

## **Kingston Parent Carer Consortium: Wednesday 14th June 12:00-13:30 Meeting Minutes**

**Parent Carer Forum / Parent & Carer representatives:** Bev Pass, parent and PCF chair (BP), Linda Nystrom parent (LN), Helen Murphy, parent (HM), Asif Mullan, parent, (AM)

**Staff:** Ashley Whittaker, Programme Director, AfC (AW), Helen Barnett, SEND Policy and Project Coordinator, AfC (HB), Megan Francis-Falkner, SEND Policy and Project Officer, AfC (MF-F), Caroline Roberts, Inclusion Development Officer, AfC (CR), Geraldine Burgess, Short Break Operations Manager, AfC (GB), Rob Harris, Parent Carer Engagement Officer, AfC (RH), Jonathan Rourke, SENDIASS (JR), Karen Lowry, AfCinfo and SEND Local Offer Website and Content Manager, AfC (KL), Kelly Nash, Education Support and SEND Strategy Manager, AfC (KN), Councillor Archer, Portfolio holder for Children's Services including Education, Kingston Council (SA), Sharron Nelson, Deputy Head of Transformation for Kingston and Richmond, Integrated Care Board ICB (SN)

### **1. Welcome, introductions and apologies 12:00-12:05**

Apologies were sent by Anna Chiva, AfC (AC)

Noted that Jo Thomas, a parent who normally attends this group is not here due to attending a strategic meeting / workshop with South West London ICS.

### **2. Parent Carer Forum update 12:05-12:10**

- BP reported that the Parent Carer Forum has been running focus groups to help develop the understanding of what parents and carers need and are looking for in relation to the SEND Futures Plan review which is due for council committee approval in November 2023. The focus groups were not quite as well attended as hoped however the level of discussion has been good and useful findings have been made. BP noted that she has not attended any of the groups as a deliberate move to allow the attendees to participate fully and openly in the session.
- In total there are 7 different focus groups, each one focusing on a different area of need within the parent carer SEND community; 5 groups have run with the final session taking place on 15/6/2023. Results of the 6 focus groups will be collated to inform an online discussion group on 28/6/2023 chaired by BP. A short survey will follow to help validate the topics raised at the discussion group and the results of this will be sent to the Council, ICB and AfC to feed into the updated SEND Futures Plan.
- BP advised that she has been involved in the administration of the financial contribution offered to all focus group attendees. This has proved more complicated than planned.

### **PCF issues raised:**

#### Blue Badges

- BP reported that across the borough there is a delay in the issuing of Blue Badges for both renewals and first time applicants. Families are experiencing hardship as a result of this and in some cases their badge expires before the replacement is received. The PCF would like to know current time scales and what plan is in place to address waiting times as children, young people and their families are hugely disadvantaged. LN noted on the chat function that her elderly neighbour had been without her blue badge for 2 months so it is a community wide issue.
- CA asked if badge holders receive a reminder letter.
- BP advised that yes a reminder letter is sent out and users are renewing in time but the process is so delayed there is often a gap between the current badge lapsing and the new one being received. Anecdotally, some residents are being asked late into the process for further information which causes delays and if they are existing badge holders this information would have been submitted upon initial application.

- **Action:** SA and AW will also make enquiries about the issue and feedback to the PCF.
- AW thanked BP and her colleagues who helped to design the format of the focus groups, specifically the ice- breaker segment which although can be quite nerve-wracking has really helped to relax the attendees and facilitate honest conversations. AW reported that MF-F has shared the write-up from the first three workshops with the rest to follow. AfC and Kingston PCF are meeting on 20/6/2023 to go through the main themes of the workshops.

### 3. Child and Adolescent Mental Health Services (CAMHS) 12:10 - 12:35

- Mental Health assessments
- CAMHS review systems
- Sign off process

- AW introduced SN who suggested that in a future meeting it would be helpful for those leading on delivery of different parts of the mental health system to join this meeting
- **Action:** SN to invite colleagues to a future meeting

SN gave an update across all services:

#### Community services

- Autism assessment process is a piece of on-going work. No major updates since the last meeting.

