Kingston Parent Consortium 14 September 2020, notes of online meeting

Attendees

Parent / carer representatives:
Agnieszka Czerwinska (ACz)
Bev Pass (BP)
Kacper Rucinski (KP)
Karen Gale (KG)
Louise Kearney (LK)
Rosy Ahmad (RA)

Staff:
Alison Stewart, Designated Clinical Officer for SEND, Clinical Commissioning Group(AS)
Anna Chiva, Associate Director for SEND (AC)
Ashley Whittaker, Programme Director Achieving for Children (AW)
Enno Kuettner, Children's Commissioner, Clinical Commissioning Group (EK)
Geraldine Burgess, Short Breaks Operations Manager, Achieving for Children (GB)
Ian Dodds, Director for Children's Services, Kingston Council (ID)
Jessica Thom, Director for Commissioning and Partnerships, Achieving for Children (JT)
Jo Steer, Associate Director for Emotional Health Services, Achieving for Children (JS)
Jonathan Rourke, SENDIASS Team Coordinator,(JT)
Karen Lowry, SEND Local Offer Website Manager, Achieving for Children (KR)
Nigel Evason, Head of Children and Young People's Mental Health and Learning Disabilities, Clinical Commissioning Group, (NE)
Peter Maasdorp, Service Manager for Child and Adolescent South West London & St George's NHS Trust (PM)

1. Welcome / intros / apologies

This is the first meeting of a new schedule of two hour 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. Reminder to professionals to avoid the use of jargon.

2. Parent Carer Forum (PCF) survey findings

LK shared the findings of the two surveys the PCF have conducted.

a. Survey 1
- Covered how people feel about access to services and how they are/ were feeling during lockdown, 40 respondents.
    - Four key service areas that parents felt could be improved:
        - Emotional wellbeing and mental health
        - Autism support services
        - Activities, clubs and access to leisure
        - School provision
    - What could be done to improve services?
        - Eligibility and accessibility of services (ensuring thresholds are correct and consistent)
        - Quality of provision
        - Waiting times
    - Re. feeling during lockdown, what would have helped?

  - Enhanced home edu support and resources.
  - Emotional and wellbeing support
  - Access to leisure and activities
  - Therapeutic support

b. Survey 2

- Access to social care assessment survey in conjunction with Special Needs Jungle.
- Key findings:
  - High number of people did not know they could have one
  - Those that do often find it hard to get an assessment
  - Uncertainty about who actually does / should do the assessment
  - Some said assessment went well and resulting family support was very useful
  - Once approved access can be problematic with long waiting times etc
  - Overall hard to get a social care assessment and thresholds seem high.
- Parent highlighted that parents only approach social care if they need help and to be met by a threshold that seems high / arbitrary not great.

AW thanked the PCF for the value they are bringing to the local SEND system with these insights and agreed that survey findings would be taken forward with seniors and social care and would be useful to make social care the deep dive in October as per suggestion in July. GB raised the importance of making sure parents clear about the difference between parent carer needs assessment and child's social care assessment. AS highlighted the appointment of a Designated Social Care Officer and their role going forward.

LK said she felt that there is significant agreement / commonality between parents and AfC and the CCG in terms of the priority / key areas of development which is a real positive. Issues raised in the surveys are also issues already being raised as being priorities by AfC and CCG.

ACTION: Social care representatives to join October meeting to address findings of above survey and lead on deep dive into social care and SEND.

3. Draft Joint Commissioning Strategy

JT presented the joint plan around education, health and social care joint commissioning and the full paper (circulated before the meeting). NE spoke about the role of the Clinical Commissioning Group and acknowledged that in the past their engagement has not been sufficient, as was reported in Kingston's Local Area SEND Inspection. Proactivity is already much improved. NE used the therapy review as an example of how joint planning, working and commissioning is already going much better than it has done in the past.

JT highlighted five high priorities:

- Service development
- Pathways
- Partnership working, including with parents, carers, children and young people
- Response to need
- Future focus

NE linked this to the centrality of personalisation and how this must feature in everything we do going forward.

