



## THE STORY OF EMPOWER AND INFORM

The project was set up with the aims:

That over 3 years

- Up to 720 people will be supported through live webinars and through recordings
- There will be 8 events a year – a total of 24
- Around 1215 will be connected to (and supported by) PCA through social media, and
- Up to 420 families will be supported through the advocacy element.

In our third year of funding:

We have held **18** events – a mixture of training and advice, consultations and opportunities for socialising and peer support, and a Special Educational Needs Conference with talks by **7** specialist speakers, which have reached **476** people through attending events, and **3752** through watching the recordings on YouTube and Facebook, a total of **4228**. With the easing of the Covid restrictions, this year more of these events have been able to be held in person.

The PCA now has **1721** (+ 330 this year) members on the Facebook Group, **989** (+302) followers of the public Facebook Page plus **548** (+ 110) Associate members, a total of **3258**. The Facebook group is very active, with high engagement from members – there are regularly over **1100** active members in a day.

Over the past year there have been **243** requests for support from our Advocacy service made by families and **4** requests from professionals. We provided drop-in sessions with our advocates during two events as well as telephone and direct messaging support, for a further **602** families, making a total of **845**.

When asked for feedback on the advocacy support provided, 97% described feeling worried or very worried before contacting the PCA.

After support:

54% felt less alone, 79% felt better supported, 67% better prepared, 69% better informed, 59% felt they had a better understanding of the law, 74% a better understanding of their rights to support and 84% that they could achieve getting the needs of their vulnerable children met.

In total over the three years of funding for the Empower and Inform project:

- **5214** people have been supported through live webinars, and events, and through recordings
- **52** events have been provided over 3 years
- **7747** have been connected to (and supported by) PCA through social media, and
- **2148** families have been supported through the advocacy element.

What went well

When this project started PCA and its advocacy service had only been operating for a few months and, from contact through our social media and meeting with parent carers, we had ideas about what support could be needed and the numbers who might request it. However, we significantly underestimated both the extent and the complexity of the challenges that families whose children have additional needs face and could not have predicted the Covid pandemic nor the cost-of-living crisis.

What we are especially proud of is how well the PCA has adapted to these challenges, how, with little technological experience, we changed our methods of working to online, providing webinars for training, specialist advice, wellbeing and reducing isolation.



We have developed systems for gathering evidence of the needs and wishes of our community and used this to responsively adapt our provision, and to provide research evidence for local and national improvement projects.

During a period where more established not-for-profit organizations have struggled and ceased to exist, PCA has instead grown in terms of provision for our community, number of and types of services provided, has built local and national links, grown in influence, and has recognised and celebrated the amazing knowledge and compassion within our community by providing mentoring and employment for members of our community.

PCA is grateful for the funding for the project and feels that having created all this provision, and exceeded the targets, whilst remaining within the grant budget, is another testament to our success.

### **ACTIVITIES and OUTCOMES**

The outcomes that the Alliance has achieved, and hopes to continue to achieve include successfully preventing children from being taken away from their family during child protection conferences, instead getting a better understanding of the needs being due to their disabilities, and not a safeguarding concern; getting the right education for children who have been out of school for prolonged periods; getting urgent mental health support for young people who are attempting suicide and getting the right equipment for a young person who had been discharged from hospital and was having to sleep in her mother's hallway. In addition to these headline successes, what families say they benefit most from can be expressed in their words from some of our most recent feedback as:

*"The Alliance has not only helped us to gain more confidence in asking for what our daughter needs but have also given us a lot of understanding of how/who to ask and what we CAN ask for. We've been helped to gain a better understanding of our daughters needs and identity and the importance of celebrating her,"*

*"The Alliance has made a massive difference, when I was on my own, I felt lost, confused, and frustrated, once the Alliance started helping me, everything felt easier and things that I couldn't say, were finally heard because Alliance gave me my voice back. This saved my mental health and my families wellbeing," and*

*"To have the support and guidance of such knowledgeable advocates in whom we can place our trust, that recognise and speak out on our behalf when we're struggling to express our thoughts and feelings, giving us a voice. The guidance, support, reassurance and understanding we've received from advocates enables us to actually feel heard and have our concerns taken seriously."*

### **Specialist advice**

In addition to the advice provided by PCA workers, free 1:1 advice sessions were provided for families with both a specialist education lawyer and an independent social worker where families could discuss their legal rights and what routes there are to have these rights met.

