

Kingston Parent Carer Consortium: Wednesday 7th February 2024, 12:00 - 13:30
Meeting Minutes

Parent Carer Forum / Parent & Carer representatives: Jo Thomas (JT) · Linda Nystrom (LN) · Bev Pass (BP)

Staff:

Chike Nnalue, Associate Director for SEND, AfC (CN) · **Diane Sanderson**, Designated Social Care Officer (DSCO) for SEND, AfC (DS) · **Helen Barnett**, SEND Policy and Project Coordinator, AfC (HB) · **Dr Jo Steer**, Associate Director for Emotional Health Service & Consultant Clinical Psychologist, AfC (JS) · **John Wood**, Head of SEND Travel Service, AfC (JW) · **Megan Francis-Falkner**, SEND Policy and Project Officer, AfC (MF-F) · **Pippa Czarnowska**, Designated Clinical Officer SEND (Kingston and Richmond) NHS South West London (PC) · **Rob Harris**, SEND Parent Carer Engagement Officer, AfC (RH).

1. Welcome, introductions and apologies

BP welcomed everyone to the meeting and explained that CN and herself will be alternating chairing these meetings.

Apologies were received from: Aisling Newton, parent carer (AN); Alys Robinson, Inclusion Development Officer, AfC (AR); Caroline Roberts, Inclusion Development Officer, AfC (CR); Claudia Isaby, Co-Chair of Kingston PCF (CI); Councillor Archer, Portfolio holder for Children's Services including Education, Kingston Council (SA); Karen Lowry, AfCinfo and SEND Local Offer Website and Content Manager (KL); Sharron Nelson, Deputy Head of Transformation for Kingston and Richmond, Integrated Care Board ICB (SN).

2. Parent Carer Forum (PCF) update

BP gave the following update:

- The PCF Administrative post remains open and until the role is filled, BP is managing the help@kingstonpcf.co.uk inbox and other administrative duties.
- The first of three seminars led by Suzy Rowland took place at the end of January, focusing on secondary schools and a positive approach towards home and school communications and relationships. More details and how to book a place at future seminars [can be found here](#).
- The first 'Have Your Say and Play' session takes place on Sunday 11 February from 1.15pm to 3.15pm at the YMCA Hawker Centre in Kingston. In response to feedback for more peer support in the community, the session provides a SEND friendly space for children and young people and an opportunity for parents and carers to meet. The session, led by the Kingston PCF, is a drop-in facility and [more details can be found on the Kingston PCF website](#).
- On Thursday 8th February members of the Kingston PCF, led by member Arlette Wright, will meet with CAMHS South West London (Children and Adolescent Mental Health Service) for a consultation meeting. This is in response to feedback from local families and today's deep dive topic will help to inform the discussion at the meeting.

3. Deep Dive - CAMHS update on waiting lists and the support available for those with SEND

JS explained that AfC is responsible for Tier 2 CAMHS in the local area and Tier 3 and Tier 4 is managed by South West London and St George's Mental Health NHS Trust. Unfortunately a Tier 3 representative was unable to attend this meeting.

Action: HB/MF-F to follow up with representatives from Tier 3 and 4 CAMHS on attending a Consortium meeting to provide deep dive.

The Emotional Health Service (EHS) is currently going through an external review, as mentioned by BP in item 2, and JS's team along with the NHS Trust have met with children and young people and spent time in schools to identify where the strengths and challenges are in the service.

JS presented on the current situation and forward planning for the EHS ([please click here for the slides](#)) and the following comments were made during the presentation:

BP referred to a previous meeting when a simplified service overview of CAMHS was discussed in order to help families navigate the EHS. **Action:** JS to follow-up with SN about the production of a one-page document

outlining the CAMHS system which can clearly demonstrate to parents how CAMHS tiers 1, 2, 3 and 4 work in Kingston.

