



## PROGRESS TOWARDS NATIONAL LOTTERY TARGETS 08/03 TO 08/09/21

### SUMMARY

The Parent and Carer Alliance C.I.C has continued to grow, gaining an additional 100 members on the Facebook Group - to a total of 1031, and additional 92 Associate members (Total 292) in six months. Facebook statistics show that during August (a quieter month due to the school holidays) the group had 868 active members, and the page reached 357.

Three parent carers agreed to be recorded discussing what impact the Alliance has had for them. 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>

55 families either have been, or are being, supported by the Alliance Advocates. 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-uiv3JU3yg>

Many of the cases that are now being brought are as a result of multi-system failures and are affecting multiple family members. Consequently, a new Advocate has been appointed, who is a Social Worker who has experience of working within adult social care.

As complex cases can mean that families need advice from legal specialists, the Alliance has made connections with education lawyers, Langley Wellington, who are both supporting us by providing webinar training, and have provided some reduced cost consultations for Alliance families; and a specialist in social care law at Scott-Moncrieff & Associates.

There have been 10 additional online events, making a total of 12 to date, with 3 more booked before the end of the calendar year. These have been attended, or the recordings seen, by a total of 398.

Lucy and Louise have attended all the webinars to ensure we also gain the knowledge being given to families, and other advisers have attended where it is helpful to their professional practice.

### LOCAL COMMUNITY LINKS

To try to address some of the main issues described by families about social care provision, the Alliance is part of a working group with the local Parent Carer 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 Alliance created a survey following requests for information, collated, and reported back the results which we have been told are being used, in part by an Improvement Consultant, to help reshape DCYPS and the way that information is gathered and processed for Education, Health and Social Care Plans.

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. As a result, Louise has been asked to join the Local Offer working group looking at these issues, working again with the Parent Carer Forum.

The Alliance is part of the Stroud VCS network and, as a result, has met with the Citizens Advice Bureau and agreed that Louise will attend a volunteers meeting to publicise the Alliance to CAB advisers; CAB experts in benefits, energy and EU settlement will provide information, support and webinars for the Alliance; a system will be set up for the Alliance to refer families to the CAB and there will be a trial of online appointments; the Alliance will contribute to CAB research and campaigns; and CAB will request that GCC add the Alliance to their consultation on Family Hubs.

## NATIONAL PROJECT

The Alliance is part of a group which includes other parent-carer led organisations from around the country as well as specialists in special educational needs legal duties, which is working on the issues raised in a report, issued by Cerebra, entitled “Institutionalising Parent Blame”. The report is in part based on the survey that the Alliance contributed to last year. Lucy and Louise have been working with the report authors, Professor Luke Clements, and Ana Aiello, both to publicise the report and to advise on strategies that could use findings of the report to make positive changes.

The International Public Policy Observatory has invited the Alliance to contribute to an event looking at the social impacts of the COVID-19 pandemic with the aim of informing UK government policymakers.

## SUPPORTING OUR MEMBERS – WEBINARS AND SPECIALIST ADVICE

Whilst the working groups and national project will take months to make progress and, as we know that many families are having severe difficulties in getting an assessment of needs arising from their child’s disability and that the process pushes families through child protection procedures when they ask for help, despite no evidence of risk of abuse - the Alliance has, in addition to getting legal advice for families:

Held a Child Protection conference which comprised of 4 webinars covering when and how child protection procedures should be done, why families with disabled children should not be automatically put through child protection, the rates of these procedures in Gloucestershire, and the new Fabricated and Induced Illness guidelines and how they may affect families. (95 attendees and 91 views in YouTube), and

A webinar on Carers Assessment – what this should cover and how support should be provided (32 attendees and 41 views on YouTube).

Feedback from these webinars includes “Made a huge difference as I feel equipped to deal with the problems that I am experiencing and have been inspired to make a plan to make changes to hopefully help other families in the future” , “It has given me confidence in my interactions with social services, the next meeting will be more comfortable for me with the knowledge that I have gained today” and “I will now be able to insist that a meaningful assessment is done. I feel empowered to advocate for myself and my son”.

In addition to social care issues many families continue to have problems with Education provision. Gloucestershire has a shortage of school places and families whose children have additional needs have been given Education, Health and Care Plans (EHCP) with no named school. In response to this the Alliance arranged free consultations with Education Law specialist Rukhsana Koser of Langley Wellington LLP for 12 families. Families said these sessions helped them feel better informed, more confident about the legal processes involved, where to get support and how to get legal aid for support at Tribunal.

To support families who can only get redress for EHCP failures through Tribunal, Rukhsana also subsequently provided two EHCP webinars, free of charge, giving guidance on how an appeal to the Tribunal can make significant positive changes to a child’s EHCP. (44 attendees and 16 views on YouTube). The recording is also featured on the education lawyers’ website <https://educationlawyers.co.uk/2021/07/19/legal-webinar-the-contents-of-an-education-health-and-care-plan/>

These are issues that can take months to resolve, but we do know of families who now have the school place that they were requesting, and feedback from families includes “I am preparing for Tribunal so this have given me confidence to insist on the changes required and back it up with the law”, and “This will make a massive difference knowing that my child’s EHCP means he will get the support he rightly deserves after years of fighting for him”. For one family whose son has a life-limiting condition and who hadn’t been given a school place, the support “Meant

everything. I've been given amazing advice. I didn't have a clue how the system worked. Lucy explained everything so well. She helped me get what I needed to file for Tribunal, I couldn't have done it without her".

The shortage of school places within the County mean that children are being expected to travel further. As many families are unable to cover the additional financial cost the Alliance arranged a webinar, given by SENTAS, explaining the rights to funded transport.

Recordings of webinars are on our website [www.parentandcareralliance.org.uk/recorded-webinars](http://www.parentandcareralliance.org.uk/recorded-webinars)

Along with the support for Carer's physical needs (February webinar), support has been provided for emotional needs with a webinar providing Therapeutic support strategies and a follow up coffee morning to discuss what Carers found helpful (23 attended). Feedback includes "I was better able to put my experiences into perspective and recognise that my responses to trauma are valid", "It was helpful to hear other Carers' experiences and to be reminded to slow down and be show myself compassion" and "I will try to use meditation more like a safe space to help me cope in times of stress and being overwhelmed".

Future scheduled webinars cover topics including Dyslexia, Power of Attorney and Deputyship, and Human Rights.

### SUPPORTING OUR MEMBERS –ADVOCACY

Families are now coming to us with multiple problems – lack of suitable education provision meaning that children have been out of school for many months (prior and post covid); lack of diagnosis and mental health support meaning children have severe anxiety, self-harm and have suicidal thoughts; families asking for support have their parenting skills blamed, despite often having other children with no such needs, or instead of support are threatened with child protection and their children being taken into care; parent carers themselves are becoming exhausted, catching covid and suffering from long Covid and are being refused support to care for themselves and their children.

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

In one case a mother came to the Alliance saying, "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". As a result of many months support from Alliance Advocates and legal specialists, she recently gave feedback, "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".

Another family was struggling with both education and medical support, their feedback is, "The Alliance Advocacy service made an amazing difference. My medical records, and my son's medical, education and social care records were wrong. The help empowered me to successfully change the medical records, gain the necessary health support for my children, and get better education support. After seeing the improvement in our son, our GP surgery has changed its policy and will swab children earlier for infections".

Other feedback is "The Advisor was fantastic. She gave advice, attended meetings 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 tough love to more supportive. The success of this meant CAMHS changed their approach too".