



contact

TOGETHER
AT
40
AWARDS

celebrating families with
disabled children

8 JULY 2019 IN THE MEMBERS' DINING ROOM AT THE PALACE OF WESTMINSTER



FOREWORD

from the Rt Hon Sir Mike Penning, MP

I'm delighted to host Contact's Together at 40 Awards in the Members' Dining Room, to celebrate the wonderful achievements of families with disabled children. Contact established these awards to recognise the countless and often unseen things families do when caring for disabled children. In this booklet you'll be able to read the inspiring stories of the 22 finalists, shortlisted from 500 entries. It's clear from the stories they've shared that families with disabled children give back to our community and economy in so many different ways we don't recognise.

I've seen first-hand in my constituency how much families with disabled children give back to their community and economy. It is a pleasure to be able to welcome all of the families to Parliament and celebrate with them.

We would like to thank our judges Gill Ackers, Charlotte Warner and Soraya Wetherell

WELCOME

Amanda Batten, CEO of Contact

At Contact we often hear about when things go wrong for families, such as the difficulties of getting the right support. This isn't surprising as that's what we are here for. But it's important to recognise when things go right and come together to celebrate.

Our Together at 40 Awards are a celebration of the countless and often unrecognised achievements of families with disabled children up and down the country. It seems right that during our 40th 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.

These fantastic awards are not only for the winners in each category, they are for all families, a community of people on your side. And ultimately that's what Contact is.



Jane Garvey, BBC Radio 4 Women's Hour

I'm delighted to be presenting Contact's Awards once again this year. There's something really lovely about celebrating the extraordinary achievements of families with disabled children – despite the daily challenges they often face.

“These awards, like Contact, are unique. Not only do they recognise the many and often hidden things families across the UK do day in day out when caring for a disabled child, they also highlight the many different ways families with disabled children give back to our communities and economy. It's a real pleasure to play a part in these awards in Contact's 40th anniversary year and help share all of these families' inspiring stories.

HOW WE HELP

We are Contact, the charity for families with disabled children. We understand that life with a disabled child brings unique challenges, and we exist to help families feel valued, supported, confident and informed.

To make that happen, we work in three closely linked ways. We support families with the best possible guidance and information. We bring families together in local groups and online, to support each other by sharing experiences and advice. And we help families to campaign, volunteer, fundraise and shape local services to improve life for themselves and others.

How you can help

Right now, we're not able to reach all families with disabled children. We want to reach more families and to be there as soon as they need us. We can only do this by raising more money. Your support could be life changing.

You can make a donation online, and be there for families when they need it most:

www.contact.org.uk/donate

SHORTLISTED NOMINATIONS

Parent Carer Award:

Jo Hercules from Buckinghamshire

Iain and Annie Petherick from Wiltshire

Rory Ellison from Sheffield

Proudest Moment Award:

Rachel Ronan from Wiltshire

Naomi Gwynne from Lanarkshire

Jack and Tom Bosanquet from Nottinghamshire

Sibling Award:

Caleb Cunningham from Southport

Freya Middleweek from London

Sebastian Black from London

Faith McFarland from Co Tyrone

Grandparents Award:

Pam Johnson from Newport

Mr & Mrs Strong from Berkshire

Carol Brades from London

We Care About Rare Award:

Hope Burchell from Essex

Cameron Alderman from Bristol

Ashley/Turner family from Lincolnshire

Parent Power Award:

Hayley Wedgbury from London

Nascot Lawn Campaign from Hertfordshire

Marcia Collins from Manchester

Excellence in Parent Carer Participation:

South Glos Parents and Carers

Bristol Parent Carers

York Parent Carer Forum

PARENT CARER AWARD

Recognising the amazing things parent carers do to ensure their disabled children can take part in everyday life.



“Every parent should have as much fun and joy with their child as Jo has with Mia and every child, disabled or not, should have a parent like Jo.”

JO HERCULES Buckinghamshire, England

Jo was nominated by her friend Gail Walshe. Jo is mum to three children Mia, aged 12, Frankie, 17, and Max, 19. Gail told us:

“Jo is mum to three amazing young people, the youngest of whom, Mia, has Down Syndrome. Jo and Mia clearly adore each other and have so much fun together. Mia loves her dolls and expects Jo to hide them in the car every day for the journey to school (a 24 mile round trip). Mia also loves it when Jo role plays with her dolls, so Jo has to pretend to be an angry Spanish lady every day which never fails to make Mia laugh.

