



SHROPSHIRE
Parent
And
Carer
Council

Shropshire Parent and Carer Council
PO Box 4774
Shrewsbury
SY1 9EX

28 July 2016

Response to Carers Strategy Call for Evidence 2016 From the Shropshire Parent & Carer Council (PACC)

The Shropshire Parent and Carer Council (PACC) is the local parent carer Forum in Shropshire. PACC has a membership of just over 500 families of children and young people with special educational needs and disabilities (SEND,) aged 0-25 years. PACC operates a representative model, collecting feedback and experiences from Shropshire parent carers, which is then used by parent carer representatives to shape and influence local and national decision making, contributing to improved outcomes for both children and young people with SEND and parent carers. The PACC Management Board are all parent carers themselves and have significant experience and knowledge of supporting young people with a wide range of conditions and needs, of varying ages.

PACC's response to the Carers Strategy Call for Evidence 2016 has been informed by general and specific discussions with Shropshire parent carers, both face to face and via social media. PACC hosts a number of monthly support groups for parent carers throughout the local area, offering regular participation opportunities to discuss key issues raised by the local parent carer community and administers numerous social media chat groups for those parent carers not able to access face to face activities.

Introduction

Recognising the role of parent carers:

The term 'parent carer' is defined by the Children's Act 1989 as an adult 'who provides or intends to provide care for a disabled child for whom the person has parental responsibility'. It is a term that has recently been taken for their own by Parent Carer Forums and the National Network of Parent Carer Forums, to describe the community they support. The term highlights the fact that parenting a child with a disability or additional needs is different to parenting a child without a disability.

Tel: 0845 601 2205
www.paccshropshire.org.uk/
info@paccshropshire.org.uk
Registered charity 1150180



When you are a parent carer you find yourself taking on multiple roles; you become an administrator (managing the endless amount of paperwork generated by having a child with a disability or additional need), an appointments co-ordinator, a Physio, a Speech therapist, an Occupational therapist, an interpreter, an advocate, a weight lifter, not to mention an expert in medical terminology that you never thought that you would be able to pronounce, let alone understand. While parents of a child without additional needs might take on some of these roles for a short period of time, it is likely that for 'parent carers' they will be lifelong roles, that might change slightly, but do not go away.

In addition to the multiple roles taken on when parenting a child with additional needs, it is also different emotionally. From the earliest years of our life we all have a subconscious blueprint for life, clear expectations about what our life and our children's lives will be. We expect that we will learn to walk, talk, go to friends' birthday parties, ride a bike, learn at school, get a job, have a relationship, create our own home and eventually have children who will do the same.

When you have a child with a disability or additional need suddenly what you expect does not happen, and sometimes the simplest of things, that other families take for granted, are not possible for you and your family.

Adjusting to this new life can be an emotional experience, constantly being faced with a life which is not as you expected, and which is often not well understood by others. This is a challenge that can leave parent carers isolated and exhausted. The impact of being a parent carer is explored in PACC's most recent report "You don't even know if you're aware of what's happening unless you are in it": the experiences of parent carers of disabled children as multi-service users. A copy of this report is attached as an appendix to this consultation response.

This is all known, yet the phrase 'parent carer' is not widely recognised in society and the picture that springs to most people's minds when you say you are a carer, is of someone looking after an elderly relative. That is why it was so important when in 2014 the Children and Families Act recognised 'parent carers' by introducing the Parent Carer Needs Assessment, which incorporates the 'wellbeing' principle. This meant that for the first time parent carers could access an assessment that considers their wellbeing as individuals, and not just in relation to their continuing ability to care for their child. It is disappointing however that parent carers are repeatedly informing PACC that their experience of requesting a parent carer needs assessment has not been positive and the most frequent response to such requests is a lack of knowledge about these assessment or how they are implemented locally.

To live with and successfully deliver the role of parent carer it is clear that the majority of individuals will need some support and for many this will be emotional as well as practical. You need people who understand your life and recognise the challenges that you face, yet the feedback that we received from parent carers in Shropshire is that in reality neither types of support or understanding are easy to find or access.

