

The Shropshire Parent and Carer Council

Accessing Social Care Support for Children with Disabilities in Shropshire

December 2015



SHROPSHIRE Parent
And
Carer
Council

Charity Number 1150180

Face 2 Face
Parents supporting parents
of disabled children



Accessing Social Care support for Children with Disabilities in Shropshire;

Summary of responses to PACC survey asking for feedback from Shropshire parent carers on their knowledge and experience of requesting social care support.

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1. Executive Summary

Before we consider the responses to this survey PACC would like to take the opportunity to thank all the parent carers who shared their experiences with us. The information they have shared about their lives is not always easy to read and illustrates how challenging it can be to care for a disabled child. PACC asked parent carers to share these experiences in the hope that we can work with those who commission and deliver services to improve the lives of families of disabled children and to lessen those challenges.

This document details the responses to the Shropshire Parent and Carers Council (PACC) survey issued in November 2015 asking for parent carers to tell us about their knowledge and understanding of how to request social care support in Shropshire and their experience of this process. This survey was prompted by Shropshire Council's proposals to review their contract with Action For Children, that would result in a reduction in the opening times of the residential unit known as The Willows, as according to the Council there was "a reduction in demand for this type of service." The survey also builds on ongoing work between PACC and Shropshire Council around the Disabled Children Pathway for Assessment and Case Criteria which is in response to parent carers raising concerns about;

- A lack of clarity in how parent carers request social care support
- A lack of understanding by parent carers about what social care support is available locally
- Reports from numerous parent carers about poor experiences when requesting social care support and being provided with incorrect information about eligibility for assessment

As part of PACC's response to Shropshire Council's proposals to reduce the number of hours that an overnight residential Short Break service is offered via The Willows, a survey was issued exploring Shropshire parent carers knowledge of how to request social care support and their experience of doing so. There was a good response to this survey, with 76 questionnaires returned, a 10% response rate based on the number of surveys issued. The responses came from parent carers' with children across all age groups, with 29 responses from the 6-11 years group, 26 responses from the 12-16 age group and the remaining coming from the pre-school and post 16 groups. Over half of the respondents had children in a specialist setting and wide range of needs were represented with the most frequent being Learning Disabilities', challenging behaviour and communication difficulties. The responses were split evenly between those parent carers who had made a request for support and those that hadn't. The collation of the responses provided some clear messages about parent carers' knowledge of how to access social care support in Shropshire and their experiences of requesting social care support for their disabled children;

- Well over half of the parent carers who completed the survey were not aware of the fact that a disabled child is eligible for a Child in Need Assessment
- Two thirds of the parent carers who completed the survey were not aware of how to request a Child in Need Assessment
- Approx. half of respondents had not heard of any of the overnight short breaks services available in Shropshire
- Only half of the respondents had heard of either Early Help, Compass or First Point of Contact and significantly less understood the role of these teams
- The most common reasons for needing support were challenging behaviour and wanting to support their child's development and independence away from home. Lack of sleep and wanting to spend more time with other children were additional significant reasons for needing support
- Over half of those parent carers who hadn't requested support said it was because they didn't know support was available and they didn't know how to request support.
- One third of the parent carers who said they hadn't requested support said it was because they were 'worried about being judged'.

PACC believes that the responses to this survey clearly show that there is a significant issue locally with parent carers not understanding the social care support service, what support is available and they are entitled to, and finally how to request it. It is PACC's belief that it is for these reasons that there is a lack of demand for the type of service that the Willows offers, rather than there being a lack of need – which is the interpretation of the Shropshire Commissioning Team.

Shropshire Council has a duty under the Children and Families Act (Section 19) to ensure that it has regard to; *“the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.”*

The results of the PACC survey would seem to question if this duty is being met in terms of disabled children and social care support.

It is also recognised nationally that ensuring parent carers are well informed about the services that are available to them and how to access them is a key issue in terms of improving outcomes for disabled children and their families. The requirement of a Local Offer for each local area (Children and Families Act - Section 30) is intended to address this and while PACC appreciates that this is an ongoing piece of work in Shropshire, the current threshold criteria for social care document does little to deliver this, since it lacks transparency and fails to present information in a parent carer friendly way.

