

## Our year in numbers



182,000
parents with information, advice and support



We increased eligible household incomes by

by helping families claim the benefits they're entitled to

920,752 visitors spent time on the advice and support section of the website



Our private Facebook group, a safe space and online community network for parent carers, reached







Our campaigns achieved changes benefiting around

1M
family carers, and clinically
vulnerable and disabled children



**87%**of families felt more confident after receiving advice and support from us

# A message from our Chief Executive

The year 2021-22 saw much of the country return to some kind of normality. Sadly however, many families with disabled children continued to grapple with the fallout from the pandemic. Health and support services have not returned to pre-Covid levels, household finances are stretched ever-thinner, and thousands of disabled children continued to miss large chunks of school, either due to shielding, staffing issues or struggling to get back into a school routine.

Throughout the year Contact has made every effort to support and stand shoulder to shoulder with families with disabled children. Despite challenges, we have built on last year's growth to continue to reach out and support families in a wide range of ways with our vital and trusted information and our parent-led campaigns.

We continued to work towards our strategic aims of reaching more families and making our services more digitally accessible, freeing up our in-person support for the families who need it most. We have committed to retain our face-to-face work at the same level as we know how important that is to families, but as enquiries get more complex we are ensuring our Family Workers' time is spent with those most in need. And our impact figures for the year clearly show the difference this has made.

manden Saver

#### Amanda Batten

## Our objectives

We support families with the best possible guidance and information

(7-15)

We bring families together to support each other (16-17)

We help families to improve life for themselves and others

(18-21)



After finding out a child has a disability, families are faced with a maze of routes to support for their child and themselves. At a time of stress and emotional turmoil everything from getting a diagnosis, help with speech and language or getting equipment and adaptations to the home, as well as finding a suitable place at school, can become a battle.

And following the pandemic, families tell us that those battles are even harder with services hollowed out and parents physically and emotionally exhausted.

Contact's advice and information services, help families with information that is specific to them, helping to navigate those mazes. At the same time our advice team, many who are parent carers themselves, provide much needed emotional support.

## Making a big difference to families

Jen is mum to five-year-old Betty and they live in Dorset. Betty had a brain tumour when she was a baby and subsequently needs care and support with day-to-day tasks. Betty has been in remission from cancer for three years. She has just finished her first year of school, which she has loved.

Jen came across Contact during lockdown, when she attended one of our SEN workshops run by a solicitor about getting an Education, Health and Care plan (EHCP) for children with special educational needs.

Jen was in the process of getting an EHCP for Betty and found the process horrendous and very stressful. She said: "We came out of hospital and suddenly had to figure out where to get support for Betty and how. It was a lot to deal with after such a traumatic two years. I feel like the local authority don't want you to join the dots and get all the help to which you are entitled. Contact helps families to join those dots and it feels like they are on our side. I sign up to their weekly newsletter which has all the latest information for parents and I am in their campaign supporter network. It feels like they are making a really big difference to families like mine."

### Helpline and online

Our helpline advisers provided a first-rate service to families, advising them on issues including benefits, education, getting a diagnosis and getting support. The challenges families raise through the service continued to rise in complexity throughout the year.

Our helpline team of dedicated parent advisers dealt with almost

**11,000** enquiries

Families who used our information and advice service throughout the year reported that

92%
were better informed about how to get the support they need



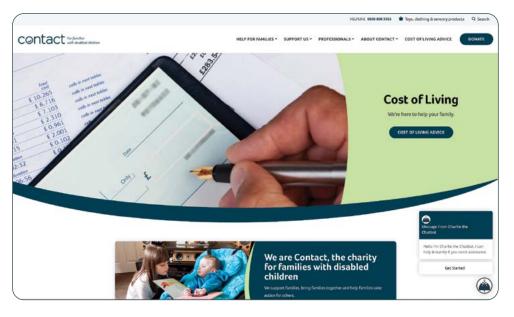


### **Digital Transformation**

As part of our digital transformation, outlined in our strategy, we continued to develop new online tools to enable families to resolve more straightforward or common enquiries directly. Throughout the year digital interactions further increased, building on the success of last year. Our most viewed pages were information about vaccines and Disability Living Allowance (DLA).

As planned, Contact's new website went live in April 2021. Funded by a major donor, this is a crucial step towards extending our reach. As a result of the new, more intuitive design and functionality it is easier for parents to find what they need.

We rolled out Live Chat on our website and expanded our Frequently Asked Questions sections, to help families navigate more easily to the information they need. During the year we also developed a chatbot – an exciting addition to our digital tools.