Identifying people as carers

Overall, how important do you think it is that carers are identified better in the future?

Please circle a number from 1 to 10

1 = not important, 10 = very important

1 2 3 4 5 6 7 8 9 **10**

As outlined above this is a particular issue for parent carers because society often sees them simply as parents and does not recognise their caring role. This also means that many parent carers do not fully recognise their caring role or the impact that it has on their lives. Clearly if individuals do not recognise themselves as parent carer then they are unlikely to access support. Even if they do request support Shropshire parent carers frequently report that they receive a response that identifies support as only being available for carers of individuals over the age of 18, because many services do not recognise their caring role.

While there is an improving focus on identifying young people with SEND following the Children and Families Act, the new SEND system does not link to carer support systems. If a young person has an Education Health and Care Plan (EHCP) in particular it is likely that their parent has a role as a carer to some degree. Opportunities are being missed in the SEND system to identify carers. Parents are rightly central to the new SEND process but in our experience there is a missed opportunity to identify parent carers and to consider their support needs as part of this process.

The other challenge is ensuring that this information about an individual's caring role is shared with other services and in particular GPs. There is often a focus on linking social care and health services when discussing improving carers support, however in the case of parent carers we need to link education, health and social care.

The other opportunity to improve identification of parent carers is at the point of diagnosis of their child as disabled. As we have highlighted above the move from parent to parent carer is life changing and challenging, both emotionally and practically, yet our research suggests that parent carers frequently do not ask for help until they are at crisis point. PACC believes that early proactive identification of parent carers is central to supporting the health and wellbeing of this group. It will facilitate early intervention and enable support to be provided to help parents transition to what is a frequently unexpected role of parent carer.

Finally it should be recognised that the identification of parent carers is not just key to ensuring that individuals' access support but also to ensure that there is robust data about the demographics of this community, which can be used to support the commissioning of services. PACC's experience locally is that there is very poor knowledge about the make up and size of the parent carer community and therefore ensuring that services are commissioned to meet local need is very difficult.

Overall how important is it that carers receive better information in the future?

Please circle a number from 1 to 10

1 = not important, 10 = very important

1 2 3 4 5 6 7 8 9 **10**

Families repeatedly tell PACC that the most effective way to access information is through contact with other parent carers. The importance of providing parent carers the opportunity to meet with those who share similar experiences is clearly important. Parent carers also report that one of the most frustrating challenges they face is getting information and advice to enable them to plan for the future. Locally carers for individuals over the age of 18 can access a carers help line and specialist carer advisors but there is no similar service for parent carers. The development of the Local Offer under the Children and Families Act and the information provision required under the Care Act is a step in the right direction. However the self service approach does not recognise the need for support in interpreting information, or the challenge in understanding how best to use information that many parent carers face when they are often overwhelmed by their caring role.

As highlighted in our introduction parent carers in most cases have regular contact with the education system. Nurseries, schools and colleges play a major role in the lives of disabled children and in the case where a young disabled person does not have significant health needs, the child care and education system is possibly the main services that parent carers interact with. There are significant opportunities for nurseries, schools and colleges to take a more holistic approach to family support. Parent carers of children and young people who are in the SEND system already should be meeting with the school for a minimum of three times a year to discuss the progress of their child. These meetings could be extended to consider other areas such as parent carer support and information provision. The

opportunity for parent carers to access specialist carers advisors through their child's nursery, school or college would be beneficial.

Overall, how important do you think it is that formal support for carers improves in the future?

Please circle a number from 1 to 10

1 = not important, 10 = very important

1 2 3 4 5 6 7 8 9 **10**

There is an increasing understanding of the role and value of carers in society, as our communities age and individuals with significant disabilities live longer. The care and support provided for unpaid carers however has not kept up with the increased number of carers and the complexity of the support they deliver. The contribution of parent carers to caring for and supporting disabled children and young people has particularly not always been acknowledged and therefore there are significant gaps in the provision of formal support for this group.

