



# PROGRAMME SUMMARY AND IMPACT REPORT

October 2020

Report on a series of support initiatives run by the Frontline Families consortium of organisations through August to October 2020. Programmes have been designed to benefit families of children, young people and adults with a range of support needs who have been impacted particularly severely by the effects of the Covid-19 pandemic and associated restrictions.

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## EXECUTIVE SUMMARY

*To the kind people who gave funding to the project, as well as to the inspirational Yvonne Newbold - thank you. Your investment will have significant (possibly immeasurable but nevertheless powerful) returns that I strongly feel have had an immediate impact and will continue to have an impact into the future - possibly through several generations of families, for example keeping families together and changing the future of troubled children into more positive futures. Thank you.*

- Feedback from a Newbold Hope Webinar

Throughout the pandemic, Frontline Families has been able to provide targeted support to between 250-400<sup>1</sup> parents and families of individuals with SEND, learning disabilities and/or autism, helping them to manage the severe practical and emotional issues brought about by the pandemic & lockdown. Families have faced an almost impossible set of challenges this year, and – as shall be made clear throughout this report – Frontline Families programmes have been vital in ensuring an effective support network of peers, information and the space to be heard.

*I found it has helped my mental health knowing the answers are easier to come across without upwards of 9 month waits for often patronising (and already tried! Advice) It's a fabulous resource please don't take it away.*

Response to Frontline Families Holidays Survey

The pandemic has not disappeared. Rising infection rates and a return to stricter lockdown measures mean that the families we have been supporting still face the same complex and challenging issues for which they continue to need support. If anything, the protracted nature of the challenge they have faced, alongside uncertainty, anxiety and exhaustion from many months of lockdown and insufficient service provision, has meant that their needs have only multiplied as time has gone on.

*"It feels like being a little boat out alone out at sea, then seeing lots of other boats with their lights on"*

- Quote from a parent, during a Bringing Us Together Zoom Meeting

This report details the programmes of support which have been offered by the Frontline Families partnership of organisations – Bringing Us Together, Newbold Hope, and the Challenging Behaviour Foundation (pages 5 to 11). It explores the impact these programmes have had in the words of families who have been involved (pages 12 to 14). Information was gathered about the months ahead and the need for a continuation of support and funding (pages 17 to 20), especially as we approach the Christmas & New Year Holiday period (pages 18 to 20).

Frontline Families has provided vital and timely support to families when little else has been available. The discussions so far have been useful, but as they have gone on families have raised an increasing number of issues with which they need further Frontline Families support (pages 14, 18). This continued demand shows the benefits derived from the

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<sup>1</sup> The highest Newbold Hope webinar attendance was 289 and the Frontline Families webpages received 261 views, with consistent attendance of 10 or more hard to reach families at Zoom Rooms. It is not possible to know how much overlap there is between those viewing or attending different elements of Frontline Families support, hence the conservative estimate of between 250-400.

programmes, and the trust families have in these organisations, as well as the necessity of continuing Frontline Families funding.

We hope that this report effectively conveys the severity of isolation and complexity of needs (often *caused by* rather than *reduced by* interactions with education, health, and care systems) which lead to high support needs. We are proud of the work we have been able to do during the pandemic to address these needs but are aware that for many of our families the withdrawal of Frontline Families support could be devastating. We are therefore offering the following as a reflection on the successes under Frontline Families to date, and as a statement of intent on the programmes we would like to deliver.

Many thanks,

The Challenging Behaviour Foundation, Bringing Us Together, Newbold Hope.

## **Background**

People with learning disabilities, autistic people and children with SEND were being failed by the systems meant to support them long before the COVID-19 pandemic began. The pandemic, lockdown and associated restrictions have meant that the families of individuals with learning disabilities and/or autism have needed more support than ever, while simultaneously facing a withdrawal or lack of access to traditional means of support.

*“He will eventually die or become more disabled as the CCG won’t buy equipment to safeguard him ... I am scared ... no one is listening”*

- Parent, Bringing Us Together Zoom Meeting

Frontline Families was created by three small family-led organisations on a small budget, provided through Government emergency Covid-19 funding distributed by DHSC. The funding was secured as a specific project within a larger grant to the CBF, which was passed on to the other 2 organisations. The aim was to work more efficiently together to meet the needs we jointly identified, by maximising the impact of our support services, and adapting the methods we use to offer this support. The funding period covered July-October 2020.

Our three grass-roots organisations have therefore worked to deliver new formats of support programmes, aimed at tackling issues which families felt were being underacknowledged by others in the sector. Frontline Families has enabled these organisations to continue to offer high quality and responsive support throughout the pandemic, as well as to benefit from the developing collaborative partnership.

### What we have offered

Bringing us Together, Newbold Hope and the CBF have collaborated in a complimentary manner, have added value to each other’s activities and offered coordinated support to families. All our work is co-produced with families and individuals with learning disabilities or autistic people. To reflect this, the vibrant and eye-catching logo (shown on the cover page) was designed by a young autistic person in a competition run online.

Our programmes have been incredibly well received by the families that have used them. This is explored in more detail in the ‘Impact’ section of this report. In summary, the programmes funded under Frontline Families have helped to:

- reduce feelings of isolation and helplessness,
- establish a community of peers,
- offer much needed support and information at a time when families have felt as though they are on their own.

92% of families attending Newbold Hope webinars said they had increased their confidence and 60% said they benefited from the signposting to other support or resources.

