

PaCC Early Years Report – October 2023

Early Years in Brighton & Hove - Collating and evaluating information from parent carers about their experiences.

INTRODUCTION

PaCC is a parent-led carer forum which represents parents and carers of children and young people, up to 25, with disabilities and additional needs who live in Brighton & Hove.

PaCC wanted to consult with parent carers of children aged 0-5 to find out about their early years' experience and identify what their families need and what is working well. PaCC was also interested in establishing whether there is a current need for a new Early Years parent carer support group, as some support groups are no longer in existence post-Covid.

A decision was taken to approach parent carers at existing stay-and-play groups they were attending with their children and ask if they would be willing to participate in a 1:1 interview.

This report is based on interviews with 11 parent carers with pre-school children. All except two of these interviews took place at the drop-in stay and play sessions at Jeanne Saunders which take place on a Monday, and the invite-only sessions which take place on a Tuesday. The remaining interviews took place elsewhere for those who wanted to participate but were not in attendance at these groups.

Of the 11 interviewees, 3 had children attending Jeanne Saunders Nursery, 7 were attending other settings and 1 was not in a nursery. Some of the children had already received a diagnosis and others were on the pathway to assessment.

Participants were interviewed individually and asked 4 open-ended questions.

- 1) What is going well for you and your family?
- 2) What are the biggest issues for you and your family and what could be done differently to help you?
- 3) Would a support group help? How would that look?
- 4) What else could help you and your family?

FINDINGS

- **Q1) What is going well for you and your family?**

Jeanne Saunders Group – All parent carers reported that the Jeanne Saunders stay-and play group was helping their family, and appreciated how welcoming the staff were and the attendance of workers from BHISS and Amaze. One participant said ***“It’s great that BHISS are here, it gives them a chance to observe my child and I get the opportunity to ask questions.”*** One parent carer commented that having the same songs and same routine really helps their child and they really look forward to coming each week, but that it was a shame that it only ran in term-time as their child expects to be able to go during holidays. Parent carers were grateful for the free Makaton courses and ‘Time Out’ courses for parent carers provided by Jeanne Saunders and had found them helpful. Several parent carers commented that the PEC system used by the centre and picture cards given to families for use at home was really helping them communicate with their child. Parent carers also talked about the importance of parent-to-parent knowledge sharing at the group, one parent stated ***“I’ve learnt so much coming here about what we are entitled to, which has really helped our family, for example how to apply for DLA.”***

Nursery & Starting School – Several parent carers reported that the support they and their child was receiving at nursery was going particularly well, including support in the setting e.g. 1:1 ratio support, feeling heard by the SENCOs and support with getting an EHCP. One parent said ***“I can’t fault the (mainstream) nursery, they have been excellent and have already started the EHCP process.”*** Two parent carers stated they were pleased with their child’s school placement for September, one had a place at Downs View and the other was going to Hill Park. Another parent carer was pleased that their child had been accepted in the Jeanne Saunders Nursery and would be starting in September.

Diagnosis – Some parent carers reported a straightforward pathway for an autism assessment for example, but this was not representative of the group as a whole as these were predominantly parent carers whose children had additional needs that were identified at birth so were already under a paediatrician consultant. There were several parent carers who stated explicitly that they believe their relatively quick diagnosis and support after was down to the tenacity of their health visitor or nursery SENCO. One stated ***“My health visitor was like a dog with a bone, in a good way, she really fought for us.”***

Therapy – Parent carers were more than happy with the speech and language therapy their child was receiving, when it was available, but expressed frustration at having just a 6-week block of sessions before ending up back on the waiting list for more. Several parent carers were either considering paying privately or were already doing so, commenting on the

importance of early intervention. One parent said ***“We are paying privately because he is now three and half and we can’t just keep waiting. He is coming along really well with the speech and language therapy. He needs physical therapy too that he isn’t getting, but we can’t afford both so we are prioritising this.”***

- **Q2) What are the biggest issues for you and your family and what could be done differently to help you?**

Waiting Lists – Parent carers raised the issue of waiting list times for both diagnosis and therapy as one of the biggest issues for their family. Parent carers stated they recognised this was due to lack of funding in services for children with additional needs but were frustrated at the wait, having to chase things up and how restrictive services were when you get to the top of the list. When therapy was received, one parent carer commented it should have been more often. ***“My child was given speech and language therapy once a fortnight, it really needed to be more intensive for it to work, for example weekly.”*** Another parent carer stated ***“We only had a total of 3 NHS SALT sessions and if we want more we’ll have to pay privately.”***

When it came to waiting lists for assessment, overall parent carers felt it was often dependent on how astute the professionals were in advocating for their child as to whether this was a straightforward process or not. Further to this, parent carers expressed the need for a multi-agency approach to assessment which would avoid a dual diagnosis being missed or another long wait in the future. They raised the same experiences for family support and said it would be helpful for service professionals to share information and work together more with regards to their child. One parent carer said ***“Families should be offered a TAF (Team Around the Family) far more readily.”***

Even being placed on a waiting list was a battle for one parent carer, who also expressed frustration at the implications of this in terms of parent carer support, ***“Since my son can’t even get on the waiting list for diagnosis, I can’t access courses for Autism or ADHD to help me.”***

Childcare – One parent carer, whose child had been offered a place in Jeanne Saunders Nursery from September, was concerned at how they would manage getting to work on time and dropping the child at nursery because of the nursery session times. ***“I’m still not sure how it will work from September, I have applied for transport, but it doesn’t solve the issue because I’ll need to have left for work before transport collects them.”*** They would like to see more nurseries like Jeanne Saunders across the city and for sessions to start earlier, to help working parents.