Support for carers tends to fall into three categories;

- opportunities to take a break from their caring role to protect their own emotional and physical health and to engage in other activities, such as work, education, leisure or social events, that others take for granted.
- Training and opportunities to develop skills that will support their ability to deliver their caring role
- Emotional support to enable carers to adapt to a new way of life and possible sense of loss

Breaks from caring:

There is overwhelming evidence about the value of Short Breaks for carers. The opportunity for carers to take regular breaks from their caring responsibilities enables them to continue to provide care on an ongoing basis, yet across the country these services are under threat, both for carers who support adults and for parent carers. The reduction of investment in Short Break services is short sighted and puts the health and wellbeing of carers at risk. The lack of opportunities for parent carers to access Short Breaks not only places their own health and wellbeing at risk but reduces opportunities for young people to develop their independence and to be prepared effectively for adulthood and a different relationship with

their parents. Our work with parent carers shows that families often do not ask for help until they reach crisis point and so we would like to see a more proactive approach to delivering support packages that include Short Breaks to parent carers.

Earlier this year PACC did some work exploring the experience of parent carers assessing social care support for disabled children in Shropshire. One of the key messages that came out of this work is that many families do not ask for support from social care because a fear of having their parenting skills judged. This situation is being exacerbated by the increasing focus by social care on only recognising and addressing 'deliberate harm' and a move away from considering the wider concerns that place vulnerable individuals at risk of not securing positive life outcomes or of having their development impaired. Children and Families Social Care remit includes promoting the welfare and development of children and young people, who might be at risk due to certain factors, one of which might be disability. The majority of families who care for disabled young people need to access social care services because they need additional support due to the impact of disability and the challenges that present rather than due to child protection concerns, but this is frequently overlooked both nationally and locally. PACC has raised this both in our response to the recent All Party Parliamentary Group Social Care Inquiry and in our report Accessing Social Care Support for Disabled Children in Shropshire (attached as an appendix). Locally this lack of recognition of the role of social care support in supporting young people with disabilities and their families to live active and positive lives is creating difficulties for families who are attempting to access support for their child, frequently resulting in inappropriate responses to requests for child in need assessments and parent carer assessments. PACC was pleased to see that this wider role of Social Care was recognised by the Government in its new vision for Social Care. We are pleased to see that in the document; 'Putting Children First - Delivering Our Vision for Excellent Children's Social Care' - there is a recognition of the role that social care support plays in the lives of disabled children. It is essential that clarity is provided for Local Authorities about the role of social care support in the lives of disabled children and those who care for them, to ensure that those families who need help are able to access it.

Breaks from caring are not just essential to maintain carers' resilience and ability to continue to provide care but also supports carers' ability to access work or education. Short break schemes in school holidays are particularly important for parent carers but parent carers frequently report that the level of provision is insufficient, placing their employment at risk. In some cases it also means that they cannot take annual leave at the same time to share a family holiday, due to the need to stagger responsibility for caring for their disabled child. There needs to be improved integration between the provision of afterschool and holiday childcare and the provision of Short Breaks so that realistically parent carers can access work opportunities. There is considerable evidence that raising a disabled child is more expensive than raising a child without a disability, yet these families currently have their earning potential via access to work significantly reduced because of the lack of support provided in caring for their disabled child.

Parent carers have also told us that being able to access support in times of emergency is important to them. Locally carers of adults over the age of 18 are able to access an emergency response service, where experienced carers are able to support individuals in their home setting, when family carers are unexpectedly not able to provide care. Parent carers are often managing multiple responsibilities, for example other young children in addition to their disabled child and possibly elderly parents and this can sometimes mean that there are family emergencies, yet there is little or no consideration in local service provision for this group.

Training and opportunities to develop skills:

Being a carer or parent carer is not a role that comes automatically to us all, yet family carers' are in most cases expected to take on this role with little guidance and no training. The challenge of tracking down training opportunities or information about how to best manage conditions or behaviours is another addition to the carers workload. Training or skill development is rarely proactively offered to carers and this can be detrimental to their health, for example guidance is rarely forthcoming on safe moving and handling techniques and many carers experience back or joint trouble after years of caring. There is so much knowledge about how best to support children and young people with a disability yet locally there is no co-ordinated package of training or skills development for parent carers. Some training is available for carers of adults 18 and above and although it is possible for parent carers of younger children to access this they are not always appropriate for younger children and young people. Also sometimes parent carers do not feel comfortable in accessing group where the caring experience is on the whole different.

