



OXFORDSHIRE PARENT CARERS FORUM

The Voice of Parent Carers in Oxfordshire

Oxfordshire Parent Carers Forum Report

Autumn 2020

Introduction

The past 6 months have been a strange and challenging time for us all.

Times when most of our children will not have been at school and many of us have been working from home. Some parents may have lost their jobs whilst others have been working more hours than they thought imaginable.

Many children have missed their schoolmates, teachers and vital hospital appointments, whilst we know there are others who have thrived during this extended period of time at home.

Here at Oxfordshire Parent Carers Forum we have been busier than ever!

There have been occasions when managing the additional demands of family life, alongside running and growing the Forum, have felt like a very big mountain to climb, but our commitment and determination has definitely paid dividends.

The OxPCF steering group has worked tirelessly to ensure the development of new ways of working. We have attended and been part of many meetings with the local authority held remotely over Microsoft Teams.

Our involvement has been welcomed by many professionals and we have been able to provide them with opportunities to engage directly with Oxfordshire families through our new Zoom question and answer sessions which were jointly hosted with Oxfordshire Family Support Network.

We have worked co-productively on several projects, as well as running our first major survey on CAMHS Referrals and producing and sharing those findings.

The forum is exceptionally proud to be able to share feedback from Contact, who have identified our new Governance work and CAMHS Survey as examples of excellent practice. They will be shared within the National Network and we feel very pleased to have received this acknowledgment.

It is recognised that the forum has very limited resources to do the extensive work required of us as a forum. Our coordinator only works 10 hours a week during term time and most of these hours are used undertaking administrative tasks such as managing meetings, transcribing meetings, managing our social media presence and our database. Our substantive work (such as survey development, analysis of data, report writing, grant management, meetings with parent carers etc) is undertaken in the main by volunteers (juggling complicated lives of their own), this is not sustainable in the long run and during the course of this financial year we need to look at a more sustainable model.

Forum Details

We currently have 6 steering group members and one forum coordinator who works 10 hours a week during term time.

Our membership and reach has increased since January 2020 as follows:

- **Main Database:** From 239 parent carers to 413 parent carers at the end of August 2020
- **Facebook:** From 448 to 622 followers
- **Twitter:** From 90 to 164 followers
- **Instagram:** From 112 to 148 followers

This report is significantly different in content, format and style, from our last report. This is due to our continued development and a need to streamline our work to be as efficient as possible. This report is formatted to reflect our organisational plan which in turn reflects our Contact Grant format. Inevitably there will be more tweaks and

changes in our reporting style as we develop our monitoring and reporting processes but we eventually hope to settle on a presentation which will make comparison from report to report easier.

Strengthening the Forum

During the last six months, we have reported on our 2019/20 Contact grant and secured a further grant for the current financial year. This grant will build on the work of the Forum to date. This year's plans and grant application were built on prioritisation work that we did at the end of the last financial year to identify and agree some key areas for the forum to focus on in the coming year.

Over the last 3 months the Forum have worked in partnership with the Local Authority on several projects. These include the ongoing re-design of the children's integrated therapies service, the facilitation of question and answer sessions for parent carers, with professionals across health education and social care and the implementation of regular catch up meetings with CAMHS, to ensure that our parent carers experiences are fed directly back to service leads.

- **Management/Data Information System**

We have begun work on streamlining how we collect and record our data to ensure we effectively and efficiently monitor, review and report on the work we do. In doing this, we plan to develop a system that reflects the reporting requirements we have including audiences such as parent carers and their families, our grant funders and our statutory partners.

- **Workstream Action Plans**

Our intention this year is to further strengthen the Forum by focusing on coordinating and managing our workload more closely and the first stage of this

process is to develop an organisational plan and individual action plans for each project (see Appendix 1 for organisational plan and project list).

- **Reporting Process**

We have started work on developing reporting processes that work with our Management Information Systems and that can feed into our internal and external reporting requirements.

- **Committee Structure and Process**

We are focusing on making sure our governance is robust and this includes establishing clear decision making processes, roles and responsibilities.

- **Memorandum Of Understanding**

One of our main priorities over the last 6 months has been working towards developing a Memorandum of Understanding with our statutory partners. Steering group members have worked with the support of SENDIASS on the development of our MOU. We are hopeful that following the sharing of this document with OCC and the CCG, that it will be signed off imminently.

