**EPIC - Luton PCF’s story**

EPIC Luton Parent Carer Forum was set up in December 2021, following the collapse of previous two forums and officially launched in April 2022.



There were certain challenges with the previous forums, which initially caused EPIC Luton PCF difficulty in generating interest amongst parents and carers. The forum has been working on rebuilding trust and currently has approximately 250 members.

At the end of March 2022, the forum held a well-being workshop to introduce EPIC and to establish what people wanted from their forum. We recruited 12 new members from this session. The forum had a stall at the Big Iftar in April 2022 to promote the forum, with more parents signing up and the committee was able to link up with other Bedfordshire PCFs.

Over spring and summer 2022 the forum worked closely with Active Luton to update their membership form to ensure it captured all the information they needed to make reasonable adjusts to allow people with complex needs to access and enjoy their facilities. The forum is continuing to work with Active Luton to develop holiday activities for children and young people with complex needs.

Committee members have been supporting health providers with interviews and have been key members of panels, this began in April 2022 and is ongoing wherever possible allowing for capacity of committee members, upcoming this will include the upcoming recruitment panel for a new Deputy Designated Clinical Officer on 15 December 2023.

The forum has worked closely with health on the development of Autism training which was delivered in September/October2023. They attend health monthly communications meetings to develop information literature and resources for families as well as professionals. a key outcome has been the introduction Meet the professional videos to provide an overview of their roles and responsibilities to enhance parent and carer understanding, a suggestion started by this forum. The forum has also been involved in the development of a Pre-diagnostic pack providing support for those awaiting diagnosis.



The forum has played a critical part in developing and updating the Local Offer since January 2022, the forum has its own website and social media presence, including a well-regarded WhatsApp group, Facebook, Twitter, Instagram and LinkedIn. The Forum have also supported Health services with scoping parents and carers with lived experience, and peer support roles project.

In January 2023, as part of the forums one-year anniversary, an ‘Ask the Experts’ event was held, this gave parents and carers especially those new to the SEND journey the opportunity to have access to wide range of SEND expertise under one roof for advice and guidance, discuss any concerns they may have around the support their child is receiving and receive appropriate signposting. Expertise included other parents and carers, Educational Psychologist, OT, School nursing to name a few. Feedback from this event showed it was particularly beneficial for early on in their journey. Job descriptions for forum roles that need filling shared with parents and carers at the event and other parents and carers. Those interested in volunteering responded. Initial recruitment event arranged for May 2023 to allow time for other commitments and Easter break.

In March 2023 we were able to secure an office space and on 9 March 2023 we changed our organisational structure from an unincorporated organisation to a Community Interest Company with three Directors. there were delays with initially setting up the bank account and which delayed the forum accessing their grants. There were also significant delays with the bank issuing debit and credit cards which delayed the process of essential purchases for full office set-up.

In March 2023 we also started compiling our annual Survey in collaboration with Healthwatch, which launched at the start of October 2023, to get the views of SEND families on Luton’s educational, health and social care services. Survey recently closed and Healthwatch are analysing data on our behalf.

in April 2023, off the back of the Ask the expert event, we organised and facilitated focus groups giving parents and carers the chance to share their views and concerns on the proposed changes to the school transport system. This session also gave us great insight into difficulties parents and carers are experiencing applying for transport, as well as getting reasonable adjustments made to make the transport fit for purpose for their children or young people.

In May 2023, the forum held a recruitment session to extend our advisory committee, interviews took place in June 2023. Currently we have 7 members including 3 directors, Treasurer and the wider committee. Please note all members are volunteers, most with restricted availability due to their day jobs. Recruitment will continue, certain roles still need filling and more parent reps to attend strategic meetings.

In September 2023 collaborated the forum with health services regarding project on obtaining consent from long term service users to add them to text/email messaging service.

Ask the Experts event was meant to be the launch of our coffee sessions known as ‘EPIC chai’ sessions. Sessions were delayed due to other priorities and commitments such as focus groups, input into Health focus week, recruitment event, annual survey as well as restricted availability of volunteers. First official EPIC chai session took place on 23 November 2023, health partners from SALT, school nurses, DCO, were invited to share their expertise to parents and carers. Structure of the session allowed experts to provide tailored support. Session was well attended by parents near the start of their SEND journey.

After a short refreshment break opportunity for parents and carers to talk to each other and discuss their expectations from future sessions. Parents and carers who are already on their send journey found this segment more useful as their chance to engage with others and share ideas. By relaxing rules for parents and carers to bring under 5s additional families were able to access the service. Turnout was quite good, written feedback and impact on membership yet to be analysed however verbal feedback has been positive.

parent and carer engagement the forum has arranged panto tickets for families. SEND friendly session, will accommodate moderate to severe needs as well, these children and young people usually unable to access these extracurricular activities. Approximately 50 new members signed up.

**Further parent Carer engagement**

We have been attending Coffee sessions held @ schools St Mathews, Richmond Hill West and East, information Stall at Lewsey Community Centre. forum’s WhatsApp group is a key communication tool with Parents &Carers key issues affecting SEND families identified from feedback.

**Some of the strategic Meetings we have been attending.**

* NDD Network quarterly meetings
* SEND Quality assurance group meeting.
* OT comms
* PCF Comms
* SEND Strategic Improvement Group
* Family Hub parent carer panel – working group.
* SWAN
* Health focus week planning
* Scoping Lived Experiences/ peer Support Roles
* Communicating consent
* Guidance for placement
* SEND & AP Change Programme Launch
* Meeting With Rosie- Gaps in CAMH’s provisions
* Emotional Wellbeing Tender Evaluation
* EHCP Process – Revision suggestions to Template (Feb 23)
* Dietetics

**Future plans**

To grow the committee by recruiting an administrator; parent reps and build case to have a Co-ordinator/ Diary manager.

To grow the membership by organising Send activities during school breaks, plans underway for activities during Feb half term.

Run further EPIC Chai sessions, next one pencilled in for 19 January 2024, get feedback from families, create opportunities to get advice of experts.

To attend SWAN, School coffee events to promote the forum.

To continue to attend meetings with local authority and health teams.