Emotional support for carers:

Becoming a carer is a major change in any individuals life, not just in terms of the practical implications but also because it often has an emotional impact too. Parent carers have told us that they have struggled with adjusting to a family life that was not as expected, where as a disabled child grows parent carers can repeatedly experience their child not reaching milestones like their friend's children or other children in the family. This can be viewed as the child or parent repeatedly failing or can mean continually experiencing a sense of loss. It also brings with it a sense of exclusion from your community, because your family doesn't fit and it is difficult to join in conversations or activities with your friends and wider family.

Locally parent carers report that they value being able to have regular contact with other parent carers, to share experiences and information, but most of all to be with others who understand. As an organisation PACC runs a number of monthly support groups which feedback from parent carers tells us are valued opportunities to share concerns with people who understand and provide essential peer support. We have also been able to offer a befriending service where parent carers are trained and supported to befriend other parent

carers on a 1:1 basis. We have seen significant benefits from this not only for those who are befriended but those who train to become befrienders and are given an opportunity to put all their experience and understanding of raising a child with a disability to positive use. PACC is also currently developing a training course that supports parent carers to explore how they feel about taking on this unexpected role and how it has impacted upon them as individuals. It is our experience that parent carers rarely focus on their own needs and feelings and because of this can suffer extreme emotional distress in silence until it overwhelms them. We believe that there needs to be a more proactive approach to supporting parents to adjust to the role of parent carer, with the provision of services that does this either in a group setting or in a 1:1 relationship. This support can sometimes be provided by other parent carers but sometime individuals might need to access professional support. PACC would like to see parent carers being able to access counselling services where needed to support them through this period of adjustment or at any time that they feel emotionally overwhelmed by the challenges of caring.

Overall how important is it that services for the people carers look after value and involve carers more in the future?

Please circle a number from 1 to 10

1 = not important, 10 = very important

1 2 3 4 5 6 7 8 9 **10**

PACC is a local parent carer forum and as such promotes services and systems being co-produced with parent carers. The Children and Families Act recognises that parent carers should be included in decision making at both an individual and strategic level because evidence shows that services are improved and more effective when designed and commissioned in partnership with those who use them. The same principle applies to carers' services. If effective carer support services are to be commissioned then this needs to be done with the input of all carers. They can tell commissioners about what works or doesn't work locally and what specific needs there are in their community.

Developing a participation pathway enables commissioners to be responsive to any changes in local need and to ensure that the quality of services are maintained. Using a representative model, such as that used by parent carer forums, enables feedback to be collected by service users' own community. This means that there is an understanding of how and where to interact with that community and a level of trust that might not be there if engagement is lead by statutory organisations. Participation also enables parent carers to

use their experience and knowledge positively and can help individuals to feel that they can reassert some control over their lives.

While all carers should be treated equally and there is a considerable overlap in the types of support beneficial to all carers, it is important to remember that some groups of carers will have specific needs that are different to other groups of carers. This means that it is important to ensure that engagement pathways enable carers from all caring groups to contribute to the design and commissioning of support services. Our experience locally and nationally is that this doesn't always happen and in particular parent carers are a group that are most likely to be overlooked when developing carer support services.

We have seen in our research that the quality of the relationships between parent carers and the professionals who support their disabled children can have a significant impact on parent carers wellbeing. Our recent report "You don't even know if you're aware of what's happening unless you are in it": the experiences of parent carers of disabled children as multi-service users, raises concerns about a lack of empathy amongst professionals towards parent carers and a lack of understanding of the challenges they face. We have recommended locally that professionals who support disabled children should all participate in parent carer led training to improve their understanding of life as a parent carer. How to interact and work positively with parent carers should be a core part of the training of all professionals who support disabled children. The resource 'Disability Matters' could be used to inform this training, as well as opportunities for health, social care and education professionals to meet with parent carers to discuss their experiences and what good support for their family looks like.