- **Attend Regular Chairs meetings with various statutory partners**

This is an ongoing focus. We value the importance of having good, clear and regular communication with all statutory partners in areas of Education, Health and Social Care. We will continue to work on how best to organise this to make sure that we are in contact with partners in all key areas on a regular basis.

In the Coming Months

Over the coming months we plan to develop a recruitment and induction process, to grow the steering group and encourage parent participation to enhance the work we do.

Following on from our induction process, we will develop a training plan for all members of the steering group to undertake to enable them to use their voices and share their experiences and the forum's voice confidently and consistently.

We are also planning on building further accountability by ensuring we are more transparent about our governance processes and the people involved with the forum. The first step in this process will be to publish appropriate governance information on our website.

Furthering Participation

Much of our focus in the last 6 months has been about being responsive to the Covid-19 situation. This has meant being adaptive and flexible, listening to Parent Carer concerns and working with our partners to try and address these issues. It has also directed our focus into digital engagement as a primary means of gathering feedback and communicating with our audiences.

- **Online Feedback Form**

We have designed, implemented and shared a new feedback form for parent carers, which can be viewed [here](#). This form gives the parent carers the opportunity to feedback on any services that a child or young person that they care for accesses. This feedback form is anonymous. We have recently started sharing this form in our newsletters, via our website and through social media and have started to get some responses. We are now devising a process to monitor and analyse this information and ultimately share it with the relevant professionals.

- **Communication Plan**

We are in the process of developing a communications plan which covers key communication areas such as; Social Media, Website, Engagement with Schools, Support Groups, Seldom heard or Harder to reach groups, Events

planning (virtual and face to face) and the delivery of surveys, polls etc. We are working closely with OCC and the CCG to implement this.

- **Social Media**

Within our communications plan, will be our plan for social media. We need to research key ways to engage parents and professionals using Facebook, Twitter and Instagram. This will include the planning of regular engaging features, sharing important information and documents, advertising events (both ours and others of interest).

- **Blog**

We have produced our first blog for the parent carer forum, which has given our parent carers an update on our current work projects and any developments. This was shared on our website, over social media and in our newsletters.

- **Website**

Over lockdown, we have been designing a new website for OxPCF. This re-design and implementation is near completion and we hope to share the new website in the coming weeks.

- **Parent Carer Facing Activities**

Our aim is to undertake at least 1 event per term (this includes surveys, polls, virtual and face to face meetings when possible). During lockdown we have mastered the use of Zoom, this enables our members to attend virtual meetings from anywhere in the county or their home.

We, alongside OxFSN (Oxfordshire Family Support Network), have hosted four Zoom Q&A sessions (Back to School after Lockdown, EHCP's legislation changes during Covid-19 and Beyond, SEND Support during Covid-19 and beyond and SEN (Education) Transport). We encourage our parent carers to put forward questions on the

subject matter prior to the session and then are able to share these with the key professionals attending prior to the meeting, we offer the chance for additional questions at the end. Each event is audio recorded so we can transcribe the session to send out to our parent carers. The links for the transcriptions for each session are included in appendix 4 at the end of this report.

It has been great to hear the stories directly from Oxfordshire families. We feel that providing answers and empowering parents is central to the ethos of our role as a parent carer forum. Our most recent session ran on the 13th October with CAMHS on the subject of Anxiety. The next two upcoming sessions will be a “Meet the SEND Team” at the end of November, a session with Oxfordshire CAMHS in January/February on Challenging Behaviours and also a session reaching out to parent carers of children with complex health issues with a focus on direct payments/personal budgets and getting more support.

- **Survey and Polls Process**

Producing surveys and polls is an integral part of obtaining feedback from our parent carers. We are currently developing processes and procedures to ensure consistency, uniformity and good practice. We have learnt a great deal from the two surveys we have already undertaken.

- **Materials and Events Kit**

We are in the process of designing new marketing materials to advertise the forum to parent carers and professionals and put together two event kits for any roadshows, exhibitions etc. We have delayed doing this in view of Covid-19 as there is no immediate need for them at present.

In the Coming Months

We are continually thinking of different and accessible ways of gaining feedback from our parent carers to ensure the greatest diversity in the voices we hear. Our plan is to design and purchase a number of comment boxes that we can then distribute to key locations such as Special Schools, Health practitioners, Support groups to encourage a more diverse group of parent carers to give their feedback. We will then devise a process for collecting and collating these responses and feeding back to the relevant professionals. However due to Covid-19 we are delaying actioning this activity until later in the grant year.