### **Family Finances**

Much of the team's work involve hour-long call backs where a family has a complex issue and we provide a detailed financial health check. As a result of our call back service, families reported significant improvements to their family's financial situation and 99% say they are better informed about their rights to benefits and grants.

In addition, we ran three Facebook Q&As, responding to 179 enquiries during these sessions. And we held a webinar on higher-rate mobility allowance for children with challenging behaviour, which had 270 live attendees and has since been viewed over 3,500 times.

Our Family Finances helpline answered

932
benefits enquiries
and completed

332 in-depth call-backs

Eligible families report being better off by an average of

**£5,050**a year, following a call-back from our Family Finances team.

## Helping families get financial help they are owed

For single mum Kohinoor, trying to make ends meet was becoming a daily struggle. With two boys, one who has severe learning difficulties, she was juggling being mum, parent carer and working part-time.

When she reached out to our helpline she felt she was owed some backdated Universal Credit, due to her son being awarded disability benefits. But staff at the Universal Credit office had refused her, seemingly unaware of special rules which allows this.

We drafted a request challenging the decision, setting out the rules and guidance. In addition we identified she was not getting the carer premium, and helped her apply for this. As a result of our support and advice, Kohinoor received arrears of almost £4,000.

In total in 2021/22, we increased eligible household incomes by £439,000 by helping families claim the benefits they're entitled to, but didn't know how or hadn't been able to claim.

Another of those families said: "What a great service. I am amazed at the information I've been given. I had no idea I was missing out. I had just phoned about getting a bursary and to be told I can get an extra £300 per month in benefits is amazing. You make such a big difference."

## **Listening Ear**

We introduced our Listening Ear service in response to the increased emotional needs of families during the pandemic. As it has become apparent that there is a continued need for this vital support we have prioritised and maintained the service.

The Parent Advisers in our Listening Ear team are all parents of children and young people with disabilities, plus they have a huge wealth of professional experience.

Our Listening Ear team supported

707
individual parents
throughout the year, with

947
appointments giving vital advice and support over the telephone



91%

of parents using the service felt better informed about how to get the support they need

## Helping families emotionally and practically

Holly, mum of five-year-old twins born prematurely was drained and exhausted, meeting the demands of two young children with additional needs, when she turned to Contact's Listening Ear service.

She wasn't getting any sleep and needed more space in the family home for her suddenly much larger family. Holly spoke to Shona, Contact's Senior Parent Adviser, by telephone on our Listening Ear service.

Shona gave Holly much-needed space to talk and offload. She provided her with advice about sleep and signed Holly up to one of Contact's in-demand workshops to learn about strategies to get a good bedtime routine. During a subsequent call, Shona was also able to advise Holly about getting a grant for home adaptations. This has meant the family is able to get an extension for more bedrooms which will enable them to care for the twins safely at home.

Holly said: "This is just a tiny snippet of the amazing support & guidance Shona provided (and still does). Contact's expertise, support and never-ending knowledge of how to fight such a draining system is life-changing. It has helped us get what we need for our children to make everyone's lives happier and less stressful."

## **Fledglings**

Contact's not-for-profit shop, Fledglings, continued to provide essential products and equipment to disabled children and their families to help make everyday tasks easier.

Fledglings sales to families with disabled children continued to grow in 2021/22 and the number of repeat customers increased.

Fledglings sales to special schools, maintained schools and healthcare settings also increased after being significantly impacted by the pandemic.

We launched a new project funded by corporate donations, that enables special schools in disadvantaged areas to be kitted out with Fledglings sensory toys and equipment. These help children be better prepared for learning and interacting with their classmates.



Part of the Contact family

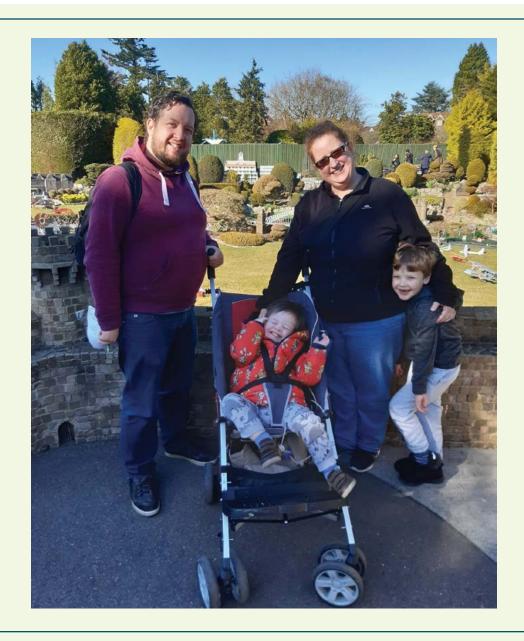


## Helping families in the early years

Gemma Diggins from London has two children. Her youngest, Ethan, aged four, has Down syndrome and a number of medical conditions, which requires him to see 21 different medical professionals at five different hospitals.

