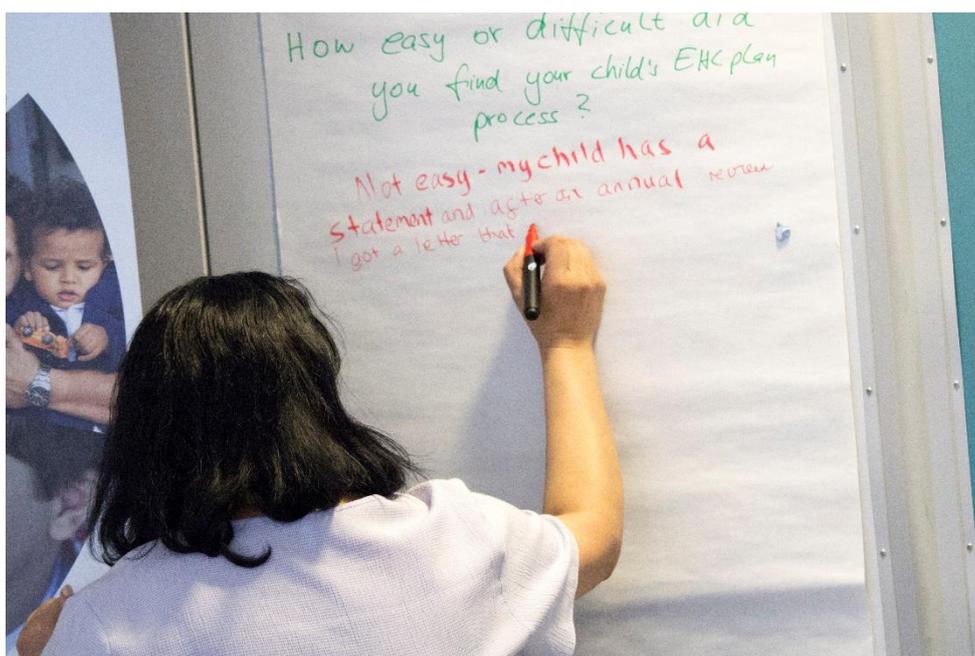


Ealing Parent Carer Forum Annual Report 2017-2018



Make your voice heard

EPCF - Annual Report

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EPCF Membership / Roles:

1. **Chair:** Matthew Jeatt (Parent)
2. **Treasurer:** Vacant
3. **Steering Group Members:**



Parent Volunteers: Mary Doody, Kirstie Ferrett,
Samantha Schmidt, Sarah Theobalds

From our Partner Organisations: Tom Quilter & Gabriel Jones (Ealing Mencap), Nick Radclyffe (EalingHELP + Parent), Joy Barton (P.E.S.T.S. & Parent), Charity Gondwe (P.E.S.T.S. & Parent), Manjit Bhamra (Ealing ISAID!), Asha Yadav (Ealing Contact)

4. **Administrator:** Brigitte Bistrick-Bryan (Parent)
5. **Parent Members:** 714 (at end of March 2018)



EPCF Chair's Report

Chair's Report

This year has seen significant increases in both membership numbers and activities. Our membership increased by 42% between March 2017 and March 2018 from 503 to 714. The number of members taking part in our events and contributing to our surveys has also risen significantly and, as a result, more parent and carer voices are being expressed.



We are engaging with the LBE, Health and Social Care services more frequently and ensuring that those voices and experiences are heard by those managing and delivering services for our families. We continue to press for a culture of co-production and participation so that we are more able to show exactly where and how the experiences and voices of our members have had a demonstrable positive impact on information and services being provided to us all.

All of this increased activity has brought us very close to the limits of our capacity as a forum and we now very much need the support of more active volunteers to help us manage and deliver our various events, workshops, drop-ins and surveys.

We would welcome support from members who are interested in being part of the future development of the Forum and who have a variety of skills and experience, for example in the areas of finance, management, events, and web development. We also welcome suggestions to develop new activities and different ways to engage with our parent and carer members.

Please come along to our AGM on the 21st September at The Lido Centre in West Ealing and talk to me and Brigitte and meet members of our Steering Group to find out more about the history and purpose of our Forum and how you could be a part of its future!

Matthew



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EPCF Administrator's Report

Dear Members,

My name is Brigitte Bistrick-Bryan and for those of you who have not met me yet I am the administrator of the Ealing Parent Carer Forum and the face behind the emails you are getting from the info@epcf.org.uk address.



