Getting It Right in West Sussex - Stakeholder Engagement Day

2nd December 2020 via Zoom

Contents

- Opening presentations
- Break-out discussions
- Actions agreed in break-out rooms
- Feedback
- Next steps

Opening presentations

Marie Willan, the PBS Commissioning Lead for West Sussex, opened the day, thanked everyone for their attendance and introduced the agenda. After giving a summary of the background to the Getting it Right project, she introduced Viv Cooper, CEO of the Challenging Behaviour Foundation (CBF). Viv outlined some of the key national issues that set the context for the Getting it Right Project in West Sussex, including the governments' consistent failure to significantly improve outcomes for children, young people and adults with learning disabilities and their families.

Gráinne Saunders, volunteer Parent Rep from the West Sussex Parent Carer Forum, followed on from Viv with a presentation on the local picture in West Sussex. She highlighted some off the key issues raised in the Getting it Right survey, which was completed by 99 local families. This included how difficult it was to access high quality information in a timely manner; the gaps in support services and feeling like they weren't listened to by professionals.

Viv and Grainne's presentation can be viewed on the Getting It Right website page on the CBF website:

https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/getting-it-right/

Break-out discussions

Alison Nuttall, Commissioning Lead; All Age Services (West Sussex), introduced the second part of the meeting. Attendees were invited to join one of four groups for discussion and action-planning on the following topics:

1. Getting the right information to families at the right time

2. Getting support right in the early years, at school, college and beyond
3. Getting health and social care support right
4. Valuing families as partners

The details and outcomes of these discussions can be found below.

List of abbreviations:

- CB- Challenging Behaviour
- CBF- Challenging Behaviour Foundation
- PBS- Positive Behavioural Support
- PECS- Picture Exchange Communication System
- SALT- Speech and Language Therapy
- SEND- Special Educational Needs and Disability
- SG- Steering Group
- WS- West Sussex

1. Getting the right information to families at the right time

Facilitators: Lindsey Butterfield (SEND Commissioning team, West Sussex), Jacqui Shurlock (CBF)

What	Short term actions	Who and by when	Long term actions	Who
Set up a WS CB Facebook group	Decide who best to host? Parent carer Forum?	Lindsey to discuss with other key parties and agree by next Steering Group meeting. CBF to contact the Parent Carer Forum to discuss.		
CB/PBS webpage on local offer, Tools for Schools and Family Information Service.	Agree info to share in the short term- link with action 5	Kier and Marie	Maintain and develop page as support offers develops	Kier and Marie
Include CB info at Parent Carer Forum events	Invite CBF family carer champions to attend next virtual event to present if appropriate.	Lindsey/ Rowan/ Jacqui	Have CB expertise at future in-person events	Lindsey/Rowan/Jacqui
Encourage use of disability register/compass cards to identify families	Amaze mailouts targeted at relevant families with CB info including new FB page details	Marie (Amaze)		

	Include stats from disability register in reports from this project.	Marie Willan/CBF		
	Use disability register stats to help professionals plan support for children with CB.	Steering Group to consider as part of future strategy		
Bring together in a simple way (diagram, video?): who does what with regard to CB in WS and how families can access it. Also, how to find wider support eg CBF and other national charities. Sharing more widely	Steering Group to agree and develop clear info	Steering group member to take a lead (Could pay a family carer to do this?) Steering Group to agree at next meeting		
Develop knowledge of other professionals in WS about behaviour support and how to refer/ signpost resources	Share info in action above with professionals e.g. Health Visitors, CAMHS etc		Work on cross-team links and knowledge e.g. shadowing, attending team meetings etc	SG to discuss
Pulling info together about what is available will flag up gaps e.g. how to reach younger children, hard to reach families, first point of contact for people who do not have diagnosis or referral but need CB support	SG to consider how to fill gaps/ possible pathway/ strategy around CB in WS.			

2. Getting support right in the early years, at school, college and beyond

Facilitators: Marie Willan (SEND Commissioning team, West Sussex); Siobhan Humphreys (CBF).