We are committed to celebrating diversity, positively promoting equality, fostering equal opportunities and tackling discrimination in all we do and particularly want to focus on increasing our engagement with the seldom heard or harder to reach groups. We hope to do this over the next few months by reviewing local data and information, writing an “Equality, Diversity and Inclusion Policy” and developing a plan of action that links in with our communication plan, thinking of inventive ways in which we can reach these groups.

As a forum, we would like to understand which groups are currently engaging with us so that we are able to make sure that we are feeding back the views of a diverse and inclusive group of parent carers. As a starting point, and as a part of our wider diversity work described above, we will develop and implement a diversity monitoring form by the end of this grant year.

In the next six months, we also plan to develop and implement a consistent set of events processes and procedures to ensure that events run smoothly and are successful. We will be using the feedback from previous events to inform our development process.

Positive Outcomes for Service

Over the past 6 months we have aimed to find a balance between being responsive to service related issues in respect of the Covid-19 situation whilst still continuing to drive forward key issues identified as a result of our priority setting exercise at the end of the last financial year (just before the current pandemic). This has not always been easy but is a challenge we have risen to.

- **Covid-19**

During the Covid-19 pandemic, OxPCF have worked tirelessly to ensure the development of new ways of working. We have attended and been part of many meetings with the local authority held remotely over Teams.

Our involvement has been welcomed by many professionals and we have been able to provide them with opportunities to engage directly with Oxfordshire families through our new Zoom question and answer sessions.

We have also created and shared many parent carer Covid-19 resources via social media and our website.

- **CAMHS Survey**

January 2020 saw the launch of our first large-scale survey. The final report can be found in the appendix section at the end of the document.

We were seeking feedback on referral experiences from families, young people and professionals who accessed CAMHS in Oxfordshire. The survey ran until March 2020 and received 606 responses.

Covid and the subsequent impact of lockdown, caused a delay in the analysis and final production of our survey report, however the survey findings and report was shared with Oxford Health and the Local Authority in August, prior to sharing with our parent carers.

Steering group representatives presented these findings to the CAMHS Assurance Board on the 1st of September and later, met separately with key leads within the service.

Some changes have already been made and we are hopeful that those will be shared with us soon. Oxford Health released a statement in September with their reaction to the report. Whilst the response we received from the OH was disappointing, we do believe that there is now a commitment and drive to bring about genuine change.

Parent Carers often find their experiences do not receive the recognition they deserve and failure to acknowledge that impact can have devastating consequences.

We look forward to working with all relevant parties and Oxfordshire families, to help improve services and learn from the many positive suggestions made as a result of this survey. We plan to revisit this survey in January 2020, to see if there has been any changes to parent carers feedback.

- **Integrated Therapies Service**

The 10 year contract for the Children's Integrated Therapy Service, (Speech and Language Therapy; Occupational Therapy and Physiotherapy; O-25 years old), is due for renewal. We have been engaged in the review process, where the views of all key stakeholders have been sought, on how the service is currently performing. As a Parent Carer Forum, we held two consultation events in January of this year, at two different venues and at varying times, to enable Parent Carers to attend. In addition, we conducted an online survey during lock-down. We have collated the responses of over 50 Parent Carers so far and have presented these responses to Oxford Health, to inform the redesign of the service, alongside an ongoing review. The redesign phase is hoped to be completed by March 2021. These findings have been well received and we look forward to being part of this continuing process of development and improvement. A final report will be made available to parent carers and others in the coming weeks.

Parent Carers are invited to continue to give their views and can use our general feedback form which is accessed via our website, social media and in our newsletters.

- **SEND Strategy**

The development of a countywide SEND Strategy in Oxfordshire is an ongoing project for the local authority. The parent carer forum has been involved in initial work and welcomes the opportunity to be involved going forward.

- **APP (Accelerated Progress Plan)**

As part of Oxfordshire's continued monitoring of SEND provision, regular visits take place between the Local Authority and the Department for Education and NHS England inspectors.

Steering group members have worked with the Local Authority around the drafting and creating of an APP (Accelerated Progress Plan) to improve send provision in the county.

This plan is produced as a direct response to concerns which still exist following Oxfordshire's SEND Re-visit.

This is an evolving document that must clearly demonstrate how proposed actions will benefit SEND families. Evidence of that impact must be clearly recorded and monitored and we are working closely with the Local Authority to help implement this.

