



## THE STORY OF OUR PROJECT THIS YEAR

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 **8** specialist speakers, which have reached **443** people through attending events or watching the recordings.

The Alliance now has **1391** (+ 253 this year) members on the Facebook Group, **687** (+145) followers of the public Facebook Page plus **438** (+ 120) Associate members. This means that the Alliance is connecting to up to **2516** people.

Over the past year there have been **149** requests for support from our Advocacy service made by families and **2** requests from professionals. This is an 11% increase on the 136 supported in our first year.

Due to the complexity of the issues being raised by families, the Alliance has made a connection with Rukhsana Koser, Partner, Education Lawyers, Langley Wellington who has provided free advice sessions to **120** families.

On an average week 13 families accessed support through the advice telephone lines and direct messaging. Making a total for the year of **895** families.

The needs of our community of parent carers and children and young people provide the drive and the focus for all of the work of the Alliance. Their response to what we provide, both in terms of attendance at events, requests for advice and support, growth of the associate and Facebook memberships, and their feedback, give the direction and scope for our future focus.

One family summarises their experience of the support provided by the Alliance:

*“This can be such a lonely and isolating path, and service providers tend to sound so confident when telling you something isn’t possible, or won’t happen, and to not even try. I love the support and kindness shown to one another by everyone in the Alliance, and the understanding of how hard it is to negotiate the services paid to support us. It means a huge amount, just knowing you aren’t alone. And that’s before you get into the amazing levels of specific knowledge you can access and the advice given from other people’s experiences, too.”*

## CONNECTING FAMILIES

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

Analysis provided by Facebook shows that in the past year there has been 1,763 posts and 15,143 comments on the Alliance Facebook Group which can have up to **1000** active members a day who are viewing, commenting on, posting, or reacting to posts.

This is as a direct result of the group membership - other Parent Carers, being welcoming and supportive, and providing accurate and relevant information to others going through the same experiences as them.

### Feedback comments made about the Alliance social media:

*“This group, to me, is a safe space to moan, rant, cry and get advice. I’ve had years of not being able to post some things on my own Facebook wall due to judgements & comments from ‘friends’. I’ve had comments from educational people saying he isn’t bad enough for this/that, he needs to learn to sit still and recently being pushed so far out of his comfort zone, he snapped. But here, I can say what I need to and get reassurance, support, guidance and help from GPCA and other members of the group, reminding me I’m not alone and what to do next. Having someone to talk things through with and them being there through meetings and EHCP reviews has been a godsend. My child had been failed all through*



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mainstream school and once already at college, I was expecting the worst recently, but it didn't happen thanks to support from the Alliance. I don't think I could have got through without them."

"The Alliance is a fantastic, supportive community. The appeal process is so daunting, and I often feel like an ant trying to fight a lion but have had some great support on here from parents who have gone through the process themselves and are an absolute wealth of information. I have an advocate through the alliance too and she has been amazing and so supportive. I don't feel like I'm going through this terrifying process alone."

"I like the way they break down whatever you're having trouble understanding into its smaller components. Sometimes all the legal stuff with EHCPs for example can be overwhelming but after sharing my questions with the group I always come away with a better understanding. Any question big or small is always answered and I don't feel judged for not knowing what certain things are. They are my virtual SEN library made up of amazing humans."

"The group online is wonderful because it's the only local space that is truly independent and truly not Local Authority or educational affiliated, so the honesty and directness, and ability to believe in people's good faith, is fairly unique."

"The Alliance is completely dedicated to supporting parents of children with additional needs. The principles are committed to thoroughly documented evidence-based plans which aim to initiate change in the provision of local service... Louise and Lucy are calm and focused whilst supporting parents suffering trauma at the hands of local service leads."

"This group is a massive help information wise and mental health wise with practical help but also support and camaraderie. Whatever the SEND issue, someone can always help."

We have also provided opportunities for families to get peer support through:

3 coffee mornings, attended by 27 families, and

through a visit to Skillzone, Gloucestershire's only interactive life skills village where people of all ages can learn how to keep themselves safe whether at home or in their community, attended by 8 families.

