Kingston Parent Consortium 9 November 2020, notes of online meeting

Attendees

Parent / carer representatives:
Agnieszka Czerwinska (AC)
Bev Pass (Chair of PCF) (BP)
Chris Campbell (CC)
Kacper Rucinski (KR)
Noreen Ahmad (NA)
Louise Kearney (LK)
Rosy Ahmad (RA)

Member
Cllr Diane White, Portfolio Holder for Children's Services including Education (DW)

Staff:
Alison Danks, Associate Director of Health Services, Achieving for Children, (AD)
Alison Stewart, Designated Clinical Officer for SEND, Clinical Commissioning Group (AS)
Anna Chiva, Associate Director for SEND, Achieving for Children (AC)
Ashley Whittaker, Programme Director, Achieving for Children (AW)
Charis Penfold, Director for Education Services, Achieving for Children (CP)
Geraldine Burgess, Short Breaks Operations Manager, Achieving for Children (GB)
Karen Lowry, AfCinfo/SEND Local Offer Website Manager, Achieving for Children (KL)
Rachel Dawson, Designated Social Care Officer for SEND, Achieving for Children (RD)

1. Welcome / intros / apologies

Apologies received from, Christine Flowers (parent), and Jonathan Rourke, SENDIASS Team Coordinator (JR)

This is the third meeting of the new schedule of monthly meetings on the second Monday of each month between parents, carers, the local authority, the Clinical Commissioning Group, Achieving for Children and providers of services.

Thanks to all for making the time to attend.

Introductions including first time attendee Rachel Dawson, Designated Social Care Officer for SEND

2. Actions from last time

Outstanding items picked up in agenda items.

3. Progress updates

a. Emotional wellbeing and mental health (AS)

   i. Emotional Health Service recruiting for new Deputy Head with specific responsibility for SEND, very positive development.

   ii. EHC SEND audit refreshed and action plan being updated. Training being delivered by AS in Dec and linked to outcomes framework
   iii. CAMHS. Progress is slow. Increasing referrals and agreements for escalation for some CYP to LD service in Wandsworth. Working is ongoing to find a comprehensive solution to CAMHS for Learning Disability and ASD. Working across SWLSG, AfC and CCG. Hope is within 2 to 3 months we have more concrete progress to report.

LK: CAMHS support form Wandsworth. Is this a stop gap or due to increase in referrals?
AS: part of ongoing discussions to improve. Wandsworth have some capacity. Probably only for those in crisis, relatively small numbers.
AW: Mental Health Summit news?
AS: to find out and revert. **ACTION**

b. ASD Pathway (AD)

   i. Under 5 pathway. Started to review this with stakeholder meetings in 2019/20 and stalled since COVID. On the to do list and need to restart that holistic piece of work. In meantime hoping to start by end of November a separate piece of work to tackle waiting list. This is an interim measure prior to longer term changes. Plan is to use Moor Lane, working jointly with CCG, includes eg Saturday clinics. May well come back to ask for help from people here.

LK: what is aim re. reducing waiting list? Specific number or just as much as possible?
AS: still looking at this, depends on COVID and how many health professionals can work at weekends. When finalised can come back and update with more detail. Also ASD assessment pathway has lots of bits to it, and some need more complex assessments than others.
LK: when we went through this process , pathway included assessments in school. Are these able to happen?
AD: as schools are open, other info collection can continue. Great that this can continue, history gathering etc. in previous lockdown could not do this.
LK: what will happen to Moor Lane assessments when building works start for new ASD school?
AS / CP: works will not impact services delivered out of Moor Lane as now the plan is for this to be a new build on field. Better outcome to build new school rather than convert existing. Good news. No fixed timelines on this.
NA: How many children are on the waiting list?
AD: do not have latest numbers but will source these as in our regular internal reports and revert. **ACTION**
BP: we did ask for these numbers last month and have been asking for these for a while.
AW: not currently in Partnership Board dataset but could add in future version.
BP: not sure why having been asking for these for several months and need this kind of detail if we are going to work together on these kind of things.

c. Therapies

   i. Therapies Oversight Group (TOG) have had a second meeting. Parents rep is AC.
   ii. SaLT therapists being recruited through Your Healthcare and AfC. Some have started and some will start in the coming months. Will also recruit more
   iii. Specialist Support posts, pre and post diagnostic support roles, 2 for RBK, adverts closed on Fri. Very positive response. Over a dozen applications. Interviewing over next week. Hoping for them to start in early Jan.
   iv. Agreeing service spec and KPIs for new contracts. TOG overseeing that and involves CYP
   v. Also services outside of scope of therapies review eg 16 to 25.