- **Relevant Meetings and Boards (3.8)**

In the period from our last report until September 2020, the steering group has attended the following groups, boards and strategic meetings:

- SEND Performance Board
- SEND Operational Group
- SENDIASS Steering Group

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- Learner Engagement and Early Help Board
 - CAMHS Assurance Board
 - Co-production Champions Group (ask Charmian)
 - EHCNA Timeline - Task & Finish Group (now completed)
 - Integrated Therapies Project Board
 - OCC's Parent Carers Catchup meetings *to be restarted after the summer break

The following meetings appear to be on hold as we have not had invitations to them during the reporting period:

- Local Offer Steering Group *in abeyance
- Post 16 Provider Network *in abeyance
- Developing the SEND Strategy *in abeyance

In the Coming Months

Towards the end of 2020, we are aiming to develop a baseline parent carer impact survey similar to a survey that Sheffield Parent Carer Forum carried out (their report can be seen [here](#)). We hope to be able to invite parent carers to complete this survey in our next grant year. This will enable us to find out about recent experiences that our parent carers are experiencing when caring for a child with SEN or Physical disabilities. We aim to work with all statutory partners to produce this survey and will release a report with our survey findings. We hope to then be able to repeat this exercise in subsequent years so we can build a picture of how experiences are changing over time. We are also looking forward to working with OCCG and wider partners on the NHSE/Key Worker pilot - an exciting opportunity for Oxfordshire.

Outcomes for Parent Carers

It is important to the Forum that we see positive outcomes for parents in the work that we do. These outcomes focus on better access to knowledge and information, increased confidence to address issues, greater awareness and improved skills. This

includes developing and increasing our use of a range of communication tools and methods to broaden and deepen our reach.

- **Parent Facing Reports (4.2)**

As a forum, we will continue to produce reports detailing parent's experiences of services a child or young person that they are caring for is accessing. These will include our six monthly reports plus reports analysing any surveys we have produced.

- **Social Media Activity (4.3)**

We will continue to plan how to best implement regular social media posts and activities. These will include links for events, surveys, polls, reports, blogs and regular contact posts

- **Knowledge based events/activities for Parent Carers (4.4)**

We received a great deal of positive feedback on the Q&A sessions that we hosted alongside OxFSN on Zoom. We had 123 parent carers attend, across the 4 sessions. Many who were unable to attend, appreciated the transcripts of the events, which also appeared on our website and via our newsletters. Transcripts of each session can be found in the appendices section at the end of this document.

- **SENDIASS Partnership Work**

We have a good working relationship with SENDIASS and have been involved with them on several projects including:

- **Information leaflets**

Steering group members have worked with SENDIASS to produce a leaflet on SEND Support in mainstream schools. It has been designed to help families start the conversation with their child's school if they have concerns about their progress. It also sets out what to expect and how to address any challenges that may arise.

We have also helped to produce another leaflet titled “Parents guide to an Education, Health and Care Needs Assessment”

- **SEND Guidance Handbooks**

We have been involved in the updating of the SEND Guidance handbooks which are used by schools and are also available for parents to access via the OCC Local Offer website. They were originally co-produced with families and are used to help establish what kind of support and what areas of difficulty a young person may have. These may relate to accessing school, identifying needs, or making progress in their learning. Steering group members have worked hard to ensure that these documents clearly state they can be used by parents and remain available to them. This allows for shared decisions between them and the school, to be made in relation to the child or young person concerned.

In the Coming Months

As written previously, in the next six months, we aim to launch our new website. This will include new pages such as: Governance page, a glossary of terms and a blog.

Emerging Issues and Non-Contact Grant Work

In addition to the work outlined in our Contract grant we also find ourselves drawn into additional projects, these are outlined here:

- **Transformation Funding and Keyworker Pilot (5.1)**

As a part of the NHS Long Term Plan, the Learning Disability and/or Autism Programme are looking to commission 14 key working pilots. They hope that parent carer forums will be a key part of these pilots. We have worked with Oxfordshire Clinical Commissioning Group to make sure that the Forum is a part of the bid and the work that comes out of it. A representative of OxPCF, attended the NHS England webinar held for parent carer forum representatives, for us to fully understand and engage with this project in a productive way.

- **Exclusion Case Studies (5.2)**

Oxfordshire County Council are working with OxPCF to understand parent and young people's experience of school exclusions in Oxfordshire.

