



# SEN PEER SUPPORT PROGRAMME 'ONE YEAR ON'

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## SUMMARY

The Parents' Forum for Bradford & Airedale began to deliver an SEN Peer Support Programme across schools in Bradford from March 2022. During the following 12 months 21 Schools were visited and we engaged with over 280 parent/carers. Our expectations of its impact have been surpassed in terms of numbers of requests and the positive impact on parent/carer health and wellbeing, empowerment and resilience. Additionally, the positive impact of hearing the 'lived experience' of families has had on schools and professionals. The programme 'a year on' has highlighted the importance of 'peer to peer' support, early intervention and support and most importantly the improved resilience and knowledge for parent/carers. The programme did have some limitations. A self-referral process restricts expansion and accessibility for all parent/carers across the district; more information around type of disability/special need would have been useful in addition to a more detailed evaluation process would improve knowledge and learning. The biggest limitation is in PFBA capacity as there is now a waiting list of schools wishing to take up our offer from September 2023.

## BACKGROUND

Parent carers of children with SEND have frequently reported feeling lonely, isolated and as though they are the only person going through this journey. Being part of a family or having a partner doesn't necessarily mean a parent is able to offload thoughts, fears, and worries. As a main carer/giver, there may be support available but people do not always understand their children's behaviours and quirks as they do. Information to support their parent/carer role is limited, can be often inaccessible and sometimes confrontational, exacerbating the worry and stress they feel. The PFBA has spoken to many parents who have felt like they had the weight of the world on their shoulders and although they love their children dearly, parenting feels so, so hard and not at all what they had expected it to be.

Hearing how so many other parent carers had struggled in the same way that all the PFBA staff had experienced sowed a seed. Could Parents Forum connect parents in similar situations at the earliest point possible in trying to address and improve the experiences for many of these families and children? An opportunity arose to provide SEN coffee mornings in Primary schools, offering parents a chance to open up with their peers and support each other through this journey.

## AIM

The aim was to build and deliver a programme of SEN support in mainstream schools that would help address a lack of information, help alleviate stress and worry for parent/carers through peer to peer support at an early stage in their journeys. The areas we wanted to focus on were:-

- Reducing parental isolation
- Building a new support network
- Introduce peer support
- Improve communication between families and school
- Help build parental confidence
- Provide information to families at an early stage
- Sign post relevant services
- Encourage resilience
- Provide learning experiences for PFBA and partner organisations
- Allow the coffee mornings to evolve through flexibility
- Be adaptable to respond to different needs depending on each parent/carer's own circumstances

## The Offer

Initially the offer was 4 peer support coffee mornings that were tailored around the issues that the parents were facing at the time. They were facilitated by Parents Forum but very much parent led so that it wasn't someone talking at the parents but someone who had been through it themselves hearing their story but also sharing their experiences too.

The very first coffee morning took place at Blakehill Primary on 9<sup>th</sup> March, 2022.

## FINDINGS

21 schools have been visited, engaging with 280 families.

From a geographical family hub perspective, the schools visited were predominantly in the East and West localities with South falling behind.

**Table 1 – Schools Visited by Family Hub Locality Area**

Family Hub Area	% of Schools Visited in this Locality (No. schools)	Average % of children on SEN support	Average % of children with EHCP	Average % of children English not 1 <sup>st</sup> Language	Average % of children receiving free school meals
Bradford East	28.6 (6)	11.5	15.8	46.4	32.1
Bradford West	28.6 (6)	14.2*	1.8*	71.5*	27.5*
Bradford South	19 (4)	14.8	2.2	21.2	42.3
Keighley and Shipley	23.8 (5)	6.74**	1.9**	16.8**	24.8**

\*% based on 4 schools. No data available for two preschools/nurseries

\*\*% based on 4 schools. No data available for one preschool/nursery

We can see from the table that Bradford is a very diverse district with many children not speaking English as a first language or entitled to free school meals. We are aware however that our sample is relatively small and we are contacted directly from schools that already recognise a need for this kind of support. Demographics do play a part but as research has already told us the same issues are being faced by those in more affluent, rural settings as those in inner city areas. There is a high level of SEN support compared to EHCP's in place. This is echoed in the parental feedback PFBA hears in how difficult it is to obtain an EHC plan for their children but also, we feel is an underrepresentation of how many children require SEN support. There is one school that has no children with an EHCP and all the geographical areas have up to 23% of children requiring SEN support. Whether the SEN support offered in each school is effective is a question needing to be asked alongside 'good practice' sharing for all schools in the district.