*“This webinar (and others in the series) have helped (and will continue to help) me and my husband to better understand our son and his needs and to better support him. I believe these webinars are making a tangible difference to our family dynamics, quality of life, and our son's future.”*

- Feedback given on a Newbold Hope webinar,

Frontline Families support has made a tangible difference to the lives of families and carers who otherwise may have been left unheard and under-supported. Through signposting, guidance, and emotional and peer support, the partner organisations have been able to ensure families are listened to and given the necessary guidance and assistance, during a period which is likely to have severe and long-lasting consequences.

#### Why Frontline Families exists

The families we all support have had to endure situations that most people never have to encounter. The pandemic has exacerbated existing issues and led to unsustainable situations. Many families whose vulnerable relatives live away from home have not seen them at all for over six months. People with complex needs may be unable to use Zoom, Facetime or other technologies. Other family carers with relatives at home with them and are dealing with intense levels of challenging behaviour, putting them and their children at risk, with no support from education, short breaks, respite or behaviour support services.

We are grateful for the small amount of funding which has enabled Frontline Families to provide much needed support through this period. But as we enter a second wave of Covid-19 and accompanying lockdown; it is clear that all their needs will not have been met by 31 October 2020. Families have identified a huge range of issues they would like to see covered going forward. Families are reporting that they are at breaking point, and as such the offer of support under the Frontline Families programmes becomes vital. As the country faces rising infection rates and a return to more stringent restrictions, it is therefore necessary that funding for these programmes continue.

*“more of the same – the more I hear...the more I learn and the more effective I become as a parent”*

- Feedback given on a Newbold Hope webinar

## WHAT WE'VE DONE

### The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) approached Bringing Us Together and Newbold Hope prior to the grant application to agree to include an amount for collaborative working within the CBF grant application. The CBF then directed the allocated grassroots funds distributed by DHSC to partner organisations Bringing Us Together and Newbold Hope who were less well placed to bid for funds during the period, despite providing much needed support to families.

The CBF conducted the background coordination work for the creation of the partnership and linked the grassroots work to our other CBF programmes and work in order to improve access to support for families from all 3 organisations.

The CBF, while still a small charity of less than 10 full time employees, has a larger capacity than Bringing Us Together and Newbold Hope, in as much as it has more staff and organisational infrastructure (including its website). As such, the CBF is in a position to utilise this capacity for the benefit of the consortium of organisations. The CBF provides a range of ongoing specialist support and resources for families, including a helpline, casework support and other online and hard copy resources – this work temporarily funded by the emergency funding distributed by DHSC is reported elsewhere, but was co-ordinated with the Frontline Families work. Within Frontline Families, therefore, the CBF has operated largely as the co-ordinating partner – with its individual contribution involving preparing the initial funding bid and reporting monthly on it, creating the dedicated webpage, collecting and collating feedback and impact evidence and the subsequent preparation of this report – all of which has taken significant staff and administrative time & costs.

Katie Clarke, from Bringing Us together, summarised the support from the CBF as follows:

*Challenging Behaviour Foundation brought Newbold Hope and Bringing Us Together to work in partnership, to share our skills, expertise and lived experience in developing our work, a plan of action and to deliver a menu of services over Covid 19 that were responsive to families' needs.*

*CBF have worked in true co-production. We have come together equally where CBF have organised and hosted regular meetings; have kept in touch via email and continued to update us all with their work with the larger collaboration. They have a very inclusive attitude and enabled us to share ideas in a proactive way. We have been able to achieve a huge amount thanks to their administration, support, back up team (Liam) and opportunity to use each organisation in the best way possible.*

Similarly, Yvonne Newbold, of Newbold Hope, stated the following:

*Newbold Hope is basically just one person, and the administrative load of running the webinars has been immense. The Challenging Behaviour Foundation were able to take on several of these onerous administrative tasks to make things easier including all the collation and organising of the post-webinar evaluation forms and chat logs. More recently, one of their staff has been joining me during the webinar sessions to ensure that the chat-log questions from participants are properly addressed and any technical issues participants may have been sorted out quickly. I cannot express what a difference it makes to have this level of support during the webinars themselves. It can be a very weighty responsibility to have sole-charge of everything*

*when some of the webinars have had over 100 live participants including many who are extremely vulnerable and need support.*

The CBF has been running a range of programmes with Government emergency pandemic funding to support families during the pandemic, including:

- regular online **carer catch-ups** for families whose relative has a severe learning disability where carers can receive peer to peer support. These are coordinated by the CBF and hosted by volunteers, facilitating peer support, reducing feelings of isolation, with the CBF also providing practical resources for attendees.
- **behaviour chats via zoom** for families whose relative has a severe learning disability and displays behaviour that challenges, allowing exploration of new or difficult behaviours with a small group including a behaviour expert and peers. Families attending are offered further follow-up support by phone, are provided with bespoke behaviour resources online or by post, and are linked to local services.
- **legal advice** for families helping family carers navigate the legal system, understand their rights during the pandemic, and providing them access to experienced legal expertise, particularly to help understanding of COVID-19 guidance. The CBF produce FAQ resources to reach more families with common queries.
- Specific **COVID-19 information sheets**, which had 389 views as of 1 October 2020
- Newsletters to provide **key information to families who are not online**
- an increase in our **helpline** and casework capacity.

While related to Frontline Families and advertised to families via the network, these programmes have been funded from separate budget lines in the Covid-19 emergency fund and have not been funded as part of the small Frontline Families partnership.

