

PACC Participation Report

Re Commissioning of Assessed Short Breaks in Shropshire

2016/17



SHROPSHIRE Parent
And
Carer
Council

Charity Number 1150180

Face 2 Face
Parents supporting parents
of disabled children



This work started in April 2016 with the creation of a 'task and finish' group in April 2016. Two PACC representatives joined this group and have provided parent carer representation throughout the recommissioning process.

This has included;

- An initial response to the recommissioning proposal
- Hosting a parent carer workshop to discuss the recommissioning proposal
- Creating and distributing a survey to 'test' key statements developed during the workshop
- Working with Shropshire Council to develop key messages and communications about the recommissioning process for the local parent carer community
- Providing comment and feedback on the business case and tender document based on discussion with the Shropshire Parent Carer Community.
- Participating in information events for potential providers

PACC Response to initial discussions at Task and Finish Group Meeting on the 18th April 2016

There are 4 key areas of particular concern to PACC with regard to this piece of work, which are listed below along with some thoughts relating to each area.

Communication: It is inevitable that in the current financial environment that a review of any service will cause concern amongst families. Assessed Short Break services by their nature are services used by vulnerable families and individuals, who are facing a variety of challenges in their lives and as such any potential change to these services is liable to cause anxiety. To help reduce this anxiety it is key that there is a real sense of transparency * around this work and a clarity about why this is happening and what the intended outcomes are. To facilitate good communication with families about this work and to reduce any associated anxiety about what it will mean for families, PACC recommends the following;

- The T&F group produce a clear and parent carer friendly briefing outlining the recommissioning process and providing background information such as why it is necessary and the intended outcomes. This should be sent directly to all current users of assessed services and shared via other routes (such as, the Local offer, PACC and other voluntary sector organisations) to the wider parent carer community.
- The Local Offer is used to share updates about the recommissioning process on a regular basis – including opportunities for parent carer to contribute to the process.
- A consultation with the wider parent carer community is built into the recommissioning timeline, which will be able to inform the specification development for the Tender.

**Pacc recognises that some of the information shared with its representatives on the T&F Group might be commercially sensitive and confidential, but we believe that there can still be a fundamentally transparent approach to communication about this work with parent carers.*

Service Offer - Structure and Levels: PACC is committed to ensuring that local commissioning is informed by robust data about the levels and type of local need. We know that historically that this level of information has not been available in Shropshire but that steps are currently in place to address this. The recent PACC report 'Accessing Social Care Support for Disabled Children and Young People in Shropshire' highlighted that currently there are several barriers to families requesting social care support and that this has given a false picture of need, suggesting that it is lower than it actually is. It is key to the success of this work that there is a true understanding of the level of need for assessed social care support services in Shropshire. Linked to this is understanding the role that these services play in early intervention and preparing young people for adulthood. To ensure that the recommissioned service is structure in a way that responds to the range and level of needs in the local community PACC recommends;

- Case studies and profiles are produced of families who might require assessed social care support. For example, families might request support due to challenges as a result of; a young child consistently not sleeping, a young person having a high level of medical needs that require 24hr care, to help a young person develop independence and confidence away from the family environment. This will ensure that the services tendered for will cover the full range of needs likely to be present in the local community.
- That current available data is analysed to provide some understanding of the make-up of the local population of children and young people with a disability in Shropshire, who are likely to access assessed social care support. Since these are services that are targeted at those young people with the highest level of need the majority of the young people who might be eligible for these services will have a statement or an EHCP. Other possible sources of information about this group are Severndale Academy, DCT, CDC and CAMHS records.