“They do car-pool karaoke together and it is impossible to tell who’s having more fun. Every parent should have as much fun and joy with their child as Jo has with Mia and every child, disabled or not, should have a parent like Jo.

“Jo has health issues of her own, but this doesn’t stop her having as much fun as possible and still fighting for the support Mia needs in school to be the independent woman she will one day become.”

IAIN & ANNIE PETHERICK Wiltshire, England

Iain and Annie Petherick were nominated by their friend Hannah Burville and Sabrina Beedie, a staff member at their son’s respite centre. They have three children, Freddie, 9, Ollie, 8 and Penny, 2. Hannah and Sabrina told us:

“Ollie has Angelman Syndrome, which affects just one in 12,000 children. He is a happy little boy, always smiling and giggling. They are an amazing family who do everything within their power to make sure Ollie has all the opportunities possible. Annie writes a blog about all the things she goes through so other parents with disabled children know they aren’t alone. She always makes it funny and sees the best out of some pretty trying situations! They also have two other children whom are very much loved and the bond between the whole family is amazing. We admire their attitude and hope that they realise they are admired from afar!”



“We use Contact’s website as the advice and information on there is invaluable.”



RORY ELLISON Sheffield, England

Rory was nominated by his wife Leanne. He is step-dad to 11-year-old twin boys Oliver and Jacob, and they have a daughter Lydia aged 6. Leanne told us:

“Oliver has cerebral palsy as a result of brain damage prior to his birth. He requires help with all aspects of daily life. As a toddler he was incredibly frustrated by his disabilities and spent most of his days screaming.

“It was at this time I met Rory. Where lots of men would have found the situation very difficult, Rory came into our lives and transformed them. Through his love and determination to help Oliver succeed, Oliver changed from an angry, unhappy toddler to a bright, chatty, happy little boy.

“Rory always has time for Oliver and has spent hours, days, months teaching Oliver to do things that doctors said he would never do. So much so that Oliver now drives his own power assisted wheelchair.

“Rory also goes out of his way to ensure Oliver has fun and enjoys life. Oliver and Jacob love football and are big Sheffield Wednesday fans so Rory gives up every weekend to take them to football matches in the city and around the country.”

“We’ve found Contact to be a huge support on social media. I discovered Contact through an article about how much more expensive it is to have a disabled child. At the time I was feeling this too and it was a support to know I wasn’t alone.”

PROUDEST MOMENT AWARD

Recognising the challenges your disabled child has overcome that fill you with pride and make you smile.



“Contact helps us as parents keep fully informed of everything going on related to caring.”

RACHEL RONAN Wiltshire, England

Rachel, six, was nominated by mum Bracken for her determination and resilience in proving medics wrong and reaching the monumental milestone of starting school full-time this year. Rachel has spent two of her six years of life in hospital. She has 22q11.2 deletion and Congenital Heart Disease and lives at home with her mum and dad, Mick. Bracken told us:

“During Rachel’s last episode of hospitalisation in January 2018, which lasted seven months, we were told that we should make the most of things, and there was limited hope for her future. But since then, Rachel has shown determination, resilience and constantly proved everyone wrong. She got stronger and was weaned off the ventilator by summer last year and she started at Frogwell Primary school in Chippenham part-time in September, going full-time in January. We were so proud!

“She is tired, and some days finds school a challenge due to her ongoing health problems, but she is such a happy girl and her positivity in such an inspiration to all of us. Every illness she has, she bounces back from, and continues to make progress.

“Thankfully Rachel has an amazing team of doctors from Bristol Royal Hospital for Children around her, and the school and hospice workers from Julia’s House Children’s Hospice are also wonderful and have helped us through recent years.”

NAOMI GWYNNE Lanarkshire, Scotland

Naomi, 10, has selective mutism and autism, and was nominated by mum Miriam. Earlier this year she came up with a clever way of letting her classmates and teachers hear her voice for the very first time. Miriam told us:

“Naomi’s class were doing Scottish poems, and she practised and practised a Bill Keys poem at home but just couldn’t speak in school due to extreme anxiety. So she suggested recording herself at home. The next morning she woke asking if her class teacher could hear her voice, so we went into school early and let her teacher watch the video. Her teacher cried. Her teacher asked if the rest of her classmates could hear her voice.

“Naomi agreed and the next day when the other children were reciting the poem they got to watch Naomi do the same via video. She even agreed to her video (and voice) being played in assembly so the entire school got to hear her voice for the first time ever!”