#### Working as a consortium

Regular meetings are held to discuss progress, provide feedback and plan ahead (see page 18). These meetings are set up & chaired by the CBF including CBF administrative time for setting up & recording, with actions agreed and taken forward by all. Yvonne Newbold has described the benefits of such meetings and collaboration:

*The importance of the warm and caring support that I've received from my consortium colleagues cannot be underestimated. Every week we have had a Zoom meeting where all our concerns and difficulties can be discussed among families who really do get it and who truly understand just how hard it has been to be able to offer support to so many people in such very difficult times. We were pulling together, holding each other up and looking after each other's mental well-being at a time when families need us to be as strong as possible and for as long as possible. Quite frankly, without the kindness, understanding and concern of the management staff team, I don't think we could have achieved anywhere near as much as we have.*

#### Bringing Us Together

Bringing Us Together held **fortnightly Zoom Room Chats** for families whose relatives are living away from home, including those with relatives with learning disabilities and/or autism (both young people and adults) in Assessment and Treatment Units, residential care homes and supported living settings. Some families joining the online meetings have also had a family member who has more recently returned home, primarily as a result of the pandemic.

The online chats helped families to build networks, offer peer support, overcome isolation and are a safe place for family members to share experiences about what is working and what is not working. Bringing Us Together signpost family members who may need more intensive support to the organisations we are working closely with. From the discussions held in these chats, the themes and issues that are brought out are then summarised into our reports, fed into strategic work, and acted upon in our collaborations with other organisations.

### Meetings so far

Meetings have facilitated discussion on a range of issues experienced by families during the pandemic. In the first Zoom meeting, held on August 3<sup>rd</sup>, Bringing Us Together offered a safe space in which families could raise concerns **on issues they felt were under-acknowledged, or where they felt they were not being listened to**. Families discussed:

- **Human rights**, including their regular experience of feeling that their basic human rights were being ignored  
*“We lose our child to the Mental Capacity Act. Our children become public property. They try to get parents out of the picture”.*
- **Communication needs**  
*“people are ignored and unheard, for example to Rapid Prompting Method (RPM) communication sits unused in boxes.”*
- **Communication with agencies and staff members** went unheard, leaving them left out of care and support decisions for their relative  
*“Parents often get cut out of important decisions because they are deemed to be too difficult.”*
- **Access to high quality services and medical care** - both physical and mental health – for their relatives with learning disabilities. Staff members, agencies and carers’ inadequate understanding of communication has led to a subsequent failure to understand medical needs. Families also felt that commissioners may be unwilling to allow necessary spending on medical items  
*“We need expert witnesses with bowel management experience. There’s no bowel management pathway.”*
- Families raised significant concerns about the **increased risk** their loved one is in without personalised care, and many parents worried that their child may not be getting the effective **advocacy** that they need as a result of the source of funding  
*“Advocacy services are often funded by the hospital or institution and so they are not truly independent.”*

From the issues highlighted in these discussions, Bringing Us Together was then able to identify needs and, if appropriate, signpost families to other organisations or specialists.

The second Zoom meeting, held on August 17<sup>th</sup>, centred on **mental health and wellbeing**, and how families can emotionally support one another. Individuals mentioned the benefits of being able to come together as a group, and the innate value that peer support has in its ability to relieve and reassure

*“Having someone else to talk to, in the same boat, can be so important.”*



*“THANK YOU. I have a spring in my step my mind still fuzzy, but I know I am not alone”*

The session touched on dealing with difficult emotions, sensitive issues, the stresses (or ‘battles’) individuals have been facing, and the fact that those who aren’t carers or parents of children with SEND often can’t understand what they’re up against. The session also allowed parents to share tips and advice on how to deal with these complex problems and emotions.

*“I have an emotional first aid kit...favourite perfume... favourite book... I need that reminder that I’m a normal person and a normal woman [...] I may be a carer, but I also have these feelings and experiences. It feels so important to do that.”*

Families stated that their involvement with this group gives them a sense of understanding, belonging and emotional support that they are not able to get through other means, it was decided that Bringing Us Together should employ this overarching aim of **emotional and well-being support** in the third session, held on September 14th.

Parents and other family members stated that they often neglect to look after their own emotional needs.

*“I have trouble thinking about me. Because like so many carers I’m focused on the needs of others and so that becomes my coping mechanism.”*

Relaxation and mindfulness techniques *“Get out in nature, see special trees and people that mean a lot to me”*, with sessions themselves directly improving their emotional well-being:

*“It feels like being a little boat out alone out at sea, then seeing lots of other boats with their lights on.”*

The issues raised by some individuals within the zoom group chats has led to the recognition that some families have more pressing, unique individual needs, which has led to the arrangement of, among other things, individual follow-up support meetings; individual support planning sessions; and identifying or creating bespoke resources for family members, and the creation of well-being certificates.

The benefits of these sessions have been clear, creating emotional and peer support, enabling discussion of problems of significance, relieving stress, and possibly leading to better outcomes for their relatives with learning disabilities themselves. One of the most frequent themes fed back to the group by family members has been that the chats have helped them to both realise and give permission to them to consider their own emotional well-being:

*“...it has helped me to be kinder to myself”*

*“It’s reminded me to look after myself.”*

## **INFORMATION SESSIONS**

Bringing Us Together held an information and support session for families on August 19<sup>th</sup> and formed a collaboration together with the Disability Law Service. The session was well advertised and very popular which showed the need and demand for legal information for those families with loved ones in residential settings and assessment and treatment units. 31 family members signed up to the event and were invited to send in their issues and questions before the event which were sent to the Disability Law Service. Priya Bahri led the

session supported by our facilitator team and presented for 1.5hrs with half an hour for further questions.

