

"All we want is for our children to access care the same as any other child"



"Ask us - you'll learn more from us than you ever will from reading a book!"

# A need, not a want

A co-produced resource about engaging with families

## BACKGROUND

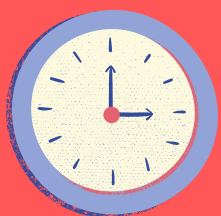
As part of the Getting it Right in the Black Country project, the Challenging Behaviour Foundation worked with family carers and professionals to improve support and services for children and adults with severe learning disabilities and their families in the Black Country.

The project identified the need to find ways to improve engagement with these families and to understand the barriers they may face in accessing local services and getting their voices heard.

Our co-produced resource commissioned by Black Country Healthcare NHS Trust highlights the benefits of engaging families and sets out ideas and suggestions about ways to do this, including ways to share information with them, and how families can influence and shape local support and services.

"When they become adults, there's nobody - just you"

"I felt like my voice wasn't heard"



## BARRIERS

- **Time** - Families have limited capacity due to their caring responsibilities
- **Communication methods** - Access to internet/social media. The times that phone lines are open - it only works if there is someone to answer the phone. High turnover of staff can be problematic when communicating via email
- **High staff turnover** - particularly with social workers. Lack of continuity and information sharing between local agencies means that families have to re-tell their stories repeatedly which can be distressing and traumatic.
- **Unreasonable demands** being made of families eg. expecting them to attend long/complicated meetings
- **Use of jargon** by professionals can make families feel that they don't know enough to participate in discussion
- **Families feel they have to reach crisis point** before they are listened to. When they are facing difficulties and try to offer feedback, they feel that they are not listened to and no action is taken
- **Families not knowing how/where to feed things in:** Some family carers are keen to engage but haven't been given the opportunity, or are doubtful that services want to listen when budgets are so stretched. **They can offer simple solutions but feel there is nowhere to feed them in**



## WHAT WORKS

- **Valued** - Family carers need to feel that their contributions are valuable and feel listened to.
- **A range of options for communication** - Families' needs and preferences vary. Using familiar venues, such as schools and community centres, can support families to have their say
- **Having a dedicated key worker**, or similar, in each local area would provide an opportunity for effective co-production and ensure consistency
- **Reasonable expectations** - Finding out what works for families to make engagement more accessible. Consider alternatives. If it is meaningful for them to attend long/formal meetings, find out what would make them comfortable
- **Proactive, not Reactive** - Providing opportunities for families to feed in at all levels. Where there are regular interactions with services, listening to families should provide insight into what needs improving, so it doesn't get to crisis point!
- **Reaching out** to family carers rather than us having to seek it out. Better use of existing registers compiled by local services to find families who want to engage in coproduction
- **Feedback** - Families need to know that it is worth engaging, it is important to have a clear process for updating families with the progress or impact of the work they are involved in.



The most effective way to ensure success for both professionals and families is to work together on an equal basis, deciding what the issue is, what is needed to address it and to come to a decision which works for them all. This process, known as co-production, means professionals and families share power in designing, planning and delivering support together



"We've had a really positive experience with CAMHS. The nurse listened to us, got to know our son and made adjustments. She visits us at home, sees him at school and checks in with us regularly"

To access our resource scan the QR code or visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

