

# Ealing Parent Carer Forum Annual Report 2018-2019



## **EPCF - Annual Report**

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## EPCF Membership / Roles:

(in March 2019)

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



**Parent Volunteers:** Mary Doody, Kirstie Ferrett, Nick Radclyffe, Ruby Sangha, Samantha Schmidt (until April 2019), Sarah Theobalds (until April 2019), Rashid Wahab, Jennifer Wray

**From our Partner Organisations:** Tom Quilter & Gabriel Jones (Ealing Mencap), Joy Barton (P.E.S.T.S. & Parent), Natalie Stone (P.E.S.T.S. & Parent), Mariya Zlatinova (Ealing ISAID!), Helen Jackson (Ealing Contact)

4. **Administrator:** Brigitte Bistrick-Bryan (Parent)
5. **Parent Members:** 960 (at end of March 2019)



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## EPCF Chair's Report



Government funding for Local Authorities has been reducing for many years and the effects are becoming ever more damaging to the lives of our children and young people and those who care for them. Services are struggling to manage a significant increase in demand for additional support in education, health and social care whilst being understaffed and under resourced and, as a result, waiting lists are getting longer and staff are having to cope with parents and carers increasingly frustrated in accessing support for their vulnerable children.

I am particularly concerned about delays in accessing support for our youngest children. We believe that early identification and assessment of needs is vital to the future life chances of our children. It cannot make sense that a child at the age of 6 or 7 might wait two years for an assessment by the Child and Adolescent Mental Health Service. It seems blindingly obvious that such a delay can only result in increased needs and higher costs in the future. The sooner children and young people get the support they are entitled to, the better their outcomes will be, and they are likely to require less (inevitably more expensive) support in the future.

Having said that, this year has seen an increase in direct engagement with the LA, CCG, Commissioners and Service Providers. The voices of parents and carers are being heard more often and more clearly. This will ultimately lead to better services and improve the quality of support available for all. Whilst it feels painfully slow at times, parents and carers are becoming more involved in sharing their experiences, representing others and contributing more often to shaping the services that their children and young people receive.

The Ofsted/CQC Local Area Inspection in January 2019 recognised the level of parental dissatisfaction with many issues around SEND in Ealing, and also noted several areas where they expect to see improvements in service availability and effectiveness. EPCF will continue to monitor progress in these areas and ensure that parents and carers have the opportunity to contribute to service development and improvement.

And finally, a huge THANK YOU to all those parents and carers who engaged with us during the year contributing their voices and experiences to our work and helping to improve the quality of the lives of our children and young people. Make Your Voices Heard!

Matthew



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## EPCF Administrator's Report

Dear Members,

My name is Brigitte Bistrick-Bryan and I am currently the administrator for the Ealing Parent Carer Forum.



A main focus of our work continues to be to reach out to more parents of children with special needs in Ealing. We regularly come across parents who have spent years thinking they were alone in their struggles and did not know about us or any other support organisations, particularly parents of children in mainstream settings. We are trying very hard to convince school SENCOs that it is safe 😊 and worthwhile to invite us into their schools to meet parents, and more and more of them have done so over this year. We believe that well informed and supported parents make better partners for the school, too, and in the end, the child benefits.

It has been great to meet so many new parent members. The more parents feed into our discussions with the LA and CCG directly, the better. We continue to register every issue and problem parents tell us about (see the summary Issue Log graph at the end of this report) which gives us reliable data to present to the LA and CCG. It is your voices that matter and our role to make those voices heard, in particular those who may be a little quieter than others.

But we also want to continue to provide you with information and support on issues you have told us you want advice on. Our monthly drop in sessions continue to be free for all and suggestions with regards to topics and speakers are always welcome.

Looking forward to the next year!

Brigitte



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## The National Picture

Whilst it is easy to feel isolated in our “Ealing world”, we are far from alone. There are 152 local Parent Carer Forums across the country, organised into cluster groups under the umbrella of the National Network of Parent Carer Forums (NNPCF).

Our cluster group is the North West London Group (together with Hounslow, Hillingdon, Brent, Hammersmith & Fulham, Richmond & Kingston, Harrow as well as Kensington & Chelsea) and it is always incredibly helpful and inspirational to meet our colleagues from other boroughs (once a term), exchange ideas and learn from them. The issues you pass on to us feed directly into those discussions. You won't be surprised to hear that parents all over London (and further afield) are experiencing very similar problems as we are here in Ealing.

