

GETTING IT RIGHT IN WEST SUSSEX

Executive summary

Families identified several positive factors, or enablers, which helped when accessing support for their relative's challenging behaviours including engaging with and feeling listened to by schools, colleges, nurseries and portage services. Receiving valuable support from practical support and services, such as SENDIASS, when preparing EHCP plans was also noted as a positive.

Regarding their own needs, families reported that Families Wellbeing Grants were of benefit as carers identified they represented a feeling of value, acknowledgement and flexibility. However, they were found to be too short-term, and others found it challenging to use the grant appropriately due to their relative's care needs. Support from the Parent Carers Forum and Carers Support West Sussex were also valued by those who accessed it.

Despite the positives, the survey identified far more barriers than enablers to accessing support. Barriers included delays, long waiting times and lack of access to support – particularly early intervention for younger children, and a dependence on families to seek out their own information and support services. Families also identified support not meeting their relative's health and wellbeing needs, lack of appropriate information and inexperienced or uninformed professionals.

A number of barriers were also identified which prevent families from accessing support for their own needs. These included lack of accessible respite services, lack of long-term planning for their relative and family, lack of early intervention support, and a lack of support for the family as a whole - especially sibling support.

Regarding the Covid-19 pandemic, families shared many different experiences around how their relative, their families, and they themselves had been impacted. These experiences included the development of new or increasing severity of challenging behaviour as well as a negative impact on the mental health of themselves and their families. It was also reported that their relative missed out on support during the pandemic. Increased employment and financial anxiety, and families needing to juggle a significantly larger number of responsibilities were also mentioned.

Some families did however experience some positives from the first national lockdown. Respondents mentioned the removal of stress that came along with engaging in activities such as travelling and getting ready for school, being able to spend more time together as a family, and finding it easier to access support online than it had previously been in person and receiving support from other family members who were also at home.

From the survey, a number of recommendations can be made to inform better support for this group of carers. The recommendations encompassed supporting the development and provision of information about challenging behaviours for parents and professionals and building on good engagement of families and partnership working in schools. Additionally, improving respite services, increasing support for young families, encouraging services to think long term about a young person's care and involve their families in this process and ensuring support is more accessible for families were recommended. This report also recommends carrying out further research to explore barriers for families from Black Asian and Minority Ethnic communities, or families with relatives in residential care.