Our next information and support session was on October 12<sup>th</sup> and within 3 days was fully booked. **A Place Called Home** is a collaboration with housing experts Alicia Woods and Jayne Knight who have volunteered their time to this event. Other issues that we have been asked to run (with further funding) and offers of support include: constipation, medication, Personal Health Budgets, postural care, more legal advice.

### **Increased Networks**

This funding has allowed us to link in with other organisations including the National Co-Production Advisory Group, Disability Rights UK, BILD, Access Charity, Disability Law Service, In Control, and the Covid 19 Disabled People's group who are keen to develop further links.

## Newbold Hope

Newbold Hope have designed and delivered a series of seven webinars for parents struggling with their SEND child's challenging behaviour, continued to maintain their online communities, and have organised "Let's have lunch together" chats.

The webinars covered a range of sensitive issues and offered guidance and expertise to families in need of help. A live chat box runs alongside these webinars, in which a community of families exchange knowledge, insights, and emotional support. This live chat enabled the families to build a peer community and helped them to overcome much of the severe isolation these families are experiencing. It is due to this isolation that the lunch chat session has been planned; a 90-minute session with 16 places allocated on a first come/first served basis.

Frontline Families funding has allowed us to provide free access to the webinars to families facing financial hardship. The webinars contents are described briefly below, illustrated with quotes taken from the live chat long – the webinars are each two hours in length, however, and so the following is only a snapshot of the topics covered.

### How to reduce extreme behaviour in SEND children

The first of these webinars, held on the 11<sup>th</sup> August, discussed '**How to reduce extreme behaviour in SEND children**'. This webinar offered advice regarding:

dealing with an often unsympathetic general public in cases of **meltdowns and extreme behaviour**

*"everyone looks at you and judges your parenting", "Yes! You feel so judged",*

**dealing with schools and professionals**

*"we've been to so called experts and I always feel humiliated to be honest", "The school just don't believe they're one of the triggers in upsetting my girl",*

Discussed the **psychological background to challenging behaviour** (including Alexithymia, Masking, and Theory of Mind), and **provided tips and practical solutions** on how to prevent/manage meltdowns – including communication techniques, using humour, avoiding the word "no", identifying triggers, fulfilling sensory needs, and using relief strategies.

### How to keep brothers and sisters safe and happy

The second webinar, held on the 18<sup>th</sup> August, focussed on **'how to keep brothers and sisters safe and happy'**. The webinar again covered a range of sub-topics within this issue. Discussions included guidance on dealing with complex emotions in families with SEND children including parental guilt, resentments, sibling rivalry and feelings of unfairness

*"worst thing is if we have a happy moment, I'm just waiting for it to go wrong, so I can't enjoy it".*

The webinar also covered how to work in partnership with spouses/partners/exes, an issue which parents consistently ask for further advice on.

*"difficult relationship with ex [...] doesn't always see the impact his words and actions have on our children" – "Snap" – "my ex is the same its horrendous"*

The webinar offered a wealth of practical strategies to encourage better sibling relationships, and parents also offered this on a peer-to-peer basis in the chat - this included sharing recommendations of board games, activities, ways of sharing attention, and other techniques *"we do random group hugs" – "I love that idea!" – "might bring back a bit of shared fun"*.

### You Can Do This! All about boosting your well-being and energy levels

"You Can Do This! All about **boosting your well-being and energy levels**" on the 25<sup>th</sup> of August focussed on the mental health and needs of the parents themselves, an area parents said they often neglect, and even feel guilty about attending to. The session was led in partnership with Malcolm Cooper, a hypnotherapist and life-coach, who offered meditation and self-calming strategies. As always, the session was practical-solution oriented, enabling parents better attend to their own mental/emotional needs as well as providing an effective toolbox of mindfulness and relaxation strategies for the future. The session asked parents to reflect on any difficult emotions and identify triggers.

*"oh golly. revelation Malcolm! I've recognised anger as panic in the kids for years. But NEVER considered that the same was true for me!!!". "That was amazing, need a recording of Malcolm saying all that to help me sleep each night!", "So powerful, thank you"*

### Understanding anxiety and how to reduce its impact on your family

The webinar held on the 1<sup>st</sup> September dealt with a similar topic, on **'Understanding anxiety and how to reduce its impact on your family'** – discussing anxiety's wide impacts and how it can both pervade parent's mental health, as well as acting as a trigger for their children's challenging behaviour.

*"I have to try and manage my own anxiety as well as my ASD twins who both get highly anxious... it can all spiral out of control pretty quickly... I feel so guilty I can't regulate my own feelings quick enough to support them"*

This session again offered advice and support which had been sorely undersupplied *"No one ever told me his behaviour was due to anxiety. If I'd known I could have done a better job at helping him, rather than feeling helpless"*.

### How to boost your SEND child's self-esteem

This webinar held on the 8<sup>th</sup> September dealt with self-esteem, particularly the reasons why children with additional needs often have extremely poor self-esteem. This issue and provided strategies to enable them to work with their child to increase their sense of self-worth and self-esteem. The webinar covered what can contribute to low self-esteem in SEND children

*"Yep we get that my daughter goes out all the time sleepovers etc but no one calls for my son. Doesn't get invited to birthday parties etc it's heart breaking",*

It covered why self-esteem matters and its long-term impacts *"My sons mental health was getting really scary because of the shame he felt"*, and again provided practical strategies that parents can employ to tackle low self-esteem.