The Steering Group agreed for me to double my working hours for the Forum from September onwards which has led to me being able to visit a lot more SEN Parent Mornings in Ealing schools. I have started to visit more mainstream schools as the majority of children with SEND in Ealing are attending mainstream schools yet the parents are often not aware of the support network available or opportunities to voice their concerns.

As I have emphasised in previous reports, in my view the Parent Forum's role is very much to ensure that not only the voices of the loudest get heard but also those who for a variety of reasons may not protest or raise their issues much but quietly struggle on. By increasing our membership substantially again over the year we are continuing to become more representative and inclusive of all. Our Issue Log, the increase in the use of Parental Surveys and more Focus Group meetings are also ways to ensure everyone gets the opportunity to contribute to the conversations and get their voice heard.

Our work can be a little frustrating at times. We have for the first time added a page on "outcomes" to this report as we believe we are making some progress in terms of Parent Participation, however, it often feels painfully slow. For me personally the best parts of the job are definitely meeting you, our members, speaking to parents individually as well as working together with our partners at Mencap, EalingHELP, CONTACT, ISAID! and P.E.S.T.S. Everything always feels a lot easier if shared with friends.

In that spirit, welcome to all our new members and I hope you find this report informative!

Brigitte



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The Boards / Groups we participated in to influence decision making in Ealing

- **SEND Executive Board:** Matthew Jeatt (Chair)
- **ESCAN / EPCF Steering Group Co-Production Board:**
All members of the Steering Group
- **Preparing for Adulthood Board:** Mary Doody & Anne White
- **SEND Reforms Review Group (post implementation) –**
Samantha Schmidt
- **Autism Board:** Brigitte Bistrick-Bryan
- **Local Offer Peer Review:** Samantha Schmidt
- **Building My Future Project:** Zane Karklina, Ruby Sangha & Jennifer Wray
- **Participation in Early Years / PVI Nursery staff training:**
Sarah Theobalds & Brigitte Bistrick-Bryan
- **Participation in Recruitment processes:** Ruby Sangha, Brigitte Bistrick-Bryan
- **National & London Network of Parent Carer Forums (NNPCF) –** Matthew Jeatt & Brigitte Bistrick-Bryan



EPCF Engagement Events

- **Family Fun Day** at Enterprise Lodge in July 2017
(together with CONTACT, EalingHELP, P.E.S.T.S., EalingMencap and Ealing ISAID!)



- **Listening Event** (to contribute to development of Participation Strategy) September 2017 (with Ealing Adult Power Group & Young People's Power Group / EalingMencap)



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- **Preparing for Adulthood Workshop in November 2017** (*together with EalingMencap*)
- **Listening Event** (to contribute to development of Participation Strategy) February 2018 (with Ealing Adult Power Group & Young People's Power Group / Ealing Mencap)



- **SEND Surgery & Advice Event March 2018** (*together with ESCAN services, EalingHELP, Ealing Mencap, CONTACT, Ealing ISAID! & PESTS*)

**EALING
HELP**



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EPCF Drop-In Information

sessions for parents and carers

Our Information Drop-In sessions are often held in collaboration with CONTACT Ealing, Ealing ISAID!, Ealing Mencap or ESCAN services.

- **April 2017:** Independent Travel (*with EalingMencap*)
- **May 2017:** Joint Early Years workshop (*with CONTACT & PESTS*)
- **May 2017:** EHCPs (*with CONTACT Ealing*)
- **June 2017:** Anxiety & Obsessions
- **September 2017:** EHCPs (*with Ealing ISAID!*)
- **October 2017:** Disability Grants / Family Fund
- **November 2017:** DLA / PIP
- **January 2018:** Toilet Training
- **February 2018:** SEN support in mainstream schools (*with Ealing ISAID!*)
- **March 2018:** EHCPs (*with CONTACT Ealing*)



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Surveys and Focus Groups

Surveys:

- **Wheelchair Service Survey May 2017** (12 responses, reported to the AJM Healthcare (Service provider) as well as the Physiotherapy service who has included the results in feedback to commissioners)
- **Bladder & Bowel Service Survey September 2017** (28 responses, fed back to the CCG and provider through meetings resulting in establishment of temporary service in March 2018)
- **Quality of EHCPs in Ealing Survey October 2017** (68 responses, reported to the SENASS team and ESCAN service leads)
- **SEN Support in Mainstream Schools Survey November 2017** (58 responses, reported to ESCAN service leads resulting in a member of the School Effectiveness Team now attending the ESCAN / EPCF SG meetings and direct discussions between the EPCF and the SET).