PACC is concerned that Shropshire Council have made the proposal to reduce the service offered by Action For Children via The Willow's, without clear evidence that the demand for this type of service has reduced. PACC does not debate that referrals to the service may have reduced but we do not support the assumption that this means that demand has reduced. The responses to the PACC survey clearly shows that families are not receiving the information that they need to request support and that on a significant number of occasions when request for support are made inappropriate responses are received from Shropshire Council staff that meant that assessments of need were not carried out.

As part of the survey we also asked parent carers who had requested support from social care to share their experiences of this with us. We are disappointed to have received a significant amount of feedback that suggests that this can be a very poor experience for families, and that as part of this process families seem on a number of occasions to have been given incorrect information from Shropshire Council staff about their eligibility for assessment or services. This clearly compounds the situation that has resulted in a decline in the numbers of referrals to services like that offered at the Willows. That this is a current issue is also supported by the case studies that PACC has shared with Shropshire Council during the last 12 months, which provide detailed examples of parent carers' recent poor experiences when requesting social care support locally.

PACC's position, based on the evidence presented in the responses to this survey and supported by the PACC Social Care case studies, is that there is significant doubt about the premise that the service offered at The Willows should be reduced due to a reduction in demand. The Short Break Regulations 2011 place a sufficient duty on Local Authorities, on which the following comment was made in the Short Breaks Partnership first Bulletin issued July 2015;

‘The sufficiency duty in Regulation 4 is very important. In order for a local authority to comply with this duty it must know (a) the population of disabled children in its area and the level of need in that population and (b) the level of service currently available to meet that need. The local authority must then exercise its judgment informed by this evidence as to whether the range of services is ‘sufficient to assist carers to continue to provide care or to do so more effectively.’

We believe that any decision on sufficiency requires the local authority to understand the size and needs of its population of disabled children and young people and review this against the level and quality of available

services. It is also necessary for local authorities to work with children, young people and families when commissioning the services to meet their sufficiency duties. This is the fundamental purpose of the requirement in section 19 CFA for local authorities to have regard to the views, wishes and feelings of children, young people and parents in everything they do under Part 3 Children and Families Act. Therefore PACC is requesting that Shropshire Council delays any decision about changes to the commissioning of the overnight Short Break service provided by Action For Children at The Willows, until it has worked with families to fully assess and evidence the level of local need for such service. If Shropshire Council does not take this approach to reviewing this service than PACC believes that it will be in breach of its duties as outlined above.

2. Details of Responses to Survey

Who responded to the Survey?

Paper copies of the survey were sent out with the PACC Winter 2015 newsletter to all PACC members and to all families who have a child attending Severndale Specialist Academy. In total nearly 800 copies of the survey were distributed, each with a pre-paid envelope for the return of completed responses. The survey was also promoted on the PACC website and on social media and electronic copies of the survey were made available for those who preferred to participate in this way. The survey remained open for 3 weeks and 76 responses were received, all of which were paper copies.

PACC Accessing Social Care Survey- Nov 2015							
38 parent carers reported that they had asked for							
38 parent carers reported that they had not asked for help							
Total responses - 76							
		Have asked for help		Haven't asked for help		TOTAL	
Tell Us a little bit about your child							
How old is your child?	0-5 years	5		4			9
	6-11 years	12		17			29
	12- 16 years	11		15			26
	16 – 25 years	8		2			10
	25 plus	1		0			1
	Not answered	1		0			1
Education Setting Attended	Pre school	1		0			1
	Specialist	23		21			44
	Mainstream	7		17			24
	Post 16	5		0			5
	Not Answered	2		0			2