We have this year for the first time arranged a larger event with our colleagues in Hounslow, when we wanted to book a speaker who charged more than one of us could afford, so we pooled our resources and parents from Ealing and Hounslow were invited (the talk on Carers Rights in January 2019). We often visit each-other's events and the Hounslow Dads' Group is open to fathers in Ealing, too.

If you are interested in the national work carried out by the NNPCF and how together these 152 Parent Forums try to influence national decision making, have a look at their website:

<http://www.nnpcf.org.uk/>

and, in particular, the annual “State of the Nation Report:

<http://www.nnpcf.org.uk/wp-content/uploads/2018/06/State-of-the-Nation-2019.pdf>

This year some of us will be attending the Annual Conference of the NNPCF for the first time. We look forward to contributing our Ealing experiences as well as feeding back to our own members whatever we learn there.



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

- **SEND Executive Board:** Matthew Jeatt (Chair) & Brigitte Bistrick-Bryan (Administrator)
- **ESCAN / EPCF Steering Group Co-Production Board:** All members of the EPCF Steering Group
- **Preparing for Adulthood Board:** Mary Doody & Anne White
- **Digitalisation of EHCP process** – Ruby Sangha & Rashid Wahab
- **Autism Board:** Annette Ridge & 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:** Pat Nekati, Ruby Sangha, Brigitte Bistrick-Bryan
- **National & London Network of Parent Carer Forums (NNPCF)** – Matthew Jeatt & Brigitte Bistrick-Bryan



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## EPCF Engagement Events

- **Family Fun Day** at Enterprise Lodge in July 2018 (*together with EalingMencap and Ealing ISAID!*)



- **Anxiety Workshop** in November 2018, attended by 79 parents and professionals
- **SEND Advice Event March 2019** (*together with ESCAN services, EalingHELP, Ealing Mencap, CONTACT, Ealing ISAID! & P.E.S.T.S.*)



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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 2018:** Speech & Social Communication (*with Ealing Speech & Language Therapy Service*)
- **May 2018:** How to tell your child s/he has Autism / ADHD
- **June 2018:** EHCPs (*with CONTACT Ealing*)
- **July 2018:** Mental Capacity Act
- **September 2018:** EHCPs (*with Ealing ISAID, incl AGM*)
- **October 2018:** Social, emotional & mental health (SEMH) issues (*with Ealing Educational Psychology Service*)
- **December 2018:** Social with EPCF partners
- **January 2019:** Carers' Rights (*with Hounslow PCF*)
- **February 2019:** Pension rights for carers
- **March 2019:** Puberty in children with SEND



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## Surveys and Focus Groups

### Surveys:

- **Bladder & Bowel Service Repeat Survey, April - May 2018** (23 responses, fed back to the CCG and provider to give first feedback on temporary service established in March 2018)
- **S&L provision in mainstream schools April – May 2018** (112 responses, reported to the SLT service managers and ESCAN management)
- **EHCP process repeat survey July 2018** (93 responses, reported to SENASS management and ESCAN service leads).

### Focus Groups:

- **Bladder & Bowel Service**, meetings in April & June 2018 (6 parents, 8 professionals)
- **EHCP process (with CONTACT)** June 2018 (15 parents, 2 professionals)
- **SEND Transport meeting** June 2018 (8 parents, 2 professionals)
- **Local Offer testing session** June 2018 (4 parents, 1 professional)
- **Speech & Language Therapy in mainstream schools** September 2018 (4 parents, 2 professionals)
- **Open meeting with SENASS team** September 2018 (22 parents, 5 professionals)
- **Speech & Language Therapy Early Years meeting** October 2018 (4 parents, 2 professionals)
- **Open meeting with SENASS team** December 2018 (3 parents, 5 professionals)
- **JSNA (Joint Strategic Needs Assessment) of SEN services in Ealing**, meeting December 2018 (4 parents, 1 professional)
- **Early Years Inclusion**, meeting January 2019 (4 parents, 2 professionals)
- **Wheelchair Service**, meeting February 2019 (2 parents, 7 professionals)



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## Ofsted / CQC Local Area Inspection

You may be aware that since May 2016, the government has introduced inspections of all special needs related services in local areas (education, health and social care) through Ofsted and the CQC (Care Quality Commission). These are separate from school Ofsted inspections and result in a simple report letter, sometimes accompanied with a written statement of action with targets for the LA to improve on.

