



THE STORY OF OUR PROJECT THIS YEAR

The first year of the Alliance receiving funding from the National Lottery Reaching Communities fund has been very busy. The Alliance has developed new systems, new ways of working, and recruited more Advocates to optimise this fantastic opportunity to turn our plans for using our lived experiences to support families into reality.

Through the year we have managed to exceed our targets whilst remaining within budget and are making positive changes on a number of levels – support for individual, and groups of, families, alongside work with Gloucestershire County Council, with Health providers and with local charities; and at a national level to change the practice and points of failure that create many of the difficulties families face.

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
- 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 first year of funding

We have held 16 events – a mixture of training and advice, along with opportunities for socialising and peer support, which have reached 534 people through attending events or watching the recordings.

The Alliance now has 1138 members on the Facebook Group, with more being added every day, 542 followers of the public Facebook Page – a total of 1680, plus 318 Associate members.

Over the past year there have been 130 requests for support from our Advocacy service made by families and 6 requests from professionals. An average of 24 families a month access support through the advice telephone lines and direct messaging, a total over the year of 424 families.

In all our work the Alliance aims to support our community of parent carers and children and young people to thrive, and their opinions on how successful we are at responding to their needs and meeting those needs are threaded throughout this report.

One family's statement encapsulates much of the feedback we are receiving:

"Parent Carer Alliance are literally life savers for all parent/carers who are experts by experience at raising children with disabilities but find themselves adrift in the very frightening reality of professional denial. The Alliance has helped me over my concerns that my child's support needs are being ignored and not taken seriously. Their experts confirmed what I know to be true, at last I don't feel alone and berated, they give me the strength to battle on without fear of being falsely accused and most of all I trust that they are genuinely on our side. The Alliance helps support parent/carers to support themselves. Thank you from the heart."

HOW THE ALLIANCE RESPONDS TO OUR COMMUNITY

All our work is in response to issues and concerns raised by our community through their posts on our social media, them filling out surveys, requesting support from our advice service, or contacting us via email and phone calls. We then provide individual families with support and advice and collate themes to decide how to most effectively create positive change. Examples of this are:

SOCIAL CARE DISABILITY NEEDS ASSESSMENT

What our community told us

Many families were describing significant difficulties both in getting a social care assessment of their child's needs and the effect of these needs on the family, and of not getting any support as a result of the assessment.



What we did

We created a survey, gathered evidence from families - 94% of families reported that getting an assessment was difficult or very difficult, and for those who did have an assessment, only 24% focused on disability related needs. This information, along with comments from the families was collated into a report which included recommendations for change.

Families were referred to our Advice Service for individual support from Advocates and several webinars were held to provide advice and support. The first set of webinars were combined to create a conference covering:

CHILD PROTECTION PROCEDURES – Duncan Siret Independent Social Worker and Alliance Adviser, discusses what they are, how they should work, and where to get help

DISABILITY NEEDS ASSESSMENT POLICIES AND PARENTAL BLAME – Professor Luke Clements, Cerebra Professor of Law and Social Justice, discusses diverting families to generic ‘children in need’ assessors, offering only short-term support responses that locate the problem in the parent and not in the special need for support that arise due to the child’s additional needs

CHILD PROTECTION TRENDS – Professor Andy Bilson, Emeritus Professor of Social Work, University of Central Lancashire, presents research which shows a dramatic increase in child protection investigations leading to a situation in which one child in every 16 in England is investigated before their fifth birthday, looking at national and local trends, and

FABRICATED AND INDUCED ILLNESS (FII) – Professor Andy Bilson discusses critical evaluation of the Royal College of Paediatrics and Child Health guidance, and publications by Bass and Glaser, on FII. This included a review of health and social work policy and practice, and suggestions of ways that these can change so that children’s social care can play an important role in protecting children from both fabricated illness and the harms caused by misidentification.

This conference was advertised widely and had 95 attendees, including professionals who support families in other parts of the country. The [presentations](#) can be accessed from our website and have had 123 views to date.

The difference we are making

Feedback from attendees includes

“Learning more about FII and CP proceedings has been really illuminating. I feel less alone. It’s helped me to more confidently challenge poor practice,”

“This webinar I think will be life changing as it has helped me understand the root cause of the problems myself and other parents are experiencing. I feel equipped to deal with the problems I am experiencing but, better than that, I have been inspired to make an effective plan to work towards achieving structural change that will hopefully help other families in the future and prevent these problems from ever arising. I feel empowered in a way that I did not before hearing the speakers and have spent the last 24 hours building relationships individually, locally and regionally and a concrete plan to take things forward and make lasting change”

and

“I found the whole day very distressing (this was not your fault) it was the subject matter. I have experienced all the worst treatment by Social Services & Clinical Commissioning Group. It helped being with others who have experienced the same. I am looking forward to watching the presentations again once they are uploaded, as they gave me a kick to wade back into the fray & fight again. I am glad to have come across your organisation. Hopefully, this will mean that I can gain back some sense of control in my life & start fighting for apologies & changes in local & national treatment of families with additional needs- for myself & others.”



What we learnt

The above description of distress at the way that families are treated was not a lone voice.