What is the impact of your child's disability?	Learning Disabilities	32		31			63
	Challenging behaviour	24		20			44
	Physical difficulties	17		7			24
	Continence issues	13		10			23
	Wheelchair users	8		2			10
	Sleep issues	17		10			27
	Communication difficulties	26		20			46
What do you know about residential short breaks and how to request them?							
		Have asked for help		Haven't asked for help		TOTAL	
		YES	NO	YES	NO	YES	NO
Are you aware that any disabled child up to the age of 18 is eligible for a Child In Need assessment to identify any social care support they might need to support their development?		25	13	6	32	31	45
Are you aware as a parent carer you are eligible for a carers assessment?		20	18	6	32	26	50
Are you aware of the overnight respite services available in Shropshire – please circle the ones that you have heard of.	Heavenbrook	2	36	2	36	4	72
	Bradbury House	20	18	6	32	26	50
	Willows	22	16	11	27	33	43
	Family Based Shared Care	9	29	2	36	11	65
Do you know how to request a Child in Need assessment?		21	17	6	32	27	49
Are you aware of the following	Early Help	13	25	14	24	27	49
	Compass	12	26	11	27	23	53
	First point of contact	8	30	10	28	18	58

Do you understand the role of	Early Help	9	29	6	32	15	61
	Compass	8	30	6	32	14	62
	First point of contact	8	30	5	33	13	63
Please tells us if you have ever requested support and what that experience was like							
		Have asked for help		Haven't asked for help		TOTAL	
		YES	NO	YES	NO	YES	NO
If you have requested help why did you feel you needed additional support?	Impact of Challenging behaviour	26				26	
	Lack of sleep	18				18	
	Own ill health	9				9	
	Need for quality time with other children	20				20	
	Wanting to support my child's development and independence away from the home	23				23	
	Other *1	16				16	
Who did you ask for help?	The majority of parent carers had requested help directly via the Disabled Children's Team. A few requests had been made via Occupational and Physiotherapist, Compass, Enhance and First Point of Contact						
What was the outcome? Was an assessment carried out and was any support provided?	There were a range of responses given to this question. In the majority of cases where the request had been made directly to the DCT then some level of support was provided as a result of assessment. There was frequent feedback however that the level of support provided was felt to be insufficient. There were several comments made about finding the assessment process difficult and distressing. There were no examples given of request for help through other points of contact that had resulted in support being provided.						

If you haven't requested support please answer the following questions							
If haven't asked for help, why not	No additional support needed			7		7	
	Didn't know it was available			21		21	
	Don't know how to make a request			20		20	
	Worried about being judged			12		12	
Do you anticipate that you might need to request support in the future? If not why not? *2				24		24	

***1 and *2 - See next page for information provided in Survey responses**

***1 Why do you need additional support – other comments**

- We have no time as a couple - ever
- I am a single parent and feeling isolated
- For a break in routine (exhausted) as I have mentioned I have 2 children with disabilities. They both have very different needs. Trying to constantly meet the needs of both of them whilst also considering their neurotypical sister has been and is exhausting.
- Allow my child with a disability to develop relationships outside of family.
- A decent break from the caring role (more than a few hours). A chance to do other activities with sibling. Very limited in places we could visit - wanted more freedom to visit inaccessible places.
- Realising our time goes on that we (husband and I) are more and more tired/exhausted at times, and more support would help us to cope better and be able to carry on.
- To give us a break
- My child is severely disabled but I have been told that I am unable to receive any more care for him. He doesn't receive any overnight care. But does receive Saturday Club in term time and 4 hours per week non-school time.
- Advice on how to keep my child safe
- Many issues no other support is available in times when to just have a coffee isn't available. Have no support from family due to family circumstances. Many reasons to feel like a normal family once in a while. When holidays are given from school my life becomes so challenging that if my child's needs get higher I honestly don't know what we will do as a family. Been told no more support available as been assessed lately.
- To get a withdrawn 21 year old out of room with Asperger high functioning and get any sort of life.
- Starting school - needed additional help with communication, social skills dealing with anxiety and mobility.
- Overcrowding in housing not been able to fit essential equipment: hoist, specialist bed, bathing aid into the house.
- Effect of his behaviour on the rest of the family.
- Not being able to spend quality time with friends/family etc (single Mum)
- All of above, inability to cope, unable to get basic jobs done like shopping, cleaning, any gardening, unable to go to any of other child's activities - football watching, school information evenings. Just basic stuff, not luxuries such as meals out!
- To have a break from the 24/7 care that my severely disabled daughter needs. She is wheelchair bound and cannot do anything for herself.

