

**contact** a family  
for families with disabled children



## **Forgotten Families**

The impact of isolation on families with disabled children across the UK

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspects of caring for a disabled child, including help with benefits and educational issues. We help families get in touch with others in similar situations. We do this through family fun days and parent events, encouraging families to get out, make lasting friendships and support each other.

## About the survey

Contact a Family conducted an online survey between July and September, 2011. We received 1,148 responses from families with disabled children across the UK.

The aim of the Survey was to find out more about the levels of isolation families with disabled children experience and how this impacts on their family life. We also wanted to find out what would help families most when they feel isolated and whether the growth the internet and social networks help.

We promoted the survey through our our helpline, regional and local offices, family support workers and volunteer parent representatives. We also used our networks that include:

- national condition support groups
- local parent support groups
- parent carers forums
- Facebook and Twitter users.

Contact a Family would like to thank all those that took the time to complete the survey.

"My younger brother has cerebral palsy so I understand how easy it can be for close family members of a disabled child to feel isolated and alone – not because there aren't enough people around, but because no one you know can relate to your experience.

"The unique work that Contact a Family does is vital in reducing the isolation that families with disabled children experience. Contact a Family provides a life line for families with disabled children. That's why I'm delighted to support the charity as it aims to raise awareness of the very real issues, like isolation, faced by families of the 770,000 disabled children in the UK."

**Strictly Come Dancing star  
Alesha Dixon**

## Section 1: Key findings

Families with disabled children have the same hopes and dreams as other families. They want to see their children reach their full potential and enjoy time together as a family. However, families with disabled children face an overwhelming combination of financial, emotional and practical pressures and, without information and support, find it difficult to cope and become isolated.

Disabled children are less likely to succeed at school, their siblings often get less time and attention and many parents feel that their own needs as carers are often forgotten.

### Findings

#### What is the impact of isolation on families with disabled children?

- 72% experience mental ill health such as anxiety, depression or breakdown due to isolation
- almost half (49%) have felt so unwell that they asked their GP for medication or have seen a counselor
- 57% say lack of support means they are isolated and not able to work as much as they would like
- 1 in 5 (21%) say that isolation has led to the break up of their family life.

#### When do families feel isolated?

- 65% of families with disabled children reported feeling isolated frequently or all of the time
- 64% reported feeling most isolated when their child was first diagnosed with a disability
- 43% said that they felt most isolated during school holidays

#### What are the causes of isolation?

- over half (56%) felt that the cause of their isolation is due to a lack of support from statutory services such as social care and education services
- 54% said that not having the time or money to do things that other families do makes them feel isolated
- 50% said that their isolation is a result of the discrimination or stigma they experience

“Kian is five and has high functioning autism. Our daughter Kirsten is 13 and loves going out to parties and being with other people. She is very understanding of Kian’s condition, though, and very supportive of her mum and dad. I never have any adult time with my husband and our life feels limited, we take one day at a time.”

Families with disabled children experience isolation in different ways: a lack of social interaction due to difficulties working and not having the time or money to do family activities others take for granted; a fear of how people will react when they go out with their child; and a feeling of being alone, even when they are surrounded by people, because no one else shares their experience. The results of our survey show that isolation is having a devastating impact on the mental health of many families with disabled children. It is also causing family breakdown and restricting access to employment opportunities.



Many of the families that responded to our survey talk about the difficulties and isolation they have experienced dealing with their child's disability, but what is clear from the survey findings is that the lack of support from statutory services, low income levels and stigma are the main causes of isolation.

"We rarely get a night out. Caring has impacted heavily on our daily lives and our work. We are self employed and when Kassie is unwell there is simply no option but for us to close our business."

Families with disabled children feel less isolated when they have contact with other families in a similar situation, and have somewhere to turn for information and advice. They also told us that their lives would improve if they had more time to simply be a parent, and feel accepted by their local communities.

