

# CHANGING LIVES TOGETHER

ANNUAL REVIEW 2018/19



contact

*For families with disabled children*





# Changing lives together

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In many ways it has been a remarkable year for Contact. Despite the tough economic climate, this year we were able to end the financial year in a stronger position than we forecast.

And the beginning of 2019 marked Contact's 40th anniversary. We started as a charity in 1979, when a group of parents recognised the benefits of getting together with other families like theirs for friendship, and to share experiences and advice. Over time that group grew into Contact, a national charity providing trusted advice and information and valuable opportunities for families to get together to reduce isolation.

Importantly we continue to reach more families year on year, and the services we offer are making a real difference to them. Families grow in confidence and feel less isolated, helping them meet the challenges of caring and enjoy family life.

Thank you to everyone who has supported Contact – by campaigning alongside us, by sharing your story, by funding our charity, by baking cakes, running and cycling. Your support makes all the difference.

A handwritten signature in white ink that reads "Amanda Batten". The signature is fluid and cursive, with a long horizontal stroke at the end.

**Amanda Batten, CEO**

## Together we support

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We helped  
**108,000**  
families with  
information, advice  
and support

**4,038**  
parents attended our  
workshops, learning  
about rights and  
entitlements, and  
getting support for  
managing challenging  
behaviour and  
helping children with  
sleep issues

Our helpline  
provided advice to  
**10,644**  
families, with invaluable  
information on a range of  
issues including financial  
support and getting help for  
a child in school

## Together we change lives

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**100%**  
of families attending  
our Wellbeing  
programme said  
it helped them to  
cope better with the  
challenges of caring

**77%**  
of families feel  
less isolated after  
receiving support  
from us

**95%**  
of families feel  
better informed  
after receiving  
support from us



# Together we empower

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More than

**26,000**

supporters helped us lobby for change on key issues for families including school transport, social care, Universal Credit and education

There are

**88,293**

members of Parent Carer Forums in England, demonstrating the huge commitment made by parent carers to improve services in their local areas

**2,700**

families fed into our flagship research Counting the Costs

# Together at 40

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We launched our 40<sup>th</sup> anniversary year with our Together at 40 Awards. It seems right that during our birthday year, we shine a spotlight on the many positives that come with being a family with a disabled child and on the wonderful parent carer community we stand and work together with.

For the last four decades, Contact has been here to help. A lot has changed in that time, but sadly some of the issues families face remain the same. So we are still here when families need us. There are now one million disabled children in the UK. Finding out a child has a disability is frightening and overwhelming. No family should face this difficult time alone.

**With your help we will continue to be here for all families with disabled children.**

# Together we get it right from the start

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**94%**

of parents feel that  
Contact's Brighter  
Beginnings programme  
made a positive  
difference to them and  
their family



Getting support early can be the difference between flourishing or spiralling into crisis for families with disabled children.

Our Helpful Guide and Brighter Beginnings programme have helped us to reach families when their children are still young, ensuring they feel valued, supported, confident and informed, rather than left alone in desperation without support.

Our Brighter Beginnings workshops help to build the skills and confidence of parents with young disabled children, as well as bringing families together to build networks of friends and support.

This year we held 13 series of four to six week Brighter Beginnings workshops, with 88 parents attending.

We engaged independent researchers, Fiveways, to evaluate our Brighter Beginnings workshops. They found they made a positive difference to almost all (94%) parents who attended. They reduced isolation by half and 52% of parents took up services following the programme.

*"I have found your Contact Helpful Guide absolutely invaluable, and I am just disappointed that I only came across it a few months back after four years of struggling my way through the 'system'."*

**Mum Katherine, whose four year old daughter Elsie has a unique chromosome deletion.**

*"Oshi is the youngest of our four children and is the first to have health issues. It's had a huge impact on us as parents and our health has suffered.*

*"I attended Contact's Brighter Beginnings workshops after being encouraged by my Portage worker to go along. I learnt an awful lot and I'm so pleased I went. Before this group I felt quite isolated. All the extra issues we had to deal with for Oshi stopped us going anywhere, and I ended up not wanting to leave the house. It was such a relief to find the Brighter Beginnings group to be so friendly and welcoming.*

*"The workshops increased my confidence and taught me that I'm doing the best I can. I found out so much information about local groups and organisations that could help us. I also made several friends, and we have met up since. I found that although our children's issues were different, we had a common understanding which I really appreciated.*