Ealing's SEND services were inspected in January 2019 and the EPCF represented parents throughout the inspection in various ways.

- 1) As we knew the inspection was imminent, we had prepared a submission with the most frequently raised issues by parents as well as case studies to support them. Those issues were:
  - a) Problems with the EHCP assessment / conversion process
  - b) Poor communication throughout services
  - c) SEN support in mainstream schools
  - d) Waiting times for the CAMHS Neurodevelopmental Team

If you are interested in reading the whole document, please do get in touch via email or look at our website.

- 2) Each LA Ofsted inspection now offers a webinar to parents where they can directly submit their views. We sent out the link to the webinar to all our members and offered 2 open drop-in sessions with access to computers to support parents with the webinar.
- 3) The inspectors met with a number of focus groups for the different services. 12 different EPCF parent reps attended the various meetings where parent representatives were allowed (no parent representation was permitted in the CCG / health focus groups). 29 parents in total attended the meeting for parents only with the Lead Inspector, members of the EPCF as well as others.
- 4) When we received feedback very quickly from parents that the webinar was user-unfriendly, we sent out a direct email address to parents instead to reach Ofsted directly. The feedback from Ofsted was that a very high number of parents in Ealing made use of this. We also submitted additional survey evidence through the email.

Ealing received the official result letter in March which you can also see on our website.



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## OUTCOMES

***The obvious question following the Ofsted inspection as well as our other work is: What difference has it made? Has parental feedback through the EPCF had any impact on Ealing services throughout the year? Are parents being listened to? Are we making progress in our efforts to increase parent participation in Ealing? Here are some examples of where we believe parents have made a difference:***

### **Ofsted Inspection:**

The inspection outcome letter stated that senior leaders within the LA and CCG had underestimated parental dissatisfaction. Evidence of some positive collaboration was noted, however, inspectors identified areas where parental feedback was not being used effectively in monitoring performance. Various services were listed and overall communication between services and parents was found not to be good enough. We felt that most parental feedback had been noted by the Inspectors

Following on from the inspection, there has been renewed focus on the weakest areas as highlighted in the results letter (CAMHS waiting times, the Wheelchair Service, communication with parents and the need to improve the EHCP assessment process). Parents' feedback into the Ofsted inspection directly contributed to Ealing's priorities action plan for services for children with SEND.

### **A new Participation Strategy:**

The work around an Ealing Participation Strategy to agree on a set of principles and ground rules has now been completed, and both the LA and the CCG (Clinical Commissioning Group) have signed up to it. Our efforts to ensure the principles of parent participation are being understood and implemented in all services are now based on an agreement all professionals have signed up to. There is still some work continuing to link the Participation Strategy action plan to the existing LA SEND Action plan. Once completed, this will be published on our website.



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### **Bladder & Bowel Service:**

Following our extensive discussions with the CCG and the provider (NHS) a permanent incontinence (Bladder & Bowel) service is now in place. All changes to the service specification suggested by parents in our meetings were taken on board (e.g. there is no more strict age limit, parents of children younger than 5 years old can access the service if there are medical reasons for this need).

### **EHCP assessments**

The process of applying for an Education Health & Care Plan is one of the most frequently raised problems by parents and was highlighted as such to the Ofsted inspection.

Last year, we organised 2 meetings between the SENAS Team (assessment team) and parents which gave the opportunity to air frustrations and grievances. Feedback from both parents and professionals attending the meetings was that they resulted in resolving some of the issues and generally contributed to a more positive relationships between parents who attended and the SENASS team.

Work has also taken place over the last year to introduce a digital application format to allow professionals and parents to login at any time to view their child's application and add to their contribution. Several EPCF Parent Reps attended the first workshops early this year to contribute their experience with the system as well as ideas for a digital format. Their suggestions of creating a way for parents to log into the system to be able to check on their child's EHCP application at any time has been agreed to, and work is continuing to make this a reality in 2020.