"My son Harrison has Tourette syndrome and ADHD. In one year we had 70 appointments, I was trying to come to terms with the diagnosis and also working. It all got too much and I had a breakdown. I feel very isolated and have never met another family in the same situation. It has also affected Harrison's two brothers. They don't understand his behaviour and Harrison himself says, "Why me?" We would all benefit from meeting other families like ours. Help from Sure Start was a real lifeline and now I'm studying a qualification in health and social care to try to get back into the workplace."



## Section 2: Recommendations

To reduce the **social isolation** caused by a lack of support services across health, social care and education, Contact a Family would like to see a single assessment process and plan that includes:

- a distinct carers' assessment that considers a parent's ability to provide and continue to provide care for their disabled child or children
- whether the parent works or wishes to work, or is undertaking, or wishes to undertake, education, training or any leisure activities
- the provision of services to meet any assessed needs
- an obligation on all frontline professionals such as GPs, teachers and health visitors to identify and effectively signpost all parent carers to sources of financial, social and emotional information, advice and support
- access to specialist parenting support for all families with disabled children that will help them to deal with the impact of their children's disability on family life, take control and plan for the future.

In addition, the government should ensure that local Health and Wellbeing Boards in England have a defined focus on the delivery and improvement of joined-up and integrated assessments and services for families with disabled children.

To reduce **financial isolation** we are calling on the government to ensure their welfare reforms address the additional and ongoing financial costs faced by all families with disabled children and make employment a realistic option. Contact a Family would therefore like to see a commitment to:

- providing at least current levels of financial support through disability additions paid in respect of a disabled child via the Universal Credit
- recognizing the higher costs of childcare for disabled children within the current Working Tax Credit system and, in the future, in the Universal Credit (for example, by covering at least 90 per cent of childcare costs for disabled children with an aspiration to increase this to 100 per cent as the economy improves)
- extending the right to request flexible working from the first day of employment for parents of disabled children.

To reduce the **physical and emotional isolation** associated with the stigma and discrimination faced by many families with disabled children, Contact a Family is calling for:

- all early years, childcare, play and leisure services to offer disability awareness training to all their staff
- all public authorities such as the Police, schools and colleges to improve procedures and understanding of disability, in order to better identify those at risk of disability-related harassment and bullying

- all council and health bodies to urgently review the extent to which cuts to local specialist and disability services impact on a parent carer's ability to have a life beyond their caring responsibilities and enable disabled children to fully participate in society, such as opportunities to make friends and have fun
- parent-led training for all frontline professionals such as health visitors, GPs, and teachers to understand the impact of caring and disability on family life, so they can recognise and respond to signs of isolation, mental ill health and family stress
- employers to promote carer and disability-friendly workplaces and practices, such as advertising posts as being suitable for those with caring responsibilities and offering flexible working arrangements from the first day of employment
- the media and those in the public eye to challenge negative attitudes and practices towards disabled people and champion the contribution parent carers make to society.



### Section 3: Impact of isolation on mental health

“Our daughter will be six this Christmas. At three months old she was found to have a very rare form of leukaemia which affects two in a million. She was given one year to live unless she got a bone marrow transplant. Thankfully, within six months, doctors found a match. The life-saving treatment made her weak, she became very poorly and suffered brain damage. She spent a total of nine months in hospital and we were given a poor prognosis, but Savannah has done tremendously well. She has learnt to walk, attends special school and has a smile that lights up a room. She has neurological problems, developmental delay and is affected by seizures. Savannah’s condition has thrown us into a world that we never knew existed, we have to adjust. Last year, I had a breakdown and was put on medication for anxiety. I had to cope and be strong for so long, that it all got too much. Me and my partner are forced into these new experiences, and we didn’t know how to talk about it with each other. My social circle has changed because I see and feel differently. I think that parents who don’t have a disabled children find it hard to relate to me and they don’t understand what I’ve been through. I have met some fantastic people along the way, other parents who I take inspiration from. Contact a Family has been a real lifeline and helped with difficulties such as a housing problems.”

Our survey findings show the devastating impact isolation is having on family life for those caring for a disabled child; 72% are experiencing poor mental health such as anxiety, depression or breakdown. Almost half (49%) have felt so unwell that they asked their GP for medication or have seen a counselor.

