

APRIL 2022



Parent Carer Forum

Devon

CONNECT - EMPOWER - INFLUENCE

SPRING REPORT



- WHAT'S BEEN HAPPENING
- SUCCESS TO SHARE
- BARRIERS AND CONCERNS

02

ABOUT PARENT CARER FORUM DEVON

We connect with parents across Devon and this helps us to understand the wide picture of what life is really like for families – identifying problems as well as what’s working well. We work in partnership with the Local Authority (LA), the NHS and other professionals to make sure that services in Devon are accessible and meet the needs of children and their families.

OUR MISSION

Connect

We connect with

- Parents and carers
- Parent carer support groups
- Neighbouring and national Parent Carer Forums
- Education, Health and Care services

Empower

We aim to empower by

- Signposting
- Networking
- Training and supporting PCFD Reps

Influence

We work in partnership to influence

- Policies
- Decisions
- Services

03

WHAT'S BEEN HAPPENING

Our first Annual Survey was a huge success for us with 719 respondents in October and November 2021. The average completion time was 13 minutes which makes a total of over 150 hours of participation.

There are some very difficult messages for professionals so we are in the process of feeding back to different groups across Education, Health and Care. We've asked for an initial response from all key stakeholders and will share these as soon as possible. We hope then to collectively agree on the next steps and be able to share headlines more widely soon.

We recently spent a whole day considering our strategic plans and priorities for the next twelve months. Hearing from families remains at the heart of all we do, but we want to make sure that our messages really make a difference where it counts. This means being able to share positive change with families, and to do this effectively we want to work more widely, connecting with more people.

For this to be successful, we will need more funding, and we are exploring different options for this.

FUTURE PLANS

We are really keen to strengthen the team here at Parent Carer Forum Devon so that we can do more connecting, empowering and influencing. Once we have secured the funding we need, we will be looking for people to help us with:

- Admin
- Events, Social Media & Communications
- Data
- Training & Development

EDUCATION

What's been happening

Our positive relationship with SEND 0-25 Team continues with our regular meetings with senior managers. There has been retirement and illness in the management team, so there are currently some gaps.

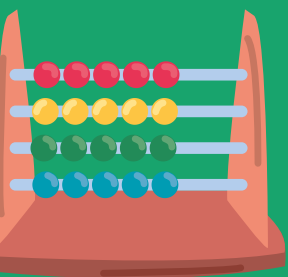
A new Interim SEND Strategic Director has been appointed and we look forward to working with her.

Plans to move Babcock LDP staff who provide the Education and Inclusion services back in-house continue, with an interim identity to bridge the gap.

Devon's SEND Strategy refresh has led to a SEND Transformation project with plans to create a new locality-based Hub model. This remains in the planning stages with limited information about the difference or benefit to families.

A new backlog team is being created to deal with delays due to EP shortages and amending plans after Annual Reviews. The forum plans to be involved in recruitment.

A recent Judicial Review ruling on Annual Review timelines was published in March. This will have an impact nationally and we welcome the clarity this judgement brings.



EDUCATION

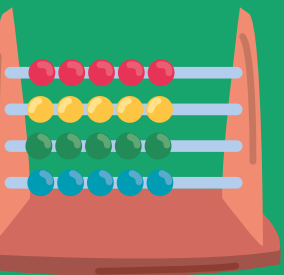
Success to share

The Forum has been involved in a new piece of work looking at improving the Annual Review process. Our role involves planning and facilitating opportunities for families to feedback in various ways. Hearing from families started with our Ambassador Volunteers feeding back lived experiences on behalf of their groups to 0-25 Team.

Alongside the new team working on the backlog and the Judicial Review judgement, we are hopeful for improvements in both the timeliness and effectiveness of the Annual Review process.

The Forum is pleased that plans for us to contribute to EHCP quality assurance continue. For now, this is in the early stages and involves ensuring proper procedures around confidentiality are in place.

