



SHROPSHIRE
Parent
And
Carer
Council

PACC's Response to the Shropshire All Age Carer's Strategy

*Understanding & Meeting the needs of
parent carers in Shropshire*

Information & Support, Influence & Change

Who are Parent Carers

- ▶ A parent carer is defined in the Children and Families Act 2014 as 'a person aged 18 or over who provides care for a disabled child for whom the person has parental responsibility' This includes foster carers and kinship carers. In Contact's 2017 report 'Caring More Than Most' it was reported that there were 620,000 adults caring for a disabled child or young person in the UK.

Impact of Being a Parent Carer – Mental Health

- ▶ It is only recently that the true impact on parent carers of supporting a young person with additional needs has been fully understood. The National Network of Parent Carer Forums www.nnpccf.org.uk championed the use of the term 'parent carer' in recognition of the additional responsibilities and roles parent carers take on over and above the role of being a parent, when supporting a child with additional needs. This additional responsibility, combined with the sense of loss and concerns about the vulnerability of their children, can have a significant impact on parent carers physical and mental health.
- ▶ The British Psychological Society comments that *'Parent carers' emotional responses are complex, varied, and – like their child – unique. Yet there are common experiences. Many identify a negative impact on their wellbeing (Totsika et al., 2011) including psychological distress (Keenan et al., 2016), stress, depression and chronic sorrow (Roos, 2002)'*

Impact of Being a Parent Carer – Physical Health

- ▶ There are significant expectations placed on parent carers, since as with any parent they carry the main responsibility for supporting their child into adulthood, but for parent carers this involves travelling new, unexpected pathways and navigating a system that is generally accepted to be problematic in terms of how support is delivered. This includes making sure that their child has access to education, as well as ensuring they can access appropriate health and care support as they grow. All of which they do while trying to process their emotional response to parenthood not being as expected. With all this in mind it isn't surprising that their physical and mental health suffer.

A national survey carried out in 2018 by 'Bringing Us Together' found that out of 1081 parent carers;

89% have experienced ill health in the last 5 years which they believe to be related to their role as a parent carer

93% believe that their ill health is stress related or made worse by stress

70% believe that their parent carer role impacts on their ability to recover from their ill health

50% have no network of support

<https://bringingustogether.org.uk/parent-carer-health-the-impact-of-the-caring-role/>

Impact of Being a Parent Carer - Financial Security

- ▶ In addition to impacting their physical and mental health, families of disabled children also face additional costs and are economically disadvantaged. In 2019 research from Scope found that 'on average, a family with a disabled child would have to pay £581 a month to have the same standard of living as a family with a non-disabled child. For 1 in 5 families, these extra costs come to more than £1000 a month'.

<https://www.scope.org.uk/news-and-stories/life-costs-more-for-disabled-children-and-their-families/>

What Do Shropshire Parent Carers Say?

- ▶ In Shropshire, PACC regularly speaks to parent carers about their experiences, through its Mad, Sad, Glad survey and more recently in a conversation about Parent Carer wellbeing. The findings from this work show that the biggest area of challenge identified are the difficulties in accessing support, with long waiting lists for services and a sense of being in a 'constant battle' to access any support. Many Shropshire parent carers highlight the impact of their caring role on their employment and how it had resulted in them having to reduce their hours or give up work totally, impacting the financial security of their family. A sense of exclusion and being disconnected from wider community support also is highlighted, with families of disabled children feeling unable to access many of the community activities others take for granted. This exacerbates the fear about the future that parent carers tell PACC they constantly live with, worrying about who will 'fight' for their child when they no longer can.

<http://www.paccshropshire.org.uk/content/uploads/files/MAD%20SAD%20GLAD%20Report%202022.pdf>

What Support is Available to Parent Carers?

- ▶ Parent carers had their rights to an assessment strengthened under the Children and Families Act 2014. The legislation places a duty to assess parent carers needs if;
 - ‘it appears to the authority that the parent carer may have needs for support’, or they
 - ‘receive a request from the parent carer to assess the parent carer’s needs for support.’
- ▶ Importantly this assessment should consider not only ‘the need to safeguard and promote the welfare of the disabled child cared for and any other child for whom the parent carer has parental responsibility’ but also the ‘wellbeing of the parent carer’.

Parent Carer Wellbeing

- ▶ The 'wellbeing' duty means local authorities must consider a person's:
 - personal dignity and respect
 - physical and mental health and emotional wellbeing
 - protection from abuse and neglect
 - control by the individual over day-to-day life
 - participation in work, education, training or recreation
 - social and economic wellbeing
 - domestic, family, and personal relationships
 - suitability of living accommodation
 - contribution to society

Improving Support For Parent Carers In Shropshire

- ▶ In terms of parent carers the evidence is clear that there is still much to do to deliver improvements in support for their wellbeing. Currently in Shropshire Parent carers who are supporting young people under the age of 18 do not have access to the Carers Support Service and while there are services such as SEND IASS, the Shropshire Local Offer and more recently PACC's PFA Navigators, to provide information, guidance and support, there is little on offer which directly considers and supports a parent carers individual wellbeing. Improving this situation is essential because a parent carers wellbeing is directly linked to the wellbeing of their disabled child.
- ▶ The priorities identified in the All Age Carers Strategy are in principle, applicable to parent carers but the evidence shows that there needs to be specific consideration of how these priorities can be delivered in Shropshire for parent carers, especially where they are supporting a young person under the age of 18.