Our findings are extremely worrying because parent carers need to remain mentally and physically well as they provide the majority of care for their disabled child. The parents who responded to the survey talk about the constant worry for their disabled child, the pressure of holding it all together and for the future if they are not around to care any longer. Many say complete exhaustion stops them participating in everyday activities. For disabled children, sleep problems are not isolated just to the early years and can affect a family’s ability to cope right through to adulthood.

“We do worry about getting older and trust that we remain fit and able to care for him as long as possible. In relation to our own mental health, I think we have become used to living on the edge although we are aware that the stress is bound to take a toll. It is difficult to find ‘me time’ and we are not able to take part in family get togethers as Gareth doesn’t cope well with noisy voices or lots of people.”

What is clear is that poor mental health caused by isolation has a substantial impact on the quality of life for many families with disabled children. The majority of disabled children are cared for at home, however if a parent does reach breaking point, the cost of a disabled child being in long term residential care is estimated to be £2,428 per week<sup>1</sup>. Evidence shows that services such as short breaks, that give families a break from caring, reduce the need for such costly interventions.

Mental ill health costs the UK an estimated £126 billion<sup>2</sup> each year. The government’s ‘No health without mental health’ strategy for England recognizes both the human costs of poor mental health to individuals and families but also the substantial economic costs that put pressure on public spending, the taxpayer and the wider economy.

<sup>1</sup> The social and economic value of short breaks, nef consulting, 2010

<sup>2</sup> Centre for Mental Health, £105 billion for England, Scotland £10.7 billion, Wales £7.2 billion, Northern Ireland £3 billion.

'The costs of mental health problems to the economy in England have recently been estimated at a massive £105 billion, and treatment costs are expected to double in the next 20 years. We simply cannot continue to allow costs to spiral upwards without ensuring that every pound of public money is being used efficiently<sup>3</sup>.'

This same strategy also outlines how an emphasis on early intervention and prevention will help tackle the underlying causes of mental ill-health. 'Timely and effective responses to people with mental health difficulties are excellent value for public money. Providing good quality parenting support to people with young children is one such example.'

Many families also talk about not having enough time to spend helping their disabled and non-disabled children with their homework. UK research has shown unequivocally that parental involvement in education contributes significantly to children's achievement. Therefore, the causes of isolation – a lack of support from services, low income and stigma, must also contribute to poor educational achievement for disabled children.



<sup>3</sup> No health without mental health: a cross-government mental health outcomes strategy for people of all ages (2011)

## Section 4: Impact of isolation on family breakdown

Parents with disabled children are more likely to experience relationship breakdown than those who don't have a disabled children<sup>4</sup>. Our survey findings show that isolation is contributing to the break up of 1 in 5 (21%) families with disabled children.

*"For the first few years, I felt very isolated, we were forced to move into a rural council estate with no amenities as our original house was too damp. Me and her father split up when she was 18 months old. I would try to take her to parent toddler things but we just didn't fit in as the gaps between her and her peers grew bigger. She was unable to sit unsupported so couldn't be on the same level as other children."*

The impact of isolation also affects relationships across the whole family such as with siblings, grandparents, friends and other family members.

*"My two daughters and I are very isolated because of Nathaniel's behaviour. He has autism, is hyperactive and sometimes displays challenging behaviour. He can't get on a bus, he will be either inappropriately friendly or very abusive. It's made more difficult because Nathaniel does not look disabled and has OK communication, so people don't see him as having a condition. I get tired of having to explain his behaviour to other people, so prefer to stay indoors. I used to work in TV and was very outgoing, but that has changed. Not having a job and living on benefits does nothing for my self esteem."*

<sup>4</sup> Exploring disability, family formation and break-up: Reviewing the Evidence (2008), Department for Work and Pensions

Parental separation has negative outcomes for both children and adults. For example, non-resident parents are often excluded from having a relationship with their disabled child, often because they don't have the right equipment or adaptations to the home to enable them to adequately care for their disabled child. The cost of family breakdown on the economy is also substantial, with estimates ranging from £20<sup>5</sup> – 40 billion<sup>6</sup>). This means that failed relationships cost each UK taxpayer £1,364 a year.