***2 Do you anticipate that you might need to request support in the future? If not why not?**

In most cases parent carers chose to tell us why they might need support in the future;

- Likely to need overnight respite
- My child is totally reliant on me for support re life skills and has no other social support outside immediate family. I've had an initial meeting with People2People.
- We are weary of assessment and panels and reports. We want help - not intrusive paperwork. Also revolving door of professionals mean we haven't time to chase up
- I do anticipate further support will be required in future when my son's placement at residential college ends
- I would like to know what is available but I also feel ashamed to ask for help, as well as guilty to let XXX go on his own at a young age with complex needs. If anything it would be more beneficial to us to do something as a family, as he has a younger sister too
- Especially when I feel unwell. I have no family in the area to lean on
- I worry about the future. As more and more services are cut and I feel constantly judged within the education system with my other child.
- Especially during summer time. My son is very reluctant to go to holiday clubs, so finding activities for him to do on a daily basis can be challenging
- Yes - whilst we do receive respite stays I don't think these fully meet my child's need - I would like more choice over what respite/where etc. We don't use our full allocation but due to the bureaucracy involved we can't reassign unused nights
- Was told we may be eligible for overnight respite when son is 6
- It is useful to know you can ask - it is not made very accessible, if we do not know it is there or how to access it.
- I was told my daughter didn't meet the criteria even though it is clear she has severe and complex needs and will never lead any kind of independent life. So yes.
- No - child now in residential college.
- I intend to try again - as we (my husband and I) regularly feel exhausted and would like more than 2 nights/month at Willows if possible.
- No we already get it
- No, my child is of an age now were she needs less support - we could have done with help a few years ago

- Possibly. Some very challenging behaviour and disruptive nights. Every day feels like a roller coaster ride!
- Yes - to develop my child's independence travelling on public transport.
- Definitely
- We may need support in the future. We tend to take each day as it comes
- Yes. My son is now 15 years old and his diagnosis of ASD with severe learning difficulties is having an effect on how we can now find the time to spend with our other 5 sons as his specific needs and requirements must always be considered first in anything we decide to do as a family.
- Yes - but don't know when
- Yes - as my daughter's behaviour is likely to become challenging in future due to her diagnosis and food issues.
- Perhaps in the future if my child's disability worsens.
- No - we are coping OK
- Possibly. Good progress so far but still a long way to go to independence.
- My daughter would like to meet other children with an overnight stay so she can feel more independent. It would be a break for me as I am a single parent.
- Yes - more and more as my daughter gets older and stronger.
- Yes - the option of overnight stays, short breaks would be extremely useful and essential for our family to function as a whole.
- Yes - I need support in the future. XXXX has lost his Mum due to cancer and I am left to care for him.
- Yes as 3 hours per month is hardly worth having. My daughter is getting older and heavier and although my parents have helped me out, they are getting on too (in their 60s) and I am going to need more outside help. My daughter does also go to Hope House but other than that, we only have the 3 hours per month.
- Yes. As a single parent of 2 children (aged 7 - 10) I find it harder now my child's needs have increased. My eldest child craves 1:1 time with me that I can't give as most of my attention is taken by my younger child's needs. My child needs to be able to form relationships with people outside the family (which is a small network) to increase his independence and experiences overnight. Stays would be wonderful but I didn't know there was a service/possibility. I'm keen to learn more about this.
- As XXXXX grows up his needs might change
- I don't know. I am hoping not.

What do parent carers say about the experience of requesting social care support in Shropshire?

"We are weary of assessment and panels and reports. We want help - not intrusive paperwork. Also revolving door of professionals mean we haven't time to chase up."

"I felt the assessment process via DCT was prompt and professionally done - but the wait to actually receive support was soul destroying."