The group identified the key issues for getting support right in early years and beyond:

1. The importance of early intervention: conversations need to be had early, and relationship building with professionals needs to start at a young age. It was noted that the most common age for referrals is 8 or 9 due to the child getting physically larger and therefore the impact of their behaviour might be more significant. More needs to be done to provide families with support and information before it gets to this stage.

2. Portage (a home-visiting educational service for pre-school children with SEND and their families) is a good service that needs to be better promoted so that carers can access it.

3. Benefits of online training: virtual training can be easier to access for hard-to-reach families who can't/don't attend face-to-face events.

4. Communication skills are key. Woodland Mead School are starting PECS training for parents and staff, but there has been difficulty securing buy-in from all parents. It was noted that the proper use of PECS is key and that it is not always used properly by teachers. The group identified there was a lack of SALT in schools and an over-reliance on individual assistants.

5. Parental involvement- especially of hard-to-reach parents. Negotiating the transition between the change of environment between home and school is an important element in early-years support and parents need to be trained and supported to implement good practice at home that is being used in schools. The group also discussed whether ideally, techniques should be started at home and then transitioned to school, as this may be easier than vice versa. The group discussed how to better connect parents and teachers if face-to-face time is not routine (e.g. don't see each other at school gates as use school transport).

3. Getting health and social care support right

Facilitators: Karin Fuchs (Consultant Clinical Psychologist, Sussex Partnership NHS Foundation Trust), Mary Spence (CBF).

The group identified the key issues for getting health and social care support right:

1. Information: the group discussed the concerning statistics highlighted in Grainne's opening presentation concerning the percentage of families that felt the information and support they received was unhelpful. It was noted that online information might be too impersonal to be helpful.

2. Integration of health and social care: the group discussed how existing financial resources, if spent differently earlier in an individual's life course could enable better health and social care support.

3. Open and honest conversations between families and professionals early on are essential to resolve any differences and set expectations from the start.

The two 'Getting the right support' discussion groups merged for their action planning session.

What	Short term actions	Who and by when	Long term actions	Who
Journey Mapping	Deep analysis of survey findings by age (especially early years)		Journey mapping as usual practice.	
Early conversations	Focus available resources on early intervention and support to make sure young people don't come into contact with services for the first time when they reach crisis.		Educate nursery staff, health visitors and other early years practitioners on way to discuss challenging behaviour.	
Low level intervention – make best use of waiting times	Alison to share information with MW about amaze door knocking approach Anne involved in sure start universal services signposting to share knowledge with group	Alison Marie Anne	Steering group to keep this item on agenda moving forward Provide drop in support chats outside of referral process	
Engage reluctant parents	Adapt language when advertising sessions – call training 'support' to make seem more friendly and less critical of parenting		Signpost reluctant parents Different levels of intervention: build community and family resilience – e.g. peer networks	
Make sessions accessible	Provide sessions across a variety of mediums: virtual sessions, face-to-face sessions, drop-in sessions, chats		Widen service delivery methods (some prefer high level training others simple chat)	
Resources and workforce	Transparent conversations in partnership with parents (as parents are expert in their child) re resources: where are there resources, are they being used as effectively as possible?		More money and people in the system Improve effectiveness of system – be creative Improve portage and SALT provision – key services	
Identify group of people in contexts that are difficult to reach (e.g. parents who are flagged in safeguarding)	Analyse survey results to identify what prevents/enables access		Research (informal or academic) accessibility and barriers to create profile of high risk families.	
Improve transition	Make smoother – ensure people don't reach a cliff edge of lack of support.			

4. Valuing families as partners

Facilitators: Grainne Saunders (WS Parent Carer Forum), Liam Doherty (CBF).

The group identified some key issues for valuing families as partners:

1. Awareness: Families not always aware of the support they are entitled to/should be asking for, including specific services such as NeuroCAMHS. There needs to be better signposting to the support services that are available. The system also needs to be easier to navigate, making it clearer how to identify and access the services in your area.

2. Families don't have access to a care coordinator/navigator/key worker to assist with process of getting the right support.