KP: Physiotherapy. Re muscle wasting disorders are still an issue and has been for several years. Child has only had one session since start Sept. These types of conditions would ideally have daily support, but once a week or once every 2 weeks should be minimum. Not sure what's happening at he moment. Frustrated and know others are too.
AS: understanding is that things should be working as normal with physio so I will follow this up with you directly. **ACTION**
KP: AC might also want to share info on physio **ACTION**
AC: AC could also add feedback to TOG when she attends those meeting **ACTION**

d. **Participation, engagement, coproduction**
    i. RA, BP have been meeting with Naha H. KL and AW
    ii. Thanks to PCF for supplying 1 to 4 nominated people for each area of priority areas
    iii. Re more film content / film content, Karen has sent information to RA to try to get parents to do "Talking Heads" films to help make language and content of Local offer more accessible.
    iv. Relaunch of disability register. Aim to do in Jan/Mar. Write to 4000 families in Kingston. EHCPs plus Oct school census for SEN Support. Discussed how to make attractive proposition at last meeting, card plus perks etc. AW has since met with Council colleagues, Eco Dev and Partnership lead, Lead of Equalities, Senior Consultation and Engagement Officer. Practical reality is still need to improve "front end" of sign up process and work ongoing with this. Write to families in January, so still some time but lots to do. Data is also much better, have ethnicity and postcode data for EHCPs so use this to contact.
    v. RA has added almost twenty organisations to the sharted spreadsheet AW has set up re target organisations. She has also met with a group re Tamil families and strong interest from them to get more involved. Very positive.

4. Feedback on progress against the Written Statement of Action (WSOA)

a. AW introduced the item, and explained the aim is to spend 4 x 15 mins receiving feedback on each area in the WSOA.
b. AW presented background to the inspection and WSOA using slides attached.
c. Parents then accessed a menti meter survey to give feedback on progress.

Q1: The quality of EHC plans is better now than in Sept 2018

On a scale of 1 to 7, where 1 is strongly disagree, 4 is neither agree or disagree and 7 is strongly agree

a. All professionals support the process, average score was 3.2
b. The end product is fit for purpose, average score was 3

Written comments:

- Health and social care still don't input into plans.
- The EHCP funding seems to be getting lost in the pot in mainstream and there is lack of access to therapies. The cracks are more visible since covid.
- It is still very much dependent on the determination of a single professional to make it good quality. Also therapies don't appear or are not provided and also health like continence services are not included

- Often out of date or don't reflect changes
- Only the Education portion seem to review the plan, so health and social care reports aren't included, even if you have got access to them
- Parents need to have more say in how EHCP money is spent.
- Mainstream school pupils don't get access to therapies
- The LA ignored and didn't update the parent contribution for many years, and it took many attempts to get this sorted. The staff were rude .
- The OT and SALT contributions were not always on time at the annual review and had to be chased up.
- No quality checks to see if what is specified in the plan is actually delivered

Verbal comment:

- Parent: in mainstream schools, parents don't see how money allocated to EHC is spent on support. Different to special schools. Contributes to problems with support, eg therapy provision. There are examples of children not receiving what they should be.
- AC : explained complexity of funding process, and how support specified in EHC plan should be so specific that should see exactly what child receives. Parents should not have to add to the support provided. Anna to follow up with Noreen on examples. **ACTION**
- Parent: reiterated the feedback the PCF receives about delivery of support / interventions in mainstream schools and things "missing" which would not be the case in special school as there all kids receive "everything". Mainstream parents less involved in what is being delivered to EHC plan children in mainstream. Feedback they receive from parents is that mainstream children receive a "raw deal" compared to special school children. Issues around the money not being ring fenced, or not being treated as ringfenced. So many pressures on school budgets that possible that SEN money / funding used for other things.
- Parent: In mainstream not always clear who is responsible for leading the support described in a plan as not always up to school. In special school it seems clearer and the special school is the advocate. Less clear who is the advocate in mainstream.

Q2: The EHC plan annual review process is better than it was in September 2018

On a scale of 1 to 5, where 1 is strongly disagree, 2.5 is neither agree or disagree and 5 is strongly agree
Average score 3

Written comments:

- Sometimes feels like a tick box exercise
- Works for us
- There is a difference between Special school and mainstream. Also when paperwork gets sent out there is always problems with it being updated.
- Parents need to be made more aware of their rights and entitlements and the SEND code of practice

Verbal comments:

- Parent: Sometimes delays in paperwork being updated and hear of a change / something not being updated 6 months later

- Parent: agree. Sometimes the meeting goes well and then the admin goes wrong. Ie receive older version, not updated properly. We don't know who our caseworkers are, they keep changing. Disorganisation around this.
- Parent: annual reviews can be a real worry. Often gone through a big battle to get an EHC plan (or not) and worry is that annual review may reduce support. Whole process is a worry about what it might result in. can feel like a tick box exercise for some and lots of worry for others. Especially if you don't hear back promptly.
- AC: not the first time we received this feedback. We know this needs to improve. Agree administration can improve. Have very recently improved the systems to track, plan and make changes for annual reviews. Now need to deliver on improvements. Also made changes to the communications process to keep parents and carers up to speed on progress.
- DW: is voice of child / young person collected and heard itn eh annual review process?
- Parent: views are in there but not convinced that this influences provision.