Focus Groups:

- **Supporting ESCAN / CAMHS bid for Building My Future project** April 2017 (13 parents, 2 professionals)
- **Looking at the Resource Allocation System** June 2017 (11 parents, 2 professionals)
- **Speech & Language Early Years Group** June and October 2017 (5 parents, 1 professional)
- **Bladder & Bowel Service Group** September 2017 (8 parents, 3 professionals) and January 2018 (4 parents, 7 professionals)
- **High Needs funding** November 2017 (8 parents, 3 professionals)
- **Speech & Language Therapy in Mainstream schools** March 2018 (6 parents, 2 professionals)



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Outcomes – What difference have we made?

With more and more parents contributing to our discussions and work, we increasingly get asked the question: What difference has it made? Does our feedback have any impact at all? A very difficult yet equally justified question and here is our answer:

We cannot in all honesty say that we are anywhere close to where we would like to be in terms of genuine Parent Participation with all Ealing and Health Services listening to the parental voice in the way we believe would bring the most benefit to all. However, we have made some steps in the right direction, in particular with individual services and the Building My Future Project. Here are what we see as the most tangible outcomes of all your feedback via the EPCF for the past year:

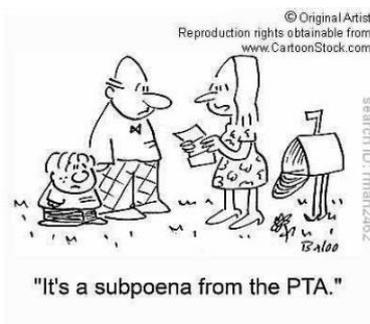
- **Early Years Speech & Language Therapy:** In meetings of a small Focus Group of parents with the service where the long waiting list and the high number of families missing appointments were discussed we argued for an appointment reminder to parents via text message. The service then managed to overcome technical problems and it was introduced at least for the very first appointment, leading to less families missing their appointments and falling to the back of the queue as a result. Our feedback was also taken into account with regards to the management of the waiting list, letters to parents and services offered to the child during the wait (S&L groups).
- **Bladder & Bowel Service:** After a parent highlighted to us the grave problems with the service in summer 2017 we approached the CCG (Clinical Commissioning Group) who fund the service and had not been aware of the issue. After several meetings with parent users and professionals supporting us a temporary service was introduced in March 2018. Most of our suggestions were included in the service specification for a new, permanent service. For the first time a parent representative was allowed to attend a service evaluation meeting between the CCG and the service provider (NW London NHS Trust) where she could highlight the biggest problems with the temporary service, mainly around product quality and delivery.



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Outcomes continued..

- Building My Future Project:** After initially supporting Ealing's bid to the Department for Education for this additional funding a group of parents has supported the project through the period of setting up the service and getting off the ground. We participated in some of the recruitment processes looking to ensure professionals coming into the team showed an appreciation of the value of parental input for the individual children as well as the service planning. The BMF team will be the first team within ESCAN who have requested a training session run by parents as part of their team meetings (which will be delivered in October 2018).
- Speech & Language Therapy in mainstream schools:** After meeting with a small focus group of parents it became clear very quickly that parents had a very different experience of the service than the Speech Therapists and together we decided to run a parental survey over the summer term to establish a base line. The results of the survey and possible changes to the service delivery will form the basis of our next meeting with the Service Managers after the summer holidays.
- Development of a Participation Strategy:** Under the lead of Tom Quilter from EalingMencap we have sat down with Nick Radclyffe from the Adult Power Group and ESCAN officials to develop an Ealing Participation Strategy. It will clearly define the principles and guidelines that would have to be followed by all in Ealing if we want to establish genuine participation of parents / young people and adults with SEND in the development and delivery of services. The draft is almost completed, will be presented to our joint ESCAN / EPCF SG meeting in September and then be passed on to the SEND Executive Board for approval. Once approved by all and launched officially it should help all of us to follow its guidance and principles consistently throughout all work carried out to improve the lives of children and adults with disabilities in Ealing.



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Outcomes continued..

- SEN support in mainstream schools:** As our Issue Log continues to highlight SEN support in mainstream schools as one of the main problem areas in Ealing it became more and more pressing to engage in conversation with the School Effectiveness Team who support schools in Ealing in different ways. Since February 2018 a representative from the team is finally participating in our joint ESCAN / EPCF SG meetings and we have started to talk about systems and structures on how parents' voices and experiences can be heard regularly by the service. We realise this is a small step but sometimes it can be an achievement to simply initiate communication before more tangible results can be produced.



