

Children & Young People Community Health Services Community Short Breaks Service Report

Parent Carer Focus Groups – Summer Term 2015

Background:

Worcestershire County Council is seeking the views of parent carers on community health services, and is reviewing each of these services to gain an understanding of what works well and what could be improved.

The community short breaks services form part of these services under review, and the council want to ensure that they are meeting the needs of the children and their families with available resources.

As part of the process Children's Services Parent Engagement Advisor (PEA) agreed to undertake a series of focus groups with parent carers to get their views on the services on offer. This was to add some contextual intelligence to the data collected via the online questionnaire.

Methodology

A number of parent carer groups were contacted via email and asked if they would be happy to take part in a consultation process. The PEA then either went along to a session and asked the questions to the group or contacted the parent carers individually on the telephone.

All the contributors were reassured that their comments would be anonymous and that the facilitator was not part of the commissioning service. All participants were told that their views would form part of report compiled by the PEA and that none of their comments would be directly attributable to them.

Each group or individual had the same brief introduction and clarification about what the Community Short Breaks services are was given. They were then asked:

1. What is good about the service you receive
2. What is not so good
3. Even better if... (EBI)

Project/Event details

Following on from the original email four focus groups were facilitated and a number of phone calls made to individuals. These all occurred during April and May 2015.

The respondents were from across the county and 10 of the children attend a special school. There was a range of disabilities from autism to PMLD, complex medical needs or disability and hearing impairment. The age of the children ranged from 5 to 19, some families had other children along with the child with additional needs where others had only the child with the disability.

In total 16 parent carers took part:

- 2 on the phone
- 4 in a parent carer forum (Our Voice)
- 3 in a special school drop in (Fort Royal)
- 7 in 2 different coffee mornings

Summary of results

For the purposes of this consultation the responses have been collated under the three questions that the respondents were asked. Individual responses

were then grouped under themes and commentary made to outline these – where appropriate actual quotations have been used to illustrate the points.

What went well?

All of the respondents said there should be a wide choice of short breaks available, to cater for all families.

When discussing what went well, parents listed the types of breaks they had used and had found useful.

Short breaks for the whole family including siblings and parents – as these allow the family to get out into the community and enjoy mainstream activities on offer. Siblings get the opportunity to meet others in a similar position and parents can get support from each other. There should be a variety of fun activities at different times, which appeal to different families with a variety of age groups. The experience of being part of a larger group enables families to relax as they are not the 'only ones', but it is important that there is flexibility to go off and explore as a smaller family unit.

'You are there with others, but not as a large organised group'

'Families with teenagers are rarely catered for – it is nice to do things together as a family but with other teens around. We went on an evening out to see a tribute act, it was such fun and something we wouldn't have contemplated alone as a family, but because our teen had friends with them we could all enjoy it.'

Holiday clubs are really important – it is good respite for the rest of the family and the children have a good time.

It's important to note that there should be a variety of holiday play schemes available as all families are different and have different needs.

In-school holiday play schemes:

- great because the child knows the surroundings and the staff – the parents have confidence that they are leaving them with someone who knows them.
- parents value that they don't have to 'settle them in' over a period of time, they can use them straight away.

'when I bought X along the first time I got really anxious as I didn't recognise

any of the staff and I thought this isn't going to work, then one person said 'Hello X' and I immediately breathed a sigh of relief I knew it was going to be ok – X knew them and responded.'

'I need to feel confident that my child is being cared for by trained staff. Some groups wouldn't know how to deal with a seizure – the holiday clubs I use do.'

Holiday clubs are really important – it is good respite for the rest of the family but thought needs to be given to making age appropriate provision.

Non-school holiday play schemes

Some children enjoy being somewhere that isn't school and they are more able to settle easily into another place, as long as it's only one other place.

Parents liked that the days are usually longer and therefore if they work it fits better with the working day.

The children get to do fun stuff and have a good time:

'I know my child gets the 121 attention they need and someone there to play with them and occupy them, it wouldn't be possible for me to give them that all the time at home'

Parents like to be able to use direct payments to pay for some of the sessions.

Families liked that each day was themed and they were given a full list of what was happening and when – they could then select the activities they knew their child would enjoy and send them on those days. If there was a cost associated with the activity they would pay for that on top, which they were able to do, but could see that for others that could be a barrier.

Regular activity clubs where parents can stay or drop their child off were also valued. Parents liked the flexibility of being able to either stay and socialise with other mums or be able to nip off and do some shopping.

