

Richmond Parent Panel

13th January 2020

Agenda

1. Introductions

Parents / carers

Louise Edwards

Kevin Sears

Ana Daruwalla, co-chair,

Kristina Dale, co-chair

Minta Townsend

Ana-Valancha Brown

Staff

Anna Chiva, Associate Director for SEND

Ian Dodds, Director of Children's Services

Karen Lowry, AfCinfo/SEND Local Offer Website Manager

Doreen Redwood, Lead Children's Commissioner for CCG

Alison Stewart, Designated Clinical Officer

Ashley Whittaker, Programme Director

2. Update on Parent Panel / Parent Carer Forum

PCF planning a launch in March

Waiting for RUILS to begin their support work including phone line, mailing list etc

RUILs have candidates for the required post

Plan is for the Parent Panel to meet once more in March prior to PCF launch

3. Therapy review

[Therapy Review](#) (link to paper on website) (45 mins)

Anna and Doreen presented on why the review happened and key findings (see attached presentation) plus:

- keen to work with parents on how to prioritise investment
- Pre and post diagnostic support needs also to be improved and is a priority

Comments from parents:

- Getting in early is right but at the moment the reality is often not bad enough to qualify.
- When therapists change, don't want to go back to the basics again. If they do change they should be able to pick up where the previous one left off rather than going back to start and reassessing etc. The "restart approach" needs to be avoided.
- Is it right that schools may be investing in this?
- What about lack of cohesion in the way that health delivers therapy until school (eg Ham Clinic) and then becomes AfC. And then nothing in the holidays.

- How would the SPA form / telephone access work. What about service requirements and eligibility criteria? How will you avoid being inundated? (*Helpline / triage line, people know about it but people don't know enough about it. Need videos etc*).
- What about recorded message with information (*this is key part of the balanced model as much is universal service*)
- How will all the different organisations / providers work together better? E.g OT, Physio etc working together.
- What about single portal where all professionals can access all information on a child - parent, child, all professionals. (*yes would be great probably 2 years e.g. System 1. E.g. GOS model, can see which consultants have been in there*).
- This is relevant for Richmond Schools and what happens if your child goes to an out of borough school because at the moment nobody supports these kids? (*at moment recharging*). At moment "pushed away from Ham Clinic".
- Couldn't you have a therapist dedicated to travelling out of borough?
- Balanced system, have you thought about the templates you will be using?
- Who would set the goals for those young people in the new model?
- Who would do the assessment?
- How would the Balanced Model work?
- I worked in a school and the therapists taught all adults in the schools about what to do and the parents have. And then the support staff feel enabled and can train others also. And then you're training experts within schools. And you get to know the children much better.
- How long do you anticipate this whole system to take? How long is this phase and how many phases are there?
- What is SCAT pathway?
- 0-5 years seems to be going well. But then schools not as advanced.
- Re pre and post diagnosis support, when child is diagnosed by community paediatrician, he is then "discharged". Luckily he went to specialist nursery but what if not?
- What about post diagnosis workshop on Local Offer?
- When lots of parents are told when they've received a diagnosis is "go to Skylarks".
- Term Local Offer is unhelpful.
- What about post diagnosis workshop for groups of parents?
- Early Bird is good when post diagnosis
- Some great local practice (e.g. ADHD) but people not aware of what's available
- It's about marketing of what's available, and people don't know what is out there
- No professional (education + healthcare) has ever told me anything about the Local Offer. People don't know. Leaflets don't work. Very stressful for parents. Need someone to talk to them. (Information officer?)
- Do things in schools, come and talk to us in schools.
- Then parents need to learn a whole new vocab
- Youth support workers need upskilling
- Upskill school support workers
- Train all school staff on Local Offer
- Health visitors need to be trained on local offer
- Voluntary sector organisations don't promote it as much as they might
- Local Offer is so big and so diverse, specialist professionals don't always promote it.

4. Disability Register

Karen introduced and explained the approach.

Parents said:

- Re name call it additional needs register. Disability is not the word to use. Moved away from special needs.
- Over a certain age it's up to young person to apply.
- How did people apply before?
- Agree with one, if opening up to send support, think about the name
- Not everyone can access via online and must be accessible route eg not speak English, may have SEN themselves, need facility for them to access.
- I didn't know it existed. We on NADS (£15 per 2 years). Didn't know about it despite Ham Clinic, etc
- Needs to be clear open to everyone. Google form went from 1 to 3. Was asking for optional details eg religion etc and maybe not necessary. People may become suspicious. Parents can be sensitive about giving information. Do you expect 16 year olds to fill it out? Or will parents do it? Impossible for young people of 16 to fill these forms in.
- My 16 year old will not. Wait until 16? (SEND COP?)
- What about 18 years olds who not capable of filling in.
- Photographs info guidelines missing (National Disability Register website)
- Review dates? When on it do you stay forever? If it review every e.g. 2 years and do AfC have the capacity to do these reviews?
- What happens when they are 25?
- Need accessible routes to sign up
- Route to contact this audience
- Really vital tool to help services be cohesive. You all looking at same set of people.
- Didn't know it existed.
- It was a part of Aiming High.
- I heard about "Aiming High" from a friend. How should it be advertised?

5. LGA SEND Peer Challenge (report attached)

- Need more emphasis on the case worker point, re caseload and stability of team
- Engage more parents etc point 2 (have discussed with PCF)
- P.11, re EHCPs quality
- P.11, parent champions great idea
- P.14, what is the plan on personal budgets? Uptake is relatively low. Internal training also taken place on this.
- P.15, transitions. I think provision is abysmal.
- Need action plan on what's being done to address all these points

6. Actions from last meeting not otherwise covered

AW needs to do the breakdown of needs of 14 parents and without the jargon

7. AOB

- Conference. Note date of 30 June. Volunteers welcome to join organising committee.

- Phase transfer page
- Eventbrite log in to register to phase transfer, not on poster. Dates are wrong? This is the attention to detail that AfC are missing and need to improve. Need more QA. And on .co.uk not .com. Need more.
- Is everyone signed up to SEND Local Offer newsletter? Karen to send email with link