What we did

We responded by setting up a webinar followed by a social event. The webinar addressed that carers can feel the loss of agency, powerless and have no opportunity for closure or resolution as well as frustration and the sense of having been treated unfairly, unprofessionally and exposed to unsafe practice. It looked at trauma, chronic sorrow, and compassion fatigue and what this means for caring - how to process it and how to accommodate and make peace with it.

Both the webinar and the following social event provided safe spaces for 20 carers to share their experiences and techniques to manage stress and to provide peer support.

The difference we are making

Feedback was

“It was really powerful to connect and share with other parents who have experienced trauma through systems as I have, and realising my experiences were common among Carers. It felt safe and compassion focused. I will try use meditation more and guided visualisation like safe space to help me cope in times of stress and feeling overwhelmed.”

PARENT CARER ASSESSMENTS

In their responses to the DNA survey, 65% of families said they were not informed of their right to a parent carer assessment.

What we did

We provided a webinar in which Professor Luke Clements discussed how to get a worthwhile carers assessment, which provides support for the parent carer – challenging the idea that local authorities have no duty to provide support following from a parent carer’s assessment.

The webinar had 32 attendees, and a [recording](#) can be accessed from our website which has had 51 views to date.

The difference we are making

Feedback was

“The most important aspect was knowing the law around carer assessments and what I have the right to access. I will now be able to insist that a meaningful assessment is done and not be fobbed off by the LAs usual tactics. I feel empowered to advocate for myself and my son.”

WORKING WITH OUR COMMUNITY

Alongside supporting families, we wanted to make changes to the systems that create stressors for families, one of the aims of the project is

[Improving services and guidance for families by being ‘Experts by Experience’ who contribute valuable quantitative and qualitative evidence for local and national projects and work cooperatively and effectively](#)

We contacted the Gloucestershire parent carer forum, got agreement for a joint approach to Gloucestershire County Council (GCC), and wrote a joint letter which was sent to the Director of Children’s Services, along with the report of Alliance families’ experiences, and requested a working group be set up to work on improvements.

GCC responded positively and set up a working group that includes the Alliance, the Forum, GCC Head of Service for Disabled Children’s Young People’s Service (DCYPS), and GCC Head of Additional Needs.



Following initial meetings to agree the terms of reference, the first meeting was held in May. The group has been mapping out the pathways within social care that families may be directed through for support, comparing both professional expectations of how the systems work, with the reality of families' experiences.

For this working group, the Alliance also reviewed online information provided for GCC for families whose children have additional needs and found confusing multiple versions of the same document, circular information pathways that led you back to your starting point, and very out of date information referring to support organisations which no longer exist.

The difference we are making

We have been told that the survey results, along with experiences shared by parent carers during working group meetings, are being used by an Improvement Consultant, to help reshape Disabled Children and Young People's Service and the way that information is gathered and processed for Education, Health and Social Care Plans.

This work has led GCC to acknowledge 6 points of failure and to agree to work to find solutions for each of these.

A major stressor for families, which can prevent them from seeking advice and support, is the fear of their family being put through a safeguarding process which does not understand disabilities, and of their children being removed.

Starting with the very first point of contact with social care, this team has been renamed the Children's Single Point of Access, instead of the Multi-Agency Safeguard Hub, to reflect that many families are asking for advice and support, not reporting harm. The working group has met with customer service staff, managers, and social workers from this team to explain families' concerns and to devise a new script to help identify families whose needs arise from disability, to ask relevant questions (previous questions focused solely on who caused harm to whom and how) and to gather information needed to direct families to the right support service.

Families have been 'falling through the gap' of being too complex for the Early Help service, and not complex enough to pass the criteria for the DCYPS team. It has been agreed that the current eligibility criteria fails to consider all needs that arise from a disability and that it is not being applied fairly and consistently. Work has begun to devise a better system and will be followed with information and training on how this should be used correctly.

To work on addressing the issues regarding information provision, the Alliance has joined the Local Offer working group looking at these issues, working again with the Parent Carer Forum.

Another point of failure is the lack understanding by social workers (other than the very small Disabled Children and Young People's service (DCYPS) of disability issues, how needs arise and what can be effective as support for families. It has been agreed to devise training for all staff using parent carer experiences. Meetings have begun with the Social Work Academy (the social care training service) to agree the content and format of this training.

The second meeting was very constructive, attended by representatives from the social work academy and Rob Tyrrell, Principal Social Worker for children and families. They are all very positive about developing training for social workers to help them better understand disabilities, how to make assessments not be about safeguarding and how to better support families.

The proposal is to work together to develop training workshops, a forum event and training resources that can be used to better understand

- What life is like when your child has a disability
- A particular condition or group of conditions
- How to ask meaningful questions to make any assessment relevant and effective
- How to build relationships and support families.



How we are making the most of the strengths of our community

We have asked parent carers to contribute to the training through writing something, creating a piece of art, having their voice recorded, doing a video/video diary, or giving a presentation/being part of a training session – either online or face to face.

Families have been sent a questionnaire to advise what they would like social workers to understand about disability and the needs that arise and, if they would like to contribute, and what format they'd feel comfortable using to do so.