“I called Contact’s helpline in quite a desperate state. The Family Finance team did a benefits check and increased our financial support considerably. Without Contact I honestly don’t know where we would be.”



“They have shown real determination and courage to follow their dreams and make the most of their many talents.”

JACK & TOM BOSANQUET Nottinghamshire, England

Brothers Jack, 19, and Tom, 16, were nominated by their mum Claire. Both have Duchenne Muscular Dystrophy and are full-time wheelchair users. They have shown real determination and courage to follow their dreams and make the most of their many talents. Claire told us:

“Jack has successfully started a degree in Biology at Birmingham University. He has matured into a confident young man who deals with all that life throws at him calmly. This includes living away from home with 24 hour care support and handling weekly medical appointments. His determination to succeed in the face of chronic fatigue and progressive physical decline is inspiring.

“His brother Tom has challenges with his learning too. We are extremely proud of his determination to succeed and work ethic to try and get to college to study a music-related course. He lights up the room, always wakes with a smile and faces the challenges of his condition positively every day. They are amazing (but then I am slightly biased)!”

SIBLING AWARD

Celebrating the often unseen but great things siblings do for their disabled brothers and sisters, or that help make mum and dad's lives just that little bit easier.



“They are the best of friends... Caleb insists we don't do anything without Noah.”

CALEB CUNNINGHAM

Southport, England

Caleb, aged 13, was nominated by his mum Vicki. Caleb is the youngest of four boys. He lives at home with his mum and 15-year-old brother Noah who has Duchenne Muscular Dystrophy, as brothers Jacob aged 21 and Morgan 20 have left home. Vicki told us:

“We are a very close family. Caleb is the most caring selfless person I know. Caleb puts Noah above everything else. He cares for him, feeds him, helps him with absolutely everything as Noah can only use his hands. They are the best of friends and enjoy playing Fifa and F1 on their Playstation together. We all enjoy watching Everton, we have season tickets and the boys are so passionate about their team! Caleb insists we don't do anything without Noah, so he does miss out on things that other youngsters of his age are doing.

“I had unexpected brain surgery two years ago leaving me with a long recovery. I have a brain condition and needed an emergency shunt inserted which left me out of action for six months. I had to rely on my parents, sister, aunts, friends and Noah's carers. Throughout this time Caleb was a superstar, he was an even bigger support to Noah and to me.”

FREYA MIDDLEWEEK

London, England

Freya, aged 8, was nominated by her mum Louisa. Freya is big sister to Lucy, aged 5, who has autism spectrum disorder. Freya is an extraordinary big sister to Lucy and they have a close bond. Freya is always looking out for Lucy and raising awareness of autism with other children at her school. Louisa told us:

“Freya is constantly supporting and encouraging Lucy. She's very patient with her and has a unique ability to make her sister laugh. Freya is a wonderful human being and not once has she ever complained or moaned about the fact that sometimes we have to do things differently to her friends' families.

“Freya was incredibly disappointed that Lucy is unable to attend the same school as her, as Lucy attends a specialist setting. Last year Freya entered herself in to the school talent show to sing and sign Makaton to the song 'A Thousand Years'. She wanted to show her school friends how her sister communicates through signing. She practised and practised and performed on her own to the whole school. When asked at school what her favourite thing in the world is, she answered 'Lucy'.

“Freya has an unending enthusiasm for life and goes to great lengths to ensure that Lucy is happy, making all our lives easier. She is super creative and draws from the minute she gets up until the minute she goes to bed. She is also a passionate environmentalist and writes letters to every business we come across if they still use plastic straws! She talks continuously about what she'll change if she's Prime Minister and we think it'd be great if she was.”



“I am signed up to Contact's Facebook page and have used the information on there for advice.”

We would like to thank the kind sponsor of our Sibling award, Fidelity International





FAITH MCFARLAND

Co Tyrone, Northern Ireland

Faith, aged 7, was nominated by mum Joanne. Her brother Andrew, aged 9, has a variant form of late infantile Batten disease. Joanne told us:

“Faith and Andrew used to do everything together - Faith mostly was the boss! 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 was left in the care of various family members whilst my husband Graham and I were at the hospital with Andrew, not understanding what was happening. When we eventually moved to the hospice to spend Christmas together, Faith talked and played with Andrew as she always had, and he laughed and smiled - which we hadn't seen for quite some time.