Q3: Health services are better now than they were in September 2018

On a scale of 1 to 5, where 1 is strongly disagree, 2.5 is neither agree or disagree and 5 is strongly agree

a. Visibility of health leadership, average score was 3
b. Waiting times for access to health services average score was 1.7
c. Quality of health services average score was 2.7
d. Primary care are more responsive to SEND need average score was 3.7

Written comments:
- SEND awareness for GP's needs to be improved
- Patchy.
- Some GP's excellent and others dismissive of issues like taking medicine
- Waiting times are simply too long for some services
- Waiting times are long and no clear way of getting assessed by OT and SALT. GP surgeries are better, much like the wider community of accepting people's additional needs and catering but they don't always have the ability to refer to the assessment

Verbal comments:

- Parent: from PCF perspective great to have AS onboard. Now have health regularly present at these meetings which is great. I have done some close working with Your healthcare too and have found them very responsive also, around speech and language therapy and that was at pre EHC plan stage. So some things are on their way and getting better. But it is patchy so for example GPs. Mmine is excellent but when I've had to see others they can be really dismissive of issues eg issues around swallowing / oral medicines. In emergency healthcare faced with having to try to educate the front line emergency services on SEND. Lack of confidence that emergency departments understand issues in addition to physical needs.
- Parent. Agree. Lots of experiences like that. GPs need to be trained. Eg GP same issue with swallowing. Found the language used by the GP with my 18 year old very offensive. Locum GP asked if daughter still has downs syndrome. Needed certificate and GP would not certify DS as a disability. Need some kind of passport system. GPs often have not read the records before an appointment and parents have to continue to remind GP of needs eg that he has Aspergers.

- AS: we are working with GPs to improve in a systematic way but if you are having these experiences now please tell me directly as you should not be having these experiences. Need to deliver training. The children and young people health group have also raised this as a significant issue.
- Parent: things are better than they were in 2018. From my experience awareness in community settings and in GP and emergency care is better, used to be much worse. At Kingston hospital on every visit they will make adjustments. Have to ask for it rather than being offered but always delivered. Better with changes from COVID around crowd / waiting room management. Has helped alot. .

Q4 Relationships with parents and parent representatives are more productive and positive than they were in September 2018

On a scale of 1 to 5, where 1 is strongly disagree, 2.5 is neither agree or disagree and 5 is strongly agree

Generally, average score was 3.7
Information about health services on the Local Offer is better, average score was 2.7
Opportunities to participate and give feedback, average score was 4
The new Parent Carer Forum, average score was 4

Written comments:

- So much information on local offer, parents need guidance to navigate services. PCF is wonderful obvs.. but need to figure out how we can best Co-produce
- Well we have one which is great.
- It's hard to find the time and keep it all going and if it's going to continue to be successful and embedded long term then we will really need to see the IMPACT of all that free input from busy SEND parents.
- The opportunities for giving feedback have increased and improved but there is a feeling that we are getting empty platitudes and nothing tangible is being achieved

Verbal comments:

- Parent: Great that we come together regularly but the work involved is really really hard. We all very busy people and this is all voluntary. Setting up a PCF is a lot of work and whilst we are pleased that we are up and running, to keep this going we need to see that it is having an impact and that something is happening because of it. We really don't have this time to spare but we will make the time if it makes a difference. Feels like give, give give and not yet seeing the results.
- Parent: So much on the Local Offer that new parents just can't access what they need when new to the system. Just can't do it through a website, you need some professional help to help navigate in the same way that you need someone to talk you through the EHC process. And there isn't anyone to do that role
- Parent: Great that we've got this forum but need to figure out how we make it work so feels like it makes a difference
- Parent: Agree it feels like it's not making a difference. For example we really pushed to get people signed up for co-production work by item, but feels like a one way street. Eg Local Offer have only heard of one positive comment and turns out that was someone from AfC. Most parents find it very difficult to navigate and I certainly do. Hard to find things and there is so much information on there it's very hard. You could be drip feeding more stuff to us to pass on to parents.

- KL: ongoing work re. websites and worried that it doesn't include parents' feedback enough. Would be good to have a session specifically on this. **ACTION.** Maybe there is a role missing for someone to sit down with parents and take them through it. SENDIASS service could also be doing this but again not necessarily know about enough.
- AW having someone is a recurring theme, particularly at post diagnosis.
- Parent: If AfC could pass more info to PCF then we can pass it on to parents. And great feedback on things that have been shared. And there have been a lots of improvements and things are getting better e.g colours and pictures and films.
- Parent: Local Offer is like looking for a needle in a haystack. If you don't know what you're looking for, you can't find it and even if you do know what you're looking for can't always find it. Something about language, categorisation. Content needs to be website ready. Need work on why people are going to Local Offer, what are they looking for. Eg section for new parents. Trying to find stuff is often possible.

AW thanked parents and carers for their honest contributions.

5. Future meetings

Based on parent carer feedback will move to alternating meetings between Monday daytime and Tuesday evenings, starting with December meeting being evening. **ACTION.** Karen adjust meeting invites.

6. AOB

AW and KL to convert Menti questions into Google survey that can be circulated to PCF and PC databases to collect more of this very useful feedback. **ACTION.**