



Care Action Protect Empower

In our FIRST YEAR we:

Ran 6 social events including coffee mornings, specific issue support events, a canal trip, and a family picnic. 83 people attended in total. These events give parents a bit of a break, bring parents with similar experiences together so that they can share information and appreciate that they are not alone, and provide an opportunity to the us to share information.

Ran two training events. The first was training to aid preparing for a SEN Tribunal, and the second was training about the legal responsibilities of children's social care in supporting disabled children. 31 people attended the training in total.

We also set up 11 engagement events with staff and managers from the local NHS and Gloucestershire County Council over the same period, with an average of 10 families attending each event. These have covered such topics as advising on local authority strategic objectives and sharing concerns and good practice with Health Commissioners and Children's Services.

In our SECOND YEAR:

Parents were sharing experiences about being accused of Fabricated or Induced Illness (FII) and the distress caused could have been avoided had medical services carried out the investigations and assessments required to achieve a diagnosis. Since collating this information into a report which has been shared with local health representatives, we have collaborated with a Professor at the University of Central Lancashire to provide evidence for his work with the Royal College of Paediatrics and Child Health on creating improved guidelines for the investigation of possible FII.

We held an Education Law advice event where families could talk to a specialist education solicitor and a benefits advice event where families could talk to a Citizens Advice Bureau Welfare Benefits Specialist. 28 families attended.

As a result of issues raised by families, we have been working jointly with Gloucestershire County Council Information Management service on a Record Keeping and Subject Access Requests Improvement Plan. The first paragraph of which states "Following a complaint from the Parent Carers Alliance (PCA) in April 2020 an in-depth investigation took place looking at the council's subject access process. The investigation concluded that the process was regularly not meeting either service users' needs nor the statutory requirements of the General Data Protection Regulations (GDPR)." The parent carer who is involved has written a report for the PCA and in it they say

"I feel confident that our involvement has made a significant difference to the IMS. Had the PCA not shared its report with them and given them opportunity to engage, I believe they would still be battling the internal governance and departments within the local authority. Standing together with our shared experience has and is making a difference not only to our communities but to this department and team. We continue to have regular meetings with the IMS and will be monitoring progress jointly with them. I feel very strongly that our input is valued and is helping to shape this service for the better. It is continually building and evolving with each discussion we have."

As a result of making links with specialist advisers, we are now being asked to provide them with evidence to enhance the work that they are doing to support families with disabled children at a national level. We contributed to a Cerebra survey about how well disability needs assessments are done and provided additional specific information on 20 families' experiences. The data has been forwarded to University of Leeds for analysis. The results will be announced on Cerebra's social media when they are published.

Professor Luke Clements, University of Leeds, states

" The most important element in supporting families when they experience the common legal problems families with disabled children encounter, is the existence of small, local, independent user-led organisations – to whom families can turn for information, support and advice.

The PCA is one of the most impressive groups I have come across in the UK – and in Gloucestershire and the surrounding regions it is undoubtedly the leading support organisation. The work of the PCA is of vital importance to families with disabled children – and all the more so after a decade of drastic cutbacks to social welfare expenditure.”

We also spent time adapting to the Covid 19 pandemic, to move our training and social events online, and to the need that families have for more individualised support.

As we are aware that parent carers are under additional strain and that social events give parent carers the chance to have a break from their caring role, enables them to share experiences and the knowledge, we arranged online pamper sessions. A Neal's Yard Remedies consultant sent out a pack of products to 12 families, including young people. She then ran an online session showing how to use the products. Comments afterwards included “Thank you so much for this pampering session! My skin feels so soft and I actually managed to switch off for a few minutes of much needed self-care.”

With funding from the Coronavirus Community Support Fund, we set up a specialist advocacy support service which has helped over 40 families to date. Some of the issues families have been successfully supported with include - Giving parents the confidence to attend child protection conference, both of which resulted in the children not being put on child protection plans; achieving a clear pathway with a Borough Council to get DFG work to adapt a house completed; giving support so a family could find a school that meets the needs of their child; and help to achieve a diagnosis from Community Paediatrician. Find out more on our Advocacy page <https://www.parentandcareralliance.org.uk/advocacy/>

To date in our **THIRD YEAR:**

Professor Andy Bilson of University of Central Lancashire requested that the PCA provide him with an update on cases of FII, 88% of responders reported that they had been accused. He took this information, along with a report previously produced by the PCA, to his meeting with the Royal College of Paediatric and Child Health to inform their decision making on national guidance for investigation of potential FII. Professor Bilson states that “the PCA work with parents who have been wrongly investigated for fabricated and induced illness in their child has led to reassessment of policies and practise in this difficult area”.

We went digital, running webinars on

- Assessing the social care needs of disabled children and their families: How it should be done and what to do when things go wrong

Feedback includes “Thanks to all for today’s webinar. It covered my concerns, questions, and experiences perfectly and has given me the information and pointers that I desperately sought and needed clarifying. I have struggled to find written or online information before this and now thanks to you guys, I stand a chance of having my child educated and addressing his independence, education needs and to perhaps gain social inclusion for him

- Special Educational Needs and Disability legal issues – covering topics such as support for specific needs, the role of an educational psychologist, Education Otherwise than at school, transitions, Post 16 provision, therapies, and personal budgets

Feedback includes "Just wanted to say thank you so much for this really useful webinar. We are about to request an assessment for an EHCP and will be going into the process armed with the information/advice from Nigel’s presentation. Providing a recording is really appreciated as although I made some notes, I know I will have missed a lot. " and "Fabulous event, very informative - and empowering to me as a parent. Would definitely use the advocacy in the future"

- Using the complaints procedures - as the PCA has seen that some families can feel overwhelmed by the thought of challenging large organisations that have a position of power over their lives, we held a ‘how to do it’ webinar which explained in accessible terms how with a bit of thought, care, and support it is possible to use the complaints procedures in a constructive and helpful way to request improvements in provision.

- Another Neal's Yard remedies pampering session focusing on hand care as that is vital during the pandemic
- An online coffee morning where we made new links with carers, build a support network of 'experts by experience' and provide an informal setting for them to relax and share their concerns and need for advice and support.

Over 50 families attended these online events.

We provided ongoing support on social media, by email, and phone calls, answering an average of 10 direct messages, 31 Facebook posts, 2 phone calls, and 4 emails a week. In addition to these, there are regularly more than 800 active members volunteering their time on our Facebook page, supporting each other, answering questions, and sharing experiences, thus reducing isolation, and helping other parents feel that their experiences are valuable in that they can help others. Grant funding has allowed us to give more time to the group which has grown the group and ensures that the information which is shared is monitored for accuracy.

FUTURE PLANS

To continue to be a source of factual, reliable information and education for our over 1000 member families, from both national and local sources, to provide peer support and alleviate loneliness, and to gather the lived experiences of families and use this information to lobby for positive change for families.

To be successful in grant applications to provide further reduced cost advocacy, both for social care and for education issues.

To run more webinars covering topics such as social care and education rights and duties, speech, and language therapy, and, as children and young people have been suffering due to the lack of access to physical therapies caused by the Covid-19 pandemic so the PCA have responded to this need by organising a Physiotherapy webinar offering home exercise programmes for Musculoskeletal, Neurological and Respiratory conditions and advice on self-care for carers.