- Joint ESCAN / EPCF SG meetings:** The continuing discussions within this forum may not seem much of an outcome in practical terms but they have led to most of the work carried out with individual services and projects. With all the frustration about the slow pace of progress and (unfortunately) the occasional step backwards we do believe in a pragmatic and therefore cooperative approach and building positive working relationships with professionals forms a crucial part in this. This regular meeting has enabled us to bring to the attention of all service managers the issues parents raise on a regular basis and keep them on top of everyone's mind and agenda.

Quotes from parents:

"EPCF fills the gaping hole left by the LA cuts to vital services for vulnerable children and young people. They provide a voice when the LA often has parents on permanent "mute". (Parent X – name provided)



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Quotes from parents continued:

“The support from the Ealing Parent Carers assoc has been amazing. I have realised that the council and other entities want to listen to what parents and carers have to say. The Ealing assoc has been fantastic in working with the local council and structuring an effective participation group amongst parents. Some really good work has been done and the foundations laid for effective changes. Thank you to the Ealing parent carers team.” (Rashid)

We also asked some of the professionals we have worked with over the last year to tell us their thoughts about the value of working with parents. Here are their responses:

Karen Benedyk (Clinical Head of Speech and Language Therapy):

“The Ealing SLT schools service was struggling to meet the parents / carers of the children they supported in school, and to understand their concerns. EPCF facilitated a joint meeting with parents and organised and managed a questionnaire to parents. As a result of the meeting and questionnaire changes will be implemented to make the service more accessible to parents. The SLT service value this joint working with EPCF and plan to work together on service developments over the next year “

Mita Mistry (Early Years Team Leader Paediatric Speech and Language Therapy):

“Working together with the parent carer forum the paediatric SLT service was able to generate clinical pathways based on parent feedback. The discussions helped form the information of what we put on the local offer and has given us the opportunity to build better relationships to continuously improve our services.”

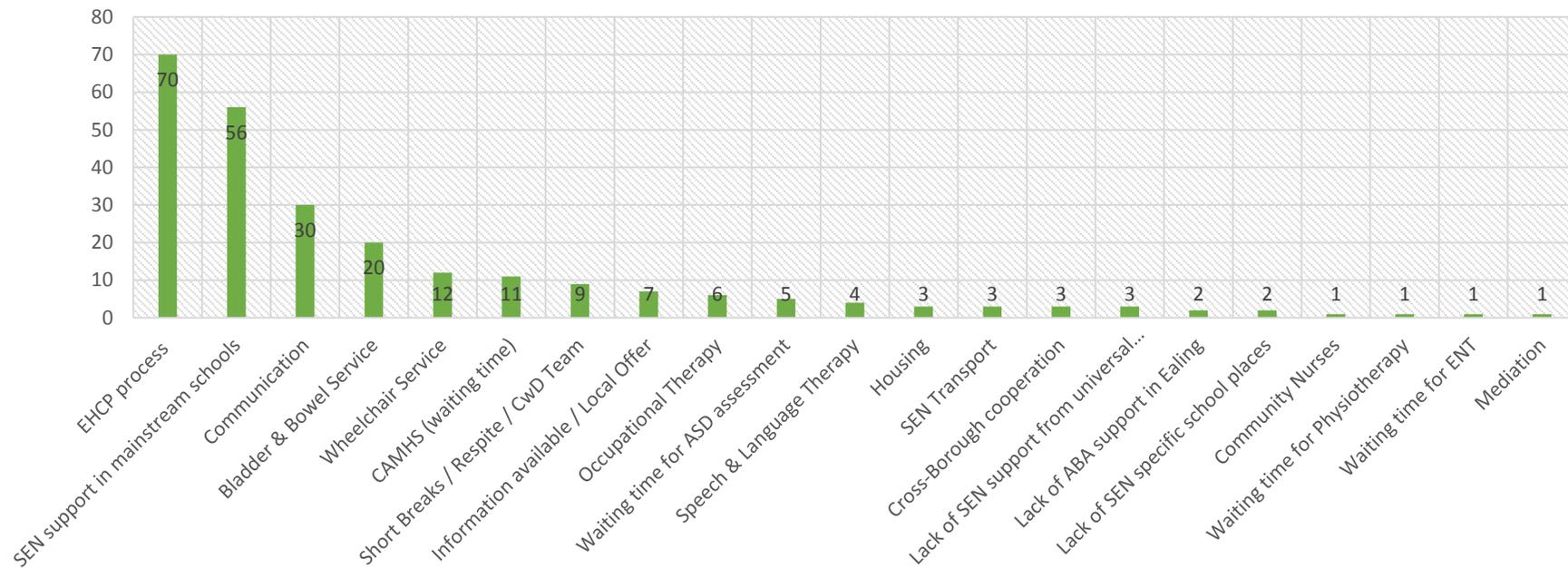
Oliver Francis (Team Leader Building My Future Project)

