


West Sussex - Family Carer Focus Groups

February/ March 2020

In February and March 2020 two focus groups were held in West Sussex to gather the views of family carers of children and young people with learning disabilities whose behaviour challenges about existing support and services, and families' vision for future support in the local area.

Focus groups were held in Worthing and Crawley. This write-up shares the findings from the focus groups and covers the following sections:

- What works in West Sussex?
- What does not work in West Sussex?
- What could be improved?
- A vision for future support



Welcome

Family Carer Focus Group

Aims
To share information about best practice with families

To hear from families about what works and what could be improved in West Sussex

Ground rules for the day

- Confidentiality
- Respect

Feedback form

What works in West Sussex?

We asked families to tell us about existing examples of good local support for them and their relatives in West Sussex.

Attendees were able to identify individual services including schools where their children had received good support. For example, one family identified having a TA with the necessary skills to meet the child's needs had been beneficial.

However, views were not unanimous around the room and cost/ available funding remained a barrier for some families.

Families identified individuals within services who had made a positive difference for their child, but there were often caveats e.g. CAMHS nurse is really good but she has no support network around her and difficult to make the initial contact.

Families mentioned specific services which had and/ or were providing good support. Although individual named services were different for different families and across the two locations, common characteristics of services providing good support were:

- Expertise/ understanding/ knowledge
- Care 'hugs'
- Personalised
- Whole family support- listen to families

In the focus groups families also identified 'mainstream' clubs and services which were accessible for their relatives e.g. Brownies and Scouts.

Peer support from other family carers was also identified as hugely beneficial.

What does not work in West Sussex?

We asked families about what doesn't work in West Sussex. Families' views can be divided into two sections:

- Children and young people
- Family carers

What doesn't work for children and young people?

- Access to specialist services

Families identified a gap in access to specialists (individual professionals and services) to support their child.

Focus group attendees shared that they regularly asked for this help/ support but were told repeatedly '*we can't help you*'. Families described the consequence of the current lack of specialists or understanding of their relatives needs, is that family carers are blamed e.g. for their child's diet.

- Timely diagnosis and lack of personalised care/ support

Families identified a gap in access to timely diagnosis. In addition, families highlighted that diagnosis doesn't always lead to a strategy or plan for support for their relative.

- Attitudes of professionals and members of the public

Families shared the negative attitude of both professionals and members of the public which had been unhelpful when trying to access support for their relative. Some of the comments families had received were as follows:

"He chose to do X"

"He's naughty"

"We can't just believe you"

"Glad you decided to turn up [to school] today"

What doesn't work for family carers?

- Lack of support for family unit

Attendees identified a lack of existing support for the family unit, personalised to individual circumstances e.g. where another family member has a physical disability.

- Financial burden

Families faced additional caring costs not only for direct support for their relative, but also the impact of not working, and damage/ breakages as a result of challenging behaviour.

- No opportunity to share concerns

Families felt they didn't have the opportunity to voice concerns truthfully and share honest experiences without risk of being judged or having their children taken away.

What could be improved in West Sussex?

We asked family carers what and how they felt support could be improved in West Sussex. At both focus groups families identified local support would be improved if it was delivered in a timelier manner and there were fewer barriers (funding/ waiting lists etc.) to access. Both focus groups also identified a need for increased early intervention support, to prevent individuals reaching crisis, and to ease pressure on crisis support when it is needed.

Focus group 1 (Worthing)

Awareness and understanding of learning disabilities and autism

- **Reduced barriers to support**

Access to good services- improved/ increased provision to remove the current barriers to services and support e.g. no diagnosis, no EHCP

Support services that work together rather than in competition/ conflict.

- **Timely and person centred/ appropriate support**

Local support services need to have a focus on early intervention and prevention, and so relieve pressure on crisis support.

Support needs to be person centred and include things like skills training e.g. shopping

- **Personalised support for whole family**

Belief in families and support for family carers including recognition as part of the unpaid workforce and more regular opportunities for input into services.

Support needs to be available for other family members, including siblings. Families were clear that this support should be offered to family members, rather than families having to seek it out.

- **Clear information about how to access support**

Accessible information helping families to know what support they and their family are entitled to. Clear information about what families are entitled to also needs to be shared with schools and SENCO teams etc.

Focus group 2 (Crawley)

- **Timely support**

Social services could be improved by switching to an early intervention approach- rather than crisis response.

Increased service capacity to reduce waiting lists, including for Portage services, and for Team Teach restrictive intervention training.

- **Funding**

Funding for services both to ensure facilities like short breaks and day centres keep running, and to reduce/ remove costs for family carers.

Increased flexibility in funding e.g. personal health budgets. One family gave the example that the cost of horse riding for their child had increased, and they asked for an extra £10 per month, but were told funding couldn't be increased unless the child's needs changed.

- **Workforce continuity**

Continuity of social care staff could be improved. High staff turnover means you don't know who you are talking to, and families had experience of being shifted between social work services without being properly informed.

- **Specialist support**

Support services for special guardianship

Vision for future support in West Sussex

At the end of the second family carer focus group in Crawley, families developed a vision for what they wanted future local support to look like. Families identified several key changes they would like to see, and then voted (each attendee had three votes) to prioritise the suggestions.

The table below shows the 'Vision' for future support, with the most important changes as identified by families at the top.

Vision	Details	Number of votes
More specialists	<ul style="list-style-type: none"> - Psychologists - Better Positive Behaviour Support 	6
Improved support pathway	<ul style="list-style-type: none"> - Getting information and support right at the start - Better neurodiversity pathway - Supporting all with challenging behaviour - Early support when challenging behaviour identified - From birth to adulthood e.g. including supported living (not knowing is frightening) 	3

Respite/ PAs – personalised to what the family needs	<ul style="list-style-type: none"> - It can be hard to trust someone to look after your child, need someone who can go with family for specific days out 	2
Personalised strategies and approaches		1
Holiday clubs/ friends/ peers/ after school clubs	<ul style="list-style-type: none"> - Opportunity to socialise - Children and parents - Give parents the choice to go back to work 	1
Use social media to link families up as part of a community	<ul style="list-style-type: none"> - E.g. parents Whatsapp group for special school 	1
Being able to enjoy child	<ul style="list-style-type: none"> - Other families providing support/ lived experience - Parents given the information and understanding to enable them to understand their child. - Emotional support around diagnosis 	1
Better support at school	<ul style="list-style-type: none"> - Inclusive, able to participate on trips etc. - Flexible education e.g. reduced timetable - More offer of schools and choice - More places at schools near to home 	
Break down prejudice in the community	<ul style="list-style-type: none"> - Project led by parents working with Local Authority 	
Education, health, social care work together and join up around the family. Know if struggling and help. Training for families		