LK commented that partnership working is key. Team around child meetings, when they are arranged, often result in professionals from different teams pushing issues to other departments. Thinks that budget issues may be driving this and wants to know how the strategy will deliver joint ownership. JT agreed that joint funding / tripartite funding is something being discussed. NE used the therapy review again as an example opf improved practice and explained how with that the CCG's money has been pooled with partners to encourage joint working and ownership. JT added the example of a jointly funded joint commissioning role. LK said that in addition to this significant cultural change is needed as staff on the frontline can be very entrenched in their own department's remit / budgets.

ACz also spoke about cultural change, and about how parents are often the experts in their child's needs and must be treated as such and included in partnership working. Parents are sometimes used to deliver information from medical consultants to other professionals. Stressed importance of this being heard and acted on, and if it is not vital information can be missed.

JT shared other priorities (in addition to therapy review) where we are looking to put these principles into action. Short breaks, improving panels and pathways to better include parent voice. AS added working with Council for Disabled Children on outcomes and staff training on improved partnership working and child and young people participation.

ACTION: JT asked parents and carers to feedback any comments they have on the draft strategy.

4. Emotional wellbeing and mental health

EK, JS, AS, NE and PM talked through a presentation of emotional wellbeing and mental health services.

EK covered how the local system works and is impacted by national government initiatives, gaps we have identified in the local system, and what we are planning to do about it. He described the "Tiered" and "Thrive" models and how these to some extent continue alongside each other. "Tiered" model describes the support offered by professionals and the "Thrive" model is more about describing how things look from the child or young person's perspective (getting help, getting more help etc)

JS described the Trailblazer scheme, the new resource hub, and how feedback is positive from families when they are receiving support. She also flagged that feedback highlights the problem is that access to support is problematic / takes too long. She also explained the option for self referrals to CAMHS single point of access - from both young person and parent / carer.

Worries include:
- Demand is rising and has been for years. This is putting pressure on the system.
- Recruitment problems exist, and some staffing issues can sometimes be made worse by national recruitment initiatives.
- Current waiting times for assessment in Emotional Health Service is approximately eight weeks, and treatment between six to nine months after that. Pre COVID was four to six months wait for treatment. Have been switching to online where they can but some e.g. art therapy cannot go online.

PM confirmed pressure at Tier 3 similar to Tier 2. Recently added one day per week psychiatry time in SPA to try to reduce. Same pressure on staffing and vacancies exist. Again a national problem.

In terms of what is being done about it, this also includes:
- AS talked about raising the profile of SEND within this broader CCG agenda and linking to personalisation agenda
- AS also covered dynamic support register (considers those at risk of hospitalisation reviewed monthly)

Answers to questions from slides:
- PM and JS described how services need to and do talk to each other to make sure that support available in one service and not in another is made available to child if that is what they need. E.g may have a child in Tier 3 who needs art therapy which is only available in Tier 2. Sometimes children can be seen by more than one tier /

service at the same time and care delivered by more than one service / organisation. Reinforces the need for individuals to have personal care plans and system needs to be flexible

