



**The Challenging
Behaviour Foundation**

making a difference to the lives of people with severe learning disabilities

Getting it Right in the Black Country

Family Survey



NHS
Black Country Healthcare
NHS Foundation Trust

 **COMMUNITY
FUND**

During May 2022 we held two virtual focus groups for family carers in the Black Country with a relative with learning disabilities.

The first focus group was held on 11th May for family carers with a relative aged 0-18 years. 11 families attended.

The second focus group was held on 18th May for family carers with a relative aged 19-25 years. 15 families attended.

The aim of the focus groups was to gather the views and experiences of local families in relation to what works well in terms of local support and services, what could be improved, and how.

The project steering group agreed to divide the focus groups by age so that the second group could reflect on and discuss their experiences of supporting their relatives through transition from child to adult services. The findings from both focus groups have been put together as similar themes emerged at both.

This write-up shares the key findings from the focus groups and covers the following sections:

- What works well in the Black Country?
- What is not working well and could be improved in the Black Country?

What works well?

Peer Support (0-25)

Families at both focus groups told us how much they value peer support, both in terms of emotional support from other families in a similar situation but also as a source of practical information about local support and services.

- Parents carer/school forums are the best and sometimes only way to find support (Autism West Midlands, Sandwell Parents for Disabled Children, school Facebook groups)
- Families found having friends who also have children with autism/ learning disabilities was helpful
- Families told us that parent support groups are where parents find out a lot of information
 - There is a charity for carers which signpost, have activities for young people and provide a place for parents to speak
 - Families told us about a young sibling group – but they regretted that they hadn't know about it until concerns were raised
- Families told us sometimes parent support groups can give grants/ financial support

“ The group also involves other family with children with disabilities, sometimes they organize meetings, parties, picnics, hangouts, gamings etc

“ Since i found the local support group,it has been eye opener and also me as a parent have learn a lot and its not so expensive

Family carer/ parent support groups that had been helpful to the families at the focus group took a range of formats.

- Health professionals bringing together families from the local area
- Carer support: carer’s forums, support from other families and around particular diagnoses

Schools/Education (0-25)

Across both focus groups families shared positive experiences of the information and support they had received from schools.

However, experiences weren’t all positive, for example, families had received much better information from special schools than from mainstream schools. In addition, one family shared how their child was now home-schooled (which was going well) but that this was because the school had not been able to meet their needs.

- One family shared their experience of a particular teacher who had had a really positive relationship with their son. The family had requested that their son stay in the particular teacher’s class for his remaining 3 years at the school. The school listened and the child remained with the teacher.
- Another family shared an example of good communication between the school, the family and the Speech and Language Therapist to demonstrate use of PECS
 - The Speech and Language Therapist and the teaching assistant came to the family home to demonstrate use of PECS. This was helpful to the family in terms of communication with their relative, but also helped the young person by providing consistency across home and school.
- Another family had a positive experience of home schooling
 - One family described how their son hadn’t been able to cope with the school environment, but, moving to home schooling has provided the right environment to enable them to learn.
- Families shared more positive experiences of special schools than mainstream schools
 - One family told us once appropriate education was provided, the child was in school full time whereas they had only attended mainstream school in the mornings.
- Families told us that their child’s school had been supportive, and the positive impact of this on their child was demonstrated by their eagerness to go to school.

Short breaks and respite (0-18 focus group)

Families at the 0-18 focus group told us how much they valued respite and short breaks provision, but also shared their experiences of how it had been suddenly cut without any communication with the family.

- KIDS charity – two families had had positive experiences with KIDS, who had provided 2 to 1 support for their relative during 2 hour sessions. One family described how her relative had been taken to the library which was one of her favourite places.
- One family described how respite had been cut but the family not informed/ given any prior warning. This had been devastating for the family because the respite had been a lifesaver.

Access to services (19-25 focus group)

Families told us that they had used a range of methods, including contact with professionals and other families, to find out about and access services:

- Families had found out about particular services/ support via a range of methods
 - “We were introduced to some [local support/ services] in the hospital and it has been awesome so far.”
 - “local services are quite affordable and easy to access” – from family carer who had been referred by health professional
 - “For me i was helped by a family friend”

Individual services

Particular services were mentioned by families as providing valuable support:

- Inclusion support services. One family mentioned they had been particularly helpful in supporting them to find a special school for their relative.
- CAMHS, and SLD support psychologist were mentioned as being particularly helpful by one family. They already knew the family’s case and would come to house or go to the school to make it easier and the family really felt like they cared.
- The early years service was extremely supportive with the first steps, including making contact with the family first, rather than waiting for them to ask for help

What could be improved?

Information and communication (0-25)

Across both focus groups families shared that open and transparent communication with professionals and services, and provision of accessible and timely information was often lacking.

- Communication needs improving with families and young people, ensuring families are listened to
- Local Offer – families felt they didn't know enough about it. Work is needed to promote it throughout the Black Country
 - Local offer needs to be easier to navigate
- SENDIASS not working as they just refer parent to a website rather than offering support, seem to just give information rather than supporting the parent through their experiences
- Better communication is needed within and between Local Authorities/agencies in the Black Country
- Improvement is needed in communication with health, education and social services involving the child and family
- Coproduction doesn't currently work as it should

Early intervention (0-18 focus group)

At the 0-18 focus group families told us they felt services were being too reactionary, and only stepping in to provide support once the family had reached crisis and they were desperate.

- Services are being too reactionary – it is important families are not made to wait until they are in crisis to receive support
 - For one family it wasn't until family members were injured before support was provided
 - The result was that the young person was now supported at a residential school out of area
- Local Authorities should be more proactive before a crisis occurs
- Invest in early intervention

Access to transport (0-18 focus group)

At the 0-18 focus group families raised their concerns around provision of transport for children and young people in the Black Country. Particular concerns related to an on-going consultation in Dudley and proposals to cut transport for pre-school and 16+.

- Transport must be provided – using public transport is not possible for some children and young people with learning disabilities, and therefore cuts would create a barrier to a range of other services
- Transport essential to enable children and young people to access education and other services e.g. short breaks
- Changes to transport policy are currently being considered locally (started in Dudley and planning to review in Sandwell as well)
 - Families particularly concerned by proposals to cut transport for preschool and 16+

Financial barriers to support (19-25 focus group)

Families who attended the second focus group for families with a relative 19-25 told us finances were often a barrier to access to services – both services being cut when funding runs out and having to pay for particular support and services.

- Finances can become a barrier for accessing services
- Support services were cut due to lack of funding
- Therapy sessions families wanted to access for their relative are expensive

Transition (19-25 focus group)

In the second focus group for families with a relative aged 19-25 we asked families about their experiences supporting their relative through transition from child to adult services. The following quotes from families at the focus group highlight that this is often a difficult time for families in the Black Country.

“ Transition from child to adult is really challenging and tough

“ To be sincere it was a really challenging and tough phase

“ There was a lot of struggling, trying to set the foundation strong

Next steps

The findings from the both focus groups have been reviewed by the project steering group and were presented to attendees at the Black Country Getting It Right Stakeholder Event on 15th June. The findings will feed directly into action planning to improve provision of support and services going forward.