"I called on 5 Jan 2015. Initially I was allocated 3 hours per week in June. I appealed immediately and in July it was increased to 6 hours. However, as of 9th November I am still waiting to use the hours as I am unable to find someone to help. An agency is supposed to be picking them up but 6 weeks on from our first meeting, still nothing. So, I am frustrated because 10 months on I am still waiting for help!"

"I've had numerous social workers in 12 years, some better than others. In general I have had support although at times it has been a very long and painful process to prove support is needed. It is a shame but to get support you have to bare your soul to complete strangers, it really is a desperate process and can be humiliating."

"The special needs private and public sector is so complex and fractured it's hard to access all that you are entitled to and there are lots of hoops to jump through when you do, so you get discouraged and run out of time too."

"It is useful to know you can ask - it is not made very accessible if we do not know it is there or how to access it."

"The support at the Willows is a life-saver, literally, without this support I would not have been able to carry our caring for my daughter. I personally did not find Bradbury House acceptable for my child - there should be some choice for disabled children and their families."

"There is no signposting or support given at all by medical profession. Feel people are left to get on with things. Needs to be more promotion on what support systems are available by SC."

Conclusions

The information shared by Shropshire parent carers, about their knowledge of how to access social care support for their disabled children and the experience of doing so, clearly evidences that a significant number of families don't know what support is potentially available to them or how to request it. There is also a significant amount of feedback that indicates that even those who do request support and receive help feel that the support provided is insufficient, but feel unable to challenge this because of the complexity and lack of transparency in the Shropshire social care system. This brings into question the accuracy of the statement by Shropshire Council that the demand has reduced for the type of service offered by Action For Children at The Willows. The responses to the survey demonstrate that the issue is that many families are neither aware of what social care support is available, nor how to request it, and this will inevitably impact on the number of referrals that are made to services like the Willows.

It is also worrying that so many of the responses commented on what a difficult experience it has been to apply for social care support. This experience also impacts on demand, since parent carers will talk about this with other parent carers and families, who in turn will be discouraged from requesting help.

The information provided in the Survey responses underlines the concerns raised earlier in the year by Shropshire parent carers that, even when requests are made for social care support, families do not always receive appropriate responses from Shropshire Council. An examples of such a situation is given in the case study in the Appendix and other experiences outlined in the survey responses also support this view. PACC is concerned that the current lack of clarity in the social care pathway for disabled children in Shropshire is resulting in confusion, not just for families, but also for professionals. This means that parent carers are receiving inaccurate or conflicting information from professionals, creating further confusion about the role of social care support services in the lives of families of children and young people with disabilities or additional needs.

In addition to all of the above there is evidence that parent carers are not requesting social care support because they are concerned about being judged as parents. Parent carers described feeling guilty about asking for help and worried about what others will think of them. This is an additional barrier that means demand is not reflecting need. The negative emotional impact that caring for a disabled child has on parent carers and how they view themselves as parents is well documented within published research, and this is clearly an area that needs to be considered when reviewing issues that affect the demand for social care support. This situation where a parent carer questions their own ability to cope with the challenges presented by their child's disability or additional need, (often despite the fact that such challenges would be overwhelming for any parent) is compounded by fears about being 'involved with Social Services' and what that is perceived to mean by our society.

The language used currently in Shropshire to explain the Social Care support on offer for families of children who are disabled or have additional needs exacerbates these fears, since it is consistently placed in the context of child protection and safeguarding. The Shropshire social care threshold document 'Multi-agency Guidance on Threshold Criteria to help support Children, Young People and their Families in Shropshire – Accessing the Right Service at the Right Time' is only available on the Shropshire Safeguarding Board (SSCB) website. The website is headed by the SSCB logo which includes the words 'Child Protection' and the phrase 'Protecting our Children from Harm'. The document is then accessed on the 'Local Links' drop down menu under the 'Shropshire Child Protection Procedures' link. While PACC understands that safeguarding processes are much wider than just protecting those children who are at risk of deliberate harm or who are suffering from neglect, in general the terms 'child protection' and 'safeguarding' are linked by the wider population with inadequate parenting or those who cause intentional harm to children. The language at the start of the threshold document focuses on protecting a child from harm and talking about children who are at risk. The document does go on to discuss the support available for disabled children specifically, but it is PACC's belief that, by presenting the

