

ESCAN / EPCF Team Meeting

10th March 2017

St Andrew's Church Centre, Ealing, 1.30-3pm

Action Points	By whom	By when
To continue to work on a map of all ESCAN boards in Ealing detailing their interactions and the flow of information between them	Helen Green & Matthew Jeatt (others as invited)	Ongoing
To conduct a survey of parents with regards to the quality of their children's EHC plans	EPCF (Matthew J to lead)	By next meeting
To send contact email of Roehampton University to Ealing Parent Carer Forum	John M	ASAP
To ensure SEN support in mainstreams schools remains an item on every agenda	Co-Chairs: Matthew J and Debbie G	Ongoing
To send reminder email to parents about the feedback option on the Local Offer website	Brigitte	ASAP
To send feedback / evaluation of the Ofsted / CQC workshop to the EPCF	Debbie G	ASAP
To send summary of summer holiday survey results to the EPCF	Danielle GV	ASAP
To look at follow up survey with regards to short breaks and holiday schemes	Co-Chairs: Matthew J & Debbie G	timing and date to be agreed subject to resources
To take up the issue of parental representation on panel in their discussions outside this meeting	ESCAN	ASAP
To send out a request for parent volunteers to contribute to the bidding process for an extended CAMHS model.	Brigitte	ASAP
To put the information on request for parental input into CAMHS bid on EalingHELP	Nick	ASAP
To distribute feedback on SEND Information Fair to all via email.	Brigitte	ASAP
To raise the problems in the Wheelchair Service with CCG commissioners.	Natasha P	ASAP

Present:

Co – Chairs: Debbie Grey (Assistant Director ESCAN)

Matthew Jeatt (EPCF-Chair)

Other members: Brigitte Bistrick-Bryan (EPCF- Administrator); Rachel Burton (PT); Mary Doody (EPCF); Kirstie Ferrett (EPCF); Oliver Francis (CWD); Dido Green (Head of Paediatric OT); Helen Green (SEN Strategy & Inclusion); Sophia Lindsay (ESCAN Health Service Manager); John Miller (EP); Natasha Patten (CCG); Rachel Porter (S&L); Nick Radclyffe (EalingHelp); Sam Schmidt (EPCF); Catherine Sholl (CAMHS – LD Team manager); Sarah Theobalds (EPCF); Tom Quilter (PfA Manager, Ealing Mencap)

Observer: Danielle Grant Vest (LBE Commissioning)

Minutes: Brigitte Bistrick-Bryan

Apologies: Chris Jones (CWT Team); Asha Yadav (Ealing Contact A Family)

1. Welcome

Matthew J welcomed all as the Chair of this meeting.

2. Minutes of last meeting

The minutes of the last meeting were agreed.

3. Action Points arising

a) Issue Log

Brigitte circulated a first presentation of the EPCF's issue log. She explained that the Forum had started to log every issue raised by a parent since June last year and that the log was currently still a work in progress. There will be more work done on the issue categories and changes over time. Matthew J (Chair) emphasised that the log will be a live document which will be updated continuously.

Debbie G thanked the EPCF for the work on the log and stated how helpful it would be for ESCAN services.

b) A map of boards and discussion groups

Matthew J (Chair) and Helen G had met to develop a map of the different groups and decision boards in Ealing to show how they interact and feed into each other. They had realised that the flow of information as well as the interactions between the groups were not clear and that others should be involved in this work. A clarification of these groups would remain an action point.

ACTION: Helen Green and Matthew Jeatt (and others) to continue to work on a map of all ESCAN boards in Ealing detailing their interactions and the flow of information between them

c) To send letters and EHC-plans to Roehampton University

John M informed the group that this had not been possible due to capacity issues. He acknowledged that it would have been very useful to give Roehampton the information they needed for their research and evaluation as it would have provided some valuable quality assurance of Ealing's EHC plans but other work had simply taken priority. Sam's offer of practical clerical help made at the last meeting had not been taken up as there were confidentiality issues with parents seeing other families' details.

Q: Sam S. asked how Ealing proposed to assess the quality of EHC plans without participating in the Roehampton University research.

A: Helen G pointed out that the SEN panel was due to hold a training day to specifically look at the quality of EHC plans.

Matthew J (Chair) reminded everyone that the published letters resulting from the Ofsted and CQC inspections of Local Areas had clearly highlighted that the quality of EHC plans was central to the success of the inspections and pointed out that a lack of monitoring and quality assurance could have consequences for an up-coming inspection of Ealing's SEN services. He added that the EPCF would do its own survey of parents with regards to the quality of EHC plans in Ealing.

ACTION: Ealing Parent Carer Forum to conduct a survey of parents with regards to the quality of their children's EHC plans.