#### Mental health services

- The team have collated strategy plans from across Kingston to feed into the South West London Mental Health Service mapping document. The map includes statutory, voluntary and community groups providing a 'one-stop shop' to focus on what is currently on offer and where there are gaps.
- **Action:** SN to contact BP to identify any gaps that parents and carers have in the mental health service offer in Kingston.
- SN reported that the issue of children and young people with autism accessing mental health services has been raised at a regional level (South West London). SN added that from experience, managing issues at a regional level expedites a response as it looks at a wider situation.
- SN added that as Kingston is one of the highest ranking boroughs for eating disorders, work is being carried out to ensure the Eating Disorder Service is fit for purpose with a clear pathway. SN has raised this issue at a regional level.
- BP raised the issue that historically the Eating Disorder Service has been closed to children with autism and in particular those who experience ARFID (Avoidant Restrictive Food Intake Disorder). The focus has been on anorexia and less so on younger children who experience anxiety with food. BP asked that a wider perspective be taken as it is as much a health issue as a mental health issue, resulting in medical intervention.
- SN acknowledged that ARFID and autism should receive equal support and this has been raised at a regional level.
- **Action:** LN asked for a status update for an online course 'Beyond Fussy Eating' for which LN made a video contribution. SN to liaise with Jo Steer for an update on this.
- **Action:** SN to share headlines from the transformation strategy document and will present at the next meeting.
- BP asked RH if any themes around mental health services have been raised in the parent carer focus groups that SN should be aware of. RH advised that a recurring issue is the length of waiting times for CAMHS referrals and the varying levels of service received between tier 2 and tier 3 (one is managed by AfC, the other by South West London NHS Mental Health Trust ).
- HM stated that a referral to CAMHS for autism and ADHD for under 5s can be made through Holyfield House. HM added there is a lot of confusion amongst professionals and parents regarding CAMHS and services available to 0-5 year olds.

- SN advised that the aim of the mapping document (see above) is to set out a clear pathway for all age groups.
- AW added that the Kingston Transition Board is looking at the gaps in the pathway from child services to adult services.
- **Action:** AW asked MF-F and HB to ensure any mental health issues raised in the Kingston Parent Carer Consortium minutes are captured and used to inform the revision of the SEND Future Plan.
- RH reported that a PCF parent champion is working with the Board at Kingston Hospital to implement autism friendly strategies for out-patients across all services. Feedback from the PCF and from other local parents of autistic children who have accessed the hospital services has been gathered to help inform the planning of a new unit.
- AW added that there is a Learning Disability Support Worker for adults at Kingston Hospital whose ambition is to expand their offer to children and young people.
- **Action:** AW asked if parents and carers would like this deep dive topic be carried forward to the next meeting and this was agreed

#### 4. Short Breaks 12:35 - 12:45

- AW advised that following a meeting with BP it was agreed that this topic should be discussed in the Consortium due to significant increase in uptake over recent years and resultant pressure on finances. This increase has been apportioned to the availability and increase in the quality of information as well as higher levels of need. Funds have been exceeded substantially raising the question of continuity. Currently, shorts break allocations are divided into two categories: needs assessed and open to all, with the Activity Fund open to both categories.
- GB advised that the particular concern is around the Additional Support Fund which is based on a social workers assessment of a family that is submitted to a Short Breaks Panel. The issue arises when the same family draws on more funds in order to access Universal Services resulting in other families not having access due to lack of capacity i.e. a mainstream after school club, holiday club or 1:1 support.
- BP explained the situation as 'one bite of the cherry' and if a family has an agreed Support Package based on assessed need they are unable to access additional funds.
- HM explained that her child has complex needs and is currently accessing short breaks at entry level but would appreciate a clearer pathway. Her child does not meet the threshold to be on the Disabilities Team caseload but is unable to access mainstream clubs.
- GB advised that HM can access the additional support fund for activities such as Challengers and the [Local Offer website](#) does show what's available to children with SEND.
- JR raised the question of a setting's duty relating to the Equalities Act i.e. providing a support worker in a mainstream setting.
- GB advised that despite quoting the Equalities Act, unless additional funds are offered, it is difficult for SEND children to access activities in certain settings. This is mainly due to gaps in staff training and the scope of a play workers job description.
- AW echoed this in relation to the themes being raised in the parent carer focus groups and a growing concern amongst families that SEND children are unable to access mainstream activities.
- LN noted that parents have contacted her directly asking how their child can access mainstream clubs at primary school. LN asked how this information is shared amongst schools etc.
- GB advised that information is shared via the SENCO newsletter which should then flow out to parents and carers.
- BP commented that information sharing must be working due to the increase in demand for Short Breaks.

- KL alerted the group to a new page on the Local Offer website '[Child Care including School Holidays](#)' highlighting where and how to access child care including contacts in the Family Information Service. This work has been done in collaboration with Jo Thomas from the PCF.
- **Action:** RH to update the SEND PCF leaflet with guidance on Short Breaks
- **Action:** GB to provide a one-page document summarising current access to Short Breaks and Activity Funds and the financial decisions to be made going forward.