## HOW THE ALLIANCE RESPONDS TO OUR COMMUNITY

### ADVOCACY

The cases that families bring to the Advice service continue to be highly complex, often with more than one family member at high risk of harm, and often involving more than one agency. This means that cases are often requiring more hours each due to the need to review large quantities of documentation, evaluate and summarise this information, attend meetings and make recommendations.



As a result there have been three periods where the Advocacy service has been unable to support families as quickly as we had been and a waiting list has been in operation for a total of two months over the year so that cases can be triaged and the most urgent prioritised.

The Alliance has responded to this increase by increasing the funding for the Advocacy service with an additional two year grant from the Barnwood Trust and by further expanding the service with the recruitment of two additional advocates.

Additionally, in recognition of the skills that parent carers develop through successfully navigating complex systems, we have established the position of Family Support worker and recruited two parent carers.

Further organisational development has taken place as Lucy has increased her qualifications to Level 3 Advocacy, training with the National Youth Advocacy Service, and the parent carer family support workers and two of our Advocates are further developing their knowledge by undertaking the CPD accredited SEN Advocacy Training by SEN Action.

Both the social workers who are Alliance Advocates offered free 30-minute advice sessions for families who wanted to discuss their cases before they committed to detailing their situation on our referral form. 9 families used this.

7 families living outside of Gloucestershire have self-funded support from the Alliance Advocacy service.

Of the 90 families who completed advocacy feedback requests and selected which statements they felt most reflected their feelings, 64% feel better supported, 52% feel less alone, 63% feel better informed, 61% feel that they have a better understanding of the law, and 66% feel more able to get improved support for their children and young people.

The Advocacy service, it's range of advisers and access to legal advice is very much appreciated by Alliance members and their families. Families have provided verbal and email feedback and like to post the successes that have been achieved with support from the Alliance on the Facebook group to provide inspiration to other families.

#### What the family told us:

"My young person who has cerebral palsy has recently had correctional surgery which has left her wheelchair bound and she has been sent home where she is now staying in the hallway on a makeshift supported bed as the hospital hasn't been able to deliver anything for her. I am having to act as her carer as much as possible but as I am disabled myself, and have other children including a 14 month-old baby, this is putting a lot of strain on me. My home is no longer disabled adapted due to the unfinished work by the council. There has been no physio or occupational therapy, and no care package put in place for my child."

#### The difference we made

"My Alliance Advocate helped in every way. From phone calls, emails and organising urgent meetings with health professionals. She made a huge difference and got a specialist bed delivered and my child's needs sorted. I couldn't have gotten through everything without them."

#### What the young person told us:

"I have autism and learning difficulties and my support and care hours are nowhere near meeting my needs. I'm frequently alone and distressed and frequently suicidal I desperately need help before something major happens the police have been involved with my life numerous times and I'm worried I'm gonna end up in real trouble one of these days because I'm just not getting the help I need and so I'm getting lonely and frustrated and bored which is leading to me doing a lot of destructive behaviour to both myself and other things."



### The difference we made

"I've now had a care package approved for 24/7 support and will be moving into supported living soon and I just wanted to say thank you to everybody that was involved in helping me fight for better support."

#### What the family told us:

"My child has leukaemia and has been failed in school. Trying to get a suitable special school place is a very long and drawn-out process but with the Alliance there every step of the way I know we can do it eventually. I honestly don't know what I would be doing without the support of the advisors, lawyer, and the other members with experience to help."

#### The difference we made

"After 18 months of asking and tribunal pending... this week we finally got notice from the Local Authority that a place is ours at our chosen setting and our child starts after half term."

#### What the family told us:

"My young person who has significant medical needs, has been through transition as covid - 19 hit the country and has not been transitioned to adult services correctly. As a result, she is being expected to attend multiple meetings with health professionals to capture her views and provide evidence for a Continuing Health Care (CHC) assessment. These meetings are causing her deep anxiety."

#### The difference we made

"The CHC funding was approved, and she was awarded a significantly increased care package. The Integrated Care Board (ICB) was so clear that our advocates' input was essential to the process, that they approved her advocacy fees for all future CHC assessments."

#### The young person stated:

"My Advocate helped me get listened too but also supported me to access what I am entitled to - which wasn't being listened to previously. She has acted as my voice and the professionals have started to listen to me through my Advocate prompting responses from them. I feel I wouldn't of got anywhere without her support and guidance. I feel happier and less stressed like a big weight has gone off my shoulders."