**“It is difficult finding time to be with family and friends because we are often tired and stressed due to having so many disturbed nights of sleep and suitable childcare is extremely difficult to find.”**

However, with appropriate and timely advice and support, many parents say the experience of caring for a disabled child brings them together and makes their relationship and family stronger. The government has recognised the importance of stable families and has put funding in place for relationship support. We are keen to see this funding continue and make a significant difference to families with disabled children.



5 Centre for Social Justice (2007)

6 The Relationships Foundation's annual index of the cost of family failure (2011)

## **Section 5: Impact of isolation on ability to work**

Our survey findings show that 57% of families with disabled children say that isolation means they have not been able to work as much as they would like.

“Our daughter Jasmine is 16, has scoliosis, autism, dyspraxia, dyslexia, selective mutism, learning difficulties, anxiety disorder and asthma. Last year Jasmine's school said they could no longer accommodate her and she had to leave and be educated at home. I was a governor at the school and also used to volunteer at a nearby parent partnership, but once Jasmine wasn't going to school, I had to give them both up, which I really miss because they were such a good source of support and socializing. I was able to switch off and have a good natter. I could be me, not just a mum and carer.

The vast majority of parents of disabled children need paid employment for financial reasons. Caring for a disabled child involves significant extra expenditure over a much longer period of time than for non-disabled children. In common with other mothers returning to work, mothers of disabled children report increased self-esteem through having an identity outside their caring/parenting role. Going out to work also reduces isolation and improves mental health experienced by families with disabled children who aren't in employment, as identified in this report.

“I would like to go to work in my chosen profession, which I had to give up because there just weren't the support services available”.

Only 16% of mothers with disabled children work, compared with 61% of mothers with non-disabled children<sup>7</sup>. Although some parents of disabled children actively make the choice to stay at home to care for their child, for the vast majority of parents this is not a choice, but a situation forced upon them. Finding affordable and accessible childcare remains an ongoing problem for families with disabled children.

7 Ordinary Lives - disabled children and their families, Langerman, C & Worrall, E. (2005), London: New Philanthropy Capital



Parents have also highlighted the following barriers:

- the volume and inflexibility of daytime appointments and meetings
- inflexible employers or managers who have negative attitudes to caring responsibilities
- lack of information, support and guidance on returning to work and their rights whilst in work.
- unreliable transport services and help in emergencies
- a lack of awareness and access to carers' assessments that consider their right to work, study and leisure opportunities.

*"I'm constantly writing letters, filling out forms, attending hospital appointments as well as all the day-to-day medical care she needs. It's definitely a full time job. At the moment I am trying to secure the funding to get her a communication aid and a power wheelchair."*

## Section 6: Causes of isolation

### A lack of support from statutory services

Over half (56%) of the families that responded to our survey felt that a lack of support from statutory services was the key factor contributing to their feelings of isolation. They have to fight to get support and often the support available is insufficient or inappropriate. They have to fight to get support and that the support available is insufficient or poor quality.

*"With a non-disabled child, you feel isolated, but with a disabled child that feeling is exacerbated. For the first two years of Nathan's life, I had a lot to come to terms with, and at the same time I had to put an enormous amount of things into place like facilities and the professionals involved in Nathan's care".*



“I would like to be a parent to my disabled child and my other children rather than a doctor, nurse, social worker, fighter and carer”

Too often, families are left to cope alone. Sometimes, this is because they don't know that help exists, so they don't know where to go and look for it.

“Knowing where to go for information and knowing the right questions to ask. To get the right services would help me feel less isolated”

“It would have really helped if the hospital had told me about the condition support group. Instead I came across it years later by accident. The group really helps me feel I'm not the only one dealing with all the different challenges and the successes.”

Some feel overwhelmed by masses of information, much of which is not relevant to them, making it harder for them to find the services they need. Families are also missing out on vital sources of information and support because frontline professionals such as GPs and health visitors are not identifying parents as carers or spotting the signs of stress or isolation and therefore, do not signpost them to organisations that could help. For example, families often miss out on vital benefit entitlements because professionals assume they already know about them.

