

PaCC Focus Group

Social Care/Residential Care - what could be done differently? 21st May 2018

In Attendance; Naomi Cox, Fiona England Chair of PaCC, Jo Levi PaCC Admin and Comms
3 Parents (anonymised)

Parent 1 (P1) - daughter 18

Parent 2 (P2)- daughter 17

Parent 3 (P3) – son – age 16 – autism and learning difficulties.

Introduction

FE- are we missing a trick? Families who've been through social care have a huge amount of knowledge and that's part of the reason we want to listen to you. This is a reflection on those moments when we really need help.

NC- what support felt like, how it started, what worked, what didn't etc.

Extended day model

Very little money and we have to think differently and use the money wisely so we need to listen to the parents who've been through it.

Early Years

- P1 – BHIP –
- P2 - lack of provision – sent her to BHIP on Saturday mornings – meant well but there was no safe-guarding – both children had injuries. We were so desperate we continued to send our children there.
- FE at that stage were any in communications with children's disability team? P1 - No – Tracey Young gave help about sleep and eating. Amazes were lifeline.
- FE – the opportunity group – pan disability – nurturing for us. All 3 say they never heard about it
- Did Brighton & Hove identify all 3 with Presens? P2 not in B&H at that stage. P3 son went to Jean Saunders and P3 daughter went to East Hill
- FE – identifying areas where we could have been signposted. P1 - East hill – found it very depressing going there because daughter didn't fit. Wasn't the right place for her. Jean Saunders wasn't appropriate because she wasn't able to navigate the stairs. Had a massive effect on child.. First 2 years went really well at Mainstream school. She's better with children who are more able for her.
- FE – One positive – Jean S have now made adaptations.
- FE - Pre-school – are you already feeling at pre-school can't cope it's too difficult?
- P2 - spent first 4 yrs not speaking to anybody. No help. Pebbles and Sweetpeas were all there was. There was nothing for us to go to – they in themselves

Parent Carers' Council (PaCC), Community Base, 113 Queens Road, Brighton BN1 3XG

• Tel: 01273 234 862 • email: admin@paccbrighton.org.uk • www.paccbrighton.org.uk

presented challenges – there was nothing else but it wasn't safe for our younger children. Siblings are a huge issue.

- FE - Pebbles and Sweetpeas still successful – do they still have families coming in where it doesn't work for them? Is there anything that could support the support groups? More skilled workforce needed to support the groups and the siblings. One child would be ok. P3 couldn't go because she had an older son she couldn't take. It was far away and parking was an issue. Park Side school Heathfield – great school – could be a good space for SEND kids. Not having places to go. Want nice places to go.

School Years

- FE - School age – when are you being actively sign posted or not?
- P1 - School? Downs Infant- daunted but took daughter on . Desperate – paying for help because they didn't get Direct Payments because she was in mainstream. I investigated Bernardos link – I did this – no one told me – I instigated it.
- FE – wrap around care needs to exist no matter where your child is. Also the emotional support not happening.
- P3 – transport issues – logistical nightmare. If wrap around care exists it's great for parents who have the issue with transport. If school carried on longer and took on transport would be amazing. Would help with issues with siblings
- Fi – something more nurturing from an early age.
- P2 – even asking for respite felt like we're asking for a holiday – time off to relax. It just wasn't like that.
- FE – could there be someone we could talk to? Can school play more of a holistic role in supporting families?
- NC – extended day. Who could be there on sight that could help co-ordinate and support?
- FE – transport yearly battle, there are battles with everything. We know there's no magic wand but professionals need to learn we find everything is a battle and nothing is joined up and it really takes it's toll on us. My mental health really dips when this happens. Then my parenting gets worse, I want to leave and throw in the towel.
- If we were supported earlier – could you perhaps be thinking – life hasn't been as difficult – I could cope then with the future and looking after my child.
- P1 – safety – people not being equipped and trained to keep child safe. It's about training. Finding a carer who can cope is like hen's teeth. Coping with rejection because your child is hard work. Carers can't cope and child rejected. More highly skilled carers needed.

Extended days

- FE Could PA development work be included somehow?
- Could there be PA groups where they can get together and support each other? Nowhere to go with the children. Could this be a place to advertise to go in B and H for PAs to come along?
- NC – providers are up for doing things differently too. Extratime , crossroads etc.
- FE common theme about PAs being an issue.
- P3 – Direct Payments – they don't care if you use them because they know we can't find PAs.
- P2 – can't do spontaneous payments too complicated.
- P3 – organising DPs is very complicated and stressful
- FE Possibility People – do they offer training? Can this PA group include training opportunities?