“Since then Faith has been a great sister to Andrew. She instinctively copies what she sees us do - tilting his head forward or patting his chest if he coughs, pressing the button on his feed machine if it bleeps, comforting him if he seems distressed, reading him stories and jumping in bed or on his chair beside him just for a wee chat.”

“Faith has been attending a siblings group through Contact and has really found it 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!”

SEBASTIAN BLACK

London, England

Sebastian, aged 8, was nominated by his mum Kylie. Sebastian's brother Mylo was born with Donnai Barrow Syndrome; an exceedingly rare syndrome of which little is known about. He is deaf and blind. Doctors fought tirelessly to save Mylo, but at the age of six Sebastian was facing the potential loss of his much wanted, much loved baby brother. Kylie told us:

“Over the last two years Sebastian has thrown himself into being the best big brother he can be for Mylo.

“Sebastian signs with Mylo and plays games that cater to his brother's sensory impairments and helps with all of his therapies. He has been able to engage in Art Therapy with Mylo and has gone to amazing lengths to combat Mylo's tactile defensiveness and sensory processing disorder. Sebastian plays the piano and guitar for Mylo and always lets him have his glasses at the end of the school day, which sound like small things but these are all the things that make Mylo love his big brother so much.

“Sebastian has never once asked 'why me?' he has never complained that Mylo isn't something more than what he is, he accepts Mylo with his whole heart and absolutely loves his little brother endlessly. Sebastian is the definition of the word 'big brother.'”



“Sebastian accepts Mylo with his whole heart and absolutely loves his little brother endlessly. Sebastian is the definition of the word 'big brother.'”

GRANDPARENT AWARD

Recognising all the wonderful and everyday things grandparents do for their family.



“She is literally one in a million... Theo adores his nanny - and so do we!”

PAM JOHNSON

Newport, Wales

Pam was nominated by her granddaughter Leigh McFarlane and Pam’s great grandson Theo who is 5. Theo has autism and significant speech and language delay. Leigh says:

“I nominated my grandmother for an award because honestly without her my life would be so different! Theo can be extremely challenging. However, my grandmother has him every day after school alongside his brother and sister so I can continue my career. This enables me to feel fulfilled so I then have the mind-set and energy to make sure my kids feel fulfilled.

“On top of this, she also volunteers for the parent teacher association at Theo’s school and she has provided many children with additional needs there with parties, activities and initiated fundraising opportunities to help the school that Theo attends! She is literally one in a million and without her our quality of life and life satisfaction would be so different. Theo adores his nanny - and so do we!”



“I truly believe my Nan is outstanding. She puts my child’s needs before herself and anybody else’s.”

CAROL BRADES

London, England

Carol was nominated by her granddaughter Emily. Carol’s great granddaughter Freya is 14 months-old and was recently diagnosed with cerebral palsy. Emily says:

“My Nan Carol is 76 years old and an absolute godsend! I have to go out to work and my Nan looks after Freya 2 or 3 times a week. She makes sure she attends play groups and is always there for me to attend appointments with Freya if I can’t. She does my daughter’s physio every day and has to travel on buses and public transport – all so that my daughter gets the care she needs and I can manage my job.

I truly believe my Nan is outstanding. She puts my child’s needs before herself and anybody else’s. I’ve already noticed a massive positive change in my daughter and I think most of this is from what my Nan does with her. I want to show my Nan just how much her hard work has paid off and how valuable she is to not just me but my daughter who absolutely adores her great Nan.”

MR & MRS STRONG

Berkshire, England

Jude was diagnosed with right-sided hemiplegia at 6 months old. Samantha is a single mum and lives with her parents, who have been her support system ever since. She says:

My parents are so incredibly supportive. Since the diagnosis they have rallied around and been my support system.

They have been by our sides through every hospital appointment, doctors visits, physiotherapy. They have both researched hemiplegic cerebral palsy as thoroughly as they can to gain a better understanding of how to help Jude. They were both there to see Jude learn to crawl and to take his first steps at 18 months old, a hugely proud and emotional moment.

“My parents are so incredibly supportive. Since the diagnosis they have rallied around and been my support system.”

WE CARE ABOUT RARE

Recognising a child or family with a rare condition and how they champion being rare.



“We are very proud of Hope because she doesn’t let her rareness get in the way of living a selfless life.”