Another parent carer said one of the biggest issues for them was working at the moment, because their child required extra support. They stated ***“The LA will only match funding for ratio-support for the amount of hours my child gets free, which is only 11 hours a week when the free 15 hours is stretched over the whole year, it shouldn’t be like this.”***

Changing settings – Parent carers spoke about the need for a broadly accepted transitional framework for when children move from one nursery to another nursery or from nursery to school and feeling that reasonable-adjustments are more likely to be made for those with severe needs. One parent carer said ***“I spoke to them, but I didn’t feel confident they would do as I had requested. It was only when I put it into writing in an email that I felt listened to. I created a transition plan on my own and presented it to them. They agreed to it but it would have been better if there was some kind of transitional framework already in place. It also meant when I accompanied my daughter, I felt judged and felt that some staff were wondering why I was there because they clearly weren’t used to it. I’m concerned about other parents, who don’t know what they can ask for or even that it’s ok to ask.”***

Lack of understanding – Parent carers spoke about experiencing a lack of awareness of additional needs in nurseries and schools, and how this impacted their families. Parent carers felt that more awareness would help schools be more welcoming for children with additional needs, if robust knowledge of SEN was established early on. One parent carer stated ***“Like a lot of children, my child has sensory items. When my child started at the school nursery, the nursery teacher didn’t know what they were or why they needed them, and my child kept getting questioned by other children and felt pressured to endlessly explain. There is no reason why this can’t be taught at a basic level for 3 and 4 year olds, and the same goes for stimming, or other things a child might do that is different from the norm.”***

- **Q3) Would a support group help? How would that look?**

The vast majority of parent carers would like there to be an additional support group they could attend with their children. Most parent carers wanted this to look like the Jeanne Saunders stay and play session which takes place on a Monday morning but suggested it might be good to have it on a different day and in central Brighton because of those living in the east of the city.

Several parent carers commented on the fact the Jeanne Saunders group only runs in term-time and they would prefer a group that ran all through the year to both keep the routine for

their child and because they really enjoyed the group. One parent carer said ***“My son relies heavily on routine and doesn’t cope well in the school holidays when there is a change because this group isn’t running. He doesn’t understand why his group isn’t on.”***

Other parent carers said it would be good to have another group because Jeanne Saunders Monday group is very popular and can get very busy at times. One parent carer said ***“Yes definitely, another group would be great because this one gets quite busy, I think Jeanne Saunders should be open all week as a drop-in for parents and children as it’s such a valuable place.”***

Parent carers at the Monday group had heard about there being a Tuesday group and were keen to attend but said this was invite-only and specifically for those who were not offered a place at Jeanne Saunders nursery. These parent carers wondered if this could be opened up to more children as they were keen to attend.

Some parent carers, who were working and didn’t have an additional day off, said a further group wouldn’t help them but said they believed it would benefit others. One parent was nervous about going to new things but would go if someone accompanied her the first time, like they had when she first attended this group.

- **Q4) What else could help you and your family?**

More guidance and support – The parent carers need more guidance on what to do and where to go for information. Several had reached out to Amaze and the SENDIASS helpline, but it had taken a long time to get a reply. Some parent carers spoke about needing this information in an accessible format, for example a diagram of available services, or where to go next, for busy parent carers who want to find out information quickly.

One parent carer said a single-parent support group for neurodivergent children would really help them. This would be beneficial to a wide range of parent carers, not just those who start their journey as a single parent, because of the unfortunately high proportion of relationship breakdowns for those caring for children with additional needs.

More spaces in SEND provision – Parent carers highlighted the need for an increase in places in special needs schools and nurseries so they wouldn’t be worrying about whether their child would get a space. Parent carers are aware that every year, Jeanne Saunders Nursery is massively oversubscribed, as are the special needs schools of Downs View and Hill Park. One parent carer said, ***“I don’t want a situation where the setting is inappropriate and results in my child not wanting to go to school, which I’ve seen happen to extended family members.”***

More SEND play sessions – Parent carers spoke about the need for more SEND sessions for them to take their children to and for these sessions to be more accessible. One parent carer stated *“My child is really challenging, when we go to the park he just wants to escape and it’s really stressful. I feel the other parents judge his behaviour and how I deal with it. It would be nice to have more SEND sessions at soft play centres and other places, and to have these at more reasonable times of day than first thing in the morning or incredibly late.”*

CONCLUSION

- The Jeanne Saunders group is very valuable, particularly as BHISS and AMAZE attend them.
- Parent carers generally feel their children are well supported at nursery, but wanted an established transitional framework, more staff training, and children to be taught early about differences.
- Some parent carers felt that their child’s diagnostic wait time was dependent on whether professionals were advocating for them and how much they, as parents, have the energy to chase things up and advocate for their child. A multi-agency approach so diagnoses aren’t missed is needed.
- Parent carers are very happy about the quality of SALT but frustrated with the waiting list. They feel they have no choice but to pay privately so their child can access this essential early help when they need it.
- More special needs nurseries are needed in the city, and earlier sessions to assist working parent carers. If parent carers need childcare and children need ratio-support, then this should be funded for all the hours the child needs.
- Similar ‘stay and play’ support groups for parent carers to attend with their pre-school children are very much needed with them running throughout the year.
- Parent carers need information to be in an accessible format, particularly when explaining how to access what their children need and are entitled to. Parent carers acquired a lot of valuable information by talking to other parent carers, both a new parent and child support group and a single-parent support group would help to facilitate this.
- Parent carers were concerned about the lack of places in specialist nurseries and schools and the impact this could have on their child’s educational journey.
- Parent carers wanted to see more SEND-specific play sessions at venues across the city and wanted them at more reasonable times of the day.

FURTHER WORK

It would be valuable for PaCC to conduct a wider parent carer survey to obtain data from a larger sample.