John M agreed to email the Roehampton contact email to Matthew J (Chair) in order for the Parent Forum to be able to use similar questions for parents to make any comparison easier. Using the SEND survey monkey process was discussed.

ACTION: John M to send contact email of Roehampton University to Ealing Parent Carer Forum

Helen G stated that there would also be an EHCP audit taking place on the 27th March 2017. Nick R pointed out that Roehampton University was one of the very few universities doing detailed research into the quality of EHC plans nationwide. John M acknowledged this but suggested that Ealing could still learn from their research as other LAs had submitted plans to them for evaluation and Ealing would be able to access their findings after evaluation.

d) All Age Disability Service

Following IMPOWER'S consultation meeting with a parent group, Debbie G informed the meeting that discussion about an all age disability services were on hold at the moment. She had spoken to "IMPOWERr" and had asked them to send information on other LAs who had introduced all age disability services (Croydon and Hillingdon) directly to the EPCF. Matthew J (Chair) told her that he had so far not received any information but that the Parent Forum would be very interested in receiving information on this service model. Nick R told the group that he had added an adult section to the EalingHelp website as many services for young people over 18 now fell under EHC plans.

e) Children's OT services

Dido G, new Head of Children's OT services, informed the group that she had taken over the service in February and that the work on a new leaflet explaining the new OT service model was nearly completed.

4. Terms of Reference

Matthew J (Chair) asked for a clarification of the group's Terms of Reference with regards to membership. He explained that it had been the EPCF's understanding that all ESCAN service leads as well as the members of the EPCF Steering Group were members of the group with the possibility of others being invited if both Debbie G and he as the Co-Chairs agreed. He suggested that the ability to have an open discussion in a non-adversarial manner was the strength of the group which could be lost if external observers were to be attend. Transparency of the meetings would be achieved by publishing the minutes for all to see. He asked the members of the group for their views.

Dido G suggested the option of holding a special open forum meeting to offer all interested parents the opportunity to communicate directly with ESCAN service leads at some point. Helen G added that in her view it was important to ensure diversity. If this group was to be the main co-production session between parents and ESCAN services we needed to ensure all groups amongst parents were represented. Matthew J (Chair) replied that this had been the reason why representatives of the Forum's partner organisations (Contact A Family, Mencap, ISAID, PESTS) were part of the Steering Group and, as such, members of this group. Together the partner groups and parent members of the Steering Group represented an extremely diverse range of parents and families in Ealing.

John M argued that the group needed to ensure that sufficient feedback on SEN support was included as this was a big area of their work now. He would like to know from the parents' perspective what happened in mainstream schools before the support of EHC plans. Brigitte B pointed out that a big proportion of the Issue Log contained issues raised by parents about SEN support in mainstream schools. She agreed with John M that this should be a big focus of the group but added that it would therefore be very helpful if a member of the School Effectiveness Team was also sitting in this group.

Natasha P added that she also thought that whilst the group could not be open to all it was important that all parents were represented on it.

Matthew J (Chair) agreed. He added that this was only the 3rd meeting of this group and that it was still in the process of developing an effective way of working together. He suggested for SEN support to be a standing item on every agenda for future meetings.

ACTION: Matthew J and Debbie G to ensure SEN support an item on every agenda

Matthew J (Chair) summarised that the general view seemed to be that the meetings of this groups should continue to be closed meetings with the option of external advisors being invited by agreement between him and Debbie G. Any member of the group wanting to invite an external advisor could contact him and Debbie G at any time. Members of the group should continue to be the ESCAN service leads as well as the members of the EPCF Steering Group. However, in future an open forum should be planned for any interested parents to attend.

The group agreed this clarification of the Terms of Reference.

5. Notification of AOB

Debbie G notified the group that she had some information for the group following today's agenda.

6. Positives and Challenges

a) Positives:

- Matthew J (Chair) noted that he and Brigitte B had been invited to an outcome workshop for professionals by John M and Natasha P which had been very helpful in bringing issues to light and reducing the adversarial atmosphere.
- Brigitte B thanked the OT service as well as all other services involved in the recent and ongoing information drop in sessions for parents (e.g. on sleep problems as well as eating issues). She also pointed out the increased communication and consultation between OT professionals and the EPCF with regards to phrasing of their service information leaflets and communication with parents.

Q: Nick R asked if Ealing had a policy on translating written information for parents.

A: Dido G replied that she did not believe Ealing did have a policy but pointed out that these leaflets formed part of NW London Healthcare.

- Sam S reported that she had attended the recent Local Offer workshop. She admitted that any progress had so far been a struggle but that she had found that over time parents' views and suggestions were starting to be taken into account. It had been a positive meeting with some requested things being implemented now. Helen G thanked Sam S for her contribution to the group.