Webinars expanding on these issues were provided with advice and guidance on what to do if your child is not being provided with a suitable education, is out of school, needs an education provision that is otherwise than at school, or needs support with special educational transport.

Such are the issues with the SEN transport provision that families were supported to share their experiences to provide evidence for specialist advice for their specific situation and for research which was presented to Gloucestershire County Council who have agreed to look at creating an improvement project involving parent carers.

Michael Charles, Chief Executive of Sinclairslaw, a specialist Solicitor in Education, Disability and Human Rights Law, and recognised as one of the leading education and disability lawyers in England and Wales, gave an in-person talk to members of the PCA covering issues raised with him by PCA members which included: False allegations made against parents when they turn for help; why are health needs being routinely ignored? what can be done?; Failure to comply with the terms of an EHCP - What next?; Children denied referrals to paediatrician/health;



What can be done when a child is in need of help and cannot attend at school? And Complaints to the council are being ignored- what can be done?

Families who receive Direct payments to purchase care for their children with additional needs described their concerns over not being sufficiently informed and supported in their roles as employers, so a specialist webinar was provided along with a more detailed, in person, workshop. These covered - the obligations you have when employing a PA to support you or your child/person you care for, including practical help around good DP package management, budgeting and how to identify any shortfalls in funding. The workshop made delegates more aware of their responsibilities and obligations as well as highlighting the support that is (or should be) available for them which included Personal Assistant recruitment and induction along with other practical issues that will need to be considered when maintaining a healthy employment relationship.

#### **Feedback comments include:**

#### **For the Alliance advice services:**

"I benefit daily from the Facebook page and try and support others on there. I have had advocacy support for my disabled children which has literally saved my life! Myself and others are able to meet our children's needs better because of the support. As a local professional I signpost families to PCA"

"I unable to put into words how having the PCA advice service has supported me! I have never felt so alone as when trying to get the correct support for my daughter. Feeling like someone else 'had my back', understood all the intricacies of the processes, and knew when to push back against misinformation from some professionals has saved my mental health and my families wellbeing. Thank you"

"The advice and support has been invaluable and eased a really stressful time. Like many families, I face daily challenges, but this is compounded by additional stress and anxiety caused by an education system that is broken for special needs children. The difference organisations such as these make is that they clear some of the over complicated processes and support you with knowing where to go and who to ask if the service from the local authority isn't fit for purpose. I would be lost without the PCA. I wish there were more of them with better funding as the need for their services and support is so much needed in this area",

"We have been given advice and had advocates which have helped immensely. We've been supported in a meeting where we would've felt very worried without help. We are so thankful for the ongoing help we receive and would truly be lost without them. I've had help out of hours which put my mind at rest. I've had help which is life changing for us and we could not have gotten where we are without the support"

"Without PCA I would have endured so many significant losses. Support from PCA was able to make positive action from a very difficult and complex situation. Without this the outcome would have been very different for the lives of me and my children", and

"Being the 3rd time we'd tried to access support, it made a huge difference having the PCA knowledge and support to back up our case. As a result, we went from having children that weren't "disabled enough" to access the specialist disabilities team, to now having support from them. PCA also secured home help for the summer holidays which meant we didn't spend 6 weeks at home, isolated from the rest of the world".

#### **Including other specialist advice:**

"I heard last night that I have won my EHCP tribunal for my son - he will now have an amazing education package, which he deserves. It is a very long, difficult journey from request for assessment to tribunal, it's taken just under 2 years. I wasn't able to afford representation, so I requested support from the PCA, attended their webinars and had a support session from their specialist education lawyer. Thank you so much, you are all such valuable support to those of us fighting to improve things for our children"



"I feel confident that the information received will speed up the process for my son receiving the education he deserves. Meaning more quality family time, less stress and worry, less impact on us as working parents",

"I felt moved and empowered and encouraged by his (Michael's) passion and knowledge. It gave me new determination", and

"It was almost a sanity check (that I am right to question) and provided guidance on how to".