There are still a significant number of topics upon which families require guidance, information, and support. These webinars have been incredibly well-received, with huge demand and scope for the programme to continue in this online format.

The final two webinars of this series of seven were scheduled for Thursday, 8<sup>th</sup> October 2020 and Thursday, 15<sup>th</sup> October 2020.

The first of these two is entitled ***"How to help a demand avoidant child cope better with life"***. It will focus on demand avoidance which is a common symptom of severe anxiety which can lead to very complex and challenging behaviour, looking at both the underlying causes and how parents and carers can successfully address them.

The final session is called ***"How to be heard as your SEND child's Advocacy Expert"*** and will explore lots of strategies to increase parental confidence and presentation skills in meetings with professionals about their child. Due to very high demand and topic requests, if funding is secured there are plans for a further dozen webinars to be delivered over the coming months.

## IMPACT

The impact of the CBF work including online carer catchups and behaviour chats, forms part of the Frontline Families 'offer' but is reported elsewhere as it was funded through a separate workstream within the Covid-19 emergency funding.

The Bringing Us Together Zoom Chats have been attended by a consistent group of families, from 7 families in the first meeting to 14 in the second, and 12 in the third - the majority of this group being made up of returning families, indicating how well appreciated the sessions have been by attendees. Newbold Hope Webinars have also maintained a high attendance rate, with the webinars (in date order) having 102, 67, 60, 79 and 51 people joining the webinar live, and 82, 39, 41, 29 and 26 watching later through the 'replay'. We can also see that these webinars had a very high level of engagement, with the live chat function receiving 603, 372, 415, 290 and 170 comments in each session respectively.

Evaluation forms circulated after the webinars help us to understand their impact on well-being – with 92% of 125 returned forms stating that the webinars have increased their confidence. Furthermore, signposting and cross-referrals promoted as part of Frontline Families are shown to have been effective, with 60% of feedback returned stating that they have been made aware of new groups or resources as a result of the webinar.

The words of the families involved tell us in no uncertain terms the impact that Frontline Families programmes have had on them and their families. The qualitative data below has been collected from families input into the sessions and from the feedback forms. Regular themes for feedback are: Peer Support & Overcoming Isolation, Knowledge & Information, Benefits of Online Format, Referrals & Signposting and finally Requests for Future Sessions.

### Peer Support and Overcoming Isolation

One of the most valuable outcomes from the Frontline Families programmes has been the fostering of a community of peers, who offer each other information, guidance, reassurance, and emotional support. These families often experienced severe isolation and a lack of professional support even prior to the pandemic, as a result of their relatives displaying challenging behaviour, having complex needs or due to restrictive responses from services. The withdrawal of social interaction and professional services thus impacted this group of families particularly hard, and the space for discussion and emotional support created by Frontline Families was of huge benefit. It was common to hear that these families had been cut off completely from their family and friends, and this isolation can have a significant negative effect on the mental health of parents

*“Just me and my two boys. I have not spoken to any adults for the past 6 months since lockdown basically. I am going mental” – Parent, Newbold Hope Feedback*

In these Newbold Hope Chat logs, we can see in the parents' own words the significance of Frontline Families programmes in helping them to overcome this isolation

*“I'm just so glad I get to meet people like you and everyone else here, I don't feel alone then” – “we are all in the same boat that's why we are all here you're taking the first steps now with us all x” Newbold Hope Webinar chat log*

The same is evident from the discussions in the Bringing Us Together sessions

*“My daughter is in the other room... when I went to the loo she said ‘oh mum, it was so nice to hear you talking to other people” – Bringing Us Together Zoom Meeting*

*“Just since I’ve met people in the same situation, it’s made such a difference [...] I don’t have to worry that I’m saying the wrong things. People just understand”* Bringing Us Together Zoom Meeting.

The community of peers provides tangible benefits for the carers involved, in turn improving outcomes for their relatives with learning disabilities. This includes the sharing of information, knowledge, and emotional support over difficult and sensitive issues

*“I really struggle with keeping sympathetic. Am so tired” – “You’re only human” – “we totally understand and don’t ever feel bad for saying it” – “Totally I often feel the same” – Newbold Hope chat log*

Reassurance and the ability to *“jump on a zoom and to be able to off-load what’s been happening”* (Bringing Us Together Zoom Meeting) gives parents access to much needed emotional support, helping to relieve stress, improve moods, and reduce feelings of helplessness.

Significantly, on top of the information and support given by the organisations themselves, families often reached out to each other to extend offers of interpersonal support *“Here’s my email in case you can’t do it” [referring to assisting with OT assessment], “I will find you in the group and pm you if you like as I feel we could speak more” – Newbold Hope Webinar*

#### Knowledge and Sharing Information: Different and complimentary

Frontline Families programmes offer different and varied forms of support. Bringing Us Together centred discussions on the issues raised by families. Instead of advising, these sessions aimed to listen to families first and foremost, and from this identify the possible support and solutions available, including signposting. This strategy had considerable benefits and focussing on developing an understanding of the families’ perspectives allowed them to feel heard and have their needs met. One individual stated the importance of this type of support, which hadn’t previously been available:

*“I feel that if only we were signposted in the first place to the right support and the right ways forward... how much difference that would have made... hopefully we can all bring something to this and just help signpost people to this”.*

Newbold Hope uses a webinar format, which focusses on offering practical solutions to parents in need. This guidance is based on Yvonne Newbold’s practical experience in the field as a parent – with this background helping the families relate to her guidance: *“Yvonne is such a compassionate, understanding and very relatable lady. She is so inspiring and with her guidance my future with my son is going to be a lot brighter”.* These webinars have had a marked impact on their ability to support their children, and their future as a family *“This webinar (and others in the series) have helped (and will continue to help) me and my husband to better understand our son and his needs and to better support him. I believe these webinars are making a tangible difference to our family dynamics, quality of life, and our son’s future. Thank you”.*

The Challenging Behaviour Foundation offered informal carer catchups hosted by a supported and trained family carer, as well as online behaviour chats with a volunteer behaviour experts and family carer trainers. These resources were well received by family carers, offering peer-to-peer flexible support and information in an accessible family friendly format.