Dido G reminded everyone of the comment button on the first page of the Local Offer and asked if the Parent Forum could remind parents to make more use of this feedback option. Brigitte B agreed to send out a reminder email to all parent members.

ACTION: Brigitte B to send reminder email to parents about the feedback option on the Local Offer website.

(Post meeting note by Brigitte: I attempted to leave some feedback and discovered that leaving feedback on the LO is only possible via email which means it is not anonymous!!)

- Helen G pointed to the Young People's Champion group as a very positive development in Ealing, which had been set up and was being managed by Tom Q (Ealing Mencap). Helen G had attended their last meeting and had found it extremely informative. Tom Q stated that everyone would be welcome to visit the group but asked professionals and parents to notify him first as the right balance between young people and visitors needed to be maintained. He reported that this was now an increasingly confident group of approximately 9 young people attending regularly. They meet once a month.
- Kirstie F stated that she had found the recent Ofsted / CQC workshop a positive experience as parents had had the opportunity to take part in the table discussions and

contribute to the feedback. Debbie G replied that she had received draft feedback on the day and would send out the evaluation to the EPCF soon.

ACTION: Debbie G to send feedback / evaluation of the Ofsted / CQC workshop to the EPCF

b) Challenges

- Brigitte reported that it was still extremely difficult for the Forum to get through to many of the mainstream schools' SENCOs which made it very difficult to get information to and views from parents of the many children with SEN at mainstream schools. Matthew J (Chair) reported that he had been invited to attend a meeting of all secondary school SENCOs in the coming weeks and that this should help to strengthen communication between schools and the Forum.
- Other challenges were to be discussed under the Issue Log agenda item (see below under point 8).

7. Service Leads Update

Danielle GV presented the results of the recent summer holiday short break questionnaire sent out to parents.

She explained that due to funding cuts it had been important to get direct feedback from parents on what parental preferences were on how to spend the reduced funds available. She had received 103 responses to the questionnaire which had gone out mainly via email through the schools and the EPCF. This number had not been as high as she had hoped but the feedback had been helpful.

Q: Matthew J (Chair) asked how many parents had been sent the questionnaire in total.

A: Dannielle replied that as the questionnaire had been sent out by the schools and the EPCF she did not have the exact number. The 103 replies hopefully give an indication of parents' preferences. Many more parents of younger children had replied than those of older age groups.

Danielle circulated the findings of the survey in data form and gave the following summary:

On the question whether their children had attended a short break during the summer holidays and if they had, how they would rate the provision the majority of parents replied that their children had attended a school based short break with the Log Cabin play club being ranked second. The feedback on rating was mainly good or very good.

Q: Kirstie F pointed out that this data excluded parents of children who do not attend short break options for a variety of reasons, e.g. lack of transport provision.

Danielle GV acknowledged that this was the case. She continued to feed back that when thinking ahead, again the majority of parents had expressed a preference for school based services, followed by the Log Cabin as a second preference.

Q: Kirstie F asked if any of the parental comments and feedback made during the consultation session in November had been taken on board.

A: Danielle GV confirmed that she had taken from that consultation how important short breaks were for parents and how there was a strong need for short breaks for older children as well as the younger age group. Debbie G pointed out that the consultation had not been about short breaks in general but a very specific pot of money for summer holidays specifically. Short breaks in general were a much bigger issue that would need to be targeted at a later stage.

Danielle continued to feed back from the survey that whilst school based provision was clearly the most popular for younger children, the response from older children had been a preference for clubs and activities in the community with more choice and independence. There was also a clear need for more funding for young people aged 14 plus. Tom Q confirmed that this was also the feedback he received from young people that they want access to the community, trips out and activities to develop life skills.

Danielle summarised the finding of the survey stating that Ealing were currently funding holiday provisions that parents appear to be happy with at the moment. She agreed to put together a summary of the survey feedback to send to the EPCF.

ACTION: Danielle GV to send summary of summer holiday survey results to the EPCF

Q: Sam S suggested that for future planning more feedback would be needed on why many parents were not using short breaks. She felt that the survey had not been detailed enough.

A: Danielle agreed that a follow up questionnaire was possible with those parents who had said that they were not using any short breaks provision. Tom Q pointed out that getting as many views as possible required a lot of marketing and time. Dido G asked if any follow up questionnaire could include a question on what therapeutic services parents would like to be included in the short breaks. Matthew J (Chair) suggested that the Forum could take on a role in accessing parents to find out a bigger picture around summer holidays schemes and short breaks in Ealing. He thanked Danielle GV for her presentation on the survey.

ACTION: Matthew J and Debbie G to look at follow up survey with regards to short breaks and holiday schemes in the future.

8. EPCF Issue Log

Brigitte had circulated the current results of the Issue Log at the beginning of the meeting (see above under 3 a)).