33 families to date have volunteered their time to help develop training. Their responses have been shared with the working group and those that have volunteered to be further involved have been contacted to see how best that can be done around their caring responsibilities.

WORKING WITH THE WIDER COMMUNITY - BARNWOOD TRUST

The Insights Team at Barnwood Trust are currently developing a research project exploring the experiences of short breaks and respite care services in Gloucestershire for disabled people and their families.

They sent the Alliance a copy of the brief and asked to discuss the project in more detail.

What we did

The Alliance discussed the project with the Lead Researcher, provided evidence of issues with social care, reviewed the proposed survey, and made recommendations to enable parent carers' and families' experiences as the initial questions had not considered these participants.

The difference we made

Barnwood Trust employees have given us this feedback:

“Personal experiences are a really crucial and often overlooked area,”

“Our discussion was really enlightening and has caused us to look again at the purpose of the research we are undertaking. With this in mind, we have taken on board your thoughts and reorganised the survey to (hopefully) better reflect the spectrum of experiences unpaid carers have across the county” and

“I really appreciate your support with both the design and distribution of this survey and sincerely hope it will gather data that will be of benefit not only to Barnwood but to your organisation and to parent carers across the county. The stories you have shared have been really eye-opening and, I'm sure, only represent the tip of the iceberg!”

WORKING AT A NATIONAL LEVEL

The survey results, and experiences that families have shared with us, have been major contributors to two projects working to effect change at a national level:

PARENT CARER BLAME

Luke Clements, Cerebra Professor of Law and Social Justice at University of Leeds, states that

“The Alliance – through its methodologically rigorous consultation process – was a significant source of data for our qualitative survey of the experiences of parent carers in their interactions with English Children's Services authorities. The resulting 2021 research report '[Institutionalising Parent Carer Blame](#)' has had (and continues to have) a major impact – both in terms of the mainstream media coverage it has attracted and in the responses we have had from statutory policy makers and non-statutory opinion shapers.



Care Action Protect Empower

The report called for significant changes, not only to the statutory policy guidance issued by the Department for Education but also for change at the ‘coalface’ – where parents first interact with officials of Children’s Services’ departments. In order to bring about meaningful change, we realise that simply amending national policy guidance (which is an outcome we will probably achieve) may do very little to change the actual experiences of families. The current phase of the programme is therefore to support independent parent carer organisations to have meaningful conversations with the Senior Strategic Teams within Children’s Services authorities. To do this we need to mobilise key individuals and organisations in the 151 English council areas.

In this endeavour, the Alliance has played a crucial role. It has facilitated a number of webinars where we have discussed the implementation process with parent carers and parent carer organisations – such that the Alliance is now acting as the *de facto* hub for communication with these with these groups and individuals. Without its involvement this crucial phase of implementation would not be practicable.

In doing this the Alliance is leading the way in demonstrating how local groups can engage in practical and meaningful conversations with their councils. The Alliance – through its experience of working with councils – is developing and sharing a blueprint that explains how councils can make meaningful changes without having to contemplate major structural upheaval and all the organisational turbulence that this invariably causes.

In this respect, the Alliance actions (and its record of these) can be seen as a pilot / demonstration model of how to effect positive change. It is mapping (and critiquing) current care pathways within a cooperating Children’s Services authority, discussing its findings and proposals with the council’s Strategic Team – and then feeding back to the wider group on what works and what does not work.

We are also proposing, in collaboration with the Alliance, a wider training programme so that frontline Children’s Services workers can be upskilled to deal with the new approach to addressing the needs of disabled children and their families. It is intended that this programme will incorporate case studies and the testimonies of parent carers. The Alliance will be crucial in obtaining this material and in developing plans to roll out such a programme.”

THE WAY FORWARD

The second project that the Alliance has made a key contribution to is [Children’s Social Care: The Way Forward](#), which states that children’s social care as it operates in England is not fit for purpose. It alienates families and communities, fails to protect children, and places older children at increased risk of involvement in gangs and sexual exploitation.

Professor Andy Bilson, co-chair of PFAN said

“I wanted to thank the Parent and Carer Alliance on behalf of PFAN for your involvement in The Way Forward campaign.

Your involvement in consulting parents as part of the development of our report highlighted national issues in the way that the child protection system responds to children with disabilities and had a major influence on our recommendations.

Your participation in the meeting helped us to raise these issues with the chair, Josh MacAlister, and members of the Independent Review of Children’s Social Care. The video of our meeting is now on-line <https://vimeo.com/670809723>”

The difference we made

Josh thanked the Alliance and said that he appreciated us raising these points as in these talks they can forget to talk explicitly about these groups of children, and he agrees with the points raised.



There are failures across the systems of health, education, and social care where systems are adversarial – too quick to investigate, with lots of people pointing at families' problems, and too slow to help or support.

Josh stated that over the past 30 years Child in Need had gone from being broad in definition, generous in spirit and driven by child welfare to help families, to being another way to triage concerns about safeguarding. This approach is not helping anyone or keeping children safe, and that he is personally attracted to recommendations from the paper to make progress in changing children's social care.