## Types of Disability/Special Educational Need

We have met with families whose children have a variety of disabilities, some with one disability and some with comorbidity. Although the majority of families have children who are neurodiverse, there should be consideration made for children who have other disabilities. From speaking with these parents, the problem of loneliness, isolation and lack of support are just as prevalent for them but they also have to contend with

health conditions that may be rare or less understood by the medical profession as well as the school leading to an extra battle to learn more and gain more support.

We have met families whose children have the following conditions:-

**Table 2 - Range of disability or special educational needs**

Developmental	Health Condition	Other
<ul style="list-style-type: none"> <li>• Autism</li> <li>• ADHD</li> <li>• Pathological Demand Avoidance</li> <li>• Sensory Processing Disorder</li> </ul>	<ul style="list-style-type: none"> <li>• Duchennes Muscular Dystrophy</li> <li>• Cerebral Palsy</li> <li>• Spina Biffida</li> <li>• Chromosomal Abnormalities</li> <li>• Sight Impairment</li> <li>• Hearing Impairment</li> <li>• Down Syndrome</li> <li>• Sickle Cell Anaemia</li> <li>• Cystic Fibrosis</li> <li>• Diabetes</li> <li>• Kidney Transplant</li> </ul>	<ul style="list-style-type: none"> <li>• Dyslexia</li> <li>• Dyspraxia</li> <li>• Depression</li> <li>• Anxiety</li> </ul>

There were some very specific chromosomal abnormalities we came across but earlier on in the programme and at that point we did not collect specifics around type of disability. As the programme became more popular we realised that we definitely weren't just seeing neurodiverse families and began to include type of disability on our register.

## WHAT PARENT/CARERS TOLD US

### **None SEND Specific**

Even though the coffee mornings are SEND specific, it has been really lovely to facilitate other discussions that parents have felt comfortable having with each other in the supportive environment that had been opened up to them. For example, SEND took a back seat in one particular school and a long discussion was had around the fact that everyone around the table had had an extremely traumatic birth in one way or another. Whether it be emergency caesarean section, prematurity, giving birth through covid times, postnatal depression or other reasons, offering a safe space to discuss this, often for the first time, is essential for mental health and wellbeing with parents saying if they were to go through similar again, they would be more likely to open up and talk about the effect it had had on them.

Some of the parents have come to this country from abroad and do not have family here so are coping alone. Being able to introduce them to other parents who live locally and attend the same school is essential for their support network.

### **SEND Specific**

The two most significant issues that have been raised at most coffee mornings are behaviour and sleep.

#### **Behaviour**

There is almost a desperation from parents of how to manage their child's behaviours. As this tends to vary from child to child and day to day, parents report that they would really benefit from support with this as early as possible. Not having information and support over a long period has led them to feelings of depression, powerlessness, not being a good enough parent and for some parents a feeling they are unable to cope with nowhere to turn.

### **Sleep**

Sleep or lack of sleep is an area that has come up in every school visited. It's not just early waking, sleep walking, night terrors or inability to go to sleep that's the issue, co-sleeping and children who are not dry through the night have been discussed a lot. We have been able to invite the SEND School Nurse Specialist from Bradford District Care Foundation Trust (BDCFT) to some of the coffee mornings to support with referrals to the continence service and any health related issues and also one of the PFBA's Trustees who is a qualified sleep practitioner. In fact a sleep session has now been built into the coffee morning offer and has been very popular with excellent feedback from both schools and parents.

### **EHC Plans**

The third most talked about issue is the difficulty in obtaining an EHC plan. Parents haven't always been aware that they can make a parental application if school is not willing to apply. One family had a child who has a degenerative life shortening condition. He was going to die but how long that would take was unknown. They wanted to enjoy every minute they had with their son. He was already wheelchair bound and behind his peers educationally. He needed specific care yet was in a mainstream school and had been refused to assess for an EHCP and they were spending precious moments fighting against the system rather than making memories with their son.

### **Other support**

We have been able to talk to parents about SENDIASS and how they can access their support. We discuss the Local Offer being good sources of information for some of their issues and have helped by showing how they can access this. We also shared examples of ranges of support groups across the district.