Outcomes: It is essential that these assessed social care services are designed to deliver a range of positive outcomes for families and not just seen as crisis response services. In the PACC Report 'Accessing Social Care Support for Children and Young People with Disabilities in Shropshire' we raised concerns that there is a current lack of clarity about the role that social care support plays in developing the resilience of families of children and young people with a disability through early intervention and of how they are essential in delivering the 'preparing for adulthood' outcomes of independent living and community inclusion. The Children and Families Act highlights the need for services to focus on preparing children and young people with SEND for adulthood and the Ofsted and CQC SEND Local Area Inspections, due to commence in May 2016, will specifically look for evidence that Local Areas are delivering these outcomes. To ensure that the recommissioning process results in services that deliver the 'preparing for adulthood' outcomes PACC recommends that these form a core part of any service specification included in the Tender.

A holistic and integrated approach: Assessed social care services should be designed so that they integrate with other services and contribute to delivering holistic packages of support. Consideration should be given to how families will be supported to access services, in terms of transport provision, Community Health Services so that young people's medical needs are fully met and how the services will link to adult social care during transition, for example. The new services should be required to contribute to EHCP process where required and staff should understand their role in the delivery of long term outcomes and a good quality of life for individual young people. To support this PACC would like to see

the recommissioning process include discussions with; the transport team to understand how their provision can support the effective delivery of assessed social care services, Adult Social Care to ensure that there is effective transition between Children's and Adult's Social Care; and the Community Health Team.

There are a number of resources that PACC would like to see being used as reference and guidance documents in this recommissioning process;

Short Breaks Toolkit – Contact a Family http://www.cafamily.org.uk/media/923948/short_breaks_toolkit.pdf

Council for Disabled Children guidance for short breaks commissioners
<http://www.councilfordisabledchildren.org.uk/media/1103298/short-breaks-commissioning-guide.pdf>

Action for Children guidance for short breaks providers
<https://www.actionforchildren.org.uk/media/5997/sbp-provider-guidance-final.pdf> 4

Preparing For Adulthood Self Evaluation Tools
<http://preparingforadulthood.org.uk/what-we-do/pfa-self-evaluation-tool>

Developing Children's Social Care in Shropshire

Parent Carer Workshop— 24th June 2016

A small parent carer workshops was held to discuss what local parent carers who like to see happen in terms of developing both overnight Short Breaks for disabled children and the provision of community based Short Breaks. Parent carers were asked to consider;

- Why these services were important to them
- How they wanted these services to be delivered
- What their priorities for these services were
- What was currently working or not working about these services in Shropshire

The Agenda for the workshop is provided below;

9.30am **Welcome and Introduction to the Day**

Housekeep

Agenda

Session 1 - Recommissioning of specialist social care service

9.40am **Introduction;**

Why this work is happening

The involvement of families

9.50am **Role Task & Finish Group and Timeframe for Recommissioning;**

Looking at current services, existing resources,

Parent & CYP comments, what important, Gaps

What is necessary – legal framework

Decision based on balance between commissioner – family – provider

- 10.20am **Introduction to discussion Activity;**
Creating a Demand Story – What, Why and How
Priorities
Current services what is working / not working?
- 10.35am **Any Questions?** (SC & PACC)
- 10.50am **Refreshment Break**
- 11.00am **Discussion Activity**

Notes from Assessed Short Breaks Workshop – 24th June 2016

Group 1 (5 parent carers)

What – High Needs Community Support Provision

Why is this service needed?

- Limited opportunities to access activities if specialist support not available
- Provides an opportunity for children and young people to develop independence and social skills away from their family – “not having your Mom holding your hand all the time” – especially as you get older
- Provides a chance to mix with other children and young people and to experience a wider range of environments
- A chance to learn in a different environment – that might be different but still familiar (the consistency of staff important)
- Time out for the family – opportunity to do things with the other children in the family or to spend time with your partner – “My other children need to be the priority sometimes”

How would you like to see this provision delivered?