information in this context, the majority of families of children with disabilities would be hesitant to identify their family as in need of support. It is important to make it clear that PACC recognises that children with disabilities and additional needs are at times subject to child protection issues, and in fact they are a group that are particularly vulnerable to being subjected to deliberate harm or neglect, because they are often isolated and lacking in communication skills. We are concerned, however, that Shropshire Council are preventing families of children with disabilities or additional needs from asking for help by placing the pathway to support them so firmly in a 'child protection' and 'safeguarding context'. This also has resulted in examples of where families of disabled children have approached Shropshire Council for support but have been told that there were no grounds for assessment because there were no child protection issues. This is a clearly a misunderstanding of the guidance by staff, and again suggests that there is an issue around clarity with regard to the process for professionals as well as parent carers.

Finally, PACC are particularly concerned about the lack of proactivity in the Shropshire social care offer for disabled children and their families and how this influences demand for services and long term outcomes for children with disabilities and their families. The introduction in Working Together to Safeguard Children – March 2015 states that;

“Local authorities have overarching responsibility for safeguarding and promoting the welfare of all children and young people in their area.”

This guidance also makes it clear that safeguarding and promoting the welfare of children includes;

“preventing impairment of children's health or development”

and

“taking action to enable all children to have the best outcomes”

This focus on taking a proactive approach and to delivering positive outcomes for children with disabilities was reinforced by the Children and Families Act in September 2014. This new Act requires all those who provide support to young people with special educational needs or disabilities (SEND) to do so with a particular focus on preparing them for adulthood, in particular ensuring real opportunities for young people with SEND to achieve in terms of employment, community inclusion, independent living and good health.

In discussing accessing social care support for children with disabilities in Shropshire, it has become clear that the emphasis is on the provision of support being triggered by parent carers requesting help from Shropshire Council. The response to the PACC Survey shows that because of concerns about being judged, a significant number of parent carers are not taking that step to request support. As outlined above, PACC also have concerns that the association of social care support for children with disabilities with child protection issues will also deter families from requesting help. Even when parent carers do request help the very step of waiting for families to reach a situation where they no longer feel able to cope means that this is fundamentally a reactive system, which waits for problems to occur before taking action. This is despite the fact that considerable published evidence which clearly shows that caring for a disabled child will bring financial and relationship challenges to a family, as well as impacting on both the physical and mental health of parent carers.

The lack of a proactive social care support system for disabled children and their families in Shropshire brings into question if Shropshire Council can effectively fulfil their duty to deliver positive outcomes in the short, medium and long terms for disabled children.

Short break services, such as the services offered at The Willows are recognised as one of the most valuable services for disabled children and their families. Short breaks improve the quality of life for some of the most vulnerable families in our community and are a cost effective approach that enables Local Authorities to avoid high cost crisis intervention. Every Disabled Child Matters recent report 'Short Breaks 2015 – An Uncertain Future

says in its introduction;

“Short breaks are among the most fundamental services for supporting families with disabled children. By providing breaks from caring and positive experiences for children and young people, they allow parent carers to focus on relationships with other children, or to have time to themselves or with their partner, leading to lower levels of psychological distress, higher levels of life satisfaction and better health. As a result, fewer parent carers reach ‘breaking point’ and fewer children require access to emergency provision or enter the looked after system. Short breaks also have a direct positive impact on the disabled children and young people that benefit from them. They play an essential role in improving disabled children’s outcomes, by providing opportunities to develop skills required to live more independently, prepare for adulthood and achieve their potential. Most importantly, quality short breaks provide opportunities for disabled children and young people to have fun, opportunities which are much more readily available to their non-disabled peers, and these are highly valued by children, young people and parents alike. The overwhelming positive impact of short breaks on outcomes for disabled children and their families, and the resulting cost saving for the state, estimated to be up to £174 million annually, is well-established. The reasons to continue to invest in shortbreaks remain as strong today as ever.”