### **Building My Future Project:**

Three parent representatives have continued to support and advise the Building My Future project. Early on, they highlighted the need to include younger children in the project and in the summer 2018 the BMF project started to target primary school leavers (Year 6) specifically, as the transition to high school often causes huge problems for children with additional needs. Apart from the practical aspects of the project, working in co-production with the team has been a valuable learning curve for us as well as the BMF Team and the experience can now be shared with other teams in Ealing.



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### Joint Strategic Needs Assessment:

In November last year a group of parents met with the LA official tasked with drawing up a new Joint Strategic Needs Assessment of children with special needs in Ealing. The resulting JSNA took on board all issues raised by parents and highlighted, in particular, the effects of social deprivation on families of children with SEND. It was presented to the SEND Executive Board meeting in June and will now inform Ealing's long-term SEN Action Plan. If you would like to have a copy of the JSNA please email us on [Info@epcf.org.uk](mailto:Info@epcf.org.uk).

### Recruitment:

Increasingly EPCF Parent Representatives are invited to participate in recruitment processes within the LA. Last year, we participated in the recruitment of several EHC Coordinators and the Post 16 coordinator. It is difficult to quantify the impact of this, but we believe that our presence and contributions in the process highlight to all applicants and professionals on the panel the value of including the parent voice from the beginning on. We obviously hope to have contributed to the recruitment of new staff who fully understand the need to work with parents and listen to their concerns.

## Challenges to Participation

There remain, in our view, many challenges to genuine Parent Participation and Co-Production in Ealing, amongst others:

- High staff turn around on all levels in Ealing
- Lack of understanding of the underlying principles of genuine participation work across many services, leading to barriers, e.g. lack of communication with parent reps, late sharing of relevant documents, last minute consultations with us rather than inclusion at the early stages of planning
- Lack of our own resources
- Overwhelming exhaustion across services

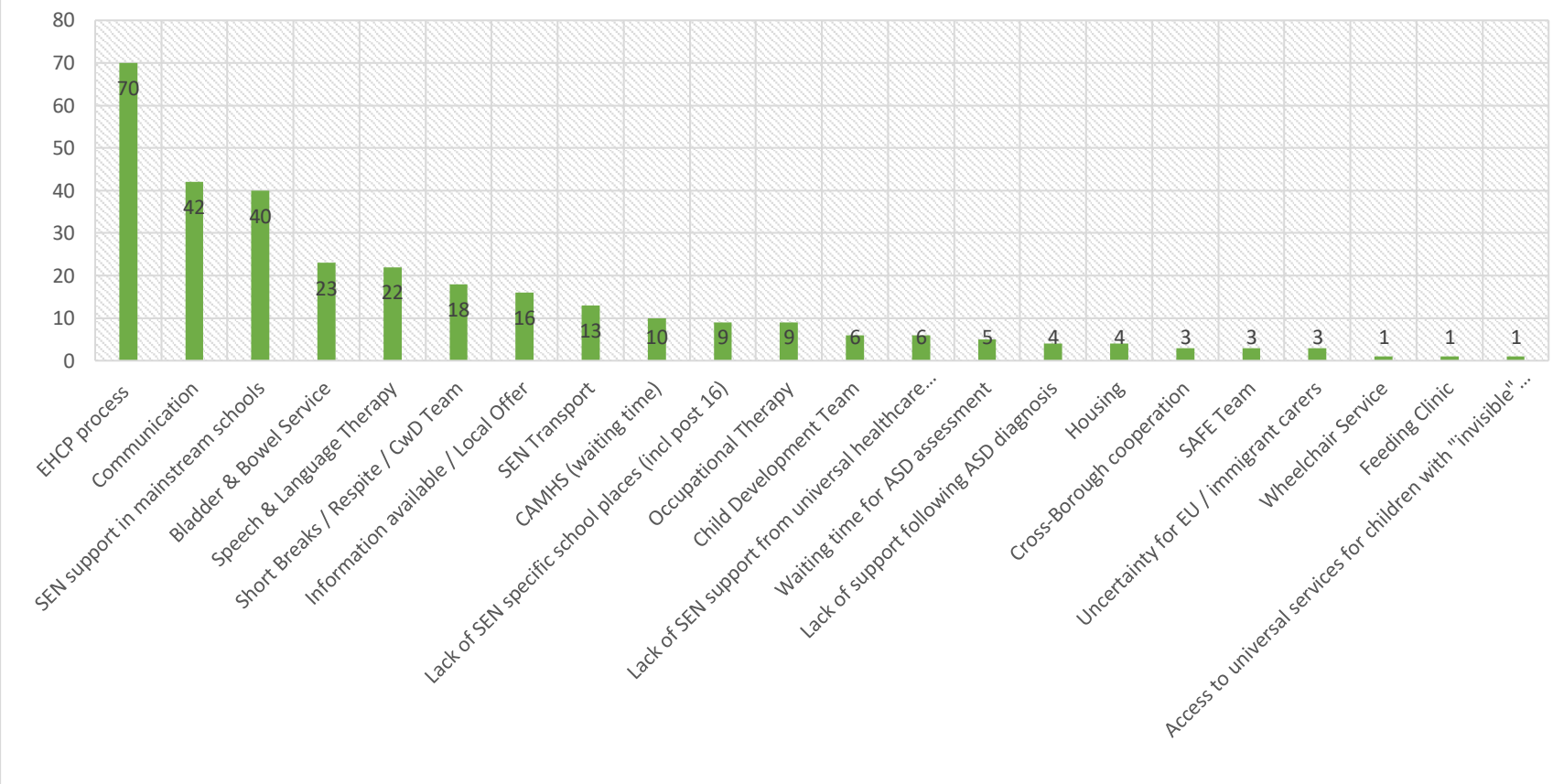
However, there has undoubtedly been some progress and a definite increase both in professionals welcoming parent contributions and in parents willing to participate and contribute their experiences. We are incredibly grateful to all those parents who over the last year have contributed their free time and expertise to help improve the services our children so badly need.