JS added that the MHST (Mental Health Support Team) has 100% coverage across the schools in the borough, the only local authority in the country to do so. More details on MHST can be found [on this page of the AfC website](#). The CAMHS SPA (Single Point of Access) team, based at the Moor Lane Centre in Chessington, manage the majority of the Tier 2 referrals with some cases referred on to the neurodevelopmental team at Springfield University Hospital in Wandsworth. JS noted that the service has recorded an upsurge in referrals, particularly within the Neurodevelopmental Assessment Team (NDT), resulting in pressure across the system and lengthy waiting lists for families. The average waiting time from the point of referral is 18 months, with the exception of the MHST who meet pupils within a few weeks of receiving a referral.

To address the lengthy waiting lists, the following initiatives have been set up:

- **Virtual waiting room:** EHS have created a virtual waiting room in order to maintain regular communication with families who are yet to be seen by a clinician. Feedback from families has been positive and they have the option to opt-out if they no longer wish to be contacted by the EHS but will retain their place on the waiting list.
- **QB testing:** This has been introduced to help with ADHD (Attention Deficit and Hyperactivity Disorder) screening that feeds into the ADHD assessment process. Results so far are that clinicians feel more confident in making a diagnosis and as it is a computer-based tool, it can be used alongside a classroom or home observation to support a referral. Due to the success of the tool, AfC are continuing to fund the project, albeit on a streamlined basis, as central funding has now ended.

Q: LN asked if children who are no longer in the system as they previously did not pass the threshold for ADHD assessment e.g. girls who mask their needs, can automatically be screened using the QB tool.

A: JS advised that only referred children currently on a waiting list can be screened using QB however there is a growth in the number of girls being referred and QB will form part of the screening process for them.

- **ERSA:** The service has recently introduced ERSA (Emotional Related School Avoidance) groups to address the rise in need across the borough. The groups, available to children and their parents and carers, are based on NVR (Non-Violence Resistance) to help improve a child's relationships between home and school, known as the 'golden triangle'. As this is a pilot scheme, a full evaluation is planned but early results are promising with some children re-engaging with their education provision (in school or home tuition) and parents feedback is very encouraging. Future delivery is yet to be confirmed as the funding for this pilot scheme has now ended but JS is happy to return to the Consortium to update on this. **Action:** HB to add this topic to the Consortium forward plan.
- **The A Plan:** This is a year long support package offered to families following a child's diagnosis of autism and funding has been secured for 2024 to 2025. Plans include introducing a post-diagnostic group for teenagers and to hopefully broaden the offer to those outside of the EHS caseload, particularly the most vulnerable children in the local area.

Q: CN asked if the future of the MHST has been agreed.

A: JS advised that the project has a substantial training programme and investments have been made so to end the funding would not make sense. Early intervention in supporting children with their mental health is a proactive way to manage pressures in the system further down the line.

Action: RH to contact JS to offer support with engaging local families with the ERSA groups and A Plan.

Q: BP commented on the graph on slide 3 of the presentation which charts a rise in referrals for the NDT, starting in 2019-20 through to 2023-24. BP questioned if the figures for 2019-20 are artificially low due to Covid and is there a plan to manage the 41% increase in referrals. BP also asked if families could try group therapy as a first option (as the waiting times are lower so help could be provided earlier) and if this is not successful could individual sessions then be introduced?

A: JS explained that the surge in NDT referrals is a national concern and is beyond the forecasted number of referrals calculated as a result of Covid. The transition back into education following the national lockdowns has been a challenge and schools are not always able to adapt to the needs presented as a result of this. Regarding therapeutic options, if a child starts a type of therapy and it is clear within the first few sessions that it is not

suitable then they would return to their position on the waiting list however once an intervention has been completed they would need to return to the start of the waiting list for access to another package of therapy.

Q: LN asked what groups are available for parents who are waiting for a diagnosis as many can be fully booked.
Action: JS advised that the team that manages the pre and post diagnosis support has been through a restructure and she will discuss with them the idea of a pre-diagnosis workshop for parents who are waiting for a diagnosis.