Oxfordshire County Council through the Learner Engagement Board have asked the forum to share some case studies with them of parent's current experiences around school exclusion, regardless of whether it is positive or negative. We have collated these and sent them to members of the Learner Engagement Board as tasked. We look forward to working with members of this board in regards to the report and valued feedback from parent carers.

- **Valuing SEND Toolkit (5.3)**

In June 2019 OxPCF was approached by the Head of SEND and asked if we had capacity to be involved in a piece of work with the consultancy firm IMPOWER. We set up two focus groups so parents could share experiences around the early identification of need. Parents provided some feedback and were then shown an already completed presentation around the development of the Valuing SEND toolkit.

This led to significant frustration and despite numerous attempts by OxPCF, to understand the exact agenda around the valuing send toolkit project, no further information has been forthcoming.

OxPCF wish to make known their concern around the potential adoption of the Valuing SEND Toolkit. The process surrounding the initial work in this project was not co-produced and despite repeated requests for further information, none has been forthcoming. We are concerned about the replacement of the SEND Guidance

Handbooks with the Valuing SEND Toolkit and would welcome the opportunity to work more closely and openly around this project.

Wider Views

We have significant concerns on the following three issues:

- **Post-16 Provider Network Group**

The section below has been taken from our last report.

It has been included in order to provide an overview of the activities undertaken by this group. Staff changes that have taken place within the LA mean that there will be members who have only limited knowledge of this group and the role it played.

Members of the steering group and the Post 16 Provider Network met in March 2019 to consider what an offer for ASD might look like at college.

The workshop was a great opportunity to do some blue sky thinking around future provision, and was well attended.

The Provider Network meets on a regular basis and has representation from Health, Education and Social Care, as well as SENDIASS and the Forum.

The forum was pleased to hear from children's social care that there would soon be a dedicated Moving into Adulthood Team in Social Care.

The group was informed that work on residential options for post-16 was ongoing and this would give families more confidence in the local offer. The long term aim is to co-commission local accommodation to keep young people in the county.

It was reported that Forum representatives had been unable to attend the Disability Rights UK Post-16 workshop in London but had been sent the presentations which would be circulated. This approach is supportive of all parties.

At the post 16 network provider meeting in October 2019, group members were informed that Kate Brennan, who had chaired this group for many years had been

asked to step down. It was suggested that an alternative lead would be found, but sadly this hasn't happened yet.

Despite passionate pleas from steering group members no further meetings have taken place. Forum representatives wish to express their ongoing concern and sadness at the loss of this very dynamic group.

The Network was identified during the 2017 SEND Inspection as being progressive and forward thinking. It was a well attended and highly respected group, providing a platform for multi agency discussions and the sharing of good practice.

- **SEN (Education) Transport**

Despite an initial positive interaction with the SEN (Education) Transport Team, we are hearing worrying feedback about families experiences with SEN (Education) Transport, specifically in respect of the return to school in September. Communication seems to be the biggest concern, parent carers are spending a huge amount of time trying to contact the department and not getting a response. We have also heard of cases where the parent carer has been misled and the department has made promises that they have not been able to deliver. This causes unnecessary frustration and concern for the whole family, at a time where anxiety levels may already be high due to transitions. We hope we can arrange another meeting to pass on additional feedback in the coming weeks.

- **SENDIASS**

Oxfordshire Parent Carers Forum are aware of a significant increase in the number of families seeking support from SENDIASS. Whilst we are aware that this is the role of SENDIASS, the pressure placed on this coalface service can not be overemphasised. We see families referred to this service by education, CAMHS, health and social care. We are seeing more complex requests for help and support being directed towards

support groups, which are neither trained nor able to provide the detailed and specialist guidance and information offered by SENDIASS.

Much of the feedback that we share with the local authority is mirrored in the experiences of families who contact this service.

We work closely with SENDIASS and are acutely aware of the pressures that fall upon this service, as the complexity of many cases increase.

Appendix

Appendix 1: OxPCF [Organisational Plan](#) and [Project list](#)

Appendix 2: [CAMHS Survey Report](#)

Appendix 3: [Statement from Oxford Health](#) regarding OxPCF CAMHS Report

Appendix 4: Transcriptions of our Q&A Zoom Sessions

- [Going back to School after Lockdown](#)
- [EHCP's during Covid-19 and Beyond](#)
- [SEND Support during Covid-19 and beyond](#)
- [SEN \(Education\) Transport](#)
- [Oxfordshire CAMHS Anxiety Session](#)