Onwards and upwards!



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## EPCF Issue Graph Summary 1.4.2018 - 31.3.2019

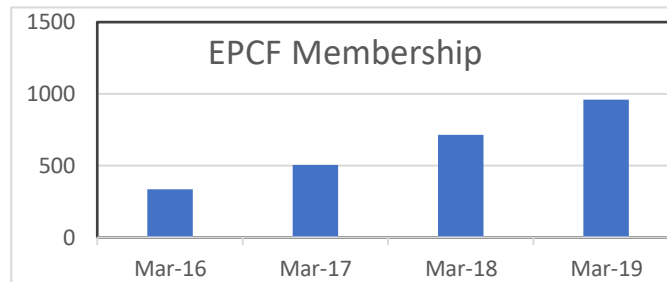


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## Ealing Parent Carer Forum 3-Year Activity report 2016-19

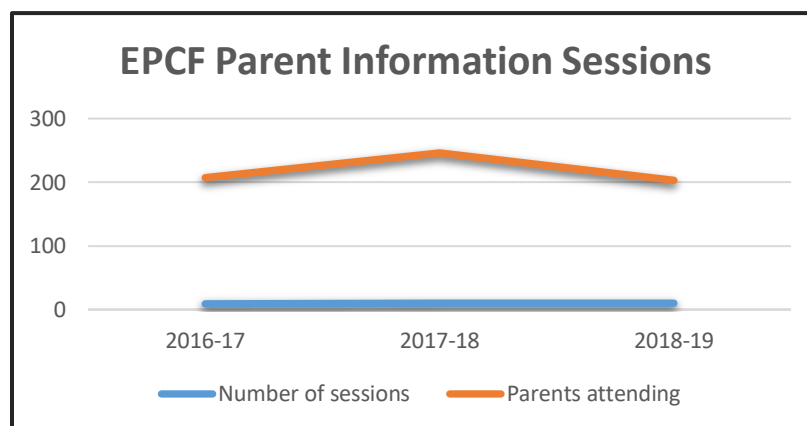
### EPCF Membership:

March 2016	335
March 2017	503
March 2018	714
March 2019	960



### EPCF Parent Information Sessions:

	Number of sessions	Parents attending
2016-17	9	207
2017-18	10	246
2018-19	10	203

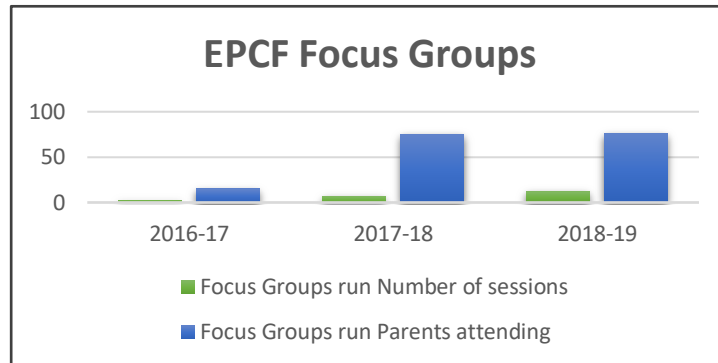


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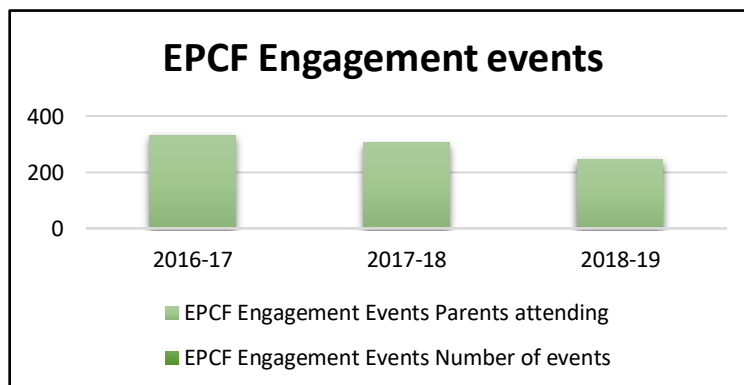
**EPCF Focus Groups:**

Focus Groups run	Number of sessions	Parents attending
2016-17	2	15
2017-18	7	75
2018-19	12	76



**EPCF Engagement Events:**

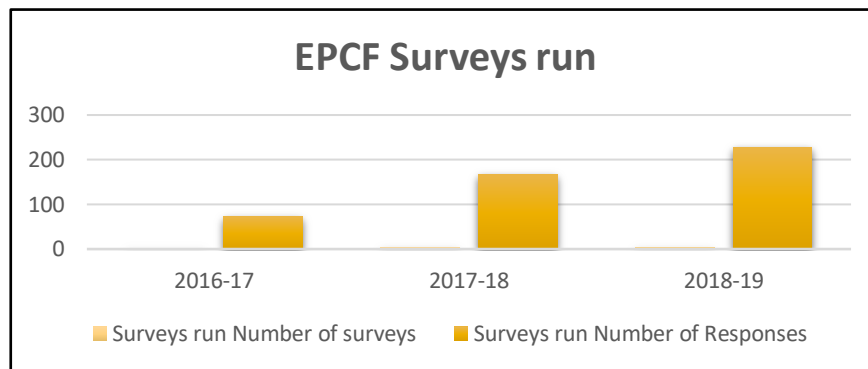
EPCF Engagement Events	Number of events	Parents attending
2016-17	3	329
2017-18	5	299
2018-19	3	244



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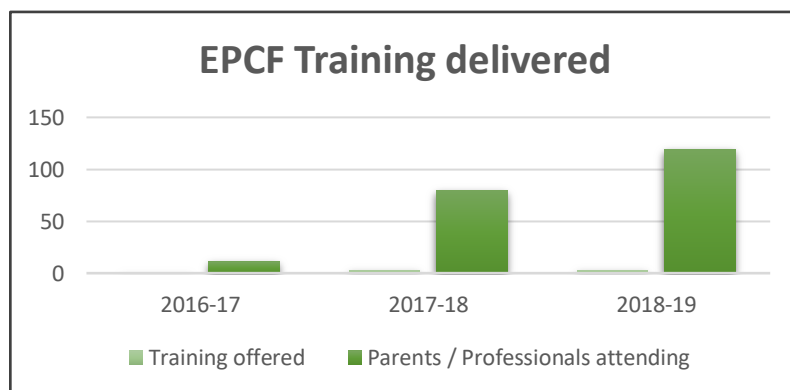
**EPCF Surveys run:**

Surveys run	Number of surveys	Number of Responses
2016-17	2	73
2017-18	4	166
2018-19	3	228