The opportunity to meet and socialise with other parents in similar circumstances is really valuable to a large number of the mums. They got support from each other, while their children had an opportunity to play and have fun.

'I found out about this club by chance and it's been brilliant, through this I've found out about other things – we (parents) all give support and advice to each other.'

'Really important that I get the opportunity to mix with other mums, while

knowing that my child is safe and having a good time. We look out for each other, and each other's children.'

'I come here just as much for me, as for my child'.

'Inclusion is great, in theory, but it's nice to have somewhere that is especially for our children. In mainstream school, my child is 'mothered' by the other children, because she isn't as able – here she gets to be a mother hen – it does wonders for her confidence.'

Age appropriate clubs, especially those for teenagers were popular, it was important that they weren't all activity based – but sometimes just give the young people space to socialise and chill out with their friends.

'Usually teens just want somewhere to chill out with their friends, maybe make a meal together, like other teens. This helps them to develop their independence and grow as individuals.'

After school clubs for teenagers, which are not based in school, but somewhere else. Offering opportunities for teens to socialise and do activities that other teenagers get to do with friends. Doesn't have to be trips out all the time, but sometimes just the chance to 'chill' together and listen to music, watch DVD's.

Need to be aware that some families are rurally isolated and therefore accessing mainstream youth club provision is very difficult, particularly if it's based in Worcester.

'What is great about the provision we use is the young people are picked up from their (special) school, taken out or to the clubs base, and then we pick them up from there. This is still in the local area, so it's something we can do.'

School run after school and Saturday club provision – where available was really popular. Parents liked that it was in school and their child is comfortable in the surroundings with staff that know them. This gives them confidence that they are happy to leave them and they can enjoy the break and their children get to develop their independence.

What not so well?

It is important to be aware that some children/young people have physical disabilities and may have mobility problems – whilst all buildings and facilities have to have wheelchair access some are much easier and straight forward than others. Thought should be given to how easy it is for those with mobility difficulties to access activities.

Some parents commented that with holiday play schemes in school you weren't told what was happening on what days until after you'd selected the days you were going to send them.

'I can see that they probably worked out who was coming and then arranged appropriate activities for those days, but it would be nice to have some choice.'

One parent suggested that the days be allocated on the basis that you're allowed x number of activity days (e.g. things that cost more such as Horse riding, days out) and x number of in-school days (with low cost activities). That way parents would know the children were getting a balance of things to do and wouldn't feel like they were missing out.

Teens are not catered for as well as younger children. Teens don't really want to stay at school in the holidays, it's good to have a mixture available.

Even better if...

The opportunity to go away for a weekend as a family but part of a wider group would also be useful – Youth hosteling weekends together would have the same benefits for the family as the short breaks 'day trips'.

Father and children activities: often fathers work fulltime and therefore don't get the same opportunities as mothers to meet peers in similar situations. Having supported groups where fathers have the chance to meet and interact with other dads and their children would be very beneficial.

Full day or activity weekends for the children only. Most mainstream provision isn't suitable for our children for a variety of reasons, but mainly that the group sizes are too large and it contains lots of 'busy' 'noisy' activities with a lot of instruction. We don't have the confidence that mainstream have the expertise to work with our children effectively.

Targeted provision would include smaller groups, a clear and defined structure

to the day, divided into small, manageable chunks and including opportunities to chill, relax and just observe – some structured downtime. The activities could include gaming opportunities, computer skills, sensory experiences as well as the usual physical based ones or craft sessions. It doesn't have to be an adrenalin fuelled day; there can be some sedentary elements to it.

It's important that there is a mixture on offer – but most important of all that you can find out about them. It's really difficult to know what is out there, and who to ask.

'I'd been looking for something for my son for four years, I'd asked school and they didn't know of anything, I found out about this group by chance and through this I've found out about other things.'

More variety – *'inclusive drama club would be great, where our young people can develop their personalities and boost their confidence.'*

Opportunities for the young people to have a 'sleepover' experience would be excellent – maybe camping in a safe environment. This would give them the opportunity to socialise with their friends, cook and chat – which would lead to an increase in confidence.

Can you mix your holiday play scheme days between providers? If so, parents need to know that.

Equity across the county, some special schools run breakfast clubs, wraparound care, others don't. If all schools ran that provision it would be easier for parents to work.

Utilise the onsite accommodation at the school during the holidays (like a hotel catering for young people with additional needs) – teens could have a 'sleepover' type experience that their mainstream equivalents have, in a safe, familiar environment.

Finally one parent responded:

'Nothing would make the service better – it is excellent, superb and we feel really supported by it.'