## HEALTH – FABRICATED AND INDUCED ILLNESS

This project has been further progressed this year.

### Joint Protocol for the management of Perplexing Presentations including Fabricated or Induced Illness

September 2022 saw the completion of a piece of joint work between the Alliance and Gloucestershire County Council children's social care, the drawing up of new procedures for the management of concerns about Fabricated and Induced Illness (FII). In February 2021, the Royal College of Paediatrics and Child Health produced new guidance for health and social care professionals for the handling of cases of suspected FII and the new local procedures are based on this guidance.



The guidance has proven to be controversial amongst parents of children with additional needs. This is because the new guidance introduces a new concept of 'perplexing presentation' – these occur for children where there is no immediate medical diagnosis for symptoms described by parents.

The fear amongst parents is that the new approach will encourage parent blame for the difficulties experienced by their children where there is no obvious explanation.

The Alliance were keen to be involved in this project and were invited to comment on the new procedures being drawn up in Gloucestershire. The consultation took well over 12 months.

Our biggest impact has been to introduce the further guidance for social workers which was produced by the British Association of Social Workers in 2022, and that have now been incorporated into the new Gloucestershire procedures. We hope this addition will reduce the incidents of parental blame by encouraging greater partnership working between health and social care professionals and parents; and the promotion of meaningful dialogue between professionals and parents.

The Alliance is disappointed, however, that the commitments made to include us in the launch and training associated with the new procedures have not materialised.

We will be watching to see how the new procedures impact on parents of children with additional needs and will ask for a review if there is evidence that the incidences of parental blame are not reducing over the forthcoming 12 months.

### **Individual Cases of Parental Blame**

2022 has continued to see the Local Authority applying parental blame in cases where parents have disagreements with health, education, and social care services, this has led to the instigation of child protection procedures.

The Alliance recognises how damaging these cases are to the parents being accused of mistreating their children and much of the work of the advocacy service is to provide support to these parents.

There have been a few notable successes in recent months. Since December 2022 three families were subjected to Initial Child Protection Conferences and the Alliance played a part in ensuring these did not end in their children being subjects of child protection planning.

In all three cases Child Protection investigations were ended and social care focussed instead on providing support through Child in Need planning. Also, in all three cases the Child Protection Conference Chairs commented on how inappropriate it was to use child protection procedures in these cases.

Advocates have also been successful in diverting cases from potential child protection through supporting parents in their approach to working with agencies in a positively, and through encouraging practitioners to work in the same way.

### **What the family told us:**

*"Families like mine are incredibly vulnerable in many ways especially due to the Local Authority's persistent unlawful practices.*

*I was helped and personally supported through a social worker assessment process which was feeding into a SENDIST tribunal process. This process had become very adversarial with the LA and left me feeling very vulnerable."*



### The difference we made

"Eventually, I won the tribunal, and the support enabled me to successfully navigate the system. It helped my mental health knowing I had excellent support when needed. The Alliance helps redress the balance and helps families obtain necessary and lawful provisions. They are a total lifeline for so many families and are desperately needed."

#### What the family told us:

"We have 3 disabled children who are not aware of danger and so put themselves at risk e.g., of falls. At their schools they each have 1:1 support but we have been unable to get any support from social care to help keep them safe when at home."

#### The difference we made

"Alliance advocates attended various meetings remotely and in person to support our family getting help through social services. It made a huge difference having their knowledge and support to back our case up. We went from having children that weren't "disabled enough" to access the specialist disabilities team, to now having support from them. Alliance advocates 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."

#### What the family told us:

"My child is non-verbal and is becoming increasingly frustrated that we can't understand what he's trying to tell us. I feel that no one wants to help us navigate what support and investigations are available to us."

#### The difference we made

"I honestly think the Alliance has saved my mental health! I feel much more aware of what should be happening, and when it isn't, and so much more supported when things aren't going as they should. Just having someone else deal with confrontation, even though I know I'm right and my child is being treated unfairly, is so helpful. It takes the pressure off me and, having someone you know is going support you and actively wants to do so, makes so much difference.

My advocate has attended meetings, questioned policies and actions and written a letter of support for a deferral of school entry that is detailed and knowledgeable. Just having someone there when things aren't being done professionally or to find answers to your questions is such a huge difference. I feel as though we are empowered as a family and much better able to advocate for our child because of the Alliance."