Currently there are just under 2000 children and young people in Shropshire who qualify for either a statement of special educational need or an education, health and care plan, indicating that they have complex needs. Within that group, over 450 pupils attend the county’s main special school, Severndale Academy, all of whom have a level of disability that will have a significant and life-long impact on their lives. In addition to this group, who are identified as having the highest level of need there are several thousand young people who receive additional help at school due to a wide range of disabilities or medical conditions that present a barrier to their learning and development. It is essential that Shropshire Council maintain an effective range of Short Break services that is able to respond to the level of need in the county.

The responses to the PACC survey and recent discussions with parent carers on accessing social care support in Shropshire paint a picture of a system that is not widely accessible to families and nor proactive in terms of providing support or interventions. We believe that it would be unwise of Shropshire Council to justify a reduction in a crucial Short Break service and a change in the service offered at the Willows, by suggesting that there is a ‘reduction in demand’ when there is every indication that the full range of beneficiaries are not aware of the service or how to access it. We further suggest that Shropshire Council does not hold sufficient comprehensive data about the number of disabled children in Shropshire to evidence that there is no need for these services. Nationally there is very poor data about disabled children and their families and this is a recognised issue in Shropshire, with no comprehensive record of children with disabilities being maintained. PACC have raised this with Shropshire Council and the Shropshire Clinical Commissioning Group, and we are pleased that this has been acknowledged as a concern that needs to be addressed urgently. It is vital that local services reflect local need, but for that to happen statutory organisations need to understand local communities, their aspirations and their needs. Considering this lack of relevant data it would seem irrational that a ‘reduction in demand’ is being used as a basis for the proposed changes to the service offered at The Willows. If Shropshire Council does not hold comprehensive data about the number of disabled children in Shropshire how can it evidence that there is no need for the service? It is also important to note that the sufficiency duty placed on Local Authorities by the Short Break Regulations requires them to know and respond to the level of need and not demand because, as we have seen throughout this report, demand does not always reflect need.

We propose that Shropshire Council should strive to develop a relationship with families of disabled children that recognises and understands the need for families and professionals to work together to ensure the best possible outcomes for disabled children and young people. This includes Social Care Services proactively planning for young people’s future and providing opportunities for disabled young people to have new experiences, learn new skills and to develop their independence outside of their family. We have made a number of recommendations which we believe would lead to this outcome.

Recommendations

With all of the above in mind PACC are urgently requesting that Shropshire Council make no changes to the current level of service offered at The Willows until there has been a full and comprehensive assessment of the level of need for this service.

PACC are keen to work with Shropshire Council and other statutory organisations to ensure that this happens and makes the following recommendations to facilitate this;

- Review the Children with Disability register so that it becomes an effective tool for planning and designing services for children and young people with special educational needs or disabilities, aged 0-25 in line with part 3 of the Children and Families Act 2014.
- Prioritise and protect funding of Short Break services for children and young people with disabilities with a view to focusing support on early intervention and away from crisis management. This includes recognising that in some circumstances early intervention will require specialist services.
- Review Social Care support for children with disabilities in Shropshire so that it becomes a proactive system that looks to empower families and increase their resilience from the point of diagnosis.
- Develop family friendly and easily accessible information about the full range of Short Breaks for disabled children and young people in Shropshire, including how to access them with details of any assessments required to enable access. Families should, from the earliest point, be made aware of the value of Short Break services and how they can benefit their family.
- Develop a strategic plan for delivering positive outcomes for disabled children and young people and their families in Shropshire. This plan should be developed in partnership by Shropshire Council, Shropshire Clinical Commissioning Group and children and young people with disabilities and their families
- Maintain an effective range of Short Break services that is able to respond to the evidence level of need in the county.
- All staff that may come into contact with families of disabled children to demonstrate an understanding of the potential impact of caring for a disabled child on a family and of the services available to support them.