There are new opportunities within the newly renamed Coproduction and Communication workstream under the SEND Partnership Board. The Forum is keen to see and support more opportunities for families to share their lived experiences, and for us all to see a difference in services that are fit for purpose. We also encourage a commitment to regular, responsive and accessible communication.



EDUCATION

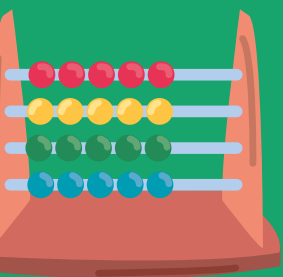
Barriers and Concerns

The timeliness of both initial EHC Needs Assessments as well as EHCP Reviews remains very poor. The national and local EP shortage is having a big impact on initial EHCP timeliness and also when additional EP advice is needed for a review. Amendments that have been agreed either take a very long time or are not completed before the next review. Glitches within the EHC Hub system are leading to inaccurate dates for the next review.

Due to the uncertainty with the in-housing of Babcock LDP (Education & Inclusion service), it has been difficult to maintain a partnership with the senior management staff, and therefore very limited or no coproduction is happening.

Staffing and recruitment difficulties with the MSI Enabling Service are resulting in some children missing up to two days per week of school and not being able to access out of school support at all. This is a really important service that provides invaluable respite and educational support to families, who are often very reliant on the service to ensure their child accesses education. We have attended regular meetings with parent carers, but they have seen little improvement in the situation.

The content, quality and structure of the Local Offer website remains a concern, despite reports from the Local Authority of high levels of customer satisfaction.



CARE

What's been happening

PCFD has worked hard to develop an open and positive relationship with Devon's new Senior Manager for Disabled Children's Service. Our regular fortnightly meetings with her and the Designated Social Care Officer (DSCO) for SEND continue and play an important role in supporting this partnership.

Devon's DSCO has been seconded as Principle Social Worker to cover maternity leave. A new interim DSCO has just been appointed. The Forum took part in the decision making throughout the recruitment process.

Devon County Council is launching a Short Breaks redesign and the Forum has representatives on this Board. There are a series of listening events planned for the summer term which will give families an opportunity to share lived experiences as well as influence the redesign.

We have recruited two new parent carer reps for the Preparing for Adulthood workstream and this is going well. We offer training and support to all our PCFD Reps to enable them to work strategically. If you would like to find out more about representing parent carers like this please get in touch via admin@parentcarerforumdevon.org.



CARE

Success to share

Devon County Council submitted a Respite Innovation Bid and was able to use some key data from our annual survey to support it. This is encouraging as it shows that our findings are listened to, and are useful not only to carers but also to strategic decision-makers.

The Forum remains a key strategic partner in some big pieces of work:

- The Short Breaks refresh under the newly formed Short Breaks Board
- The review of the arrangements for Direct Payments. This will mainly have a social care focus but is likely to have implications for all payments.
- Feeding into the Joint Commissioning Plan for Devon
- A new focus on Early Help brings opportunities for the Forum to be involved right from the beginning



CARE

Barriers and Concerns

While Devon County Council has worked quickly to appoint an interim DSCO, this will mean a period of relationship building and upskilling.

Families have told us they find the eligibility criteria for Disabled Children's Service (DCS) difficult to understand and interpret. This means many families don't find the DCS easy to access and sometimes don't feel supported. Although families will have a chance to share their lived experiences through the listening events planned for the summer term, these issues are not new. It's important that any changes lead to clear, straightforward and easy to understand information being available for both families and professionals.

Unfortunately, issues with the Direct Payment cards haven't been fully resolved. There is a Direct Payment focus group planned for late April for parent carers to discuss future options.

Serious concerns about wider Devon Children's Social Services continue and this may mean there is less focus and priority for improvements needed within the DCS.