The majority of issues related to difficulties in communication with school and services, accessing information and support, a lack of understanding of the lives of SEND families and the impact this has on parent/carers mental health and wellbeing.

Table 3 provides a list of the most relevant and numerous issues and barriers that parent/carers raised.

**Table 3 – Areas and Barriers**

<b>Lack of understanding (Lived Experience)</b>	<b>Communication</b>	<b>Access to support and information</b>	<b>Other</b>
Lack of support and understanding in education and health for children who have life shortening illness Lack of support and understanding when there is a medical condition not just autism Lack of knowledge or support from health visitor when there is a suspicion of need Poor understanding of SEND in health services and schools Lack of school nurse support Lack of knowledge and understanding of autism in school Masking Mental health struggles Behaviour Challenges Emotional Based School Avoidance Pathological Demand Avoidance	Parent blaming Toileting needs not being adhered to in school Parents not being listened to Lack of communication between all services involved Schools refusing to apply for EHCP Schools not understanding that EHCP doesn't just cover education	Long waiting times for assessment Inability to get a social worker Not being able to get on the assessment pathway Inability to get a carers assessment Difficulty in speaking with health visitor/school nurse Continance issues and how to get support if wet day and night Annual reviews Sleep Issues Behaviour Support Sensory Issues Bedwetting Poo Issues	Sibling support Worries about the future Worries about transition to high school How to talk to young people about sex and periods Inability to get adjustments made to the house for physical disability

Parent/carers in general were appreciative of the Senco of their schools and one parent commented on their school being a 'good fit' for their child.

## IMPACT

When the programme was first rolled out it was expected to have a positive impact on parents but we didn't realise how much impact it would have not only on parents but also children, schools and professionals.

*"This is the first time I have ever really spoken about my son. I thought it was going to be difficult but as soon as I started talking, it all just came out. It makes a big difference talking to someone who understands" - Parent*

### Impact on Parents

Parents gave feedback on the sessions and reported feeling more confident, less isolated and relieved to know other people are going through similar situations. There was surprise that there were so many other children within the school that had disabilities and it made parents feel as though they were better connected. For some parents it's been the first time they have spoken honestly and openly about their children and because it is in such a supportive environment, it's been like a weight lifted from their shoulders. It doesn't solve all of the problems but it gives an opportunity to share with people who understand and are removed from their personal situation.

Being able to hear and connect with someone with lived experience, receiving information about support groups, SENDIASS, Local Offer, max cards and some positivity about life made parents feel like there was hope.

Parents in a number of schools have formed WhatsApp groups so the support network doesn't just occur at the coffee mornings and during school time.

*"My son's class has a What's App group. They were all talking about a birthday party and my child was the only one not invited. I was so upset and it was cruel. After meeting others at the SEND coffee morning, we have started a new What's App group and I know that this will be supportive and not at all like the other one" - Parent*

### Impact on Children

The sleep session in particular should have a positive impact on children. Better sleep for both parents and children can only be a good thing. As this is a relatively new part of the SEN support coffee morning offer we are yet to hear from parents whether there has been an impact because these things do not happen overnight but we will stay in contact and ask. Parents certainly liked the suggestions given and were very willing to try them out.

One school was going to consider running a silent disco to be more inclusive of those children who had sensory issues and the music was too loud. In some schools parents had arranged meet ups in the park in the good weather so children could socialise with understanding and without judgement.

### Impact on School

Discussions have been incredibly honest, emotional and powerful. For many SENCo's it was the first time that they have heard what kinds of situations the families are dealing with. Yes they might have an understanding of what the disability is but to hear first-hand exactly how it impacts on the family life and wellbeing on a day to day basis is a real eye opener. Hearing lived experience enables professionals and practitioners to consider

and have insight into more holistic, solution focused learning and support. Additionally a better understanding of 'reasonable adjustments' that work for both school and families.

Feedback such as how different the approach might have been to insisting on a 9am start if the school had known that the child and parent were only getting three hours sleep per night and really struggling to get to school.

Or how they might have been a little more relaxed on the uniform situation if they'd had a better understanding of sensory issues and how physical pain can be felt from a pair of trousers or how socks can cause such anxiety leading.