The report has been sent to the All Party Parliamentary Group for Children. In the Media, Taliah Drayak was interviewed by Victoria Derbyshire on [BBC News](#).

Articles have been published in [Professional Social Work](#), the British Association of Social Work's magazine, and in [Community Care](#)

THE ROAD TO RECOVERY PROJECT - EDINBURGH UNIVERSITY

The Road to Recovery project is looking at understanding the impact of COVID and recovery phases on children and young people with Intellectual Disabilities and their families

Intellectual disabilities (ID) are characterised by social, and cognitive difficulties that are often associated with challenging behaviours. Challenging behaviours indicate levels of severe mental stress and distress reactions in those with intellectual disabilities. Increased levels of mental health issues have been reported in children and young people with ID and their caregivers. The COVID-19 response strategy entailed limiting access to education, respite care, and specialist services, therefore reducing the available support for families, with unknown consequences.

The relative vulnerability of children with ID was highlighted by a recent report by the Children's Society (2020) which indicated that children with ID are more susceptible to wellbeing and mental health issues as a result of COVID and require urgent support in adapting to routine changes and understanding what is going on.

What we did

We were asked to share a specifically targeted survey with our families and 40 completed the survey. Lucy Fullard (Director) agreed to be filmed whilst interviewed on the impact of covid for her family.

The difference made

Our families were able to share their experiences with Edinburgh University who are directly advising Government. The results of this work will be analysed by Edinburgh University and shared with us.

EDUCATION

What our community told us

Multiple families report long delays in getting support for their children in education, with many children spending a year or more with no school place. Families are struggling to get suitable transport to get their children to their education setting.

What we did

We provided advice through our advocacy service, directed families to specialist advisers IPSEA, helped families draft letters and complaints, advised on legal aid, and provided webinars explaining the benefits of specified and quantified education, health and care plan and the rights to Special Educational Transport.

We gathered evidence through questionnaires, produced reports for Gloucestershire County Council Head of Additional needs and provided an online forum for families to meet directly with the Director of Children's Services, Head of Additional Needs and Head of Service, Disabled Children and Young People's Service.



GCC requested more information, this time on Education, Health and Care plans, and another survey was created, and families' experiences reported back directly to the Head of Service for Additional Needs and Head of Service, Disabled Children and Young People's Service.

Gloucestershire County Council have been working with Peopletoo to look at the current Education Health & Care Plan pathway and representatives of the Alliance have contributed families' views during consultations.

We sent out a survey asking parent carers what they would like to ask Chris Spencer, Director of Children's Services, and hosted an online meeting so that parent carers could talk directly to Chris Spencer as well as Sue Hall, Head of Service, Disabled Children and Young People's Service, and Amanda Henderson, Head of Service, Children with Additional Needs.

The challenges

During the meeting Chris Spencer and the Heads of Service stated that Gloucestershire are only managing to get about 30% of EHCP completed in a timely way, and there are some services and teams where there is 50% absence due to staff isolating or ill with Covid.

Every local authority across the country has had a huge rise in EHCP requests, so finding available, good quality caseworkers and educational psychologists (EPs) to recruit is a significant challenge.

Additional specialist provision is needed across Gloucestershire, current data indicated that, should the trends continue as they were, at least an extra 100 places a year would need to be commissioned. New provision takes time and some of it is dependent on capital bids from the Department for Education.

The difference we are making

Feedback for general education advice provided by the Alliance includes

"The information and advice I received was great, moving school was the best thing I did, my child has flourished in the new setting and has learnt more in 12 months while fighting cancer than in just over 3 years attendance at the previous school", and

"I was given advice and information which put me in touch with a solicitor and meant I could get real help and support. I am now in a position to get help for my child and make sure they get the education they are entitled to."

The EHCP webinar had 44 attendees, a [recording](#) can be accessed from our website and has had 31 views to date.

Feedback from the webinar includes

"This is hugely empowering and makes us feel like we can get the right support going forward even if it is going to be a battle",

"I am preparing for tribunal, so this has given me the confidence to insist on the changes required and back it up with the law" and

"I am learning to understand some areas of law & find out what exactly should & could be made available for my child's unmet social care & therapy needs."

The SEN transport webinar had 12 attendees.



How our community has changed the way we work

Not all families have felt able to fill out referral forms, especially those where the parents also have additional needs, and these more complex cases often need legal advice. Working with specialist education lawyer Rukhsana Koser, partner at Langley Wellington LLP Solicitors, we have arranged free advice sessions for 36 families to date.

The difference we are making

Families have been given step by step instructions as to how to apply the law in their specific cases to get the right education for their children. This has included the need for specialist reports and how to access legal aid.

Feedback for specialist education advice includes

“It gave me the clear understanding of how to progress if my daughter was left without a school place for much longer. Thankfully later that week the Local Authority managed to get her into one of the four schools we requested,” and

“We had a free half an hour phone call with a lawyer, which felt like a longer conversation actually, and was extremely helpful in putting the situation in to perspective in practical terms. We now have a clearer vision of what we need to aim for, what phrases we can use when requesting support from Local Council and how to counteract negative or derogatory input from them. We feel less alone in that it is obvious many families are struggling with similar issues and have a direction that we can move in once/if we find the financial resources to take the course of action we need to. The latter is very frustrating which is nothing to do with the service provided but indicative of a system that is broken in terms of education and social care.”