Q: JT asked if there is any evidence of the effects on children and their families who have to wait months for therapeutic input and could this help to strengthen the request for more funding?

A: JS advised that teams do use the waiting list to predict costs but to her knowledge there is no evidence of the health effects of the lengthy waiting lists. JS added that the Tier 2 CAMHS is funded by the Integrated Care Board (ICB) with regular data sharing between the ICB and AfC but the funding remains the same amount. PC referred to a national research project launched around 2010 which focused on the impact of the lack of investments in health care and what impact this would have on the nation.

Action: PC to contact SN regarding this project and feedback any findings to JS and this group.

RH added that he is working with Alison Danks (Associate Director of Health Services, AfC) on a new post-diagnostic team involving input from parents and carers into the recruitment process.

BP thanked JS for the update and concluded that amongst the lengthy waiting lists are groups of concerned families and vulnerable children and delays in treatment are exacerbating the existing needs. Despite this, it is encouraging to know there are resources available for families who are waiting to be seen.

Action: HB to contact JS about asking the MHST to present at a future meeting.

More information about the Emotional Health Service can be found [on this page of the local offer website](#).

4. Participation, Engagement & Co-production update

RH provided the following updates:

- Dysart School hosted a parent carer coffee morning at the end of January
- Kingston Carers Network have set up a support group for parents and carers of children with SEND (up to the age of 25 years old). [More details can be found on this page of the local offer](#).
- [The Stay and Play Sessions at the Moor Lane Centre](#) continue every Wednesday morning from 10am to 12pm during term time. This is an activity and support group for pre-school children with disabilities and their parents (siblings also welcome).
- New and updated versions of the Local Offer information leaflet will be available soon including electronic versions with hyperlinks to signpost users to other resources.
- The Carers One Stop Shop sessions continue on a monthly basis in New Malden - [more details are on this flyer](#).
- The [RBKares charity](#) has food banks available for vulnerable families in the local area, the sessions are on the 1st Tuesday of each month.
- SEND Parent Champions continues to grow and gain more interest with five new recruits starting at the beginning of March, bringing the total number of Champions across both boroughs to 15. Recently, Nicola Wilson, Care Manager at Cross Roads Care ran a training session for the Champions on how to support local parents through clubs and groups. One idea being explored is a support group for fathers of children with SEND.

Q: JT asked if the offer from Crossroads Care is available to families in Kingston as previous attempts to access their resources have not been successful. LN advised that in the training the understanding was that the service is available to all families. BP added that this is useful feedback for Crossroads Care to ensure their messaging is clear.

Action: RH to contact Crossroads Care for clarification on their offer and who can access it.

Update: RH contacted Crossroads Care who explained that Kingston families are able to access their benefits advice and respite care at home and in the community, however Crossroads projects are funded for Richmond families only. These include the Saturday clubs, mentoring and therapies.

- The Family Hub will be open at Malden Manor Children's Centre from April with more details to follow in the March meeting.
- Meetings continue with Kingston Hospital to make the space more accessible for neurodiverse children.
- The Kingston ADHD Partnership Board met again last week to continue their work on creating a local area policy to support Kingston families. RH reported that there is an inclusive approach to the project and the council are seeking the voices of local families to inform the policy.
- RH will be organising focus groups in the coming months with local parents and carers to feed into the updated Accessibility Action Plan for Kingston.