#### What the family told us:

"My child's communication can sometimes be misinterpreted, and he is struggling to be at school without getting a suspension. As a single mum of 4 children all the meetings etc are having a huge impact on everyone within my household.

#### The difference we made

"Thank you so much for all of your help, going into meetings with the Alliance advocate by my side put me at ease knowing I had the support from someone whose knowledge knows no bounds. Thank you for your support in meeting with the school Governors, for pushing for referral to paediatrician, OT



and hearing specialist for diagnosis, helping with applying for EHCP, and getting the Advisory Teaching Service and Educational Psychologist involved. School are now being supportive and I'm incredibly grateful that you were appointed as our advocate, you're absolutely amazing and inspirational."

## EDUCATION

### What our community told us

Suitable and sufficient education which meets the special educational needs of children in Gloucestershire continues to be a huge concern for families, with many children still spending a year or more with no school place or being given a place at an unsuitable setting, even if that setting has stated that it cannot meet need.

Families are finding that they cannot get suitable support for their children without an Education, Health and Care Plan (EHCP), that requests for assessments for an EHCP are being rejected, that assessments are not fully describing the needs of their children, that plans are being written without the inclusion of suitable provision, that suitable provision is not available and, that even when families have succeeded at getting a legal ruling in their favour at Tribunal, that their children's needs are not being met.

Families tell us that they are struggling to understand the processes and legal timescales that they need to follow, and don't know how to access specialist advice. Families are desperate to ensure that their children receive the best possible education, but with limited funds and the increased cost of living, struggle to know how to spend any available money to get the best result. They also don't know what to expect from often expensive, expert reports.

Families often say they don't know the routes to redress and are concerned that raising a complaint will result in loss of, or further delays to, provision.

### What we did

We provided advice through our advocacy service, directed families to specialist advisers IPSEA, helped families draft letters and complaints, and advised on legal aid.

Through our connection with Rukhsana Koser, Partner, Education Lawyers, Langley Wellington we have provided a webinar on Education in Early Years, and Rukhsana has provided free legal advice sessions to 120 families.

So that families could hear from experts who Rukhsana has worked with in getting appropriate support for families through Tribunal, we held a Special Educational Needs conference with talks by 8 specialist speakers. The conference also had information stands for ten organisations who support families whose children have additional needs and was attended by 90 families.

The aims of the conference were to provide specialists who could inform families of the rights to support for their children who have special educational needs, the legal duties to provide that support, ways to try to ensure needs are met and what to do when they aren't, and also to provide an opportunity for experts to answer families' individual questions.

Talks were given by –

Professor Luke Clements Cerebra Professor of Law and Social Justice: Health and Social Care rights in the context of SEN

Melanie Hartgill, Independent Educational Psychologist: The role of Educational Psychologist in Special Education

Nancy Arnaud, Independent Speech and Language Therapist & Patricia Rush, Independent Occupational Therapist: The role of Therapy in Special Education

Shazia Akhtar, Barrister, Gatehouse Chambers and Rukhsana Koser, Partner, Education Lawyers, Langley Wellington: SEN Law and Tribunal. Whilst the slides provided for the talk on SEN Law and Tribunal are very detailed on this area



of law, the speakers felt that it was important to also respond to the specific themes collated by the Alliance, of the issues being raised by multiple families, and so focused on these in their talk.

Wendy Rainbow, Legal Team, IPSEA: Exclusions & Disability Discrimination Law

Jessica Kong, Investigator Local Government and Social Care Ombudsman: Out of school and out of mind – Ensuring children out of school get a good education.

Recordings from the conference, and contact details of the support organisations who attended, are [on our website](#).

37 families provided feedback for the conference.

100% felt that attending the conference meant that they are better informed,

97% felt that they have an increased understanding of their child/young person's rights to support and that they understand better how to get improved support,

95% felt that they have an increased understanding of the law, and

81% feel more able to get their child/young person's needs met.