HEALTH – FABRICATED AND INDUCED ILLNESS

This project was started prior to the National Lottery funding, suffered significant delays, largely due to the impact of covid and the availability of social care managers, and has been progressed this year thanks to the Lottery funding

What our community told us

Parent carers shared 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.

83% of families felt strongly that the allegations of FII (or child abuse) came about as a direct result of a request for additional support or as a response to making a complaint. In all those cases where a complaint had been made prior to the allegation of FII, the complaints were about a lack of support or the inappropriateness of services that were already being offered.

In 75% of cases diagnoses were made during or after the FII allegations that demonstrated that they were correct to ask for services or to challenge the approach taken by professionals. In one case a diagnosis is available but is not being recognised by service providers in Gloucestershire, the child is therefore not receiving the services required.

In all but one case the allegations were not substantiated, and child protection procedures were not instigated or were ended very quickly. In the remaining case it is unclear that child protection procedures would have been used without the issue of domestic abuse. The plans were ended after three months, and this case closed after 12 months.

Families have described how frustrated, emotionally drained and devastated they feel when they are not believed and being left having to fight for what they know is the levels of service to which they are entitled. They feel exasperated at the failure of agencies to work together and their failure to make child centred decisions. Accusations that the needs of their child have been fabricated, when they know them to be genuine, has destroyed their family life and trust in the agencies. The parents feel that the deep anguish that has been caused to them through the



systematic abuse of failing services has stolen years from them, years with their children that should have been far easier and enjoyable.

What we did

The Alliance created a report of these experiences with the aim of raising the profile of the issue and as a basis for holding a conversation with Gloucestershire County Council and health agencies.

The report came out at a time when there was national interest in the way the authorities, throughout the UK, appeared to be using FII to bully parents into accepting fewer services than their children need or as a form of punishment to those parents who dare to challenge.

The report was picked up by the BBC and used in features about FII on Radio Gloucestershire (twice), twice on Radio Five Live and twice on regional television over the summer.

The Alliance met with Chris Spencer, the Director of Children's Services. His response to the report was very positive, he seemed to recognise and understand the impact of allegations of abuse and poor care on parents who are doing no more than trying to get the best for their children. He invited us to work with a senior manager from Children's Services and a senior manager from the Clinical Commissioning Group in order to support a rewriting of Gloucestershire's FII child protection procedures that determine the way agencies respond to FII allegations.

The Challenges

There was a significant delay in progressing the development of new Gloucestershire procedures due to the anticipated production of perplexing presentation guidance from the Royal College of Paediatrics and Child Health.

Once the RCPCH guidelines were published in March 2021 the Alliance hosted a child protection conference in which the advice given by Professor Andy Bilson, Emeritus Professor of Social Work, University of Central Lancashire, is that there are significant problems with the guidelines including that there is no evidence base, there are problems with diagnosis, many of the alerting signs will be found where children have undiagnosed illness or unusual presentation, and that lack of a gold standard diagnostic test means a high likelihood of false positive diagnoses.

The difference we are making

Despite our concerns about the new guidelines the Alliance has been working with the CCG and Social Care to rewrite Gloucestershire's child protection procedures to incorporate the new paediatric guideline. We have ensured that de-escalation, independent evaluation, access to advocates and openness with parents have been included in the draft procedures. Children with disabilities and their parent carers should now be treated with more understanding and their individual circumstances and communication needs considered.

The next stage will be to extend the consultation to the wider network of partners and stakeholders prior to submission to the Children's Safeguarding Partnership for their approval.

GCC have agreed that we will work jointly on providing senior social workers with health training and that we will work together on a six-monthly review after these procedures are implemented.

There's already interest from other councils that may potentially adopt the procedures in their Authorities.

HEALTH – THERAPY PROVISION

What our community told us

Families were sharing with us the significant impact of the pandemic on the therapy provision for their children.



The Alliance gathered evidence by asking families to answer questions about their child's additional needs; about therapy provision before and during the pandemic, the current situation; and about the impact on the child and on the family.

Families described the impact on them,

"I lost my job of 10 years. My job had funded my child's private therapies, that I felt I had no choice but to pay for, because the support was needed so badly. After losing my job, I had to use my life savings to go through tribunal and pay for private therapies. The tribunal judge agreed that my child had been fundamentally let down by local services using a 'one size fits all' approach. She stated that providing leaflets only as support from the OT service, and a similar approach from Speech and Language Therapy would never have been enough to help a child with needs as severe as my child's", "Ignoring families is heart-breaking and irresponsible and has led to my being injured giving essential care to my child, I now need surgery" and "Huge distress, frustration, stress, exhaustion, feeling of loneliness, feeling unsupported like nobody is there to help".