- A parent acknowledged the proactivity and value of recent professional support, but also described how she'd been told by a Tier 3 practitioner that a certain type of therapy was not available to her child when it was available in a service supporting lower risk needs. Agreed that personalisation is key, but not sure that what's been said about services working together above always works in practice.
- A parent asked about how use of the Emotional Health Service Resource Hub will be monitored / measured to see what usage is. KL explained how we can measure the number of web page hits and there will be other feedback that goes to Local Offer and to the service. All feedback welcome. Service knows that it needs more material for young people as currently biased to parents / carers and professionals.
- Yes parental emotional wellbeing is something that services can work with the PCF on delivering some kind of webinar if definitely of interest. Some voluntary sector groups do provide support e.g. Express CIC, iCope. Some feedback suggested ICOPE may not be useful for some parents of children with disabilities. Are there any plans for an iCope type course that is geared towards parents and carers of SEND?
- Process when child / young person is discharged when no change in outcome. JS explained how Emotional Health Service sometimes discharges when things are still difficult but normally refer up to Tier 3. Sometimes if change is in progress might have therapy break or period of consolidation. Desire to keep moving to take up new pieces of work means cannot keep cases open indefinitely. PM acknowledged that sometimes interventions are not working and can sometimes make things worse. Normally then refer to support groups and social care in these situations plus shared care with GPs who monitor risk and health and refer back. Parent feedback included evidence that referral from CAMHS to social care can then just result in referral back to CAMHS. EK added that it is important to have a different approach to SEND, as this cohort sometimes needed longer interventions. Part of discussions on national agenda. Politically acknowledged but not currently funded.
- One parent said the approach should be more about simple practical approaches in which professionals listen to the voice of parents more and include their voices and experiences more. Families should be given more choice eg what type of therapy they want and where they want it e.g. maybe not delivered in schools and at home might be better
- NE linked this back to earlier conversations about teams working together and sharing information and who is holding the lead to formulate a proper plan to support someone to stay at home, at school and within their local community. Often a huge number of teams involved in mental health and SEND is a key priority for him and JT to lead on the plan going forward. Need a cultural shift in terms of how teams work. A mental health summit is planned and GPs are also key.
- JS explained that 75% of choice appointments advance to treatment with the Emotional Health Service. And this is based on choice of family, informed by waiting times, other options etc. No staff like having to tell families how long they will have to wait. EK explained how referrals are up about 45% in three years. Adding practitioners early on in the referral process is something that commissioners want to deliver, and pre COVID did have investment for this. A good telephone check in as early as possible could help a lot, rather than the stop / start model we currently have. Parent said lots of talk about early intervention but reality doesn't seem to reflect this.
- Different teams work on same children and liaise through team around the child meetings. Attendance at online meetings during COVID by multi agency professionals has been better than it was previously when eg travel time for sometimes preventative.
- Re Trailblazer, parent feedback that therapy within schools is still seen as "unusual" and feels like if a child seeing a therapist was more normalised it would make it easier for children to access. Trailblazer whole school approach aims to help this (JS)
- Re reducing waiting times, offering group interventions is being used / offered as an option. Emotional Health Service based on average of 8 sessions, maximum 16. Exceptions to this eg children looked after. Parent made point that some children with SEND will take longer to build a relationship with a therapist and they should perhaps be given more sessions.

- Question about how parents know if they are on the dynamic support register. AS explained that would be done in conjunction with family so if they are on it / being considered for it they would know.

AOB

- EK explained that there is still a gap in mental health support for children and young people with learning disabilities. Currently short term arrangements with him covering and buying in from a Wandsworth specialist learning disability CAMHS service but needs to be improved with a long term plan to support this group with severe learning needs. Often significant emotional and behavioural needs. Clinical Commissioning Group aware of this group and gap. Plus the group with slightly milder needs than this, sometimes possible to fall through the gap between.
- NE explained several other improvements planned e.g. in investment in CAMHS single point of access and when out of COVID hope that more funding will be available to make these changes. New South West London CCG Director of Mental Health already looking at differences in funding across boroughs and hopeful that Kingston will benefit from this.
- EK shared how national target is now for 35% of children with at least one mental health need to have access to a specialist mental health professional up from 25% previously. Flagged that as a society he feels we still lagging behind in acknowledging the size of the issue and resourcing it correctly.
- ACz highlighted need for therapist to be trained in how to write advice for an EHCP (JS confirmed that therapist are attending EHCP outcome training)
- AcZ suggested when Child in Need Plan has mental health objectives shouldn’t therapists be more joined up with social care staff? Experience is that they not as joined up as they could be, and plan could be closed without mental health objectives achieved

ACTIONS:

- All to feedback on Emotional Health Service Resource Hub
- KL to look at language and accessibility of materials on Local Offer
- JS to liaise with iCope re applicability for SEND parents and possibility of SEND specific support
- JS to liaise with RA on plans to co-deliver webinar for parents
- NE to keep this group up to speed with mental health summit
- AS to discuss with LK the development of the dynamic support register
- AW to discuss with colleagues re teams working together better
- NE and JT to produce narrative to pull together all these different pieces of work in a single document / place
- AfC / CCG to take up PCF on their offer to run another survey to help inform service development and make contact with certain groups and revert with next steps