**EPCF Training delivered to Parents or Professionals:**

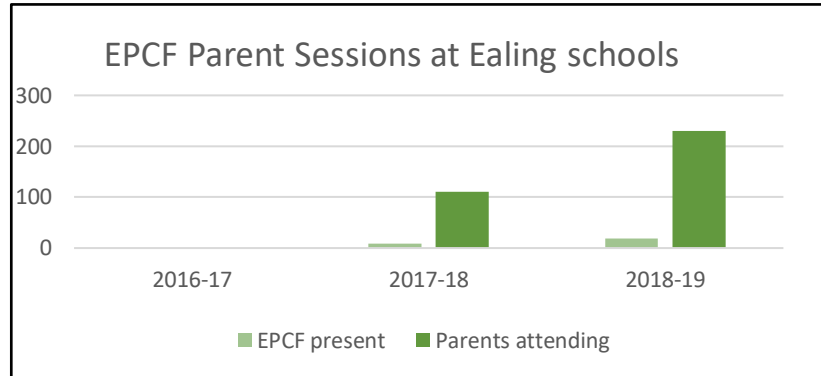
Training delivered to parents or professionals		
	Training offered	Parents / Professionals attending
2016-17	1	11
2017-18	3	80
2018-19	3	119



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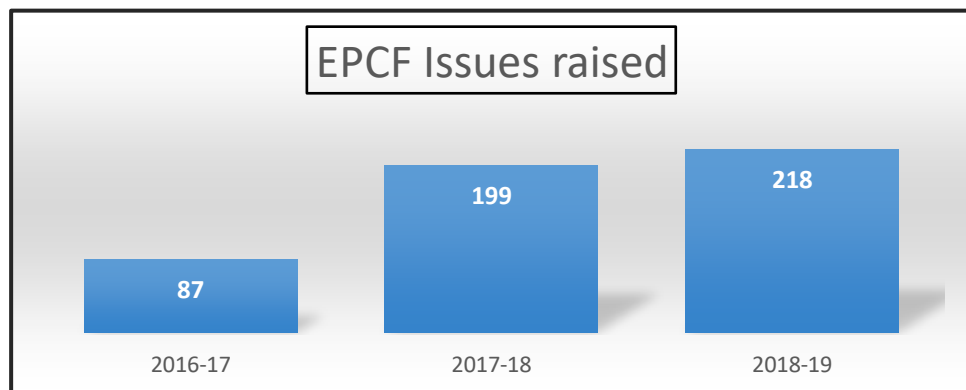
**EPCF Parent Sessions at Ealing schools:**

Parent sessions at Ealing's schools		
	EPCF present	Parents attending
2016-17	0	0
2017-18	9	111
2018-19	19	230



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

Issues raised with Ealing services via EPCF Issue Log	
2016-17	87
2017-18	199
2018-19	218



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## EPCF Finance Report

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 tranche 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 ad hoc support for example the “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 78% of total expenses this year, paid roles include: Chair, Administrator, Treasurer and Communications. The next largest costs this year relate to Infrastructure including computer hardware and software, office equipment, subscriptions and insurance. Events including Workshops and Drop In sessions continue to attract more attendees and continue to reflect a growing confidence in the Forum and the support we offer to our members. The increase in staff costs reflects the further increased activity of the Forum and a further rise in membership of nearly 285% (335 to 960) between March 2016 and March 2019.

See table for details on next page



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<b>EPCF Income</b>	<b>2016-2017</b>	<b>2017-2018</b>	<b>2018-2019</b>	<b>3 Year Totals</b>
DfE	15000	15000	15000	45000
LBE Core	7269	10000	12000	29269
LBE BMF	0	6667	10000	16667
<b>Income Totals</b>	<b>22269</b>	<b>31667</b>	<b>37000</b>	<b>90936</b>
<b>EPCF Expenditure</b>	<b>2016-17</b>	<b>2017-2018</b>	<b>2018-2019</b>	<b>2016-2019</b>
Staff	22715	27035	29135	78885
Events	4468	2846	2232	9546
Meetings	865	288	772	1925
Infrastructure	1008	1640	3041	5689
Training	524	1320	340	2184
P/C compensation	0	300	330	630
P/C expenses	0	220	0	220
Info & Resources	1008	796	820	2624
<b>Expenditure Totals</b>	<b>30588</b>	<b>34445</b>	<b>36670</b>	<b>101703</b>