### The difference we are making

When asked what difference attending the conference will make to them/their family, replies include:

*"In the midst of 2 Tribunals (one for each child), it has given me fire to persevere.*

*More confidence to question and to ask for things that we have a right to.*

*Increased my understanding of what is the law, and what is a myth.*

*I feel empowered to challenge and feel lifted to keep fighting.*

*I am more able to seek remedies for the extended period of non-provision and will use this knowledge to off-set some of the disadvantage that we have suffered.*

*Has provided support and advice that we didn't know despite going through the EHCP process for a year."*

Families also describe how being at the conference has helped them:

*"I now know that there is a large community with similar experiences that I can get help and support from.*

*It was reassuring to see that I am not the only person in this position.*

*Meeting others in a similar position has eased some of my stress. I'm now more confident and calmer.*

*It was great to have the chance to network with other parents in the same situation and to talk to support organisations that I didn't know about.*

*It's given me a great sense of community."*

In order to ensure that the Director of Children's Services, Chris Spencer, could hear about these issues directly from parent carers, we sent out a questionnaire asking parent carers what they would like to ask, and hosted a face-to-face meeting, 22 parent carers responded.





## The challenges

During the meeting Chris Spencer stated that Gloucestershire's recent OFSTED inspection had a positive narrative about the direction of travel, but Children's services still require improvement and are still unable to provide a sustainable good service. He said that Covid disrupted services and reduced the resilience of families, who are still suffering the consequences along with the impact of the cost of living.

There are 136 children who have an Education, Health, and Care plan (EHCP) but who are out of education due to a lack of special school places as all the current special schools have expanded to capacity.

Not all children who don't have a school place are getting their legally required education. Legal timescales aren't being met in ~35% of cases – Children's services are not being run as a legally compliant service.

In addition some alternative providers are not being paid and schools are telling parents that there are 'cuts' coming in March, due to changes in the top-up funding formula, which will mean that they can't meet the SEND needs of their pupils.

Families are frustrated by difficulties in getting a response from the EHC casework teams and in the administration of the EHC plans – amendments are not being included in plans and plans are being received with specific needs being crossed out. There is an expectation that the number of EHC plans will double, but despite additional funding for caseworkers, staffing hasn't doubled due to being unable to fill places.

The aim of improving Children's services is to overcome historical and cultural issues to create a more professional and informed service which is better paid and less admin based.

## The difference we are making

Chris Spencer has agreed that personal cases can be [emailed to him](#), however he is retiring at the end of March.

The Alliance have a date booked in April to meet with his replacement, Ann James

As the challenges are so great, and do not have quick solutions, we are proud that families are benefitting from the free sessions with the education lawyer, and from the SEN conference – both in attending in person and watching the recordings online.

Chris Spencer has provided feedback on the Alliance:

"As the time approaches for my departure from GCC and the role of 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.

The work we have done related to FII is an exemplar of the relationship at its best where we have taken what is probably the thorniest issue one could chose, unpick it, and come very close to a consensus on how the perplexing presentations pathway should be managed locally and at the same time remain informed by national guidelines.



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 but in the hope that we have made a positive difference to some families.

I wish you and your organisation well for the future and I would encourage the PCA to maintain the role of critical friend to the LA.”

### What we did

In addition to the specialists who spoke at the conference, we have provided 2 webinars given by Rukhsana Koser, specialist Education Lawyer –

one in which she discussed and gave advice on the law relating to being out of education, Education Otherwise Than At School (EOTAS) and what steps to take if your child does not/may not have, a school place for the next academic year, and

the second on the law relating to Early Years education - how to apply for a EHCP whilst in Nursery or primary school, how to ensure the EHCP is followed, and transition to primary, and within, primary school.

These webinars were attended by 59 families.

We also provided a webinar on the inclusion of Physiotherapy in an EHCP.

This covered the role of Physiotherapists, advice to be included by Physiotherapists in an EHCP, how this should be documented, Mediation and Tribunal. 16 parent carers attended and 6 provided feedback.

100% felt that they have an increased understanding of how to help the person that they care for, and 83% felt that they are better informed, and that they have an increased understanding of their child/young person's rights to support.

Feedback from the webinar includes:

“The knowledge was absolutely brilliant – things I wouldn't have even looked at especially the section F and G, so I'm better informed on that now. Also, I didn't think of independent physiotherapy which I have now booked. Just so happy I was able to attend I feel such a relief that my daughter will get the help she requires. With the right people to help add into the EHCP.