"The first parent workshop I went to was Contact's Early Years one and I loved it so much and found it so useful that I booked up for all the other Brighter Beginnings workshops that were available! I've also attended the workshop about handling meetings. I absolutely loved that one because it gave some really valuable advice and ideas about things I hadn't even thought about before, simple things like taking someone with you to your meetings with professionals to take notes for example. And the speech and language workshop really helped me understand that it's OK if Ethan is non-verbal as long as he can communicate with us in other ways.

"All the workshops I've been to have given me confidence and the knowledge to move forward and not feel so alone. The Contact team running the workshops has lived experience of caring for a child with additional needs and an amazing passion for their job which shines through. They share so much useful information – I've been raving about Contact to everyone I meet."



### Workshops

This year the number of parents reached through our online workshops has increased. Throughout the year we held 535 online workshops attended by 4,757 parents.

In response to parents' requests, over the year we developed a new range of workshop topics including, Understanding the Diagnosis, Getting ready for Transition (school aged children), Toilet Training, Supporting parents of children with Anxiety and Early Years Entitlements.

Throughout the year we continued offering our Brighter Beginnings workshops online, for parents of young children aged 0-8. Designed to tackle some of the unique challenges young families face in the early years, they cover topics including encouraging positive behaviour, understanding sleep and money matters. In total we held 65 Brighter Beginnings workshops attended by 1,147 parents.

of parents attending our
Brighter Beginnings workshops
reported feeling less isolated





## Reaching families in hospital

Our By Your Side project helps families facing the most difficult of times when their child needs hospital care.

We continued delivering our crucial support at the Royal Hospital for Children in Glasgow throughout the year and were delighted to be back supporting families at Birmingham Children's Hospital in February 2022.

At the Great North Children's Hospital in Newcastle, we held successful sleep and behaviour workshops for parents whose children are inpatients or regular attendees at the hospital. Paediatricians now refer parents to Contact for one-to-one support on sleep and behaviour issues. Of those parents we supported, 87% felt better able to manage their child's behaviour and 88% had more strategies to improve their child's sleep.

Our teams in the regions, nations and London, including By Your Side in hospitals, managed

3,413 enquiries and one-to-one appointments



## Supporting families around the UK

#### Northern Ireland

We launched a new Transitions project working with schools to provide workshops, peer support, career fairs and training for teachers to support disabled children and their families as they move to adult services. Our family workers continued to offer vital one-to-one support and advice to parent carers signposted to us by professionals such as clinicians, social workers and teachers.

#### Liverpool

At Alder Hey Hospital we worked with partners to run focus groups with patients about their experiences, and they made a number of recommendations to make the space more user friendly for children with sensory needs. These included offering sensory toys and ear defenders in specific areas, additional artwork, including a fun treasure trail to distract from crowds and noise.



#### Wales

Our Strengthening Support Network for Parent Carers project continued to reduce parent carers' loneliness. The project supports and encourages groups to reach out and help parents in their area. The team also trained parent carers to deliver workshops, giving them new work skills and confidence, and delivered Forest School events.

Thanks to funding from the Welsh Government, we were able to send 106 play boxes full of Fledglings sensory toys to families in Wales in most need.



#### Scotland

Our team worked closely with multiple statutory and charity groups to ensure the needs of disabled children are considered and parent carers voices are heard. We also provided information, one-to-one advice and workshops to parent carers, including Scottish-specific information such as on the new Child Disability Payment.

#### **North East**

We supported families at risk of their child needing admission to assessment and treatment units in the North East region. We worked with partners providing intensive support to work through issues and improve wellbeing in a bid to avoid crisis interventions.

#### London

We continued supporting families in Wandsworth, Ealing and Lewisham, and were delighted to get funding to start up again in Lambeth. Not only are our London teams providing support to families on important issues including housing, benefits and education, they also organise family meet-ups and events and trips to benefit the whole family's wellbeing.





In Ealing we secured funding to provide intensive support from neurodevelopmental teams to families awaiting assessment and diagnosis for their child. This is in line with our strategic aim of reaching out to families earlier in their journey. During the year this service was extended to Hounslow and Hammersmith and Fulham and has already shown positive results. As a result, we have expanded our team.