“EPCF and specifically Brigitte, Zane, Ruby and Jennifer have been involved in the development of our BMF Team at every stage. Design of model, recruitment, team training and ongoing participation in development of the team model and the generic learning from the BMF model. Their contribution and participation is imperative and I feel this contribution is guiding BMF /Ealing in a much more positive direction in respect to the development of services for young people with additional needs in Ealing. This work will be ongoing until the end of 2019 and I very much look forward to working with EPCF throughout this period and personally value their contribution to our service greatly.”



Make your voice heard

EPCF Issue Graph Summary 1.4.2017 - 31.3.2018

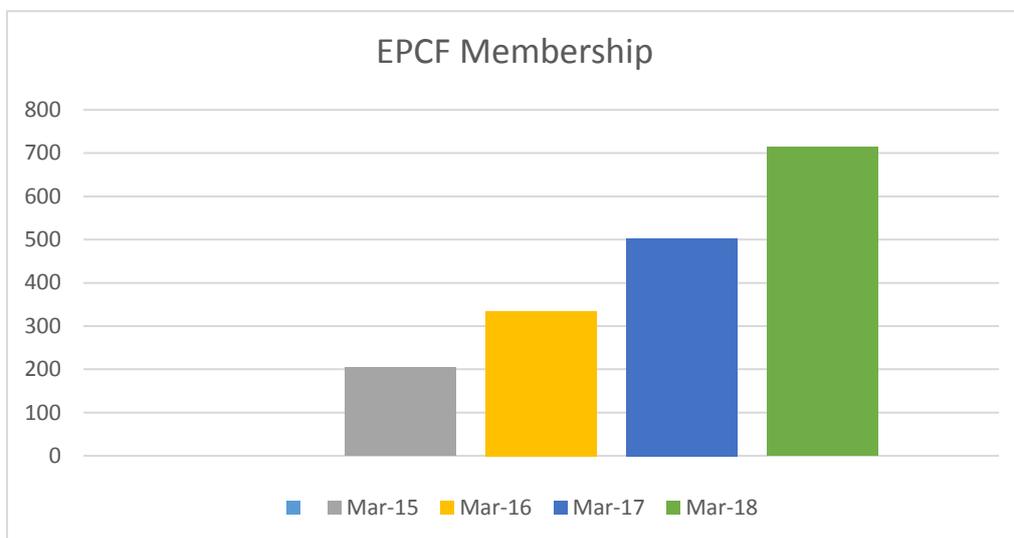


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Ealing Parent Carer Forum 3-Year Activity report 2015-18

EPCF Membership:

March 2015	205
March 2016	335
March 2017	503
March 2018	714

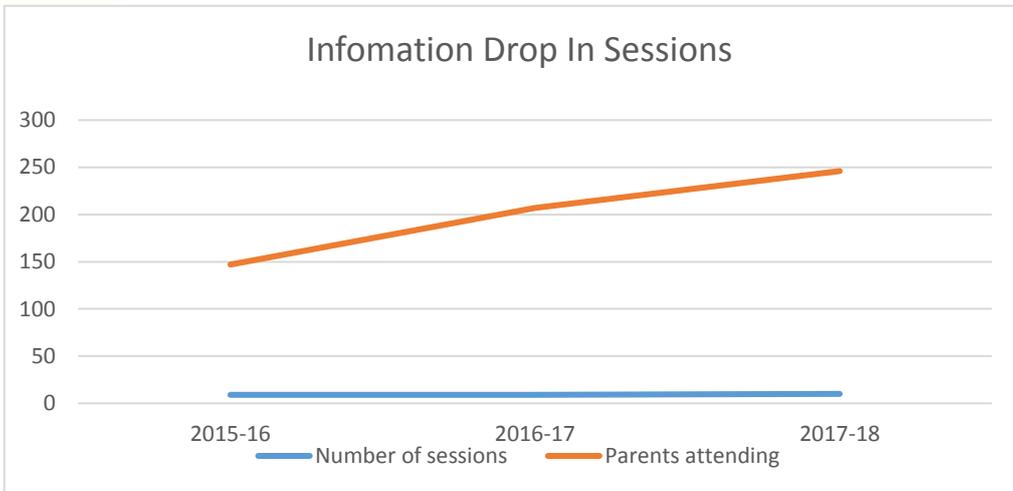


EPCF Parent Information Sessions:

	Number of sessions	Parents attending
2015-16	9	147
2016-17	9	207
2017-18	10	246

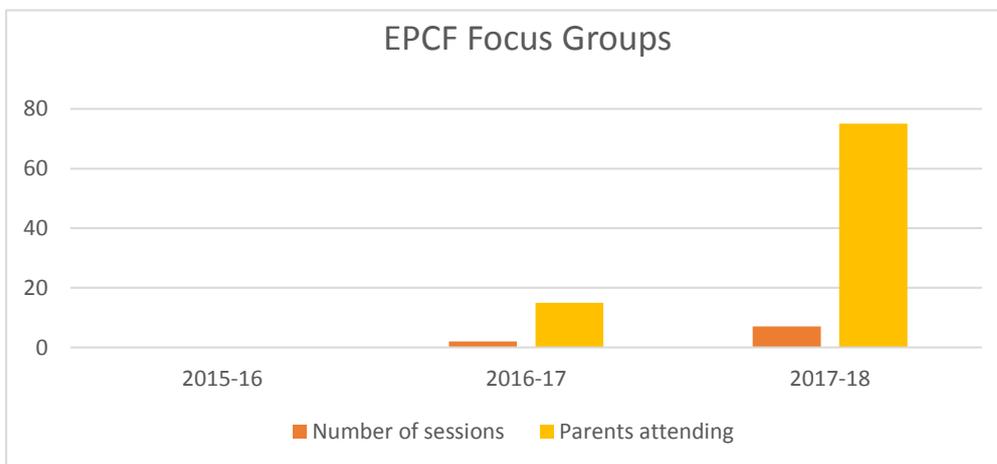


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EPCF Focus Groups:

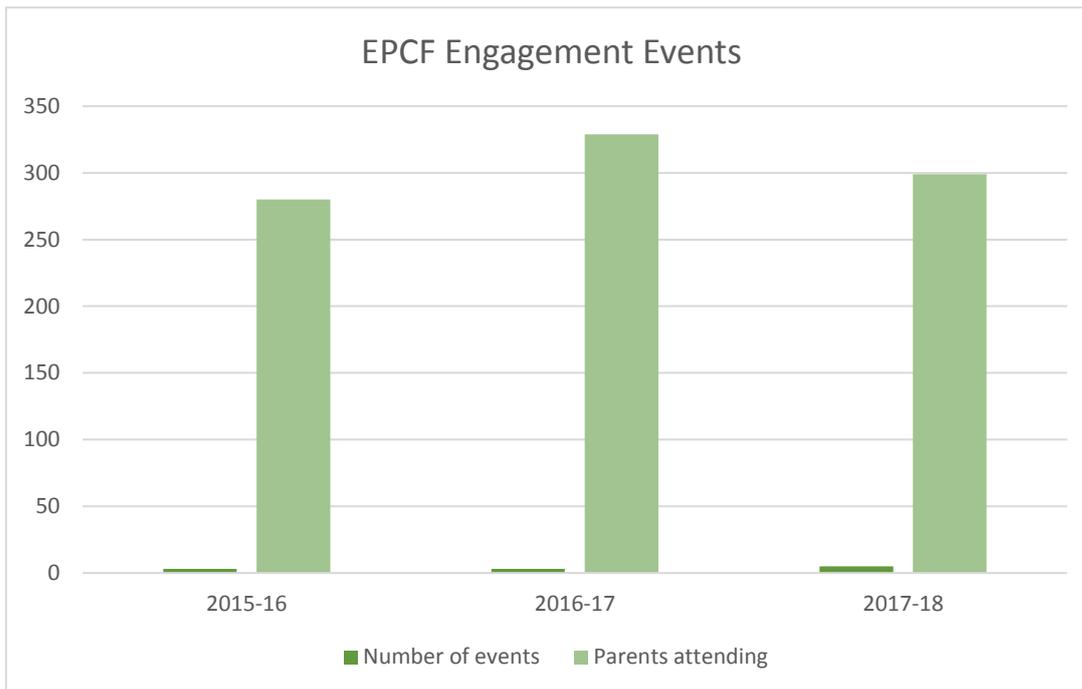
Focus Groups run	Number of sessions	Parents attending
2015-16	0	0
2016-17	2	15
2017-18	7	75