*"Since doing the Brighter Beginnings workshops, my stress has reduced, as I'm now able to reassure myself I'm doing my best and I'm not on my own."*

**Victoria is mum to Oshi who is two and a half and has a rare genetic condition, global development delay, speech and language difficulties and Type 1 diabetes.**

# Together we help at times of crisis

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## BY YOUR SIDE

Our By Your Side project team worked in five NHS children's hospitals throughout the year. Our specialist parent advisers meet families inside the hospital, providing them with emotional support and practical advice. Families with children in hospital can face overwhelming levels of stress and trauma. They may have just received a diagnosis and be coming to terms with what that means for their child. Or their child may have ongoing assessments and critical treatments. Following our support, 98% of parents felt better informed about how to get the support they need, and 84% felt more confident.

## WELLBEING

Our Wellbeing programme made a real difference to families attending this year. The Me-Time activities and sessions for parents and siblings are designed to build resilience and coping strategies. They include fun, recreational activities that they choose themselves. Those attending reported better relationships within the family and reduced stress levels, helping them cope with the challenges of caring.

**1,393**  
families received  
emotional and  
practical support  
in hospital from  
our By Your Side  
programme

More than  
**£5,000**  
per year better  
off after advice  
from our Family  
Finances team

## FAMILY FINANCES

Our dedicated Family Finances helpline team provide expert advice to families with disabled children about financial support. Families with disabled children are more likely to live in poverty because of the extra costs of raising a disabled child and the difficulty of combining work and caring. It can make the world of difference to a family getting the financial support they are entitled to. After receiving help from our Family Finances team, those families who were expected to gain income were better off by an average of more than £100 per week or more than £5,000 per year.

## INFORMATION AND ADVICE

Our helpline took over 10,000 calls this year from families looking for guidance on a range of difficulties, including getting a diagnosis or support for their child at home, and understanding their rights around help in school. Our website and digital channels continue to be a trusted source of easy-to-understand information, helping families searching for answers at any time of the day or night. Parents report feeling better and informed and more confident after receiving Contact's advice.



*"I called your helpline in quite a desperate state. I was struggling financially and very isolated. It turned out we were missing out on much needed financial support - because we have two disabled children, both my husband and I can claim Carers Allowance which we didn't realise. That increased our benefits considerably. Not only that but because my son was so severely disabled you informed me that he could qualify for his own bedroom which increased our housing benefit."*

**Miriam Gwynne mum to 11-year-old twins Isaac and Naomi. Isaac has neurofibromatosis type 1 and Naomi has autism.**

# 100%

of families attending our Wellbeing programme said it helped them to cope better with the challenges of caring



# Bringing families together for support

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Putting families in touch with others for support remains at the heart of what Contact does. We do this through workshops and family events, and we support the parent carer participation programme in England, all of which continued to be popular and thrive throughout the year.

This year we were proud to mark the 10th anniversary of the Parent Carer Forum network, which involves more than 88,293 parent carers working at a local, regional and national level to improve services for disabled children and their families.

Our Family Fun days are a chance for families to get together with others in a similar situation, to relax, have fun as a family and make connections and friendships. This year 2,834 parents and children came along to one of our 58 family fun days, which included trips to the seaside, art workshops, sports days, and outdoor forest school events. Contact's Forest School project was featured in a BBC One Countryfile programme in October 2018, highlighting the positive impact of families and disabled children getting outdoors and enjoying nature together.

We also bring families together online in our lively Facebook community.

*"We are the grandparents of a happy, funny, affectionate and beautiful six year old boy called Jamie. He also has ASD and associated sensory problems and learning difficulties. Supporting a child with special needs can be an isolating experience for anyone; in our case the feeling of isolation is increased because we are the 'wrong' generation as well.*

*"We got in touch with Lewisham Contact after we received Jamie's diagnosis, and the welcome, understanding, friendliness and acceptance which we have felt from everyone involved has meant a great deal to us. We have recently attended some wonderful events and one of the most liberating things about them is that Jamie is accepted, by everyone, as Jamie. He can be as exuberant as he likes, he can squeal with delight, he can jump up and down, he can shout. It's impossible to overestimate the value of feeling totally accepted for who you are, whether you are carer or child. Contact provides a space where support is available and acceptance is total."*

**Ruth Hathaway, grandma to Jamie who has autism.**

2,834

children and parents  
came to our Family  
Fun Days

more than  
40,000

followers on Facebook shared  
tips and information



# Together we support all families

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Life can be particularly challenging for families whose child has a rare condition. Finding information and support is all the more difficult when you are faced with professionals who have never heard of a condition and don't understand how it affects a child.