This year our London teams achieved the Advice Quality Standard accreditation, a nationally recognised quality mark.



We bring families together to support each other

Parents tell us time and again that they feel isolated as they don't know anyone else with a disabled child and don't get to meet other parents at toddler groups and the school gates, like other parents do. This isolation can have a negative impact on the health and wellbeing of the whole family. To combat this, Contact brings families together face-to-face or online, to build networks, connections and reduce isolation.

## **Family events**

Despite the challenges of continued lockdown disruptions, we held family fun days and events when restrictions allowed. They included forest school days, trips to Legoland and Silverstone, as well as activity sessions aimed at parent wellbeing such as online yoga.

We held

105

family events attended by

738

children and

969

parent carers

### **Better Together**

We were very pleased to launch our Better Together series of family events funded by the Masonic Charitable Foundation. These are designed for the whole family, and activities during the year included a virtual storytelling, cinema trips and the Lap of Lights event at Silverstone. Parents who attended said they felt less isolated (86%), and 75% of children said they made new friends.

### **Online communities**

We continue to run private Facebook groups for parent carers, which offer a safe space to come together online and to share challenges, joys and advice from lived experience. During the year our Contact group grew to 12,500 members and our HemiHelp group to 6,000. These groups are moderated by Contact, which allows us to give additional support and advice where needed.

### Parent support group grants

In 2021, we awarded grants to 83 parent carer forums and rare condition support groups to help them continue supporting local families of disabled children.

The grants – made possible thanks to a match-funding partnership between Pears Foundation and the Department for Digital, Culture, Media & Sport (DCMS) – formed part of the Government's £750m emergency Covid-19 funding charities package. The grants enabled local groups to continue supporting families at a time of great need.



There are more than one million disabled children in the UK. Sadly they still face significant discrimination and inequalities in many aspects of their lives. And the pandemic and cost of living crisis disproportionately affect families with disabled children. Together with families we campaign to change this.

More than 3,000 parents joined our Out of Energy campaign and signed our letter calling on government to give more financial help to disabled households, who are disproportionately affected by higher energy costs.

Aminah (aged 8) has Spinal Muscular Atrophy and needs a lot of electrical equipment essential for her quality and safety of life, including a lift in the family home, a CPAP machine, electrical bed and wheelchair.

Mum Noor said: "Both me and my husband work and we are just about holding it together. I feel so disheartened at how hard it is. Our energy use is high, because we need gadgets and life-saving equipment to help Aminah. There's literally nothing we can cut back on. It's not just energy, everything is going up. I've noticed an increase of £20-£30 in our weekly shopping bill. I find it scary that we are not being offered any help.

Our Out of Energy campaign resulted in a package of financial help from government, including a £150 for people on a disability benefit.

#### **Parent Carer Forums**

Despite the year's challenges, Parent Carer Forums and the parents who run them continued to champion the needs of others and support parents locally. The forums reached out to families still struggling with the aftermath of the pandemic and reflected their views and experiences in their meetings with local officials.

Contact's Parent Participation team supports Parent Carer Forums in all 151 local authorities in England. We provide a core offer of support for each Parent Carer Forum, including a dedicated Parent Carer Participation Adviser who forums can access via phone and email to help them run their forum effectively. During the year, the Parent Participation team provided 6,029 hours of support to Parent Carer Forums.

There are

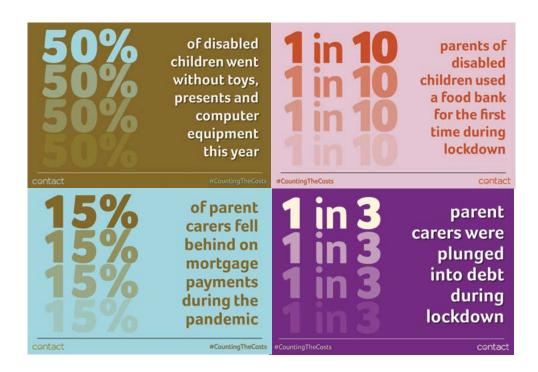
99,811 forum members, which is up from last year.



## **Counting the Costs 2021**

Our bi-annual research report has been collecting evidence on the finances of families with disabled children over the last 14 years. We know families with disabled children are more likely to live in poverty due to the difficulty of combining work and caring. The research has enabled us to campaign for further financial assistance for families. Over 4,000 parents responded to the 2021 Counting the Costs survey.