The impact on their children is described as

"Child struggled tremendously in mainstream school due to the lack of support and was excluded from school whilst we went through tribunal for therapies and change of setting. Child is still struggling with anxiety and low self-esteem caused by the abandonment of services. The placement may not have broken down had the services needed been provided", "Extreme anxiety, had been getting somewhere now got to wait again despite worsening of self-harm and suicidal thoughts" and "Child struggles to communicate and is falling more and more behind their peers and is becoming increasingly frustrated that we are unable to understand them fully."

What we did

We used this evidence to create a report and had an initial meeting with health representatives. There was agreement to hold a future meeting to focus specifically on the issues raised by families

What our community told us

During the interval between the first and second meetings with health, families began discussing that the challenges with achieving meaningful support from health were significantly exacerbated by the cumulative effect of waiting times: services require a referral from a Paediatrician – there's a waiting list for the appointment with the Paediatrician, then a wait whilst the referral is made, then you join the list for an appointment with the therapist, etc.

What we did

We gathered information in 2 ways – with a Facebook poll and with a different questionnaire focusing on waiting times.

What our community told us

98% (118) responders to the poll replied 'No' when asked "Do you feel that the health services and therapies in Gloucestershire meet the needs of your disabled children?"

In both comments on the poll and in responding to the questionnaire families reported long waiting times which have such an impact on their child's development, physical and emotional wellbeing that they are having to fund private treatment.



Care Action Protect Empower

Families reported children at risk due to lack of mental health support –

“My son has been waiting a year to see CAMHS he is marked as emergency on their list and has been for a year, still not been seen, meant to be called every 8 weeks to see how he is, no calls, I have rang sent emails to chase and our GP has also sent emails to stress how much he has deteriorated as well and No reply!” and “My child has been risk assessed as having a likely risk of accidental death due to self-harm, with the consequence being major,” and yet the family are not being contacted by CAMHS despite a recent visit to A&E after a suicide attempt.

Access to therapies in general has been described as

“Getting access to some therapies is nigh on impossible. Self-referrals aren't always accepted, getting hold of professionals who will refer you can also be tricky. Once in the system the wait for therapy is LONG! Once therapy arrives it can be great, but it can be a long wait between appointments, 'episodes of care' can leave you exasperated and if your child doesn't have a good and regular access to a TA who can attend the sessions to carry out therapy properly in between the 'SALT/Physio/OT/ETC' actually visiting then it's useless. Some try to sign you off after each episode of care and unless you have school staff on the ball to re-refer after every episode you can get cut off and end up with nothing again... and have to start over with referrals again.”

What we did

We shared the results of the poll and the questionnaire with senior representatives of Gloucestershire County Council and Gloucestershire Clinical Commissioning Group and attended a meeting with them and one of the Designated Clinical Officers who works within Gloucestershire Health and Care Trust (the provider of children's therapies).

The difference we made

A commitment was made to hold future meetings to

- Review the pathways into therapy services,
- Co-create future pathways which reduce waiting times and interdisciplinary referrals and
- Establish quality feedback loops which provide meaningful information to be used to identify problems and improve services.

Our Community Partner's views

Bren McInerney says

“I continue to find Gloucestershire Parent and Carers Alliance to be outstanding and a phenomenal independent voice for the county. As a community volunteer, with local and national responsibilities, looking at how we hear the authentic voice of people and communities that support and challenge public services, I remain very proud of the organisation and its amazing leadership.

I draw on examples of what I see on, for example Facebook, on reaching out and connecting with parent and carers in Gloucestershire, many who are in very stressful situations and need genuine support and action. I also draw on my involvement in joint meetings with the Director of Children Services at Gloucestershire County Council whereby he stated how positive it is to work with the Gloucestershire Parent and Carers Alliance on Fabricated Induced Illness on a much better policy document for the council. Very recently, with the Gloucestershire Clinical Commissioning Group on access to and experiences on therapies for children and how they are failing the parents and families.



To conclude, I am sincerely proud of the Gloucestershire Parent and Carers Alliance for consistently holding on to their values and purpose to be, and remain, an independent voice for the parent and carers in Gloucestershire and provide the actions needed to be a trusted and authentic organisation. I am very happy to be contacted and clarify/expand on any of this information cited.

Bren's roles include - Chair of the People and Community Advocates Forum for the national Community Nursing Plan board for NHS England/NHS Improvement, and National lead for the pilot on National Leads Better Connecting with local Community and Neighbourhood group

ADVICE AND INFORMATION

In addition to the webinars detailed in the report above we have provided webinars on

Power of Attorney and Deputyship	25 attendees, 5 have viewed the recording
Dyslexia	10 attendees, and
Human Rights	22 attendees.

In total 16 presentations which have reached 543

Another aim is that of

- [Providing a reliable resource base to enable increased understanding of legislation and rights to support for families whose children have additional needs, as well as practical advice on how to achieve this](#)

Getting feedback from families has been challenging, however of those who did respond

76 said they had increased understanding of the law, 66 of their rights to support, and 61 felt better able to achieve this.

CONNECTING FAMILIES

How we are making the most of the strengths of our community

Facebook statistics show that during January the group had 990 active members (members who viewed, commented on, posted, or reacted to posts) and the page reached a further 408, a total of 1398.