### **Conferences**

PCA held two conferences during this year.

In the first Academic Professor Luke Clements and Leigh Day human rights solicitor Sarah Westoby agreed to meet with the PCA families to listen to their concerns about the numbers affected by the issues of fabricated and induced illness (FI) accusations and parent blame that have been raised by Gloucester Children's Services social workers.

Families told the PCA they are criticised for 'overstating the needs of their children' when they request support, especially if there is not a clear diagnosis. If families seek health investigations, they report being accused of FI, then subsequently their concerns can be found to be valid when an additional diagnosis is made.

Families described being unable to access social workers trained and experienced in disability. Instead, families say they suffer assessments which can focus on blaming parents for their children's needs, carried out by social workers who the families say follow safeguarding procedures at the expense of identifying the needs which arise as a consequence of children's disabilities.

As a result of this conference families had their stories heard and were supported to consider whether there are legal routes available to them to help address the issues they are facing.

The second conference gathered together amazing experts in Education Law, Health, and Social Care to speak families about the real-world challenges, and to provide them with practical tips and advice on overcoming the barriers. Talks covered Special Educational Needs Home to School Transport, Speech and Language Therapy Provision, Physiotherapy provision, Powers of Attorney, Court of Protection and Ongoing Administration, Social Care Provision, Legal routes to support and redress and how the Local Government Ombudsman can make a difference.

This was also the first event that we provided in person advocacy support sessions, bookable on the day, which were fully booked and very well received.

The conference talks were both livestreamed, recorded and made available on [PCA Facebook page](#) - this has been very successful in meeting the needs of families who were unable to attend in person.

### **Feedback comments made about the PCA conference:**

"Fabulous conference. Massively supportive and informative staff. Great feeling of solidarity. Very welcoming and hospitable.", "Really impressive conference. I feel empowered and now know how to support my son to get his needs met.", "I feel so much better informed and now know that there is a trustworthy organization who has all the information I need and can sign post me. I feel seen, heard and less alone. I don't feel mad or an imposter now for wanting support" and "The best part was being able to do a breakout session to discuss Post 16 options for education."

### **Feedback from professionals (Gloucestershire County Council and NHS) who attended includes:**

"Very helpful to hear about the experiences of families in Gloucestershire, I am committed to changing the culture for social workers" and



*"Lots of fantastic information for my work as a social prescriber – what a fantastic organisation! Just what parent carers (& professionals) need"*

### **Social events**

Four coffee mornings were held where parent carers could meet their peers, reduce their isolation, and consequently improve their mental health.

These events are also used as opportunities to learn more about the needs of the PCA community and how effective the support is that PCA provides. When these events are scheduled close to dates which directly affect parent carers – such as the date that secondary school places are announced, additional support is provided so that e.g. parent carers can discuss any Special Educational needs issues that you are having with our team of specialist advisers- especially any that are about Phase Transfers.

Two other trips for families were provided – one where families could visit Skillzone, Gloucestershire's life-size safety village 'where learning to stay safe is never dull', and experience home, fire, 999 and road safety scenarios and learn about making safer choices in different scenarios whether that is at home, while travelling or taking part in activities, and

A relaxing day out on the water with the Willow Boat Trust with the aim of providing a unique opportunity for those with a disability or serious illness to enjoy a therapeutic day out on the water.

To recognise the importance of carers, and to support parent carers with the cost-of-living crisis, a free Christmas lunch was provided.

### **Feedback comments include:**

*"It was really lovely to meet two people I have conversed with quite a lot online via the PCA in person, and to have struck up a good connection with them",*

*"Lived and shared experiences are so important to feel less alone. ", and*

*"It was lovely to be able to attend an event with others, to have the opportunity for my son to be included".*

### **Local Projects and Engagement**

As part of the ongoing work on improving the process of disability needs assessment, PCA has this year worked with parent carers to record their experiences of social care assessments so that these could be shared with social workers through a presentation at Gloucestershire's Social Work Academy

### **Feedback from Rob Tyrrell, Principal Social Worker - Children and Families**

*"This was an important event that I hope we can build on! Positive feedback reflects some of the immediate impact and how ideas might develop"*

### **Participants' feedback includes:**

*"Having parents and families working with us to educate us with their experiences, to inform our practice has been valuable" and "Lots to reflect on and begin to implement in my own practice!"*

PCA worked closely with the Director of Children's Services (DCS) when families felt they had no other option but to protest over failed education provision for their families. PCA hosted a meeting where all parties were able to work to resolve these issues, followed by providing advocacy to individual families in subsequent personal meetings with the DCS. Many families were given a suitable education placement as a result of support from the PCA.