- With a straight forward assessment process that doesn't make parent carers feel worse – reduce the assessment burden – it takes too long and is a difficult experience for families, focuses on all the negatives not what difference the service can make
- The provision should be flexible and offer choice – “we have one holiday scheme and you either take it or leave it – what happens if it doesn't work for your child or family?”
- It should be a provision that is aspirational for our children and not inappropriately risk adverse
- With well trained staff and responsive to any new training needs
- The service should deliver consistency in staff and quality and work to an agreed plan for each child
- Should offer support to parents on family days out or even on holidays
- The staff should build good quality relationships with both the child and the family
- There should be clear outcomes agreed for the support provided
- Progress towards agreed outcomes should be regularly reviewed and the support provided should be responsive to the changing needs of both the young person and the family
- If a personal budget is offered help should be available to parent carers to find and engaged a service or PA – a brokerage service

- The service should be able to respond to a range of needs, including medical needs and profound disability – there should be as much of a choice of availability and activities for this group as any other and it should not be limited by the lack of medical care available.

What – Residential Short Breaks Provision

Why is this service needed?

- To support parent carers to access / maintain work or education, especially during holiday periods – time to catch up
- No other family support networks available locally
- The friends I would usually ask to childmind can't cope with my child
- The get a good night sleep – “my child doesn't sleep for more than a few hours” “my night is always disturbed by having to administer medicines” “my child doesn't just wake me – they wake the whole house”
- “To keep me going through the school holidays!”
- “To provide some periods of normality for me and my other children”
- Parents need a break to keep on caring – “we've been doing this for a long time”
- To develop young person's independence away from the family
- To help my son understand that there are other people who can help him not just family and not just in school
- To help parent carers to trust others to care for their child
- To enable the rest of the family to do ordinary things
- “I am too tired to address / change behaviours – I need help to do this”
- To help me maintain a relationship with my wider family by being able to go to family events such as weddings, my other children's graduation etc – If I can't participate in my other children's lives they resent their disabled sibling
- “So that I can spend some time with my partner”
- To support us in times of family crisis or illness
- To help families prepare for the future

How would you like to see this provision delivered?

- Overnight support offered both in and out of the family home
- With effective communication, using a range of types, especially email and texts
- In partnership with other support offered to my family – so that everything is co-ordinated
- With good links with school so that each services supports each other – sharing information and re enforcing each other's work – sharing targets and outcomes etc
- To have the option of short but frequent stays
- For the child and family to be well supported during their introduction to the services - parents need to know exactly what is happening and when

- Clear individual outcomes to be delivered by the services for each child
- In partnership with the family – good communication so that it is clear what support the child needs and how the service will work towards developing independence
- Visits from the service provider to the family home – get to know the child in a variety of environments and build a quality relationship
- Outreach to be provided by residential provider – build on the relationship
- Make sure that there are enough staff to cover emergencies “my child had to go to hospital in an ambulance by herself because there was not enough staff on duty for one to go with her – there should be a contingency to cover this – somebody on call to come in if there is an emergency.”
- As part of early planning – is it likely that residential care might be a possibility in the future, what does it look like – introduce the idea to families to make it less scary when it is needed.
- So that families have a choice of provider – once the level of need is assessed and the level of support needed agreed then families should be supported to look at all the options available to explore how their needs can be best met
- Opportunities for families to visit the residential units to look around them and feel comfortable – including grandparents and siblings
- They should be accessed via a short and responsive assessment – parents are already exhausted in most cases when they request help and then a long assessment is really difficult. Provide interim support and care while assessment is being completed.

Priorities

- The service can respond to a child or young person’s individual needs including medical needs
- Parent carers have confidence in the service, particularly;
 - The services ability and commitment to maintaining good communication with the family
 - That the service is safe because of appropriate staffing ratios, with knowledgeable and well trained staff, that are person centred in approach
- The service is flexible and can respond to changing needs and family commitments
- The service offers a plan to deliver agreed outcomes for each child and young person, which is agreed with home, school and other services that offer support to the family – delivering a collaborative approach to support
- A service that offers continuity in staff and quality relationships with the child and family.