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EPCF Engagement Events:

EPCF Engagement Events		
	Number of events	Parents attending
2015-16	3	280
2016-17	3	329
2017-18	5	299

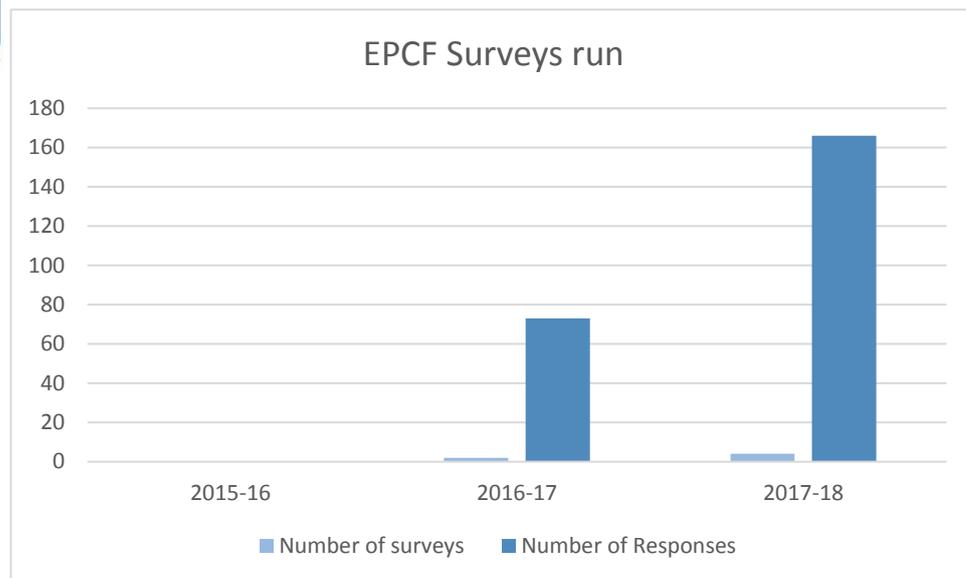


EPCF surveys run:

Surveys run		
	Number of surveys	Number of Responses
2015-16	0	0
2016-17	2	73
2017-18	4	166

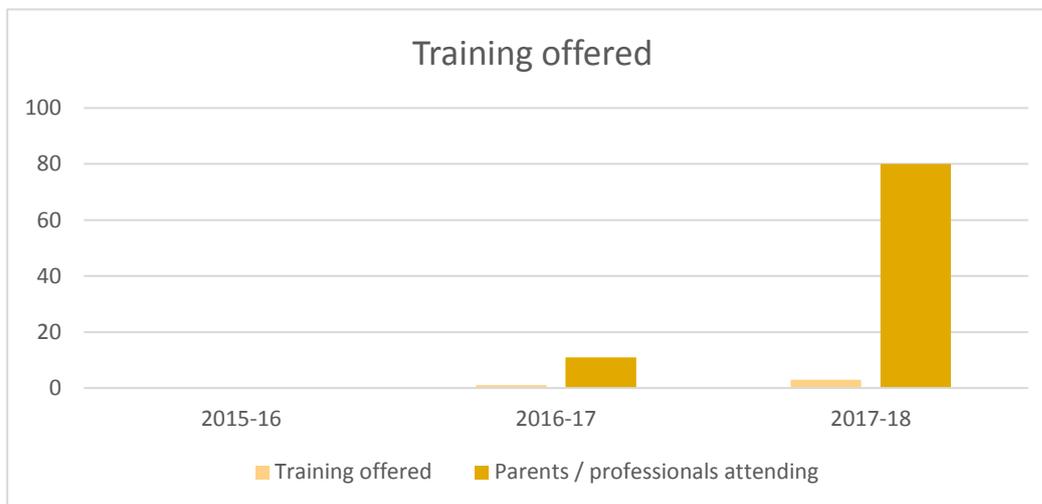


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EPCF Training delivered to Parents or Professionals:

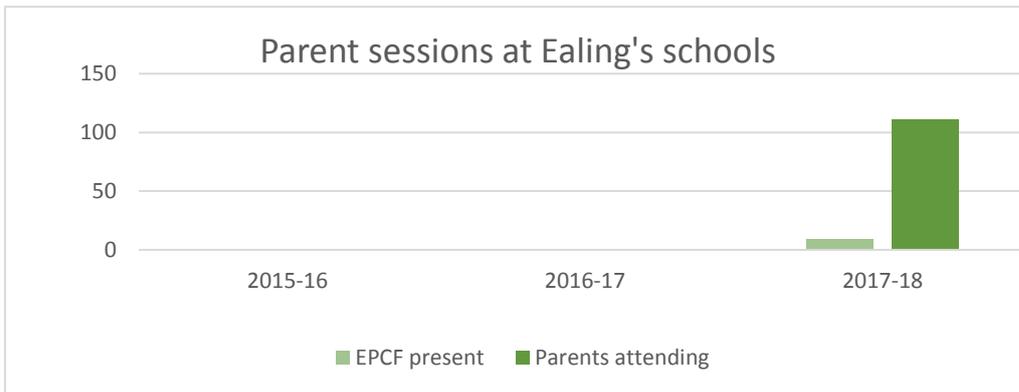
Training delivered to parents or professionals		
	Training offered	Parents / Professionals attending
2015-16	0	0
2016-17	1	11
2017-18	3	80



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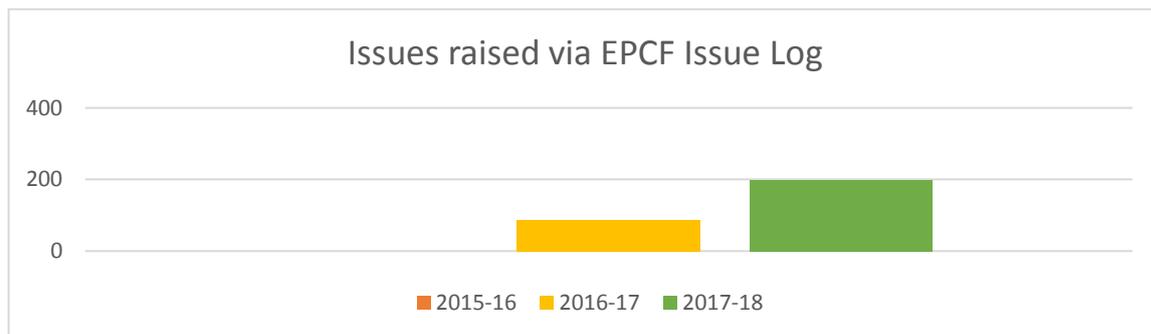
EPCF Parent Sessions at Ealing schools:

Parent sessions at Ealing's schools		
	EPCF present	Parents attending
2015-16	0	0
2016-17	0	0
2017-18	9	111



Issues raised with Ealing Services via the EPCF Issue Log
(started in June 2016):

Issues raised with Ealing services via EPCF Issue Log	
2015-16	0
2016-17	87
2017-18	199



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EPCF Finance Report

The Forum receives funding from the Department for Education and the London Borough of Ealing.

The Department for Education (DfE) currently gives grants of £15000 each year to all qualifying parent forums nationally. The funds are administered and managed by Contact and released in two equal instalments of £7500 with the second only being released after we have accounted for the first.

The London Borough of Ealing (LBE) supports the work of the Forum by providing funding each year that is variable, with an annual “core funding” amount plus occasional specific support for example the current “Building My Future” (BMF) project.

EPCF remains a wholly independent organisation managed and led by parents and carers and never directed by others.

Our major expenditure is on staff costs representing just under 73% of total expenses over the last three years, paid roles include: Chair, Administrator, Treasurer and Communications. The next largest costs relate to Events, Workshops and Drop In sessions all of which are attracting more attendees and reflect a growing confidence in the Forum and the support we offer to our members. The increase in staff costs reflects the increased activity of the Forum and in particular the rapid rise in membership of nearly 350% (205 to 714) between March 2015 and March 2018.



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EPCF Income	2015-2016	2016-2017	2017-2018	3 Year Totals
DfE	15000	15000	15000	45000
LBE Core	10000	7269	10000	27269
LBE BMF	0	0	6667	6667
Income Totals	25000	22269	31667	78936
EPCF Expenditure	2015-16	2016-2017	2017-2018	2015-2018
Staff	10631	22715	27035	60381
Events	5684	4468	2846	12998
Meetings	0	865	288	1153
Infrastructure	888	1008	1640	3536
Training	180	524	1320	2024
P/C compensation	0	0	300	300
P/C expenses	0	0	220	220
Info & Resources	452	1008	796	2256
Expenditure Totals	17835	30588	34445	82868



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