Whilst the 2 Directors of the Alliance monitor the posts within the group and have recruited more members as moderators as the group has grown, the community is so supportive that often other members provide the right advice and support without our intervention.

A parent describes what it means to be able to support others

“Being part of the Alliance has helped me feel more confident. In turn I've also been able to advise others on areas I am familiar with, and that has helped, too. A lot of our knowledge is hard won through failing our children through ignorance and arriving at knowledge too late. Trying to support others earlier in the path can soothe that to some extent.”

Three parent carers agreed to be recorded discussing what impact the Alliance has had for them, these have been viewed 68 times.

The first explains how so many Parent Carers are "in the darkness, like me, needing somebody to turn on the light", and how the Alliance helps to illuminate the way, <https://www.youtube.com/watch?v=gba1gZdnErk>



The other 2 Parent Carer videos describe life before support from the Alliance, how they have gained friendship, support and confidence and 'back-up' by joining the Alliance, and how the Alliance Advocate support has been successful:

at EHCP Tribunal <https://www.youtube.com/watch?v=qLezg15hKdE>

in arranging emergency care for surgery for cancer <https://youtu.be/u-uiw3JU3yg>

ADVOCACY

In addition to all that families have told us that is listed in the report above, families are now coming to the Alliance with multiple issues – having more than one child with additional needs, having additional needs themselves, needing medical treatment for one or both parents.

The pandemic has had a huge adverse impact on parent carers who are becoming exhausted, catching covid and suffering from long Covid and are being refused support to care for themselves and their children.

As a consequence, the Advocacy service has been expanded so that there are advisers with specialist knowledge of special educational needs; children, and adults, social care; and of supporting young people. A new referral process was developed to receive requests for support for families from other professionals who are working with them. 3 families have been supported to make successful applications for legal aid.

The Alliance has been contacted by 26 families living outside of Gloucestershire asking for an advocate. Only the 12 families who have been able to self-fund have been supported.

Of the 125 families who completed feedback requests, 40 feel less alone, 23 feel more recognised and 50 feel better supported, 55 feel better prepared, 78 better informed and 22 feel encouraged to champion getting the needs of their vulnerable children met.

The Advocacy service, its range of advisers and access to initial legal advice is very much appreciated by Alliance members and their families.

What the family told us

“At one point we felt completely hopeless and depressed, my children were suffering because of unreasonable intervention from social services and school even though one had a brain injury and the other extreme social anxiety after being bullied. Medical intervention for the brain injury was also withheld.”

The difference we made

“My child in the very worst-case scenario might have died if lockdown did not happen, as forcing her to return to school was making her brain injury worse. The advocate argued on her behalf for medical intervention and a second opinion which we were threatened against seeking. Social Services threatened to remove our children if we sought it. He was the voice of reason when social services were being bullying to us and our family and provided a balanced honest view that could not be manipulated by other professionals that were fabricating information against us, as we had made formal complaints against them. We felt supported and it decreased all our stress levels. We can't ever thank the Alliance enough.”

What the family told us

“Last year, I was severely ill with Covid. Social Services became involved & the focus has been on my illness & style of parenting. There has been very little discussion around my child's needs as an autistic child & how this affects our family. My ex-husband has not engaged in courses or learning about autism & is wanting to take the house, the family benefits & family assets for himself. I am deeply concerned about the future wellbeing of our children.”



Care Action Protect Empower

The difference we made

“Sarah understood my situation and she helped to advocate for my position with Children's Services. She was extremely skilled and professional, articulating my situation in a way that I could not. Her input has meant that I am being listened to and that my voice is heard. This led to a fairer outcome, my children receive better care and the intimidation I was on the receiving end of has reduced dramatically. My contributions are being recognised and shared parenting of our children is being acknowledged, which will help me to continue to advocate for our children, one of whom is autistic and one of who is a young carer. Sarah's work has meant that I am coming through an incredibly difficult set of circumstances and the outcome will benefit my family for the rest of our lives.”

What the family told us

“I'm single parent carer to a son who has complex needs, home 24/7 as education placement not working out and had already been out of education nearly 3 years. I have long covid and been quite ill for several months. Current relapse is severe, and I am awaiting cardiology appointment and long covid clinic. Told to pace and rest to recover but unable to. My child struggles with sleep too so I'm not even getting sufficient sleep.

I have felt completely overwhelmed at times and traumatised by negotiating social care, health, and education systems for my disabled child.”

The difference we made

“Having the Parent and Carer Alliance support me has helped me feel less alone and stronger. It's lightened my load through highly stressful times. Having Duncan in meetings has meant he can support if I get fatigued and keep notes for me too. Duncan, Lucy, and Louise have all helped me through some very difficult times and although still challenging, I feel better able to navigate these systems now and my family are recovering.”

What the family told us

“I requested emergency support due to the escalating behaviour of my eldest. School has since submitted a request for an emergency assessment through social care and an initial assessment was carried out, but weeks have gone by, and I have heard nothing. My eldest's behaviour has deteriorated to the level where I have no respite and I am concerned about the impact on my youngest.”