I have a clearer understanding of what the Local Authority is not providing and therefore how they are failing my child. I feel much better equipped to ensure my daughters ECHP is specific and meets her needs going forward. I will be fighting for change at her next review meeting. This will ultimately mean her physical comfort and wellbeing will be greatly improved!”

### ADVICE AND INFORMATION

Another aim of our funding 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.

### What our community told us

Families describe wanting redress for safeguarding referrals being made despite having proof that it is not true, for their children who are out of school for months and years with no suitable education and for situations where families have a high turnover of social workers, whose work may not be professional and when they complain they are told that the person has left so there is no case to answer.



## What we did

We provided a webinar explaining Children services' complaints procedures – both Corporate and Social Care, how to make an effective complaint, what to expect from the local authority once a complaint has been made, and what can be done if you don't get a good response. [19](#) booked.

We made a connection with Cerebra, the national charity helping children with brain conditions and their families discover a better life together, to hold a workshop to support families who are encountering difficulties in relation to the provision of health, social care and education support services.

The aim was to provide general strategies that parents can use to get the services that they need for their child and family, such as

Identifying commonly occurring problems facing families accessing services and recognising different types of dispute,

Coming up with problem-solving approaches to these problems, and

How to use a number of template letters when corresponding with public bodies. [21](#) booked.

### The difference we are making

Feedback includes:

*"I have been able to see a way forward and to make contact with the local authority with confidence."*

### What our community told us

Families describe struggling to understand the different assessment routes to support for their children and being 'caught in the middle' when there are disagreements between services about which is responsible for assessing and meeting needs.

### What we did

To address the confusion of conflict between Social Care and Health over funding responsibilities, we provided a webinar on Continuing Health Care. Professor Luke Clements considered:

the responsibilities of the National Health Service for care to meet health and associated care needs,

how a child with a disability should qualify for CHC,

50/50 funding between social care and health, and

how to challenge if necessary. [45](#) attended and have viewed [the recording](#).

### The difference we are making

Feedback includes:

*"The explanation, history and how it should work was extremely useful. We did not know about chc, and our child clearly meets the criteria. I'm about to build a template to collect day to day information as they would in a care home and this knowledge should make the process easier."*



## What our community told us

Families raise issues on the Facebook group about the difficulties of managing a direct payment and the challenges of recruiting and retaining Personal Assistants, and in response many families are replying that they didn't know they had a right to an assessment for support through a direct payment, nor how they would manage such a budget.

The Alliance made a connection with David Ashley, the National Training and Development Manager for Mark Bates Ltd and their sister company, the Independent Living Group. He provided a webinar in which he discussed how to ensure direct payments adequately cover all costs in being an employer and what to do if they do not.

The webinar also covered how to challenge the Local Authority (LA) if a direct payment package is not adequate and how to deal with over bureaucratic LA's frequently auditing, raising inappropriate use of funds, and removing of funds and discussed the original purpose and ethos of direct payments, how this has been eroded- and the impact of this. 45 booked and 18 families have viewed [the recording](#).

### The difference we are making

Feedback includes:

*"It was highly informative, and gave much information on my rights and how to challenge refusals for Direct Payments which will enable my son to enjoy many activities and get help*

*This has been really beneficial to me as I have heard of Direct Payments but had no insight or understanding so I have been paying for private support. I can now argue and fight for my children based on legal information presented through webinar that no one had told me about.*

*Very clear guidance on legal duties as an employer, differences when using self-employed providers, and the right to support from the Local Authority, that will save us from legal fines."*

## What our community told us

Families whose children have disabilities often struggle with finances, especially if one or more of the parent carers is unable to work due to their caring role. The impact of the rise in the cost of living, particularly energy costs, disproportionately affects families whose disabled children are dependent maintaining the temperature in their home and on vital medical equipment.

### What we did

Due to our connection with Citizens Advice, Helen Lyons, an Advice Session/Welfare Benefits Supervisor/Caseworker working for Citizens Advice Stroud and Cotswold Districts Ltd, provided a webinar answering families' questions on Disability Living Allowance (DLA), Personal Independence Payment (PIP), Universal Credit and post-16 benefits, and giving advice on getting support to fill in the forms and what to do if you get rejected.