It is also important that parent carers are supported to understand how they can effectively engage with the system and individual services. "All carers are automatically expected to be able to do this, but that is not reasonable. Expressing your opinions and sharing experiences and knowledge is a particular skill that does not come easy to everyone. It is key as part of preparing and supporting individuals to deliver a caring role that they are introduced to tools that can help them to clarify their opinions and to share their thoughts and preferences. Personal centred tools such as one page profiles and considering what works and does not work are proving to be successful in supporting parent carers to do this. The approach in the new Education, Health and Care Plan process that starts with parent carers and the young person they care for completing an 'All About Me and All About Us' section is a positive approach to involving carers in support planning and showing carers that they are valued. In some cases parent carers will need 1:1 support to express their views and thoughts and the provision of advocacy services is key in this. The Independent Support service provided to support parent carers to engage in the EHCP process is a good example of this.

Overall, how important do you think it is that support for working carers improves in the future?

Please circle a number from 1 to 10

1 = not important, 10 = very important

1 2 3 4 5 6 7 8 9 **10**

We have mentioned earlier both the emotional and financial impact of supporting a child or young person with a disability. Being able to work can help parent carers cope with both of these challenges, yet it is almost impossible to maintain employment and support a disabled child and young person. Parent carers tell us that the opportunity to work is important because it provides a chance to be somebody other than a carer and many see it as a break from their caring role. It can help reduce isolation and increase reliance, self identity and sense of achievement. It is important however that employers recognise that the individual carer's role does not go away when they are at work and sometimes it will impinge on the work environment. Parent carers class themselves as lucky if they find a work role an employer who will support them in their caring role while working, and it is the exception rather than the rule that this happens.

The lack of school holiday and after school care for children and young people with disabilities significantly limits parent carers opportunities to work. The role of Short Breaks in supporting parent carers to work is a grey area and needs clarifying. The requirements around child care provision in local areas have been strengthened nationally, however there is insufficient child care for disabled children and the market needs to be developed in a way that delivers sufficient and affordable child care for this group.

If the role of family carer was more valued and better support was in place then it is possible that accessing work might not be a priority for some carers. In some cases the care and support needs of a disabled child or young person are such that it is impossible for the parent carer to take on a work role. In such circumstances it is important that individuals feel valued for the caring role they deliver and the contribution that they make to society even if not in a formal work role.

As disabled young people move into adulthood we currently see an increased reliance on family carers to provide support. There is a lack of willingness in many local areas to support young disabled individuals to move into independent living, instead the expectation seems to be that they will continue to live in family homes with family members providing the majority of care. This reduces the opportunities for carers to work or access education or leisure activities even more, as well as limiting outcomes for the disabled young people themselves.

The ability of carers to work and have a life outside of their caring role is fundamentally linked to the quality and level of support available for disabled individuals. Carers should have the opportunity to work or access education and leisure activities in the same way that other members of society do.

"How to improve support for carers: additional evidence – relevant survey area"

Survey areas are as follows:

- **Services and other formal support for carers**
- **Valuing and involving carers when helping the person they care for**

PACC has completed two reports recently that explore and highlight key issues related to the wellbeing of parent carers. Both these reports are submitted as part of this consultation response.

Services and other formal support for carers;

In December 2015 PACC published the report 'Accessing Social Care Support for Disabled Children in Shropshire'. This report explored the experience of parent carers requesting Short Breaks for their disabled child to enable them to have a break from their caring role and to enable their child to have new experiences away from the family home.

Valuing and involving carers when helping the person they care for;

In April 2016 PACC completed a project funded by Healthwatch Shropshire exploring the reality of being a parent carer of a child who is a multiple service user, "You don't even know if you're aware of what's happening unless you are in it": the experiences of parent carers of disabled children as multi-service users. This research highlighted the key role that parent carers play in co-ordinating and joining up the care of their disabled child and how relationships with professionals can impact negatively on parent carer wellbeing if they are not positive and well managed.

If you have any further questions about any of the content of the consultation response or the reports attached to it please contact;

Sarah Thomas
Participation Co-ordinator
PACC
enquiries@paccshropshire.org.uk
0845 601 2205