Our rare conditions information officer has information on over 2,000 rare conditions, along with details of support groups available and where families can get help. Our Medical Advisory Panel is made up of paediatric consultants and professors, and helps us to ensure the accuracy and validity of our medical information.

And all our services – from our helpline to our family events – are open to all families with disabled children, including those with a rare condition or those without a diagnosis.





*“At the end of 2017 Andrew had a severe and rapid regression of his condition, becoming a wheelchair user, needing to be tube fed and no longer able to communicate within the space of a few months. Faith has been a great sister to Andrew, comforting him if he seems distressed, reading him stories and sitting next to him in his chair for a wee chat. Faith has been attending the siblings group through Contact’s Wellbeing project. She has found it really beneficial to spend time with other siblings of children with additional needs. She was initially nervous but now often asks when the next one is and can’t wait to go.”*

**Joanne McFarland from County Tyrone in Northern Ireland has two children, Faith aged seven and nine-year-old Andrew who has Batten disease, a rare and life limiting condition.**



# Together we are building partnerships

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**5,000**  
members in our  
Hemihelp Facebook  
group

**450+**  
products that help  
children with  
additional needs are  
on sale in our new  
online Fledglings  
shop

Building partnerships with others to maximise impact, continues to be central to the way that we work at Contact. This partnership work took a more formal route this year, as we welcomed charities HemiHelp and Fledglings into Contact.

Both charities were at risk of closure and approached Contact to ensure their services continued for families in need. Throughout the year we transitioned the services that HemiHelp provide to families living with hemiplegia. There is great synergy between HemiHelp and Contact's services and we are delighted that we have been able to continue the support to families whose children have hemiplegia. We are now offering families a more holistic service and recording a significant impact.

We know that families often don't know what equipment or support is available, and having the right aids in place can make a real difference to families' lives. In February 2019, we took over Fledglings, a national charity providing products, equipment, toys and practical advice to families with disabled children. The takeover now enables families to access products that make day-to-day tasks easier for children and families in the same trusted place as Contact's wider support offer.

# Together we are empowering families

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We continued to lead the Disabled Children's Partnership, bringing together more than 70 charities to have a louder voice for change. Throughout the year we worked towards the launch of the Give It Back campaign, in partnership with The Sun newspaper, calling on the government to give back the money cut from disabled children's services.

We launched our flagship research Counting the Costs in 2018 to raise awareness of the unique financial difficulties that families face, which was featured on BBC Radio 4's Woman's Hour and in The Guardian newspaper.

We highlighted the impact of cuts to school transport for disabled children and their families. 10,000 families signed our petition calling on the government to stop more and more disabled teenagers being denied free school transport, which two amazing families delivered to Downing Street.

Over the year we reached 838,645 people through our digital media channels. This includes Facebook, Twitter, YouTube, as well as users of our online community and visitors to our website – that's an average of 209,661 digital users each quarter.

**10,000<sup>+</sup>**  
families signed our  
petition against school  
transport cuts

We reached  
**838,645**  
people through our  
digital media channels





Our media work  
helped us reach  
an audience of  
**16.2M**  
people with our  
messages

# Our awesome supporters

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Our awesome supporters, who took part in marathons, bike rides, bake sales, raffles and coffee mornings throughout the year, raised an amazing

**£46,888**



**288**  
miles run, raising  
**£31,913**

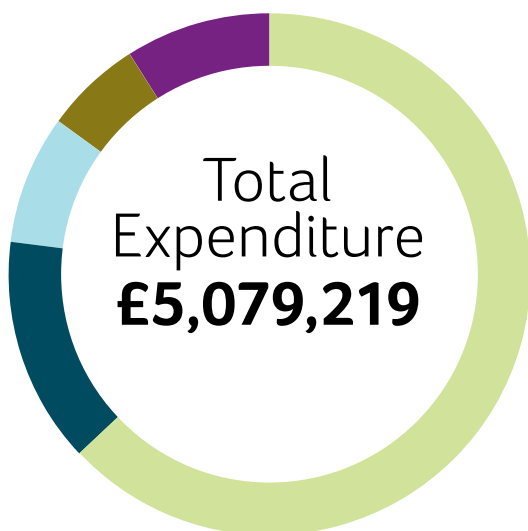
Bake sales, band nights  
and picnics, held across  
the country raised