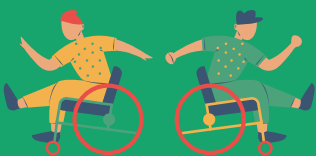
HEALTH

What's been happening

Our positive relationship with the Clinical Commissioning Group (CCG) remains based on our regular monthly meetings with our neighbouring Parent Carer Forums, Commissioners from the CCG as well as the Designated Clinical Officers for SEND. We discuss any topical and local SEND related issues with an open agenda.

The Forum remains a key strategic partner in some big pieces of work:

- **Key Worker Pilot Scheme** These key workers will work with families who have a child with a learning disability and/or autism who have recently been admitted to hospital because of their mental health. They will also work with these families where community services are finding it challenging to meet the child's needs and professionals may be considering admitting them to hospital.
- **Annual Health Checks** It's really important that young people with a learning disability are offered an Annual Health Check. The Forum has been involved in a one year project with the Burdett Trust exploring how we can improve the uptake of these checks.
- **Autism Strategy for Devon** The Forum has been involved in feeding back on the language and content of this important piece of strategic work

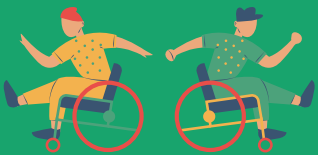


HEALTH

Success to share

Children and Young People are identified as a priority under the newly formed Long Term Plan board which covers Devon, Torbay and Plymouth. Six game-changers have been identified as workstreams under this Board, including Speech, Language and Communication Needs (SLCN) as well as Neurodiversity. This is an exciting time to build partnerships within and beyond health across the geographical footprint of Devon, including three Parent Carer Forums. PCFD welcomes this new focus both on children and young people, as well as on Special Educational Needs and Disability (SEND).

In the spring, for the first time, the Forum was invited to be part of the procurement process for new NHS provision in Devon. This involved a lot of preparation work with very short time scales. It reflects our wide understanding of the local area, the challenges faced by our families, and in particular the specific needs of children and young people with SEND. We look forward to being part of future procurement decision making in the spirit of true coproduction.



HEALTH

Barriers and Concerns

Families still experience fragmented and disjointed services.

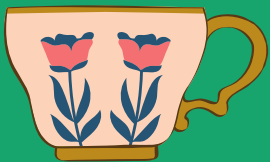
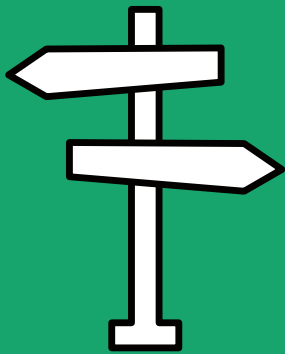
The main provider of community children's services, Children and Family Health Devon (CFHD) commissions a local charity to do their engagement work and does not work directly with the Forum. Despite repeated offers from us, they feel they do not have the capacity to meet. As a result, coproduction with them is very difficult.

Waiting lists are very long.

For Autism Assessment, CFHD only shares the average wait time which is around 52 weeks. However, we have families reporting waiting up to or longer than 2 years. The numbers on the waiting list have dropped. It is not clear whether this is due to increased efficiency or whether it is just more difficult to be accepted onto the list. 89% of those assessed receive a diagnosis of autism.

For Speech and Language therapy, there are more than 3500 children on the waiting list, with an expected wait of up to two years.





INFORMATION, ADVICE & SUPPORT SERVICE

What's been happening

The collaborative partnership between Devon Information, Advice and Support (DIAS) and the Forum continues.

The number of children and young people with EHCPs has grown massively over the last few years, but there has been no additional funding for DIAS. They have worked hard to increase capacity by exploring lots of different ways to meet needs including booking online or phone advice slots and increased training for parent carers. They are planning a website update.

The Ambassador Volunteer Project continues to offer signposting, training and support for parent carer Ambassador Volunteers within their communities and more widely into a network across Devon.



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