Many families are in contact with a range of services and professionals and have to deal with a bewildering amount of appointments and assessments. This leaves them feeling like they spend too much time coordinating different agencies rather than being supported to care and be a parent. As a result many don't have the time to take part in everyday activities such as going out to work, going to the park or helping their children with homework and, as a result, feel isolated.

All families need support from time to time, and the benefits of putting help in place early before problems escalate are widely accepted. 'Early intervention services improve the mental and physical health, educational attainment and employment opportunities for individual families, along with economic benefits and cost savings to the taxpayer'<sup>8</sup>.

“Elisa is eight, she has cerebral visual impairment and mild cerebral palsy. Cerebral visual impairment is a much misunderstood condition. The most isolating time for myself was being told, “We don't know”. Raising a young family and having what seems like nowhere to turn for answers is very isolating. Especially when you are aware of the need to start as early as possible in the right way.”

Short break services are seen by families with disabled children as an essential source of support offering families increased independence, improved quality of life and reduced social isolation<sup>9</sup>. Indeed, there has been a significant increase in the availability, choice and quality of short breaks for many families over recent years, particularly in England. Local councils have also started to see the economic and social benefits of using short breaks as a preventative measure rather than just offering short breaks to families who are in crisis or at breaking point.

However, despite commitments to continue to fund short breaks in some parts of the UK, parents are increasingly reporting that local authorities are tightening their eligibility criteria due to pressures on reduced budgets, so only those with the most critical or 'crisis' needs get support. For example, some parents are having their short breaks substantially dropped without reassessment or being told there is no money left. Parents continue to report that assessments rarely focus on their needs as a carer and inconsistencies in the allocation of services following an assessment of need remain a problem<sup>10</sup>.

“Budget cuts are a constant worry, as any cuts to services are a contributory factor to isolation for many families, so our fingers are crossed every new financial year”.

Access to advice and information is, therefore, critical in helping families understand their rights and what they are legally entitled to in terms of assessments and support services. The tightening of local budgets are also putting pressure on voluntary sector disability and carer services who help families understand their options and navigate the system. This support from local organisations help families to feel stronger, more in control of family life and feel less isolated.

8 Allen Review (2011) <http://www.dwp.gov.uk/docs/early-intervention-next-steps.pdf>

9 McConkey, Truesdale and Conliffe, 2004; Tarleton and Macaulay, 2002; Chan and Sigafoss, 2001.  
10 EDCM (2011) Raised Expectations: Parental experiences of short breaks

## A lack of income

Families with disabled children are at greater risk of living in poverty<sup>11</sup> and our survey results show that 54% think this is one of the main causes of isolation.

“Harriette is three, and was born three months premature. She was doing very well, but then caught pneumonia, was then diagnosed with cerebral palsy and is now fully ventilated and has a tracheostomy. I had to give up my career as a sales manager, lost my house and had to move into council housing. I lost all my confidence and feel very isolated.”

Families with disabled children face two, specific financial challenges that are additional to those faced by other families. Firstly, they incur considerable extra and ongoing costs in caring for their child – it costs three times more to raise a disabled child<sup>12</sup>. Our report ‘Counting the Costs 2010’, revealed that families are going without essentials - almost a quarter are going without heating and one in seven are going without food. This situation is likely to be much worse today, as cost of living has risen considerably, especially the cost of household food and energy bills.

Families with disabled children, particularly those from black and minority ethnic (BME) families, are also missing out on vital income because they are not taking up essential benefits. This is often because families are not told about sources of financial support by professionals and/or need support to complete the forms. The stigma associated with being on benefits also affects take-up levels. There is concern that the drive to reduce the ‘benefit bill’ and the negative media reporting on disability benefit fraud will further reduce take-up levels.