What about the Current Services is Working / Not Working

Working;

- Good quality of support at clubs and outreach

Not working;

- Assessments are difficult for parents and take too long, leaving families in crisis and with no support
- Not enough activities and choice for children with medical needs
- No brokerage service for Personal Budgets – parents are left to sort everything themselves

- No emergency cover – especially where cover can be provided in the home
- Lack of long terms aims/outcomes for individual children, which progress can be easily measured against
- Help is provided too late – needs to be considered earlier in a proactive way
- Lack of transparency about eligibility criteria
- Parents don't understand what is available or what the services look like
- Lack of capacity in disabled children's team
- Frequent poor experiences when families ring first point of contact to request support
- Limited days offered during school holidays – makes it impossible to work

Group 2 (5 parent carers)

What – High Needs Community Support Provision

Why is this service needed?

- To access after school clubs when 1:1 support is needed
- Supports a consistent routine that helps address anxiety
- Enables participation in clubs to support health and fitness
- Provides a bit of normality for the disabled child – they can choose an activity and do things that other children do

How would you like to see this provision delivered?

- With support workers who actively engage with the young person and build a genuine relationship
- Assessment done by people who know the family – GP's or SENCO – some families are put off by contact with social services
- With plenty of provision for the early years children at weekends and Wednesday afternoons when Severndale nursery closed – under 5's are tired after school
- Use facilities outside of Shrewsbury that are currently under used – for example Wem Sure Start Centre – plenty of parking and train services
- Vary the venue of regular clubs such as the AFC Saturday morning club
- Use Schools as venues at weekends
- As a continuous service up to 25
- Work with parents to set a target (outcome) for child to achieve while having community support
- Providers have a copy of child's EHCP or if they don't have one write a one page profile
- Providers to share a generic set of paperwork for each child (maybe held on line) so parents do not have to fill lots of different forms in
- Involve child in decision making as much as they are able to – so they can make their views known and say what they want to do
- Link advocates to community activities

What – Residential Short Breaks Provision

Why is this service needed?

- To provide emergency overnight care if parents ill or there is a family crisis
- Some families of more than one disabled children and other disabled family members and are overwhelmed by caring role
- To enable parents to spend time with siblings and extended family – it can be very isolating for parent carers who have to stay at home with a disabled child
- Parents need a break from caring and the system
- So that I can be the best parent I can be – the break helps me recharge and keep going
- If you are a single parent and there is an emergency

How would you like to see this provision delivered?

- So it is flexible and able to respond to the needs of families
- So that it can meet the needs of high functioning autistic children who have behaviours that challenge
- So that overnight breaks can be offered for the under 5's
- More clarity and information provided by places such as CDC about what is available for overnight short breaks
- As part of early intervention and future planning for children and families – so they can integrate short breaks into their lives – need a longer transition into the service
- A clear lower level assessment that will provide info about how to access high needs services and indicate if you might be eligible
- Staff to be well trained – particularly Makaton, other alternative communication systems, peg feeding – minimum NVQ level 3 – managers NVQ level 1
- Staff trained in personal care and not assume that everyone can change a pad properly!
- With a sense of humour!
- Involve parents and children in recruitment of staff
- Know the children's interests and be responsive to them
- By staff who are physically fit and cope with the physical demands of our children

Priorities

- Community and residential support available before aged 4 – so little for pre school children currently
- Joint commissioning of services between health and social care
- Deliver a focus on developing independence of young people, e.g. travel training and independent living skills
- A higher level of support during school holidays
- A brokerage service to tell families what their options are when spending their personal budgets
- Maintain a residential service that can respond to the level of need

What about the Current Services is Working / Not Working

Working;

- There has been improved access to DCT – this needs to continue

Not Working;

- Need a familiar member of staff when staying overnight – doesn't always happen – more continuity for child needed
- Better understanding of mental health issues by DCT staff – in some cases relationships between team and families are not good enough
- Need better information about services – short and clear and less forms to fill in

Testing Key Messages developed based on Workshop discussions

Following the workshop PACC developed a series of key messages reflecting what parent carers felt was important in relation to overnight residential short breaks and high needs community based short breaks. A wider group of parent carers were then asked to ;

- State if they agreed, disagreed or neither agreed or disagreed with the statements about why these services were important
- State if they agreed, disagreed, or neither agreed or disagreed and to indicate the top 3 messages in relation to how these services should be delivered.