3. The importance of listening to families and valuing 'semantics', to ensure that individuals do not end up in the wrong service or place (e.g. difference between brain injury and brain damage). Professionals need to listen to all the information families have to contribute to getting the right assessment of need.

4. Proper holistic assessment of what is going on for the whole family. The differences between families should also be valued; there's no one-size-fits all approach.

5. Difference between behaviour presentations at home and school, both experiences need to be considered.

6. Getting support is difficult without a diagnosis, as well as the risk of getting the *wrong* diagnosis leading to further harm including mental health issues. Teachers etc. may be treating symptoms without addressing the cause.

What	**Short term actions**	**Who and by when**	**Long term actions**	**Who**
Development of strategic voice/group to advocate needs. Families to talk to *each other* and organise around needs. Doctors have limited time/capacity to refer parents to specific support, families may be best poised to offer this signposting.	Challenging behaviour groups/networks of parents organized through schools – peer-to-peer support, signposting needs. Families could also use closed, local Facebook groups. Could be established easily, perhaps with small amount of funding for facilitator – either a parent or an expert 'link' (e.g. Marie or Grace Morris) who knows what services exist. Families maybe don't have time, and could find it difficult to say 'I need help' – a friendly face could be the best person to step in and offer this. Family/strategic meetings to identify three key points that they all agree with to help proactive support.		Long-term culture change where families can go out and talk about their problems, support needs to be offered proactively before families are at crisis-level.	

Families should have a phone number to call when they have problems or questions, health visitors often only help at the start/young age.	Hold discussions to capture what people want more of to ensure that the right support is on offer (e.g. specialist health visitors). Challenges families face change throughout a child's development, regular checks would help especially if through one familiar person.		Need more specialist health visitors (only 6 in county), these can offer support until age 19 but there are too few of them.	Health visitor/ Key worker/ family outreach worker
Ongoing training sessions should have information of families' perspectives built in, so that workers are aware of the problems families are likely to face when interacting with systems of support	Annual support 'MOT'. Development day for those working in services, where conversations are held with families, so they know what families need and where the support on offer fits into that.		Culture change – recognizing families as experts in their own child. Multi-agency learning to transmit information between services to better support families – would help semantic consistency and prevent families getting lost in jargon & not getting the right support.	
Documents, resources and support is often written in language inaccessible to families. Makes strategies and advice unusable.	Regular conversations with families around concerns, needs. This would better enable services to identify what support is needed, and in long-run might improve proactive intervention		Investment in supporting families with appropriate training and empowerment to support and influence strategically. Families are the experts in their children & their children's behaviour. End of 'deficit' culture, where families are treated as lacking the skills to engage in support. Families must be met where they are at, rather than where professionals assume they should be.	

Feedback

After the break-out discussion groups, all attendees came back together to feedback their key points and discuss ideas. Some points that arose during this session were:

- Ensuring that the information resources developed as a result of this project are shared widely, so that friends and family can also best support individuals with learning disabilities whose behaviour can challenge.
- Short information webinars could be created for parents to make training more accessible.
- It's crucial to invest in families right from the start and take a proactive approach to empowering them

- Peer support is incredibly valuable and creating a platform for family networking should be a priority. Ideally this would also provide families with access to professionals and *vice versa* the opportunity for professionals to just listen to families and hear their reality.
- A joint up approach is crucial in ensuring limited funding and resources are being used to best effect. Creative, outside-the-box solutions to maximise the impact of the money that is available should be encouraged.

Next Steps

Marie Willan closed the day by outlining the next steps for the Getting it Right Project:

- The action tables from today will be written-up, shared with you and the Steering group will start planning their implementation
- The West Sussex Steering group will continue to meet after the CBF funded involvement comes to an end and will work to address the issues discussed today and highlighted in the Getting it Right survey
- The Steering Group will be in contact in the future for more suggestions and ideas, as well as feedback on how families feel the work is progressing
- Please don’t hesitate to get in touch if you have any follow-up questions or thoughts after today. Marie.Willan@westsussex.gov.uk

Marie thanked the attendees and facilitators for their time and closed the meeting.