... *“I was in a much better place and felt confident and strong to start fighting for my Son and what was right. Also, the documents, which I am still reading through, gave me energy to continue”.*

### Advantages of the online format

The pandemic has made all of us adapt our working practices to meet new challenges – and in some ways this disruption has led to the creation of more effective ways of working. We have found families reporting that the development of online sessions as part of Frontline Families has been hugely beneficial

*“I know coronavirus is bad, but I’ve been able to attend more webinars and conferences as a result of it!” – “Agree, its actually been helpful, as a single parent I usually can’t attend things” – Newbold Hope Webinar chat log.*

Families had a range of reasons why traditional support measures were inappropriate, including due to their **children’s support needs** (*“the pandemic has given us access to so much help online its fantastic – from Newbold Hope Chat log*), **distance** (*“a very wonderful silver lining to the lockdown months as I don’t think I would have made it to workshops in London and have learned so much” – Newbold Hope Feedback*), **social pressures** (*“I couldn’t really talk about my issues and concerns in the local area, because it would have such a ripple effect in my area which is small... having those others on the social media, it gives me the tools to move on” – from Bringing Us Together Zoom Meeting*) and **financial stresses** (*“I think these webinars are vital for single working parents like me without much support so cannot get a babysitter which means I miss out on courses” – From Newbold Hope Webinar Feedback*). *“Thank you for the meeting of this morning. It was nice to be able to meet other parents who are in the same situation as me. I learned quite a few things from the meeting” – from CBF behaviour chat.*

Moving to these online sessions may have developed a new notion of good practice and inclusion, overcoming the access issues prevalent in traditional support measures. Due to the continued support needs of families it is obvious that the programmes should continue in this online form while the pandemic persists - but it is also possible that we should implement these online programmes as best-practice in the long-run in order to reflect the financial, social and location-based access issues which online programmes alleviate.

It should be noted however that there are many families who do not have internet access- these families will be experiencing the same issues and isolation, without a mechanism for benefitting from the positive impact the online resources deliver. These families will therefore be experiencing even greater isolation and hardship. The CBF recognises that many families are in this situation and is working hard to address this issue through distributing information and newsletters by post.

### Requests for future sessions

One way to measure the impact of these support resources is in the continued demand they generate. Since they began running, families have identified further issues for which they would like discussion and support. In Bringing Us Together Zoom Meetings families have identified the transition from child to adult services, testing for COVID-19, advocacy, communication, personal health budgets, relaxation tips, technology, and further sessions on emotional and mental health support as areas for which future sessions could be beneficial. Families have requested that Newbold Hope run webinars on cooperating/dealing with

schools, use of computers/gaming addiction, parenting as a team with a partner/ex, dealing with pathological demand avoidance, more work on anxiety, mental health and self-esteem and also simply “*more of the same – the more I hear from SEND VCB* (The SEND VCB Project is a Newbold Hope initiative; an acronym meaning “Special Educational Needs and Disabilities, Violent and Challenging Behaviour) *the more I learn and the more effective I become as a parent*” (From Newbold Hope Feedback Form). The CBF carer catchups and behaviour chats will continue as valuable peer to peer resources for families at this time.

The continued demand for more sessions tells us three things:

- firstly, that families **have appreciated the sessions so far**,
- secondly that there **are further issues for which they require support**
- thirdly that they believe that **Frontline Families organisations are best placed to provide support on these issues.**

All three factors indicate a need for Frontline Families programmes to be continued.

As well as being beneficial for the families who have used the Frontline Families programmes, the organisations themselves have also experienced considerable benefits from this new collaborative partnership. The next section shows how Frontline Families has enabled its partner organisations to benefit from collaboration.



## BENEFITS OF COLLABORATION

Working in partnership has enabled each member of the consortium to increase the reach, impact, and value of their work.

### Strategic Impact

Topics which families raise for discussion within the programmes help the consortium to develop a clearer idea of the issues facing families, which is then fed into their strategic work – strategic work which has increased scope when delivered in partnership. This increased scope can be seen in, for example, a recent consultation conducted by NICE over testing for COVID-19. The CBF is a registered stakeholder with NICE, but the other consortium organisations are not. When completing the consultation, the CBF included evidence and input from Bringing Us Together – without the Frontline Families partnership, Bringing Us Together would not have been able to have their voice heard in this consultation, and the consultation may have lost valuable information as a result. Being able to work more closely together has enabled the organisations to respond and gather information quickly and gather a wealth of input from the individual expertise that each organisation has, delivering more effective advocacy on a national scale.

Furthermore, the funding distributed by the DHSC has facilitated a greater connection with other organisations external to Frontline Families. Bringing Us Together, for example, report that the funding has allowed them to connect and develop relationships with groups such as Respond and BILD, with greater understanding of where work overlaps and what can be of use to families when signposting. They have an improved ability to develop strategically on the lessons learned from families and wouldn't have been possible without Frontline Families funding.