Parent Carers' Council (PaCC), Community Base, 113 Queens Road, Brighton BN1 3XG

• Tel: 01273 234 862 • email: admin@paccbrighton.org.uk • www.paccbrighton.org.uk

- Could there be a grading that the more experienced, qualified carers get more money? They should be on a higher rate – our children need a higher level of care.
- P1 – is there opportunities for link ups with the social care team at university? Is there more potential for links? Students from Uni – could be carers? Could student midwives be carers? PA usually a root to something else.
- FE – important for B & H to acknowledge different levels of care. These students could really understand these levels of care.
- **NC - Opportunity for extended days and hubs – emerging still - if you're saying Saturdays more important – or what works? Exploring the schools being open on Saturday. After school clubs – if people could have dinner at the club? Would that help?**
- P3 – the ideal would be if they can get transport home. Adds to stress having to pick child up too
- NC – how late for the child? All agree 5/6ish. Flexibility about time? Half day options?
- FE – bedtime routine – is there scope for someone to come and help support with the evening routine?
- P1 – wouldn't work for us because hard to have carer and me in the house at the same time.
- FE – someone instilling routines early on as help.
- NC – could be a short term thing – to help instil early on.
- P1 – just checking in with parents on how they're coping – advice for parents would help. Hard for a lot of children to cope with having someone coming in from school. Someone from a different team? Just having someone to talk to and have advice could help.

Behaviour support

- P1 – health visitor amazing – came round all the time to support and would come to appointments – did referrals. Fantastic support. Matt Howson – social care team – support. Mary Bond in CAMHS was able to help.
- P2 - would just be a relief to have just one person to support you.
- FE someone to sit and talk with once a term who will helpfully support and nurture. Schools need to play more of a nurturing community relationship role.
- P2 – I hate these big meetings – some of them don't know the children, not enough time, everyone sits there with bar charts and behaviour charts – just want to see people who I trust and know. Having an advocate/voice would help.
- P3 – lots of people don't know what's out there. There's no central place. Arbitrary about what help you get. If you don't ask you don't get. Unfair that people fail. Crisis model.
- **NC – do you think if we did things better sooner we could avoid a crisis and wouldn't need so much support now?**
- P1 – Teacher at Hillside set up behaviour groups which really helped. Helps give more energy to support.
- FE – behaviour courses – should be part of a normal process.
- P2 – if part of early years could fit it in.
- FE – extended days – could we tailor it? Could there be a behaviour course that fits in with times? While the children are actually at the club? Saturday club – there's a parallel training course going on at the same time.

Holidays

- FE – how to cope in holidays. If the special schools offer extended days but nothing in the holidays? Would it be better to have 2 days in the week and more days in the holidays.
- FE - Coping in holidays virtually impossible. Is it at this stage that you start asking for residential overnights because it's all too much?
- P1 – Barnado's link – the dynamic was they were doing me a big favour and I just had to be grateful for what we got. Drove Road felt better.
- FE – are you saying Drove road had expertise and knew what they were doing?
- P1 – felt safe and Drove rd only place where I feel she's safe.
- FE – not the level of skill with PAs as there is in D road in other places.
- P1 – there are dynamics to deal with – children trigger other children. Drove road manage that because they have to.
- **NC- Drove rd and Tudor house – spending a lot of money running this but not a lot of families are using this. If we'd done things better earlier could people manage better?**
- P1 – used to feel guilty dropping off with a carer but didn't feel this with Drove road. Has shifts which makes easier. Link family couldn't cope – that was the voice that was heard in the end – that even the link family couldn't cope.
- FE – adds to stress levels that you have to keep telling people that you're not coping. Perhaps the extended day model could have absorbed some of the stress. Also something about nurturing role of the school would have helped.
- P1 – if there was an extended day – siblings could have friends over – extended day would make a huge difference to family and siblings.
- P2 – feels like you're always trying to get something out of this but just telling how it is.
- P1 – if you're suffering in silence could be very hard. Bruising – had a phone call – end up police involved. No one warned us this could happen. How do schools deal with that? Can't families be warned and get advice? Also advice that you should always mention bruises in home school books.
- FE – extended day – could be looked at as social care provision. Assessment process is difficult and onerous. We know there's budget constraints. Is there the hope that extended day could remove some elements of the assessment process?
- NC – could get to position where social care part makes agreement with school .
- P3 – children change – teenage years.
- FE - Should be assumed that it will get harder as kids hit teen years. Falling off the cliff moments.
- P2 – if we'd just got support. Stuck with people sometimes who you don't get on with – having an advocate would help in these situations. Advocate instead of the social worker.
- **NC – looking to next generation coming through – what would have supported you to need less overnights?**
- P2 – help in the holidays. If I could have 2 weeks holiday with my family. Somewhere you could send your child for 4 nights even. That would help.
- P1 – holidays are the hardest thing. If you miss deadline for extratime. Limited spaces at extratime
- FE - Need extratime to offer more.
- P2 - Only option is extratime nothing else on offer. Even if they just offered morning or afternoon. Doesn't need to be a full day. Half day would be a great option.

- FE – some issues could arise because of an extended day. Child has already been there all day. They'll need to think about how it changes from 'school area' to something else.
- P1 – daughter goes to drumming club or dance group.
- FE – other organisations could come in and run things.

Key themes and recommendations.

Having appropriate places to go in Early Years

Hard to find appropriately trained workers and PAs

Siblings not being safe in social groups

Transport to and from provision a difficulty

Holidays – very difficult to find support and places to go

Having the stress of having to battle for any kind of support