Citizens Advice also provided an Energy Advice checklist to help families to save money and take advantage of other energy offers that may help your household. Both of these can be accessed from our [finances page](#).

### The difference we are making

Feedback includes:

*"I've gained more awareness and knowledge and feel more confidence in my ability to succeed in getting the right benefits for my young person."*



## SOCIAL CARE DISABILITY NEEDS ASSESSMENT

### What our community told us

Many families continue to describe significant difficulties both in getting a social care assessment of their child's needs and the effect of these needs on the family, inappropriate use of child protection procedures and of not getting any support as a result of the assessment.

### What we did

In addition to the work listed above – providing Advocates for support, providing the complaints webinar and the specialist talk from the Local Government and Social Care Ombudsman,

a webinar on Child Protection was held where:

Professor Luke Clements talked about the personal and wider social-economic consequences of institutional policies that have the effect of blaming parents for the challenges they experience when caring for a disabled child, and

Professor Andy Bilson presented data about the increasing numbers of children assessed as having a disability or mental illness and what the data can tell us about the outcomes of these assessments nationally and in Gloucestershire.

The webinar had 58 attendees, including a representative from Barnwood Trust.

### The difference we are making

Feedback includes:

*“Thank you all for the session today, really interesting and startling at the same time. Really looking forward to seeing how this data can be used to start influencing and changing the system.”*

## WORKING WITH OUR COMMUNITY

Another of the Alliance aims 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*

The Alliance has continued to work as part of the working group alongside the Gloucestershire parent carer forum, and Sue Hall, Head of Service, Disabled Children and Young People's Service (DCYPS), at Gloucestershire County Council (GCC).

We have provided parent carer experiences, reviewed processes and pathways and made recommendations for improvements to the Children's Single Point of Access so that parents requesting advice and guidance should not be put through a safeguarding process, to the eligibility criteria for support from DCYPS so that it encompasses more children and families with complex needs as well as ways to simplify the process so that families can reach the right support more quickly.

The Alliance has also worked with representatives from GCC Social work academy on developing a range of learning opportunities and resources that will make a difference to social work practice and improve the service that families receive.

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

Parent Carers have provided their experiences, and one of them agreed to be interviewed to provide recommendations for ways in which social workers can have a greater understanding of the needs of families whose children have additional needs and, in particular, how to make disability needs assessments more effective.



### **The difference we are making**

Feedback includes:

“Thank you for sharing the feedback from parent carers – it offers lots of potential for different learning and development opportunities and resources. It was another great meeting that enabled us to move our ideas forwards into some action.

Many thanks for your continued time and input into the development work and improving the journey for disabled children and young people. We have taken your comments on the eligibility criteria and updated the draft.

They (the parent carer videos) are really powerful. There are so many important messages within them. I am of the view that we are on the cusp of creating a very innovative approach and that we have the opportunity to create something with meaning and impact.

We're also tremendously grateful to you and to the parents that have contributed to the development of these learning materials, along with your willingness to collaborate with our staff in their ongoing learning. This is an important area of focus for us which we remain committed to. “

### **WORKING WITH THE WIDER COMMUNITY – BARNWOOD TRUST**

The Alliance have contributed to the Barnwood Trust's research project exploring the experiences of short breaks and respite care services in Gloucestershire for disabled people and their families.

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

Parent Carers' experiences were shared with the Barnwood Trust, and a focus group was held where young adults were supported to share their views.

### **The difference we are making**

Feedback from Dan Jacques, Lead Researcher, Barnwood Trust:

“During 2022, Barnwood Trust collaborated with Gloucestershire Parent and Carer Alliance to undertake a piece of research into local short breaks and respite care provision. The support of the Parent Carer Alliance and their professional expertise has been key in ensuring a relevant focus for the research and enabling a variety of accessible ways to participate.

Their expertise and the support of their networks ensured our research was accessible to a range of groups, including disabled children and young people. To enable this, they organised and marketed a focus group with young adults and worked with us so that this focus group could also be facilitated by one of these young people.

Moreover, with the Alliance's support and experience, our survey was able to reach more families and ensured we asked the questions that addressed issues of relevance to both parent carers and young people.

Our relationship with the Alliance has not only supported the delivery of this project but has also enabled us to co-produce accessible ways to participate in research.”