Priority 1. Early Identification and Support for Carers of All Age

What PACC would like to see in place:

- ▶ Practitioners throughout the statutory system understand the legal standing of the term 'Parent Carer' and understand the role and its impact. Information about being a 'parent carer' should be readily available at all points of the system where families of children and young people with additional needs interact with the system.
- ▶ Parent Carers are identified through the use of existing data including, but not limited to:
 - Utilising the Special Educational Needs (SEN) Support Register held by education settings
 - Education Health Care Plan (EHCP) data
 - Health Identifications- if relevant (Paediatricians, Child Development Centre, Health Visitors)
- ▶ Parent Carers are able to access the Shropshire Carers Support Service for information and advice

Priority 2. Building Carer Friendly Communities in Shropshire where Carers are Recognised, Listened to & Respected.

What PACC would like to see in place:

- ▶ At point of identification, Parent Carers should be provided with relevant information for support groups; community activities; and Parent Carer Forum. Specific advice pages should be developed for the Local Offer, supported by specific information resources aimed at parent carers
- ▶ The local system should invest in opportunities where parent carers can connect with each other and benefit from peer support.
- ▶ Local services, including education settings, should receive training on how to work in partnership with parent carers and understand the legal duties around and value of co-production.

Priority 3. A life of their own outside of their caring role
– supporting carers to balance their caring responsibilities with their own aspirations and needs.

What PACC would like to see in place:

- ▶ A sufficient range of Short Break opportunities for parent carers to enable them to consider and respond to their own needs and wellbeing
- ▶ Parent Carers are provided with all information relating to services available to them and their child/ young person and are supported to understand this offer
- ▶ A post diagnostic support offer specifically for parent carers, offering support to adjust to this new role and the responsibilities it brings
- ▶ Mental health services understand and acknowledge the emotional impact of being a parent carer and develop support to help parent carers to adjust to this new role and to recognise the importance of meeting their own needs

Provision 4: Carers have good physical, mental, and emotional wellbeing

What PACC would like to see in place:

- ▶ Parent Carers feel confident and supported enough to continue to care for their child/ young person and have access to support when needed
- ▶ Parent Carers are supported to consider their own health needs and health services offer appointments which are accessible to parent carers in terms of timing
- ▶ Parent Carers have access to timely mental health support with a focus on early intervention through courses specifically aimed at parent carers e.g. Healthy Parent Carers Programme <https://healthyparentcarers.org/>
- ▶ Training is provided for Parent Carers around how to minimise the impact of lifting and carrying children or young people with mobility issues

Provision 5: Access to timely, up to date information and advice in a variety of formats that is easy to read and understand and readily available.

What PACC would like to see in place:

- ▶ Ensuring Parent Carers are aware of the Local Offer and how to access it
- ▶ Create a section on the Local Offer that specifically offers information about Parent Carer health and wellbeing which is clear and easily understood
- ▶ Ensuring professionals are aware and understand the life of a Parent Carer and the need for information to be provided in a timely manner.
- ▶ Provide 'navigator' support for Parent Carers of younger children similar to the PFA Navigators

Provision 7: Transitions during the carer role. Ensuring carers, of any age, are supported through the stages of their caring role

What PACC would like to see in place:

- ▶ Parent Carers are given accurate information and a clear outline of the journey they can expect for their child/ young person, including an understanding of what the future might look like
- ▶ Parent Carers are actively signposted to information and services to help them during transitions and key areas on their journey.
- ▶ Provide an outline of key transitions across services (i.e., Children's to Adult's Social Care).
- ▶ Ensure that practitioners understand the emotional impact of supporting a young person with additional needs into adulthood and how to work with parent carers in an understanding and compassionate way.

Provision 6: Co-ordinated services within the whole Health and Social Care Sector

What PACC would like to see in place:

- ▶ Health and Social Care services work in partnership with Education settings to provide co-ordinated care to reduce Parent Carer stress
- ▶ The correct support is available to Parent Carers, regardless of their location, personal circumstances, or caring responsibilities.
- ▶ Improved information sharing across services to reduce Parent Carers having to constantly repeat information
- ▶ Ensure Parent Carers can request a Parent Carer needs assessments separate to a social care assessment for their child

Shropshire All Age Carers Strategy Consultation

PACC will be submitting these recommendations to Shropshire Council as part of the current All Age Carers Strategy Consultation

If you want to share your views you can access the survey on

<https://www.shropshire.gov.uk/get-involved/all-age-carer-strategy-2022-2027/>

The consultation closes on the 6th March 2023