### Reach – Signposting and social media

Throughout the time that Frontline Families has been in operation, the partner organisations have increased the reach of each other's support and information resources. Through sharing partner organisations' posts on social media, advertising each other's sessions and signposting, the consortium has increased the audience and possible beneficiaries of the support available.

A dedicated webpage has been created on the CBF site (<https://www.challengingbehaviour.org.uk/supporting-you/for-families/frontlinefamilies.html>) to provide a central space to advertise the support available for families of individuals with learning disabilities and/or autism during the pandemic. The page, co-produced by the partner organisations and supported by Communications support from CBF staff, directs visitors to Frontline Families partnership organisations. It has had **261** views as of **1 October 2020**. By this signposting within their networks, the organisations are able to offer families that they are in touch with a much wider range of support.

### Information sharing

Furthermore, as part of Frontline Families, the partner organisations have held regular meetings to discuss plans for programme delivery, advertising and impact recording, as well as to learn more about each other's services, expertise, and capacities. This information sharing has strengthened working relationships between the three organisations and allowed for a better understanding of what each can offer to families, enabling better signposting and more accurate support provision for families. This allows for a more effective strategic working relationship, in which the consortium can fill gaps in support for families in a complementary way, rather than risking duplication.

As a group of small organisations, working in collaboration increases overall capacity, enables the consortium organisations to add value to each other's operations, and allows us to achieve things that would not otherwise be possible.

*Working together with Bringing Us Together and The Challenging Behaviour Foundation as part of the Frontline Families consortium has enabled Newbold Hope to offer a very high level of support and practical help on-line to vulnerable families who have been particularly badly affected by the pandemic crisis. As the smallest of the three consortium organisations, the support that the other two organisations have been able to offer has been invaluable. [...] Thousands of families lost their entire care package overnight, and at a time when they also were unable to be supported by their immediate circle of trusts friends and relatives.*

*The workload for Frontline Families has been intense, and at times very stressful. In many cases our organisations were the only support available to families, which has been a tremendous responsibility and at times very difficult due to the huge number of harrowing stories that families have told us. We have been able to pool our resources, brainstorm our ideas, share the administrative burden, promote each other's events across our own social media networks, signpost families to each other's organisations – the list goes on and on about how much more effective we have been due to the many strengths of working together.*

*Joining together under the umbrella of Frontline Families, all three of our organisations were able to collectively offer so much more than would have been possible without the strength and goodwill that has underpinned everything that the consortium has successfully delivered to families in real need.*

- Yvonne Newbold

## THE FUTURE OF FRONTLINE FAMILIES

Having demonstrated the value to families of continuing the delivery of programmes under Frontline Families we will explore ways of making this happen. This includes delivering the sessions that remain to be delivered on issues which families have requested, as well as the potential to 'scale-up' our operations.

### What families told us during sessions & in feedback

We detailed at the end of Section 3 the requests that have been made for future sessions. In particular, Bringing Us together has identified the well-being work as being much needed for families, and intends to run further sessions dealing with this issue. Specifically, continued funding would enable Bringing Us Together to run its weekly events and fund the administrative work needed to deliver programme. Part time administrative support (2 days a week) would provide a low cost solution to improve efficiency and reach and would include paying facilitators and funding report writing, as well as funding the cost of twice-weekly co-ordination and development sessions.

Similarly, Newbold Hope has identified recurring areas of concern for families that have arisen in feedback throughout the webinars thus far. In particular, parents appear to be struggling with being on the "same page" when parenting, either as partners or with an ex. Newbold Hope would like to explore these issues further and look more deeply into a father's experience of SEND parenting. It has also been highlighted that more direct support is needed online for both SEND children and their brothers and sisters regarding well-being and emotional regulation, as well as in self-esteem. Newbold Hope has a series of 20 webinars in total to deliver, but there are also options to scale up the programme beyond simply a continuation of this programme, as well as the potential to deliver more "Let's have lunch together" informal chats.

Families have often been in contact following the webinars with further concerns, or specific support needs related to topics discussed. Further funding would allow Newbold Hope to better attend to these queries and needs in two ways:

- the burdensome administrative load could be alleviated with funded support, allowing Newbold Hope to assist families in a timelier fashion.
- the support and online community could be extended through an online membership club to support families after webinar attendance.

Funding would enable Newbold Hope to fund the development of such features, as well as continuing to offer free places to those unable to afford any related subscription price. Further development of web functionality to allow the videos of past webinars to reach a wider audience and upgrade the video hosting software used has also been identified as a next step. In the impact report we have highlighted the benefits of this online service for many families and improving the online functionality of these programmes is of self-evident benefit.

## Frontline Families – Holidays Survey

Frontline Families identified managing the festive season as a future concern for families. We jointly created a short survey, which was sent out to family carers and parents, asking them four questions: We asked:

- what challenges they expect to face this Christmas period,
- what support may help,
- what Frontline Families specifically can do for them, and
- whether they had any other comments.

This identified what we can do to support our families during Christmas time – a period which is always a challenge for individuals with learning disabilities and/or autism & their families (even more so this year) and to demonstrate the severity of need facing these families.

This work is an example of Frontline Families' forward planning and being in touch with the lived experience of families as we approach what will be a uniquely difficult Christmas & New Year holiday period. Frontline Families have been effective at providing targeted support during the pandemic, and the information collected via this survey will allow us to further implement this strategy.