The results were published and featured on BBC 2 Newsnight and Channel 4 News. More than 600 supporters got involved and nearly 27 MPs took action. The report made a range of recommendations that we are working towards securing over the coming months.





## **Disabled Children's Partnership**

Contact continued its leading role in the campaign coalition group the Disabled Children's Partnership (DCP), which now comprises 100 disability charities.

This year, alongside parent carers, we took our message to Parliament calling for better education, health, and care support for disabled children.

In February the government announced £30 million of short breaks funding. This was a welcome step in creating a better health and care system of support for families with disabled children. Of course, there remains lots of work to be done and the Disabled Children's Partnership will continue the fight for more support.

## **Campaigns and media**

A large focus of the year was our campaign for priority access to the Covid vaccine for family carers and clinically vulnerable children. This was in direct response to families asking us to campaign on this. As a result, we formed a new alliance of health charities and influenced decision making in vaccine deployment prioritisation.

Our media work highlighting the issues experienced by families with disabled children reached over

29.5M
people with an equivalent advertising cost of

£988,500





## **Parent champions**

We help to build skills and confidence in parent carers to help them get the support they are entitled to, as well as other aspects of daily life including routes to paid employment. This year we trained a group of parents in giving interviews to the media and the power of sharing their story to affect change. We also secured funding to expand our parent champion work next year and are excited to build on this work. In Wales, we continued to give parents the opportunity to use their expertise to support others in a formal way.

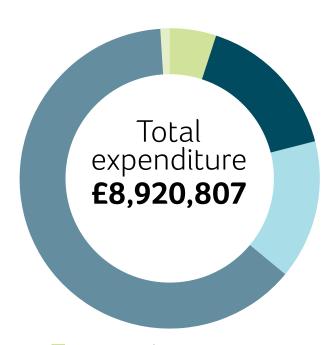
Lucy Roger from Powys in Wales attended Contact's workshops and was keen to be more involved with the charity. When the opportunity came up to become a Contact Parent representative, she jumped at the chance and has been delivering online drop in sessions with Welsh families, providing advice, information and support.

## **Our finances**



- National Lottery Community Fund £233,266 (3%)
- Charitable trusts£1,298,123 (15%)
- Special events/other £43,419 (<1%)
- Investment income £112,664 (1%)
- Individuals £313,249 (4%)

- Local government grants £65,449 (1%)
- Devolved nations government grants £1,007,997 (11%)
- UK government grants£5,363,677 (61%)
- Traded income £349,399 (4%)
- Property income £1,087 (<1%)



- Raising Funds £474,204 (5%)
- Supporting families central information, advice and support £1,429,264 (16%)
- Supporting families locally £1,307,458 (15%)
- Bringing families together £5,584,767 (63%)
- Helping families take action for others £125,114 (1%)

## Our incredible funders

Grants and donations from the Department for Education, National Lottery Community Fund, NHS England, local authorities, companies, trusts and foundations and philanthropists enabled Contact to deliver our life-changing services. We are incredibly grateful to our funders for their generosity during another challenging year for families, which ensured we could continue to provide our vital support.

Allen and Overy Foundation



John Ellerman



The Golden Bottle Trust

Basil Samuel Charitable Trust Fidelity UK Foundation





The Network for Social Change

**Bolt Burdon Kemp** 







Unum

**British Land** 



Next PLC



Catalyst Discovery Programme



Peacock Charitable Trust

Team Consulting

## Our awesome fundraisers

Our marathon marvels ran

286 miles raising over

**£30K** 



Special thanks to our longterm supporter Sheila Mumby who donated £1.000 in lieu of her annual theatre and dance production. Sheila from Nottinghamshire has been putting on dramatic shows in aid of Contact for decades, but this year was unable to due to Covid restrictions. However, Sheila still generously donated to help us continue to support UK families with disabled children.

Our fabulous fundraisers, who took part in marathons, bike rides, bake sales and coffee mornings throughout the year, raised almost

**£40K** 





Wellingborough Prep School raised an amazing £2,800 for Contact's hemiplegia services over the year through events including a Wheelathon (scooting around the school corridors), a pizza night, and Wear Red day.

Dad-of-two Agustin
Crespo took part
in the Deloitte ride
across England – a
nine-day event that
saw Agustin cycling a
gruelling 100 miles per
day, raising a marvellous
£1,000 for Contact.





Cake sales, coffee mornings, community donations and our annual fundraiser Dino Day raised

£6.5K

## Get in contact

FREEPHONE HELPLINE

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Access to interpreters helpline@contact.org.uk www.contact.org.uk

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.