It is, therefore, essential that welfare reforms address the increasing additional and ongoing financial costs families with disabled children currently face and address the barriers to work. Unfortunately, some of the reforms could substantially reduce the financial support currently available to some families with disabled children. This is most pronounced in the government’s proposal to halve the basic disability addition paid in respect of a disabled child via the Universal Credit. Current government figures suggest this policy will impact on around 188,000 low income and out-of-work families with disabled children. For families without transitional protection, this will result in a benefit

cut of £1,400 per year. This loss of income will have a huge impact on a family’s ability to financially cope and also increase families’ isolation.

“My son is 15, partially sighted and has autistic traits. I’ve had to fight the local education authority to get Harry into a special school. Because I also worked for the council I had to give up work because I was fighting against my employers and that put me in a very difficult position. Other parents look at me differently. Sometimes we can’t get out of the house. We are restricted by appointments with the OT, orthopaedic surgeon, doctors, so the family lose out on the normal day-to-day interactions. Giving up work has had a considerable impact on the family not just socially, but also financially.”



<sup>11</sup> Households Below Average Income showed the risk of relative poverty for families with a disabled child but no disabled adult family member has increased from 20% to 25%, meaning disabled children are now at greater risk of living in relative poverty than non-disabled children. (Department of Work and Pensions 2006/07)

<sup>12</sup> Paying to Care: the costs of childhood disability by Barbara Dobson and Sue Middleton (Joseph Rowntree Foundation 1998)

“I would just want my son to smile, drop him at school happy and afford to take him out at the weekend, swimming and bowling.”

“I don’t go out much or on holiday because I’d worry about money. My heating bills are huge because my son’s condition means I have to have the radiators on full.”

#### **Stigma and discrimination**

Our survey results show that 50% of families with disabled children say that the stigma and discrimination associated with caring for a disabled child has caused their isolation. The families who responded to our survey share accounts of a lack of understanding and ignorance about disability from family and friends, their local community, frontline professionals, employers and complete strangers.

“I can’t cope with my life and I’m sick of parents and teachers trying to push my son out of the school. Even my own family refuse to help. They just say he is naughty. He’s a beautiful little sensitive boy and, with the right help and understanding, would fit in just fine but I have to deal with people’s stupidity and ignorance about disability.”

“More tolerance in the local community would help me, so I wouldn’t have to worry about going out to the supermarket and having people stop and stare.”

One of the key findings from the Equality and Human Rights Commission (EHRC)’s inquiry into disability-related harassment, identified that many of the victims were socially isolated, which put them at greater risk of harassment and violence<sup>13</sup>. The EHRC report reviewed dozens of attacks against people with disabilities, including the case of Fiona Pilkington, who in 2007 killed herself and her disabled daughter after years of abuse by local youths. The inquest found that failings by police in not identifying the family as vulnerable, contributed to the deaths, as did the failure of Leicestershire County Council to share information. Although this case is extreme, it does highlight that prejudice and lack of understanding causes many families with disabled children to become isolated and can lead some to breaking point if their needs are not identified and supported.

Parents also talk about a lack of recognition about the contribution they make as carers, feeling their needs are often forgotten. Families think that people working in frontline services – police, social services, GPs and teachers need to be trained to understand, recognise and respond to the pressures that families with disabled children are under.

“My needs are often forgotten, this makes me feel isolated.”

“Education is needed on disability for the whole family including aunts, uncles and neighbours!”

<sup>13</sup> Hidden in plain sight (2011)



## Section 7: When do families feel isolated?

All parents will experience periods of isolation, often following the birth of a child. Our survey found that 65% of families with disabled children reported feeling isolated frequently or all of the time. A total of 43% said that they felt most isolated during school holidays, while 64% reported feeling most isolated when their child was first diagnosed with a disability. Around the time of diagnosis, parents often go through a range of emotions including shock, denial, grief and anger. Many families say they would like to be able to talk to another family who has a child with a similar condition, particularly if the condition is rare. The way in which a diagnosis is given to a family and the information they receive at that time, has a significant impact on their ability to cope in the future.