Appendix 1

References and Legislation

- Shropshire Council Consultation – Short Break Services: Residential Stays at the Willows
<https://new.shropshire.gov.uk/get-involved/short-breaks-service-residential-stays-at-the-willow/>
- Children and Families Act 2014
<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
- Working Together to Safeguard Children – Statutory Guidance
<https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>
- Multi Agency Guidance on Threshold Criteria to Help Support Children and Young People and their Families in Shropshire
http://westmerciaconsortium.proceduresonline.com/pdfs/shrop_thresh_crit.pdf
- Short Breaks Regulations 2011
<https://www.gov.uk/government/publications/short-breaks-for-carers-of-disabled-children>
- Short Breaks Partnership – Bulletin 1 (July 2015)
http://www.cafamily.org.uk/media/887938/short_breaks_bulletin_july2015.pdf
- Every Disabled Child Matters – Short Breaks 2015 – An Uncertain Future
<http://www.edcm.org.uk/campaigns-and-policy/short-breaks/short-breaks-research/short-breaks-in-2015-an-uncertain-future>

Appendix 2

Below is a case study of one family's experience of requesting social care support for disabled child in Shropshire during 2014/15.

A number of case studies were collected by PACC in the last 12 months to inform discussions with Shropshire Council about concerns with regard to accessing social care support for children with disabilities.

The case study below has been included in this report to provide an example of the situations that families are facing.

Young person 16 years old with Down's syndrome and health issues – needs a high level of supervision

Parents made an initial enquiry to Shropshire Council, First point of Contact, in October 2014, with regards to the possibility of receiving respite care for a weekend once a month. The family had never previously requested respite care, but now felt that there was an urgent need for both for parents to have a break, (parents are 63 and 66) and for daughter to make appropriate steps towards independent living.

Parents were then encouraged by teacher and the vice-principal of Severndale Special Academy's 6th form programme to follow up possible respite care provision when they took part in her Education health and Care Plan assessment at Severndale school on 7th January 2015.

Parents received letter from Shropshire Council dated the 15th of January 2015 stating that they had no grounds for respite care.

Parents were not satisfied with the opinion stated in this letter and felt that a suitable assessment of their daughter and their needs has not been completed (as required by the Children Act 1989 s17 (c) and the Working Together guidance). No physical interview was granted and the very brief discussion on the phone was conducted (in Oct 2014) under very hurried conditions as parent explained to the person that he had to drop his wife off at work, it was also difficult to hear the lady clearly as the phone volume was very low.

Parents were very concerned for their daughter's future as she is getting older and she needs to branch out and practice independence, which depends on the possibility of experiencing different and new situations. Parents own ability to care for their daughter is also a concern as they rarely are able to do anything without their daughter, as she is highly dependent and requires constant supervision. The need for some respite was felt to be urgent, and without it there could be a failure in health and well being of the parent carers. The Mother has very high blood pressure condition and some time off could only be very helpful for all concerned. Parents have no back up as such and caring for their daughter affects all aspects of the family's life, for example they do the shopping with their daughter waiting in the car working on her puzzles, etc while mom dashes out and dad remain with her. The young person attends clubs 2 days a week in addition to any clubs at Severndale school, but her father has to stay at the clubs as she is not totally continent, and under most circumstances requires 1 to 1 support. She also rides with RDA weekly and her father is always present for that.

Daughter loves variety, going out and meeting people and her parents are concerned that she is not getting the stimulation she needs.

Twelve months ago, young person was diagnosed with Graves Disease (Hyperactive thyroid gland), for six months up to the point of diagnosis she was suffering from quite disturbing symptoms, she lost 25 Kg and during this time she suffered from anxiety and tremors when making any physical efforts. She also had disrupted sleep which affected all of the family as well as suffering some continence issues. Family are attending a special clinic which requires having to go in for regular blood checks every 6 weeks.

The young person is now doing well and has stabilised. This whole experience has had quite a wear and tear effect on all of family, and they did not make this request for respite without a lot of thought and consideration.

The family approached PACC with their concerns about the response from Shropshire Council to their request for support. PACC signposted the family to guidance provided by Contact A Family on Child in Need assessments and suggested that they contacted the Shropshire Disabled Children Team directly to discuss the situation.

Following a discussion with the DCT Manager a full assessment was carried out and 30 days respite care per year were provided to the family.