**£6,597**

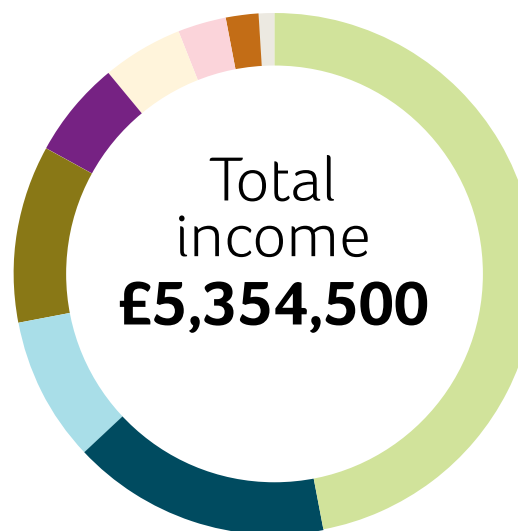
**760**  
miles covered by cyclists,  
trekkers and skydivers raising  
**£8,378**



# Our finances



- Engagement and Support Services  
£3,221,950 (63%)
- London Community Projects  
£718,614 (14%)
- Cost of Generating Funds  
£406,235 (8%)
- Policy and Communications  
£294,620 (6%)
- National Development  
£437,800 (9%)



- UK Government Grants  
£2,527,743 (47%)
- Big Lottery Fund  
£865,454 (16%)
- Local Government Grants  
£482,723 (9%)
- Individuals  
£563,502 (11%)
- Charitable Trusts  
£353,150 (6%)
- Special Events/Other  
£261,223 (5%)
- Devolved Nations Government Grants  
£137,642 (3%)
- Investment Income  
£861 (0%)
- Traded Income  
£97,315 (2%)
- Property Income  
£64,887 (1%)

# Our incredible funders

The achievements highlighted in this annual review would not have been possible without the vital support of our funders. Grants and donations from the Department for Education, Big Lottery Fund, NHS England, local authorities, companies, trusts and foundations and philanthropists enabled Contact to deliver our life-changing services. We are extremely grateful for their support.

Bolt Burdon Kemp  
 BioMarin  
 Community Development and Health Network  
 Fidelity International  
 Freddie Wakeham's Charitable Trust  
 Gale Family Charity Trust  
 George & Esme Pollitzer Charitable Settlement  
 GM Morrisson Charitable Trust  
 Gwendoline and Margaret Davies Charity  
 Hadrian Trust  
 Holskjaer Charitable Trust  
 John Lyon's Charity  
 Next PLC  
 Pears Foundation  
 PF Charitable Trust  
 Rachel Charitable Trust  
 Sir James Knott Trust  
 Sir James Roll Trust  
 Souter Charitable Trust  
 Team Consulting  
 The Atlantic Foundation  
 The Ballinger Charitable Trust  
 The Barbour Foundation

The Benham Charitable Settlement  
 The Calleva Foundation  
 The De Brye Charitable Trust  
 The D'Oyly Carte Charitable Trust  
 The Ernest Kleinwort Charitable Trust  
 The Evan Cornish Foundation  
 The Eveson Charitable Trust  
 The Golden Bottle Trust  
 The Goodenough Charitable Trust  
 The Hugh Fraser Foundation  
 The Ione Vassiliou Charitable Trust  
 The Iron Bridge Trust  
 The Lake House Charitable Foundation  
 The Lawson Charitable Trust  
 The Mildred Duvén Charitable Trust  
 The Pilkington Charities Fund  
 The Sobell Foundation  
 The Steve Morgan Foundation  
 The Strangward Trust  
 The Walter Guinness Charitable Trust  
 The White Oak Charitable Trust  
 The Wixamtree Trust  
 The Wyfold Charitable Trust  
 Vera Outhwaite Charitable Trust  
 Westminster Foundation



Big Lottery Fund



Department for Education



Bolt Burdon Kemp



Esmee Fairbairn Foundation



Children in Need - Wales



Garfield Weston Foundation



Comic Relief



Pears Foundation





# GET IN CONTACT

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FREEPHONE HELPLINE

**0808 808 3555**

Access to interpreters  
helpline@contact.org.uk  
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Open 9.30am–5pm Monday to Friday

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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.