Hearing how the child is at home after a day at school when they are masking makes them more likely to look at changes that could be made in the school environment to support home life too.

Both schools and parents have realised how important communication and the relationship is but this will only be developed if a parent feels listened to when they raise a concern about their child in the first place. If they feel blamed or unheard the relationship may already be damaged.

*"Peer support for our parents is incredibly important. There is only so much we can do and the numbers of children with additional needs is increasing. We will definitely be recommending the coffee mornings to other schools in our academy" - Senco*

### Impact on Professionals

As previously mentioned, we have been able to link up with the SEND Specialist School Nursing Team and invite them along to some of the coffee mornings. Being able to see how the peer support works first hand has had a profound impact showing the power of parents supporting and empowering each other. They feel that this peer support model could fit in with their work too.

### OUR LEARNING

The peer support model really works. The initial target was to work with 5 schools but it has been so popular that there has been involvement with 21 schools and there are 9 schools on a waiting list to begin sessions in the new school year beginning September 2023.

The main learning from this piece of work is that the coffee mornings have to be massively flexible and can move in any direction depending on what is going on for the parents in attendance at that time in their life and what they want from the sessions. Some parents want information, some want a safe space to vent frustrations, some just want to listen and so on. Parents want to hear how the facilitator (with lived experience) has coped, what strategies they have used and how have they overcome barriers. This leads to open conversations where parents can pick up tips and hints from others and SENCo's can hear this , appreciate what families are coping with and maybe try some of them in school too.



Sleep and behaviour are the two single biggest issues talked about. We accommodated a sleep session in the offer but a behaviour session would be a fantastic addition too.

There have been a few things that haven't gone so well that we have learned from. Sometimes parents just don't turn up for whatever reason. Usually life happens. There have been a couple of occasions where one parent has attended so they have had more of a one to one session. However, there have also been occasions where parents have found the coffee mornings so valuable that they have come in their pyjamas. They have had a struggle getting their child to school but have not wanted to miss out.

There were two schools who already had a coffee morning set up so only wanted me to attend once to talk about PFBA and speak from lived experience which PFBA are happy to do as part of their engagement plan.

There was on occasion where a parent disclosed information that raised some concerns. The SEND specialist school nurse was present so took forward a referral to social services but it did lead to discussions about confidentiality and what to do if there is a safeguarding concern. Our safeguarding training and policy has been updated and firm plans put in place if similar were to happen again without a healthcare professional being present.

The original aims of the project were modified as we moved along. Initially we were going to set up some coffee mornings, facilitate them and then hand over to the parents to continue with a structure. It became very apparent, very quickly that after hearing parents share their experiences we were building confidence and resilience, sharing information, signposting, building a new support network, improving communication and relationships with school.

The feedback we have received not only from people directly involved with the coffee mornings, but external conversations about how powerful they are has been fantastic and how amazing it would be for this offer to be available to ALL schools and not just the SENCo's who contact us and ask for them.

## Conclusions, Recommendations and Limitations

It is imperative that this programme is delivered by someone with lived experience of supporting a child with SEND. That is the element that gets parents to open up and share their own experiences when they hear how someone else has really struggled with the same issues so understands. It is also essential that this programme is not just an autism or neurodiverse specific coffee morning but is offered to families of children with all disabilities so as to promote inclusion and not distance them further than they already feel.

- Future plans include developing a more detailed evaluation broken down by health, education and social care but discussion would need to take place to identify what services would find useful.
- Evaluating longer term to ask parent/carers about increases in knowledge, resilience, mental health, empowerment and improved outcomes for their children and family.
- Improving better ways in sharing impact and lived experience with key stakeholders.
- We would seek to align with family hubs to integrate with the early year's services, offer support and information at the earliest opportunities and build relationships with specialist teams.
- We will like to provide ongoing support and training to schools as and when required once PFBA has stepped back and seek to maintain connections built with schools.

PFBA would love to deliver peer support coffee mornings in all schools but also develop the relationship with the family hubs to deliver in conjunction with them too.

Delivering such a positive and empowering programme has emphasised the importance of good communication, early help and support, equality of relationships and working in co-production with families.

We already know this model works and are delivering it to full capacity currently so would make sense to roll this already running and successful offer district wide. Therefore the biggest limitation is not having the funding to expand, recruit more staff and offer this districtwide.