrating. In some but not all cases parents also talked about their children finding fun in their lives.

When asked to think about the future and the words they would like to be able to use to describe their lives, parent carers hoped for lives that were calm and predictable and where they had confidence that their children would be cared for and cared about.

With regard to the lives of their children's future there was a significant emphasis on young people being as independent as possible and fulfilling their potential, as well as them being happy and safe.

The parent carers present were then asked to think about what needs to happen to so that they and their children can move from where they are now to where they want to be in the future. In these discussions there was again a significant emphasis on needing to develop the independence and life skills of young people with disabilities or additional needs. It was clear that the parents present also felt that there needed to be more of a long term vision for their children, with clear goals and opportunities for achievement.

Parents also highlighted a need for consistency in the support provided, for flexibility and for the need for their children to be helped to make friends.

When asked how Short Breaks could help to deliver the above the discussion was lively and creative. There was a strong sense that more could be done using short breaks to prepare young people for adulthood. Most children learn life skills incidentally through play and the parent carers present felt that their children and young people could still learn these skills through fun activities, but the learning aspect might need to be more explicitly supported and that it might take longer. Parents stated that they would like to see an emphasis on proactively supporting young people to develop their social skills and to develop friendship, with groups being run with that focus and where the activity is more a means to an end rather than the sole focus. There was also an acknowledgement that sometimes parent carers themselves would benefit from support to encourage the growth of their child's independence. Specific suggestions for groups included a cookery club, that also considered shopping and budgeting and a long term drama group. For both these suggestions the opportunity to work towards a celebration of achievement event was also highlighted, for example the cookery club preparing a meal for invited guest or the drama group presenting an annual show.

There was also discussion about the need for good communication and planning with regard to short breaks. Comments were made that providers could benefit from an increased understanding of individual children's needs and how to work in a more person centred way. Parents said they would like clear and explicit information about activities so that they and their children know what to expect and would like to be confident that providers understand how to promote positive behaviour in their children.



## Feedback from the Shropshire Short Breaks conference 2013

31 parent carers booked on to the event. 20 parent carers actually attended the event with 7 sending apologies for not attending and 4 parent carers not showing up. 10 professionals attended the event.

17 feedback forms received = 85% response rate

We asked parent carers - Has attending the event.....?

	No change	A Little	A lot
Helped you to feel more connected to other parent carers	1	8	8
Helped you feel more able to support your family	2	10	5
Increased your knowledge on services	0	9	8
Increased your ability to influence services	3	6	8

94% of the parent carers said that the event helped them to feel more connected to other parent carers

88% of parent carers said that the event helped them to feel more able to support their family

100% of parent carers said that the event increased their knowledge about services

82% of parent carers said the event increased their ability to influence services

We asked parent carers to rate the following.....

	Poor	Good	Very Good
Venue	0	3	14
refreshments	0	2	15
Presentations	0	7	10
Discussion Activities	0	7	10



## **Comments from parent carers included:**

- Discussion activities were thought provoking and informative
- Presentations were very informative and interesting
- We need more activities away from Shrewsbury (Whitchurch, Market Drayton and Wem)
- Extremely enjoyable conference very thought provoking!
- Not surprisingly most parents came up with the same ideas, problems and planning ideas, hopefully professionals can think along our wavelength too
- I would like to add to our discussion about short breaks helping both our children and family, that it would be very useful if support providers could integrate a bit more..... My son needs 2:1 to access Sharks, Shropshire Activity Service can only find 1 member of staff at the moment to work with him, but another service provider said they can supply a worker too, but the two different agencies won't get together on this. Therefore my son has missed out on 12mths swimming because of this red tape!
- Lovely food and facilities, good access
- Thought all discussions were thought provoking and generated great responses
- Presentations gave a good broad overview, good group discussion – ice breaking
- Very stimulating and empowering for parents. I think name badges (sticky labels?) would also help
- Katherine's presentation was informative and honest – really useful
- Very useful to be able to put forward ideas/views about how to improve services
- I really enjoyed 'parent' speaker. I think her presentation was spot on
- I think it was interesting that the 4 groups had very similar issues and ideas about how to solve them
- Need more for 19 and over

- Extremely good, really found a lot of information available for me and my children
- I have found out that you can make different activities for different disabilities and that siblings can access some activities too
- The conference was very good and informative and now I can access different agencies who may help me find the right activities for all the family not just my children with disabilities
- Suggestions for improvements; regular parent and child feedback questionnaires/evaluations and meetings to discuss findings in order to make the services more appropriate and enjoyable - summer club to be held at more appropriate venue i.e Severndale and not the Priory (Severndale is safer, has more facilities i.e sensory room) - all clubs need to have written appropriate (for children with disabilities) rules that we know and children and parents need to adhere to – I feel that the London Rd Sports Staff have a higher expectation of the children due to lack of understanding / information – they need more training ie behaviour management strategies and that our children learn differently and more slowly – Something like IEP's (Individual Education Plans) for clubs identifying outcomes and a plan of action.
- Lovely food, presentations were very informative, thank you
- Katherine Slade's research was down to earth and it gave a greater understanding of what people actually experience as parents of a special needs child
- Presentations were long enough to be interesting but not too long to be boring!
- Good discussion activities – small enough groups to all get our points across
- Great venue and catering – excellent speakers and good subjects relevant to any aspect of disability, excellent support for any further information required – lots of ideas for sibling support and family support as well as activities and help for the disabled child – we already receive respite care and I would like to understand a bit more about how the Short Break team can help us as a family achieve a family holiday.
- Discussion activities were very good, informative and positive