22 responses were received in total - 13 paper copies and 9 online

The ages of the children of the parent carers who responded were;

0-5 = 6 6-11 = 8 12-16 = 6 17 – 25 = 2

10 parent carers who had responded had accessed residential short breaks

9 parent carers had accessed Community Short Breaks

Figures include 5 families who have accessed both

On a few occasions parent carers did not answer individual questions meaning that there are not always 22 responses to all questions.

The responses given are provided on the following pages.

Below are key message that the workshop discussion indicated were why residential and community support short breaks are important to parent carers in Shropshire

	Agree	Neither Agree or Disagree	Dis - agree
Residential and community support short breaks are essential to enable me to continue in my caring role	15	7	
It is important to me that residential and community support short breaks offer opportunities to develop my child's independence and new skills	19	3	
I would like residential and community support short breaks to enable me to maintain or start work	17	4	1
Residential or community support short breaks help me to maintain my relationship with the rest of my family	16	6	
I need increased access to residential or community support short breaks during the school holidays	18	3	
Residential and community support short breaks are an important part of preparing me and my child for the future	18	2	
My family needs residential and community support short breaks to be available in times of family emergencies or illness because we do not have other sources of support	20	2	

Comment

Parent carers who had not accessed any assessed short break support were more likely to answer neither agree or disagree to the following statements;

“Residential and community support short breaks are essential to enable me to continue in my caring role”

“Residential or community support short breaks help me to maintain my relationship with the rest of my family”

Below are key message that the workshop discussion indicated are important to parent carers about the way that residential and high needs community support short breaks should be delivered.

Key considerations for residential and community support short break provision	Agree	Neither agree or Disagree	Disagree	Identify your top three priorities for the provision (Mark with a tick)
Residential and community support short break services should be able to respond to a child or young person's individual needs, including medical needs	21			6 ticks
Residential and community support short break services must be committed to maintaining good communication with the child's family	21			5 ticks
Residential and community short break services must have appropriate staffing ratios, with knowledgeable and well trained staff, that work in a person centred way	21			7 ticks
Residential and community short break services should be flexible and able to respond to changing needs and family commitments	20	1		3 ticks
Residential and community support short break services should offer a plan to deliver agreed outcomes for each child and young person, which is agreed with home, school and other services – delivering a collaborative approach to support	20	1		1 tick
Residential and community short break services should offer continuity in staff and quality relationships with the child and family	20	1		3 ticks
Residential and community short breaks services should be available for children under the age of 4	12	6	3	
Residential and community short break services should be funded and managed jointly by health and social care	15	4		1 tick

Residential and community short break services should focus on developing the independence of children and young people	18	2		2 ticks
Residential and community short break services should offer a higher level of support during school holidays	19	1		5 ticks
Families need a brokerage service to help them purchase support with personal budgets	17	3		1 ticks

Comments

All parent carers who either ticked 'neither agree or disagree' or disagree in responses to the statement "Residential and community short breaks services should be available for children under the age of 4" had children who were considerably older than 4 i.e. 9 or above.

Conclusion

It is clear from the discussion at the workshop that both residential and high needs community based short breaks are services that are valued by parent carers. They are services that parent carers see as key to maintaining family life, and for a significant number of parent carers are seen as essential to enable them to continue in their caring role.

Short break services play a particularly important role during school holidays.

The quality and experience of staff is key to parent carers having a good short break experience, as is good communication with the family and co-ordination with other services.

Parent carers are also clear that short breaks should play an important role in supporting their children towards independence and adulthood. They want these service to provide opportunities for their children to spend time away from the family network, to develop new skills and confidence.

Shropshire Parent and Carer Council

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Information & Support, Influence & Change



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