### What families told us about their support needs

We asked families what challenges they expected to face this Christmas period. Sadly, the issues raised are both common and expected. **25%** of respondents anticipated an **increase of mental health challenges**, discussing either anxiety, depression, distress, mental health or similar:

*“Ongoing anxiety about how long we can go on like this and how long it might be before things can improve”, “*

*Lots of anxiety about Christmas day, presents and rising Covid rates”*

Similarly, **23%** expected to experience **high feelings of isolation or loneliness**:

*“I am a disabled lone parent with a very challenging 7yr old. Due to being a domestic violence survivor, we are isolated and alone with no local friends and no family. As my son gets older, Christmas gets harder and I am dreading this year already”.*

**28%** of respondents anticipated an **increase in challenging behaviour** for their relative:

*“Unable to leave house, no respite, extremely challenging behaviour.”*

**11%** expected to face **financial stress**:

*“Difficulties managing expectations around Christmas presents due to reduced financial capabilities”,*

*“We dont have much money this year because we have been paying for specialist reports because youngest needs a specialist school. Also, our roof leaked very badly, and we have had to pay a lot and go into debt to replace it”*

**10%** anticipated problems with **families and relationships**, due to the lack of visiting and support from extended family or increased pressure on family relationships:

*“My daughter is Autistic but loves spending time with my brother and sister. She has not seen them since pre Covid, I can see how this is affecting her relationships with them”*

These are much the same issues that Frontline Families has been providing support for in recent months, however these challenges are likely to increase drastically over the Christmas period.

We know that Frontline Families is well-positioned to offer timely, trusted, and much-needed support on these issues. However, with the ending of funds distributed by DHSC, and the increased needs generated during the Christmas period, it is absolutely vital that our support options remain in place. When we asked families what support they would need, **77.2% of respondents told us that continuing the ongoing Frontline Families programmes** (including webinars, zoom chats, catch-ups, specialist behaviour chats and signposting) **would be a benefit over the coming months. 29.8% of families said that they would like Frontline Families to deliver new or different programmes**, reflecting the aforementioned scope to expand our projects. To be able to fulfil this demand we urgently require funding.

We asked families what programmes that we, as grassroots charities, might be able to provide to help them deal with the challenges of the months ahead. Some of the requests for new, different, or expanded programmes were insightful, and ones we hope to implement if funding is secured. Many of these suggestions revolved around coping with isolation or loneliness, both for families and their children with learning disabilities and/or autism:

*“I love the idea of a virtual lunch meet up although I couldn’t make the last one. Informal support meetings would be great, maybe some in the evening? A ‘virtual pub trip’ might be fun!”*

*“Zoom chats with someone outside the family for our daughter to talk to about her worries etc.”*

*“I have no-one else to help me and nowhere for my adult son to go to. Someone to understand or befriend my son.”*

Other suggestions reflected families’ need for emotional support:

*“Emotional support / intervention available to support the individual with their mental health, this would help with preventing more problems at a later date, which is what seems to happen if support isn't provided earlier”*

*“Virtual chat sessions for parents. Virtual anger management/emotional regulation sessions for children e.g. zones of regulation etc via zoom for young people directly. Someone, not the parent, helping children to understand their emotions.”*

Some requests were specific to the Christmas period:

*“Could we do a special online calendar where there was something each day that was positive for them? just a different way of doing things and embracing the digital during Covid”*

And others were based on the information services that Frontline Families can offer:

*“Webinars to refresh on how to handle behaviour in the home. Pdf action plans for families or useful resources made available. Information on nearby services.”*

*“Having access to a group, webinars, support groups continually in place to ask questions, learn and seek advice. Develop a telephone service.”*

However, we also know that these families face far more challenges than we – as grassroots organisations – can solve. When asked what else might help them over the Christmas and new year holiday period, respondents asked for:

- Emotional support including counselling- **68%**
- Better local community support including behaviour support - **68%**
- Services working in partnership with families to meet - **63%**
- More financial support - **58%**
- Priority access to health and education services - **56%**
- More virtual services – **40%**
- More practical support for families – **51%**
- Ability to visit relative in residential care more regularly – **18%**

Additionally, in the ‘Other’ option, families requested assistance such as respite services, continuity between services and better guidance around visitation amongst other things.

It is clear that there remain issues in finances, services, care and support which, if left unresolved over the Christmas period, will compound many of the challenges families already face. While unable to solve these issues directly, Frontline Families provide much needed emotional support, build peer networks, offer information, listen to families’ concerns, improve resilience, mental health and wellbeing, and reduce feelings of loneliness and helplessness. Our aim is to equip and empower them with practical information and support to deal with the unique challenges that they face.

The survey ended with an opportunity to add any further comments. The responses to this question showed once again how important and highly valued the Frontline Families programmes are:

*“Thank you for your ongoing support ❤️”*

*“Front line families are doing amazing work and have helped so many families with SEN children “*

*“Frontline, immediate support is crucial. Being able to post vent or talk to someone right away and have support tight away is so emotionally needed. Thank you so much!”*

*“Thank you for all you do “*

*“Life is incredibly difficult for everyone right now but for families like us, it’s scary, dangerous and really worrying”*

*“The funding so far has been amazing to enable so many families to reach Yvonne's amazing work! Please keep up the good work. Thankyou”.*

*“Thank you for providing such a valuable service at this difficult time. “*

*“Thank you from an exhausted and worn out mother fighting the system.”*

*“Thank you for listening. We can’t celebrate Christmas; I remember what it used to be like. I miss it””*

We welcome discussions to explore how we can continue this much needed work.