HOPE BURCHELL

Essex, England

Hope, aged 13, was nominated by mum Stephanie. Hope was born with Congenital Central Hypoventilation Syndrome, an extremely rare condition, which means she does not breathe when she’s asleep so needs a ventilator to keep her alive. She lives at home with her mum and dad, Gavin, and has a brother and three sisters. Stephanie told us:

“Hope is 1 in 2 billion and was only expected to live a few days but has proved the doctors wrong at every stage. She now enjoys dancing, musicals and school. She doesn’t let her condition define her, and goes out of her way to help others. Last year Hope was asked to share her story in order to raise money for a travel incubator at Addenbrookes hospital. Hope travelled in a travel incubator when she was 4 days old to Addenbrookes in Cambridge. She’s now 13 and jumped at the chance of spreading her rare story. The campaign raised over £40,000 – apparently the biggest donation ever raised for one of these campaigns.

“We are very proud of Hope because she doesn’t let her rareness get in the way of living a selfless life.”

We would like to thank the kind sponsors of our We Care About Rare award, BioMarin.

CAMERON ALDERMAN

Bristol, England

Six-year-old Cameron was nominated by mum Carla and family friends Hannah and Denise. Cameron was born with Norrie Disease, a rare genetic condition causing blindness and progressive hearing loss. Carla told us:

“I am so proud of all the battles Cameron has overcome. Finding out about his condition at just 8 weeks was very frightening but Cameron soon taught us to remain positive and celebrate every little milestone he achieved.

“Through our Facebook page Cameron has taught so many people about Norrie Disease, and about differences in the world. I feel he has helped give other parents who are just starting out on this journey hope from afar! He has an unforgettable smile and the most radiant personality.”



“We have a copy of Contact’s Helpful Guide, which has been a great help in signposting us to relevant websites, benefits and services.”



“It’s not always easy to have a ‘normal’ life when you live with a rare condition but we try to have fun as a family.”

ASHLEY/TURNER FAMILY

Lincolnshire, England

Mum Emma-Jayne nominated her family for their dedication to raise awareness and fund research into Congenital Myotonic Dystrophy, a very rare, life limiting condition. She told us:

“Dregan was diagnosed aged 15, after years of misdiagnosis. Receiving the diagnosis was a relief as we finally had an answer, but this didn’t last long once we realised what it actually meant. He inherited the condition from his biological father, who was diagnosed not long after Dregan and passed away suddenly aged 39. We didn’t know it was in the family so the diagnosis was a huge shock.

“Dregan is funny, kind, loving, and a big brother to Xander and River. Even though his brothers don’t have the condition they cope amazingly with the impact it has on Dregan and our family – often better than the adults do!

“It’s not always easy to have a ‘normal’ life living with a rare condition but we try to have fun and make sure we support the younger boys as siblings can often get overlooked. Dregan’s step-father and myself decided to dedicate our lives to raising awareness of Myotonic Dystrophy and advocating for those with this rare condition, their loved ones and carers. Dregan is rare – and we are proud – we want everyone to know so we can maybe show that actually it’s not as rare as we were told – just not known about!”

PARENT POWER AWARD

For an individual, family or a group of parents who have campaigned or worked together to make life better for other families with disabled children in their community.



“Through Hayley’s grit and determination she has left a lasting legacy for disabled children, who can now join in with other children having fun in their local parks.”

HAYLEY WEDGBURY

London, England

Hayley was nominated by her friend Nandini for successfully campaigning and raising money for wheelchair-accessible swings in her local parks. Hayley’s daughter Mia, aged 12, has cerebral palsy and scoliosis. Mia is often in and out of hospital. Nandini told us:

“Through Hayley’s grit and determination she has left a lasting legacy for disabled children, who can now join in with other children having fun in their local parks.”

Hayley says: “Mia loves to play and interact with other children, so it was pretty disheartening walking through the parks at the weekend and during school holidays unable to join in, being on the side-lines watching other children play.

“I decided to join the local Parent Carer Forum, Parents Active, who put me in touch with the council’s parks team. The council agreed to match-fund whatever money I could raise. I set about crowd funding and raised an incredible 22k, which includes contributions from my GP practice – Park Medical Centre, Dr Elise Aitchison who ran the marathon in Valencia for the cause, and Parents Active who successfully bid for a grant from the Tesco’s Bags of Help scheme.

“The swings were installed in the parks along with a wheelchair accessible roundabout and trampoline, much to the delight of Mia and many other children.”



“Contact supported our campaign through the Disabled Children Partnership.”