Most recently the PCA has been working with GCC's Senior Commissioning Manager, Children and Families Integrated Commissioning Hub, on reviewing the referral form and providing initial feedback on the Holiday Activities and Food Programme (HAF) funded by the Department for Education and, as a result, has been asked to join the HAF steering group, and has been asked to take on the role of specialist community connector, helping to improve the provision for children with additional needs

PCA has continued the work with NHS Gloucestershire focusing currently on therapy for speech, language, and communication (SALT) needs as this is has the most significant waits within community services.

In order to raise awareness of the work of PCA and the ways in which we support families whose children have additional needs in communities who currently are underrepresented in our membership - PCA attended the Annual Fundraising and Social Dinner/Dance of Gloucester FM (GFM) Radio Station, which is a local community radio station with a licence to play music of a black origin, and the Unreflected Reflections event. Unreflected Reflections was initially founded to capture, film, and share the history and stories of the Muslim community in Gloucester, and the event aimed to bring together community members, organisations, and arts/ culture sectors to share the work and to build activity within Gloucestershire more widely.

#### **Feedback from Chris Spencer, Director of Children's Services:**

*"I wanted to write to say thank you for your time, support, and challenge during the five years I have been in role at GCC. The contact I have maintained with the Parent Carer Alliance (PCA) has been an important element of the Children's Services improvement journey. The challenge and insights of the PCA have been an important source of information to us in our attempts to improve services for children and young people across the county. My meetings with your membership have at times been very uncomfortable, but it is crucial that I hear the real feelings of the parents and carers of children with disability and the problems they face if we are to make a real sustained difference to the life chances of our young people. I leave my role at GCC acutely conscious that there remains important work yet to complete if we are to reach our ambition of providing sustainably good services to children and young people across a range of services and I would encourage the PCA to maintain the role of critical friend to the LA".*

#### **OFSTED**

During the recent Gloucestershire SEND inspection by OFSTED, the PCA were thanked for the reports that they had sent to OFSTED and asked to contribute families' experiences to the inspection due to PCA being 'a significant group in the area, as recognised by the local area partnership and the Parent Carer Forum'.

#### **Listening events**

PCA is proud of our growing reputation for the accurate representation of the experiences of families whose children have additional needs. PCA were asked to organise listening events so that parent carers could share their experiences with:

Nigel Thompson, Deputy Director Multiagency Operations, of the Care Quality Commission (CQC), who wished to meet families to hear their experiences of Special Educational Needs and/or Disabilities (SEND) and of health services in Gloucestershire - as Ofsted and the Care Quality Commission (CQC) launched a new joint framework for inspecting provision for children and young people with (SEND) within a local area which has a greater focus on hearing directly from children and young people with SEND, and their families, so they could get a better understanding of what it's like to be a child or young person with SEND in Gloucestershire, and

with Social Work England, which is the regulator for all social workers in the country who are responsible for ensuring social workers meet a minimum standard of practise. They were keen to speak with parents and carers of children who have been subject of a social work involvement so they could learn and look at how they can improve social work.



### Feedback from Social Work England:

*"Thank you for working with us on this. I appreciate not only the time but the very personal experiences which everyone shared".*

### National Engagement

Following research with our community that showed that social care assessments were focusing on safeguarding, not on the needs of the disabled child; and work with the Gloucestershire social work academy that showed that social workers say they feel that they don't have the right training to carry out disability needs assessments, and are worried about using language that causes offence, PCA was commissioned by Professor Luke Clements and the School of Law's Legal Entitlements & Problem-Solving (LEaP) Project at the University of Leeds, to undertake a consultation into Disability Needs Assessments.