## 5. Participation, Engagement & Co-production update 12:45 - 13:00

- RH gave an overview of the SEND Futures Plan and how the current parent carer focus groups are feeding into this to help identify priorities and how resources are allocated. To date, 5 focus groups have run with the final session taking place on 15/6/2023. This culminates with an online session chaired by BP including only PCF members with no AfC staff attending. The topics covered so far: Neurodiversity, Early Years, Secondary, Post-16 and Complex Needs. Some sessions have been attended better than others but all conversations and comments are valid and based on a 'you said, we did' strategy.
- In addition, RH is running focus groups in June and July with parents in 3 schools across Kingston - Dysart, Burlington Junior School and The Kingston Academy.
- [Parent survey will go live within](#) the next few days until the end of July as another way to capture parents' voices.
- RH met with Linda Jackson from Tolworth Schools to discuss their special resource unit and the high levels of parent interaction. RH is hoping this will lead to more [SEND Parent Carer Champions](#) joining the forum.
- RH met with Noreen Ahmad (parent champion) to discuss the cancellation of the ethnic diversity focus group due to no sign ups. RH stressed the importance of hearing from minority ethnic groups regarding access to SEND provision so joining an established community group, sending out a targeted survey or including ethnic groups in general surveys are areas being explored to gain more traction. BP highlighted that a range of people have attended all the focus groups.
- LN asked if leaflets were made into different languages would this increase participation. RH advised that the Local Offer website is available in 150+ languages but a digital solution for a leaflet in other languages should be explored.
- KL added that a directive came from Central Government to stop providing large quantities of translated printed materials as they can often go unread and the information dates. There is a facility to translate a webpage into another language and a specific need or format can be catered for. BP thanked KL for her work on this and stated that the area to work on is raising awareness of the services available.
- KL added that the translation licence is due for renewal so it was helpful to hear that it is still relevant and of use.

## 6. Health, Education, & Short Breaks update 13:00-13:20

### Short Breaks:

- CR advised during the May half-term, Alys Robinson, Inclusion Development Officer at AfC and herself visited 4 settings across the borough with positive results - in particular it was noted that in the Kingston group no agency staff were employed during that period.
- CR and Alys Robinson also attended the Active for All sports day in Chessington but due to a train strike attendance was lower than anticipated. The session was available to children and adults with SEND and gave an opportunity to engage with families and explain how to access the service.
- Summer applications for [Additional Support Funding](#) are being processed with a reminder from CR that the earlier the application is received the quicker they can be assessed.

- Local offer updates:
  - [Stay and Play group on a Wednesday](#)
  - [Social group for 11-13 yr olds](#) unable to access mainstream providers.
  - [Hampton Court is piloting a £1 entry fee](#) from 9/7/2023 running for 4 weeks.
  - [Gripped Hounslow \(outdoor activity centre\)](#) are offering an annual family pass for £99.

Health was addressed by SN earlier in the meeting.

#### 7. Actions from previous meetings for further discussion 13:20-13:25

- **Action** JR to share benefits leaflet with HB to be circulated with these Minutes.
- **Action** LN requested more information on ERSA (Emotionally Related School Avoidance) and AW to add this topic to the deep dive list and include Sheldon Snashall.
- **Action** SN and RH to follow up with Karen Gayle regarding outreach for a family

#### 8. A.O.B 13:25-13:30

AW presented issues raised by LN following her contact with local parents and carers:

- Inconsistency across schools regarding transition from primary to secondary and what families can expect if a child is on SEN support or has an EHCP.
- **Action:** AW to invite Sheldon Snashall (Associate Director Pupil Support at AfC) to a future meeting to outline the process and present the latest information. AW referred to [AfC's website which includes best practice for schools.](#)
- LN shared an issue raised by a family regarding access to OT having been refused twice.
- **Action:** AW will contact colleagues for clarification about the decision.
- LN expressed the confusion that many parents share around the EHCP process, specifically timings, the appropriate time to apply and what happens if they have needs but do not meet the threshold for a plan.
- **Action:** AW to prepare information on this to be presented at a future meeting
- BP referred to [Ordinarily Available Provision](#) and the work between PCF, AfC and other providers in clarifying what families can expect within the general offer from a school. A lot of work has been done and continues with schools to ensure OAP is readily available and at what point an EHCP application should start.
- JR emphasised that the majority of EHCP applications come from schools and is a widely discussed topic at SENDIASS. More work needs to be done with agencies regarding the language used around EHCPs and ensuring the SEN support level is in place before starting an EHCP application.
- HM asked, is it lawful for a trust of schools to share a SENCO? AW advised there is a variety of approaches including full-time SENCOs, shared roles etc. which are outlined in the SEND Code of Practice.
- **Action** HM to email JR directly for a response once the statutory guidance has been checked.
- **Action** PB asked that all parents promote the online session on 28/6/2023 amongst their groups. The session will cover all the themes from the focus groups chaired by BP and is open to all.
- **Action** KL to share link for the online session ahead of the Minutes

Next meeting: **Tuesday 11th July 12:00-13:30**

**Forward plan of deep dive topics:**

<b>Meeting date</b>	<b>Deep Dive Topic</b>	<b>Owner</b>
Tuesday 11th July	Mental health services	Sharron Nelson, ICB
	Blue Badges	Nkem Obianyor - Head of Customer Experience for Kingston and Sutton
August - no meeting		
Tuesday 12th September	Transition to secondary school for children with send	Sheldon Snashall, AfC
	Graduated response	