



Care Action Protect Empower

**In our FIRST YEAR:**

The company 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.

The company ran two training events. The first was training to aid preparing for a SEN Tribunal; this was provided by a solicitor from SOS SEN, an independent helpline for special educational needs. The second was provided by Professor Luke Clements from Leeds University and was training about the legal responsibilities of children's social care in supporting disabled children. 31 people attended the training in total.

The company 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, sharing concerns and good practice with Health Commissioners and Children's Services.

Became aware that parents were sharing experiences about being accused of Fabricated or Induced Illness (FII) and were telling of the trauma these allegations were having on them and their children. During the autumn of 2018 we asked members of our Facebook page if they were willing for the PCA to use their stories to talk directly to agencies within Gloucestershire to improve the way parents are being treated. In every case these parents (and their children) have experienced high levels of distress that has had a huge impact on their lives. Allegations of FII were made in ten of the twelve cases without a diagnosis of the children's condition having been made. 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.

**In our SECOND YEAR we:**

Held an informal meeting where the local authority, education, social care, and health, managers and heads of service, discussed current strategies e.g. the Joint Additional Needs Strategy and how to identify priorities for parents and carers and agree how to work together.

Held an Education Law advice event where families could talk to a specialist education solicitor which covered topics such as the legal definition of SEN, what is an EHCP, how to get an assessment, the Tribunal appeals process, annual reviews, securing funding for an independent school, importance of evidence/experts and myths about Education law

Held a benefits advice event where families could talk to a Citizens Advice Bureau Welfare Benefits Specialist, which discussed issues such as Universal Credit for young adults with disabilities, DLA to PIP transfer for children and other relevant disability benefits

These advice events help families ask questions directly to experts without having to fund such advice themselves. They inform families of their legal rights, and those of their children; explain how those rights apply in their circumstances; identify and clarify the systems organisations such as the local authority, schools and the health services should have in place to support families with additional needs and how to access them; and explain the processes for redress if such organisations fail to support families in accordance with their legal duties.

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. Cerebra issued a survey to obtain the views of Parent Carer support organisations about how well assessments are done in their area.

A key objective of the survey was to find out whether issues raised by families such as assessments being carried out by practitioners with no knowledge of disability, focusing on child protection not disability needs, it being an insensitive and distressing experience are an isolated or a widespread problem. We completed the survey on behalf of our families and also provided additional specific information on 20 families' experiences.

We also spent time adapting to the Covid 19 pandemic and the need that families have for more individualised support.

We set up a specialist advocacy support service which has helped 36 families to date. The main 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 in order 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.

Comments from parent carers about the advocacy service include "For us you have been a huge help in not only guidance but actually someone who is willing to listen to us as a family. We have many challenges within our family and we have found that most social workers are not experienced in children with mental health issues and therefore are quick to blame the parents. You have helped our voice to be heard and you look at each family as individuals" and

"Just wanted to say thank you so much for everything you've done for us from being that listening ear to reading reports and sitting in with meetings, which I found very reassuring that you were there, thankfully everything went our way and we are happy with the outcome."

In addition to the services of the advocate, we spend several hours a week dealing with distressed or frustrated families who are desperate for support and guidance. Some cases can be resolved by asking a question on the Facebook Group for advice from other families in the same situation, with a Director overseeing the discussion to ensure that any advice given is suitable and appropriate, others can be answered by signposting to organisational information such as the local authority 'Local offer'. Many cases however need more in depth support such as contacting a senior employee of a service provider on behalf of families who wish to remain anonymous for fear of reprisals, advising on complaint processes and how to access the Local Government Ombudsman for independent adjudication. Where sufficient families raise similar concerns the PCA seek to meet with the service providers themselves to advise on effective change.

As a result of issues raised by families, we have been having online meetings with Gloucestershire County Council Information Management service. They have been working jointly with us 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 subject access process is seen by service users as an important tool in helping them understand decisions made about their life and, in some cases, to be able to hold the council to account for bad practice, the value of which should not be underestimated. 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)."

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 2 online sessions showing how to use the products.

Comments afterwards included "Thank you so much for organising! Skin is feeling gorgeous." And "This was amazing and 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."

At the start of our **THIRD YEAR** we are supporting over 1000 families. In this year we hope to do the following and any funds that you can offer to support this will be most appreciated:

To continue using social media, direct messaging, online conferences, emails and telephone calls to be a source of reliable, factual information from both national and local sources, provide peer support, gather the lived experiences of families about their difficulties, including those created by Covid-19 and to use this information to lobby all relevant parties to ensure that positive changes are made so vulnerable families stay as safe as possible. To continue the work started on the information management system used by the local authority,

Providing on-going advocacy. Our current advisor is a retired social worker and will continue to advise families in areas where has the expertise. In providing advocacy for the past few months we have learned that some families need specialist advice in how to obtain and keep the right education support for their children. As a result of this need one of our Directors is undergoing training by specialist education lawyers to be qualified in supporting and advising families whose children and young people have special educational needs and disabilities about the legal framework and the duties on local authorities, schools, nurseries and post-16 institutions, funding would provide dedicated time for this support to be provided.

More specialist advice and support sessions such as:

Social care system and legislation on Disabilities training – 17 families attended our first webinar on this topic which was recorded and will be uploaded to our website to be available to many more families who were not able to attend.

Neurodisability Physiotherapy webinar

Child Protection and

Speech and Language.

Your funds would help us to meet the costs of the specialist speakers as well as publicity to advertise these events, marketing to understand the needs of those attending so as to tailor the events to these needs, and sharing advice after the events with those who cannot attend.

Another Neals Yard Remedies pampering session aimed at protecting the hands as parent carers need to reduce infection risks for their vulnerable families and this takes its toll on their hands

Sending a cake to families so that they can log on and join online 'Coffee and cake' mornings where we can make 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. This would enable us to tailor our work to our families' needs.

We also have running costs which include Website hosting and management, Insurance, Accountancy and printing hard copies of information for families without easy access to the internet. Any contribution to these costs is always gratefully received.