The aim was to utilise the experiences and expertise of Parent Carers and their families, and to incorporate their ideas, as to how a needs assessment could be done more effectively and result in better support for families whose children have additional needs. This was sent out for consultation with our community and with that of other parent carer support groups around the country.

We adapted the assessment following this consultation and this version, as well as parent carer recommendations for guidance for social workers, was presented to national statutory sector leaders for their views to be included, and has now been published as "[Draft Guidance - Assessing the Needs of Disabled Children and their Families](#)" published in July 2023 where reference 41 links to the proposed assessment. The aim of the guidance is to effect change at a government level, and the Alliance contributed to the Department for Education consultation on its proposal to update the 2018 'Working Together' guidance.

Following an invitation from a local community leader, the Alliance attended a meeting at the House of Lords to discuss with leaders of NHS services how organisations, such as ourselves, are able to support communities so well, and to share how this is achieved.

### Feedback from Professor Luke Clements, Cerebra Professor of Law and Social Justice:

*" The Alliance is leading the way in demonstrating how local groups can engage in practical and meaningful conversations with their councils and can be seen as a pilot / demonstration model of how to effect positive change and is playing a vital role in bringing about meaningful change for the hundreds of thousands of families with disabled children. The template form and your work on operationalising it is a tremendous initiative, and it would be great if this could be recognised and adopted widely".*

### Learning

We are very grateful to the National Lottery for seeing something worth supporting in PCA, and for providing the funds and the time for PCA to develop a better understanding of the needs of the community that we are supporting, as well as developing the business function, gathering evidence and the skills to make successful funding bids.

With the experience gained by the work done within this project has come a greater understanding of both the issues faced by our community, a better understanding of the ways to support them – including signposting to other local and national organisations, as well as the limits of what the Alliance can provide.

It is challenging to run a business that supports a community which is amongst the most disadvantaged in society and that is one of the least able to pay for support. Understandably, when making the application for this project, PCA was considered to be high risk due to our size, previous levels of funding and inexperience of running such an organisation.



We have demonstrated that we are no longer so great a risk, have met every target, have coped with, and adapted to, the huge challenge of supporting our vulnerable community through Covid as well as growing year on year.

External strengths review of PCA was done in April 2022, and stated “The Alliance’s key strengths are centred on the impact it has on its members and in the wider community. The Programme and External Linkages Spider gram shows visually that influence based on an excellent analysis of the external environment and tracking trends in field of operation are key strengths. It is not surprising, therefore, that effectiveness of work is also a key strength.

Whilst the organisation is undoubtedly effective in meeting its stated aims the greater financial stability would give PCA the opportunity to grow to meet the ever-increasing demand on its services. It would therefore benefit from support in developing a strategic vision for the future and a roadmap to achieving that ambition”.

This support has been provided through the provision of a business mentor and support from the Cranfield Trust as well as developing links with a very experienced advocate for staff mentoring and a Human Resources specialist. We plan to build on our reputation and the evidence of need that we have from our community to develop further sustainable income sources to secure the future of PCA.

PCA are proud that, along with the growth in the services we have been able to provide, that we have also expanded our staff numbers by recruiting from our community. In their applications candidates stated that:

*“ I value the Parent Carer Alliance independence and how it enables advocates to work with a family’s best interests, with no other agenda. PCA brought hope, shared the heavy burden of worry and concern whilst using their knowledge and skill to support us in achieving the best outcomes for my daughter with complex needs. The advocates have played a pivotal role in my daughter’s SEN journey and my ability to support her. I would love to use my skills to support the many other families like ours” and*

*“Navigating the world with my children (who have additional needs) has brought great challenge as well as great pride. Due to the complexities of our lives, I have extensive first-hand experience with health services, children’s social care and education. I would like to give back into PCA some of the immeasurable support they have given to me and my family over the past few years”.*

PCA feel confident that, with the continuing support from the National Lottery, and from our amazing staff and supporters, that we will continue to provide support for vulnerable children and young people who have additional needs, and their families, will adapt to the changing pressures on our community, and will continue to create positive change.