The difference we made

“Multiple child in need meetings were held where I was given support by an Advocate who also took minutes. As I am so involved in the meetings it has been invaluable to have someone take comprehensive minutes which helped document the statements from everyone involved, especially the local authority. This provided evidence that resulted in my eldest being admitted to his specialist school as a residential student - something we desperately needed.”

What the family told us

“My husband and I were foster carers. We had a false allegation made against us and the police were involved. As a direct result of this my husband took his own life due to the stress. I felt very alone and had little to no help in fighting my case.”

The difference we made

“I have had some amazing advice and help. I have been given sound advice and information written/emails sent. They have been advocating and liaising on my behalf. I just would not know what to do without their help. I simply can't put into words how important their support has been and how much it means to the family.”



What the family told us

“Mine and my sons medical, education and social care records were wrong. Delays in treating repeated infections meant that my child was having a lot of absences from school.”

The difference we made

“Their help empowered me to continue to change medical records, get health support for my children and better educational support. As a direct result of the alliance involvement, our GP surgery has changed policy and will swab children earlier for infections, hopefully meaning faster, more-effective treatment.”

What the family told us

“My son was excluded from school, then offered places in Wales and Hereford – too far for him to travel. As a result, he has been hospitalised with severe anxiety as well as diagnosed with Autism and ADHD. He has been refused any support from the disabled children’s team. My daughter has an eating disorder, my husband is disabled, and I need urgent surgery but am unable to get any care provided for my family without my children being taken into care.”

The difference we made

“As a result of many months support from Alliance Advocates and legal specialists, both my children now have legal help with EHCP, and social services challenged. I am feeling stronger and supported. I knew the local authority wasn’t doing things correctly, but it took solicitors to start the Tribunal court case to get them to do what they should have done in the first place.”

What the family told us

“My child struggles to leave the house since covid and only leaving to go to school. He has always struggled with school friendships with crowds. He really needs a set routine and plan of what is happening each day. At present the school’s approach is very ad hoc as to when they can provide assistance, and I get told he needs to build his resilience. I am worried if something more formal and structured isn’t in place he will go further downhill.”

The difference we made

“Advisor was fantastic - she gave advice, attended meeting with us, without her we wouldn’t have got the support we needed. Completely changed the route the school was taking with our son from a ‘tough love’ approach to being more supportive. This also then made Child and Adolescent Mental Health Service change their approach too. This is all thanks to the support we had. Also had excellent training to help us fill in an EHCP.”

Other feedback comments

Fewer families have responded to requests for feedback than we expected. We provided a shorter feedback form which can cover any type of support or advice received from the Alliance and collected this information as well as emails and Facebook posts which show what the Alliance means to our community:

“Parenting two children with high and complex needs can be lonely and exhausting. The Alliance is key in making it feel less so. I always get good advice from the Facebook group and coffee mornings help me feel less isolated”

“I was given fantastic advice and support. The Alliance shows such care as they appreciate how hard it is to keep battling for even basic legal entitlements. It is great to know you are not alone as life can be very hard. Their help means I’ve felt more secure, valued, and confident”

“As a parent I am less ‘fobbed off’ by outside agencies when I demonstrate that I am aware of the law/rights. This has helped progress appropriate support for my child.”



“It has been the only light in the deepest dark - my family would have fragmented entirely without the Parent Carer Alliance advice.”

BUDGET

Once the planned strengths review has been completed the grant underspend for the year will be around £1100. The underspend is a result of

- Events being held online, so no venue costs, and information being supplied online rather than needing printing has reduced office costs,
- Most webinars being given by speakers who did so for free, despite charging the Alliance previously, as they want to support our work, no face-to-face meetings have been attended by volunteers so there is no expenditure to reimburse and having only a few face-to-face advocacy sessions means reduced travel costs.
- Organisational development expenditure has been spent on developing systems for the Advocacy service, and staff training on courses on Special Educational Needs and Disability Law, and on an Advocating on Behalf of Children and Young People (Level 3) course. This expenditure has not yet been as high as the budget due to several months delay in receiving advice and a quote from GRCC. As Barrie Wyatt of Nvision Consulting has now been commissioned to do a strengths review in early April -his invoice and travel expenses, plus the cost of time that Alliance staff will need to spend with Barrie during the review, will use the remaining money.

Overheads are overspent due to the increased income resulting in a higher insurance cost than that paid previously, which had been used to set the budget.

The budget was intended to cover 8 events. Due to moving online, the increased interest in Alliance webinars, and the generosity of most of our speakers giving their time for free we have managed to double that total. Each event has needed marketing, tailoring to the needs of the audience, and hosting. Those that have been recorded have needed editing and uploading. As a result of holding more events the Marketing and Events budgets have been overspent.

PROPOSAL FOR YEAR 2

We are budgeting for an increase in the

- Advocacy budget to recruit an additional advocate;
- Organisational development budget to cover any training needed for the new advocate;
- Overheads to cover higher insurance costs;
- Marketing and events to cover at the level achieved this year and;
- Monitoring to keep track of the increased workload.

These increases will be funded by reducing the Professional fees and office budgets to be closer to the expenditure of Year 1. The underspend carried forward from Year 1 will enable some flexibility in these budgets.