5. Education, Social Care & Short Breaks update

Education update

- CN advised that Thursday 15 February is the deadline for parents and carers of children with an EHCP (Education, Health and Care Plans) to receive an amended plan with the named school for Year 7. CN added that this can be an anxious time for families and encouraged them to contact their EHCP Coordinator with any queries or worries. The majority of families have their preferred choice of secondary school but due to a shortage of provision in the borough, some children with severe learning difficulties are yet to finalise their plans but the EHCP team are working with families to resolve this.
- The deadline for amending EHCPs for post-16 year olds is 31 March and the SEND team are currently consulting with colleges and post-16 placement providers.
- There is an information event organised from 5pm to 7pm on Tuesday 26 March at Kingston Guildhall to help support incoming Year 5 families of children with EHCPs with the secondary school application process. CN and the team of EHCP Coordinators will be available to explain the process which differs from the mainstream offer.
- CN met with Alison Danks to discuss the statutory health notification of under 5 year olds and how SEND information can be shared to support early intervention. Work will soon begin with local families to establish what areas of support are needed.

Social Care update

- DS advised that this month South West London ICB have been audited with a focus on children with trauma and mental health needs and what support is in place for this cohort. A moderation panel will meet in the coming weeks and DS will share the findings of this with the Consortium.
- The bi-monthly audit process has begun, which involves taking a deep dive into the cases of four tracked children by professionals from education, health and social care. A key element is the involvement of children, young people and their families and the logistics of this are yet to be agreed. DS will update the Consortium at the next meeting.
- The timeliness of statutory social care advice hit 100% in December 2023 and 90% in January. DS will continue to quality assure each piece of advice until April, adding to the bank of examples that can be used as best practice.

SEND Transport update

- JW advised that to date the SEND Transport team have delivered 180 individual online sessions to parents and carers to address any concerns or worries. The feedback has mostly been positive but there are areas to develop regarding communications between home and the service and the timings of school transport.
- JW added that the culture in the service is changing towards a more positive, co-produced system with opportunities to signpost families to other services.
- BP noted that anecdotal evidence from local families is positive and they feel heard by JW and his team.

6. Actions from previous meetings for further discussion

All actions from January were completed, with the following actions carried over:

- **Action:** HB to follow up with Tom Mann (Customer Experience Team Manager, Kingston Council) about setting up a co-production working group with Kingston PCF for concessionary travel in

Kingston. This would address the role and cost of the independent assessment team, introducing a parent and child point of view, data analysis of the number of children cases and joint working between JW's and Tom Mann's teams.

- **Action:** JW to follow up with Tom Mann in early February and will be able to provide an update in the next meeting on ways in which their teams can work together to create a single touch service for families to avoid the repetition of information or their child's story.
- **Action:** Jonathan Rourke to contact Alys Robinson/Caroline Roberts to arrange for a member of the SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service) team to attend the Moor Lane Stay and Play sessions.
- **Action:** Jonathan Rourke to share the job advertisement with KL to be uploaded to the Local Offer.

Update: an action from January's meeting was for HB to share details of the contact at Kingston Council who advises on designing accessible spaces. The contact details are:

Email - majorprojects@kingston.gov.uk

Telephone - 020 8547 5000

Website - <http://www.transformkingston.co.uk/leisure-centre>

7. A.O.B

Action: HB to contact KL to ensure the F.U.E.L (Feed Ur Everyday Lives) presentation scheduled for the March meeting, is promoted in the local offer newsletter.

Next meeting: Tuesday 12th March 2024, 12:00 - 13:30

Forward plan of deep dive topics:

Meeting date	Deep Dive Topic	Owner
2024		
Tuesday 16th January 2024	SEN Transport	John Wood, Head of SEND Travel Service, AfC
February 2024	CAMHS Tier 2	Jo Steer
March 2024	F.U.E.L (Feed Ur Everyday Lives) project	Seema Sehgal, Policy and Projects Officer-FUEL Lead, AfC
April 2024	Health Services - current challenges relating to resources / budgets	Alison Danks, AD of Health Services, AfC
TBC	Neurodevelopmental pathways for 0-18 year olds inc post-diagnosis support	Sharron Nelson, ICB Karen Gale, member of PCF
TBC	Speech and Language workshop on eating	Carmel Brady / Fraiza Sword from Your Healthcare
* Items to be carried forward to a future meeting		