The log showed up EHC plans, SEN support in mainstream schools and waiting times for an assessment and diagnosis of ASD as the three issue most often raised by parents.

EHC plans

John M pointed out that improvement of the quality of Ealing's EHC plans continues to be a work in process. He had fed back to Debbie G after the recent outcome workshop that more co-productive work with parents was needed. Matthew J (Chair) pointed out that there was obviously a real problem with multi agency working. He reminded the professionals that the multi-disciplinary meetings were hugely important to parents and supposed to be an integral part of the EHC plan's process. He also suggested that the issue was not simply quality assurance of the plans but the quality of the entire

experience of going through the process for parents. Helen G pointed out that quality assurance included the question of parental experience.

John M stated that it had been discussed at a previous meeting that parents would be trained to be able to sit on the panel for EHC plans. Matthew J (Chair) expressed some surprise at this and stated the EPCF had not been aware of the plan of having parent representatives on the panel. He very much welcomed the idea.

A discussion took place around the question of whether parents could sit on the EHC plan panel. Helen G suggested that the problem of confidentiality could be resolved by parents signing a confidentiality agreement as long as parents had undergone appropriate training which the Parent Forum could offer. Dido G pointed out that there was still an issue with potential breaches of confidentiality as no one outside the clinical team should have access to clinical issues. The person who provided the medical advice would not have agreed to the information being shared with a parent.

Kirstie F asked if parents would be paid for any work done as panel members.

Debbie G summarised that the issue of parent representatives potentially sitting on the panel should be taken up and discussed further outside of this meeting due to confidentiality issues and the range of agency reports that contribute to the SEND statutory assessment process. Matthew J (Chair) agreed but also reminded professionals that any parental input into the panel would need to carry equal weight as the professionals' input and should be remunerated accordingly.

ACTION: ESCAN to take up issue of parental representation on panel in their discussions outside this meeting

9. AOB (due to time constraints AOB was addressed at this point in the agenda)

- a) Debbie G reported that Ealing had been successful in getting through the first round of a bidding process to extend a model of supporting children and young people, mainly with a diagnosis of ASD, and mental health issues. The lack of support had emerged in this area over the last few years. She was happy to report that the Ealing bid had gone through to the second round of the bidding process for the DfE's innovation fund. The bid now needed to be developed and finalised for the deadline in April. She asked if parents as well as young people with experience of SEN and mental health services were willing to contribute to the bidding process.

Brigitte B asked if Debbie could send her the exact wording of the proposal which she would send out to parent members to find interested parents. Nick R agreed to publish the information on EalingHELP as well.

ACTION: Brigitte B to send out request for parent volunteers to contribute to the bidding process for an extended CAMHS model.

ACTION: Nick R to put the information on EalingHELP

Matthew J (Chair) informed the group of the upcoming Expert Parent workshop specifically for CAMHS services the EPCF was running with the Council for Disabled Children on the 17th March.

Q: Brigitte B asked when the deadline for the application was.

Debbie G replied the deadline was towards the end of April.

Catherine S added that within ESCAN there was already a service for children with Learning Difficulties but that there was a gap for children with no or little LD who currently get very little or no support with mental health problems. Debbie G told the group that there would be a workshop on the 14th March to discuss further details. Interested parents would ideally be parents of a child or young person up to 25 years old.

- b) Matthew J (Chair) asked if a list of Ealing's ARPs with their specific entry criteria could be provided on the Local Offer or handed to the EPCF for distribution to parents.
- c) Nick R encouraged everyone to watch the BBC1 program "Life animated" which was available on I-player.
- d) Brigitte B circulated feedback the EPCF and partners had received on the SEND Information Fair. She agreed to send the feedback out to all via email.

ACTION: Brigitte to distribute feedback on SEND Information Fair to all via email.

- e) Brigitte B also highlighted the fact that despite taking up a very small proportion of the Issue Log, the problems raised by parents and carers with the Wheelchair Services were extreme and shocking. Families regularly wait for an appointment even for urgent reassessments for over 18 months which leads to children and young people using unsuitable wheelchairs for long periods of time. She asked if this could be taken up as an urgent issue.

Debbie G replied that since the Wheelchair Service did not fall under ESCAN this would have to be raised with the CCG. Natasha P agreed to pass on the issue to the relevant commissioners.

ACTION: Natasha P to raise the problems in the Wheelchair Service with CCG commissioners.

Matthew J (Chair) thanked everyone for attending the meeting and summarised as the main focus the discussion around summer holiday schemes, the ongoing discussion around Ealing's EHC plans, mental health services and the need for a diverse, representative parental presence in the group, including the plan to hold an open forum for all parent at some point in the future.

The meeting ended at 3.00pm