NASCOT LAWN CAMPAIGN

Hertfordshire, England

The Nascot Lawn Campaign was nominated by several group members following a 17-month campaign to save the respite centre from closure. Nikki and Angelina told us:

“Nascot Lawn was our beloved nurse-led respite centre, supporting some of the most sick and disabled children and their families in the area. We came together as a group of parents after our local Clinical Commissioning Group (CCG) announced that they were stopping funding it. We fought a long battle to keep Nascot open, challenging the CCG twice in the High Court, as they and the council squabbled over who should fund the vital service. We were there to help each other through the anger, tears and frustration.

“As a group of concerned parents, we achieved so much more together than we ever could have done as individuals.”

MARCIA COLLINS

Manchester, England

Marcia was posthumously nominated by her friend Carolyn for helping so many families with disabled children through difficult times. Carolyn told us:

“Marcia came into our lives at the right time when things were very dark. I had been struggling to get a diagnosis for my daughter Charlotte and she was becoming more and more ill: she’d missed every milestone and couldn’t be left for a second as she was constantly sick. We hit it off immediately. She was there for Charlotte’s operations, and helped for years afterwards at appointments, with DLA, even helping me move house. She became a true friend at a time when I was feeling very alone and unsupported.

“Marcia was selfless. She helped so many families through difficult times and fought tirelessly for them. I was devastated to find out that Marcia passed away in March 2018. Although she isn’t here to know about it, I thought that nominating her for an award might give her family some comfort in knowing that others loved Marcia and appreciated everything that she did for them.”



“Marcia directed me to Contact’s medical directory when I was looking into a further diagnosis for Charlotte. Again, she believed that I was right. Later Contact helped me with a challenge with PIP – thanks Derek!”

EXCELLENCE IN PARENT CARER PARTICIPATION

For local parent carer forums who have gone that extra mile to champion partnership work and co-production with local councils or health services.

SOUTH GLOS PARENTS & CARERS

Bristol, England

South Glos Parents and Carers was nominated by forum member Julie. It was founded in 2009 by now Chief Executive Rachel Trueman along with two other parents. Rachel has two sons aged 19 and 21, both with additional needs. Julie told us:

“South Glos Parents and Carers is much loved by parent carers in the area. Not only is it a force for change, the forum is also a hugely supportive community for families. The forum team have worked hard to build relationships with the local council and health service to improve services for local families. And in addition they run a counselling service and training for parent carers to empower them to get jobs and participate in their child’s support. They have just secured funding for a support base for parent carers in Kingswood and are working with parents outside the group so that it meets local needs. The group really support each other, holding a red carpet awards ceremony to show how much they value their volunteers. Rachel and her fabulous team are truly inspirational.”



“Contact helped us with the Department for Education grant to enable us to be involved with co-production of local services.”



“Contact’s regional support worker Sue Mennear offered steadfast support to Caroline as the forum developed into a powerful local voice in shaping and influencing local service delivery.”

BRISTOL PARENT CARERS

Bristol, England

Bristol Parent Carers and former chair Caroline Temple-Bird were nominated by Kathryn. The forum was set up in May 2010 by mum-of-one Caroline. Kathryn told us:

“Some of the forum’s most notable achievements include setting up a short breaks transport service and reaching out to black, Asian and minority ethnic communities in the city and getting parent carers involved in participation. Caroline is an amazing woman and it is a privilege to know her and call her a friend. She was determined that local services should consider the needs of the 91 language communities in our city and has left a lasting legacy in that.”

“Caroline is prodigiously productive and has an elephantine memory and amazing intellect. She has the ability to consider the interests of the wider parent carer SEND community whilst being the main carer for her disabled child. She has got the forum to an amazing place.”

YORK PARENT CARER FORUM

York, England

York Parent Carer Forum was nominated by Jess Haslam, Head of Disability and Special Educational Needs at York City Council. The forum was set up in 2013. Jess told us:

“York Parent Carer Forum have from the very beginning worked really hard to work in true partnership with the City Council to drive improvement and development in services for children and young people with additional needs. Despite complex home circumstances they demonstrate a drive, commitment and so much energy to developing new and innovative services.

“They have picked up issues, such as needing intensive support in the home for families where children have autism and challenging behaviour and worked with the council until a new service was developed. They are working on a new therapeutic short breaks centre that will change how we can support families to get a break.”



“Contact has provided useful support and information for us.”



Registered with
**FUNDRAISING
REGULATOR**