## WORKING AT A NATIONAL LEVEL

The Alliance continues to work closely with Luke Clements, Cerebra Professor of Law and Social Justice at University of Leeds, to both draw attention to the negative impact that the processes and procedures that are used when assessing the needs of disabled children and their families have on their lives, and to make recommendations for improvements.

We have attended a conference on addressing the commonly occurring social care difficulties experienced by disabled children and their families, where we presented [families' experiences of Parental blame](#) and the negative impact that this has on the whole family. A [recording of the presentation](#) is available on the University of Leeds website.

We have asked families for their recommendations for improving the disability needs assessment process both through questionnaires and through providing a template for a new approach and sharing this with families online with a video explanation. 117 families have engaged with this to date.

The template has been updated in response to comments from families and is now a key component of materials and recommendations being developed of a working group of independent parent carer led organisations, including the Alliance, being run by Professor Luke Clements to progress this further to make change at a national level.

### The difference we are making

In recognition of the work that the Alliance does, we were given an award for 'Making a Positive Difference to Society' by the University of Leeds.

## HEALTH – THERAPY PROVISION

### What our community told us

As reported in our Year 1 report, families were sharing with us the significant impact of the pandemic on the therapy provision for their children.

### What we did

Following initial meetings with health representatives, a joint working group was formed with the Alliance which includes representatives from the Parent and Carer Forum.

As Health have data from NHS England and NHS Improvement (NHSEI) from January 2022 which estimates that some of the most significant waits within community services are within speech and language therapy services (SALT), it was agreed to make this the initial focus of the working group.

Several meetings have been attended to agree the aims of the working group which are to fully scope all issues affecting CYP speech and language support and, as a result, develop ambitious, robust, and meaningful co-produced plans for how improvements can be made and continually assessed and evaluated across Gloucestershire.

Families were invited to a face-to-face event to share their experiences but were unable to attend. 9 families responded to the invitation created by the Alliance, and many stated that online would be more convenient.

### The difference we made

The Alliance provided 2 online opportunities for families to describe their experiences.

16 families responded, with 4 asking to give feedback by another method, and with 8 families being able to attend the sessions.



At Health's request the online sessions had independent facilitators who have asked for the support of both the Alliance and the PCF, in ensuring that their reports of the themes arising from the discussions with families are accurately recorded. The next working group meeting to present this report takes place in March.

### Our Community Partner's views

"I have been very privileged to know and work with/alongside the Gloucestershire Parent and Carer Alliance (Alliance) for over 4 years. In this time, I have been invited, and attended, numerous meetings with local parents and carers and have experienced how positive these meetings are. In these meetings the environment created by Alliance has been warm, open, safe, and inclusive.

I have also seen how the views and experiences of what is said has been turned into positive action, such as working with the Gloucestershire County on revising their policies, an example being Fabricated or Induced Illness.

I have been particularly impressed with how the Alliance has maintained and valued their independence, in words and actions, and kept true to their promise to the parents and families they serve. I have personally seen this in their relentless challenge on local health therapies that are not serving the children and families, or, in social care provision that has been identified but is not being delivered.

I have been at two amazing conferences planned and delivered by the Alliance where it is clear education and awareness of legal rights for parents are not always understood, but now they have this knowledge and understanding.

In my national role I am honoured to invite and have the presence of the Alliance, be it with meetings with the Care Quality Commission, or recently on the 16<sup>th</sup> of February 2023 at the House of Lords, when I organised national and community group leads to come together to share what matters to the people the charity serves.

At all stages of my work with the Alliance I have found Lucy and the small team to be hugely integral and value based. During my extensive time with the Alliance I have seen and heard from parents on how much they need an independent and focused organisation that they can trust to truly meet their needs. This the Alliance consistently do in such a sincere and authentic manner."

Bren McInerney: Chair of the People and Community Advocates Forum, National Community Nursing Programme for England; Member of the Care Quality Commission's national External Strategic Advisory Group.

### AUDIO AND VIDEO TESTIMONIES

Members of our community kindly agreed to be videoed talking about the benefits of having support from the Alliance

In getting care support for her child when she needed emergency surgery for cancer

<https://youtu.be/u-uiw3JU3yg>

What support from the Alliance means

<https://youtu.be/gba1gZdnErk>