“I would love to be able to know that I could go anywhere with my son, because everywhere would be set up to cater for the needs of disabled people. My son is desperate to go to the local park and play with the other children but he can't because there are no disabled swings there. I hate walking past the park as he just cries, because he wants to go there more than anything. I dearly wish that I could walk past any park, see all the children playing and take my son in to join them.”



## Section 8: What makes a difference?

### Contact with other parents

Almost all families that responded to our survey indicated that being put in touch with other parents in a similar situation helps reduce feelings of isolation.

“Knowing we aren't alone in experiencing this stuff makes it much easier, breaking that sense of isolation.”

Contact with other parents, either through disability support groups or through online networks provides an opportunity for parents to share experiences and concerns. They also provide a forum to share solutions to specific problems associated with their child's condition or disability, such as managing school or finding suitable equipment. Parents also learn about local support services and how to access them from other parents. They are often also the first place many parents find out about vital benefits and other entitlements. Many support groups also organise family events and outings.

Unfortunately, many families with disabled children aren't told about these groups or online forums. In a recent Contact a Family survey, almost three quarters (73%) said that their GP never offers them support in their role as a carer. If professionals such as GPs did help families with disabled children get in contact with other parents as a means of support, this could reduce feeling of isolation and, therefore, perhaps the need for medical interventions.

### Knowing that there is help available

When we asked families about Contact a Family services, 40% said that just knowing that someone is there for advice, information and support on the phone or in person helps them feel less isolated.

Without information parents can be left feeling overwhelmed and anxious about how they will cope and worried about their future. If provided with information, parents know where they can find out more about their child's medical condition, how to best support them and access help for themselves and their child. This reduces some of their stress, helps them become confident in their ability to manage their situation, able to plan for the future and feel they are back in control of their lives. As a child grows older, their family's information and support needs are likely to change, so knowing that there is help available makes a huge difference.

## Having time to be a parent

What is clear is that parenting a disabled child goes beyond 'ordinary' parenting.

Too often families spend too much time doing caring tasks and dealing with a web of interdependent and often uncoordinated services, leaving them with a lack of quality time for parenting and helping their children to reach their full potential. In our survey, we asked families how they would like to spend an ideal day. The comments illustrate they just want to do everyday things that other families would take for granted.

*"This sounds terrible but my ideal day is one without the huge responsibility of keeping my son from harm or getting lost."*

*"Sam is 16, he needs help and supervision with personal care. He is becoming more independent in that he can make a sandwich or dress himself but it's all done with supervision. My ideal day would be not to have to worry about him and having a day out as a family."*

*"I'd like to be able to take all my children to the park and end with having a meal in a restaurant."*



## Section 9: How Contact a Family helps prevent isolation and builds stronger families

There are 770,000 disabled children under the age of 16 – that's one child in 20. Contact a Family are the only UK charity that provides vital support and information for families of disabled children whatever their condition or disability. Last year we helped 340,000 families to access life-changing help.

Our freephone helpline offers a single point of access or 'one-stop-shop' advice service to families on any aspect of caring for a disabled child including welfare rights, education and housing issues. It has access to interpreters and a UK-wide database of relevant organisations.

Our family support service and volunteer parent representatives provide face-to-face support including:

- providing emotional and practical support for the whole family
- ensuring families have access to up-to-date information and training about their child's diagnosis or condition
- helping families to think about the next stages of their child's development and services needed
- help to access additional services at the right time for the family and disabled child.

Our medical directory – see [www.cafamily.org.uk](http://www.cafamily.org.uk) – provides reliable information on more than 400 medical conditions, including rare syndromes, and also provides details of UK condition support groups.

Our family linking scheme, network of parent support groups and online communities such as MakingContact.org, Facebook and Twitter help families get in touch with others in a similar situation and find other parent carers who have a child with a similar condition. This is particularly helpful when a child has a rare condition.

We also have an extensive range of parent-friendly guides, on topics including relationships, siblings, sleep and challenging behaviour.



## About Contact a Family

### Campaigning

We campaign for rights and justice for all families with disabled children.

### Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

### Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

### Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

### Medical information

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 440 conditions and UK support. Each entry provides an overview of the condition with details of support groups where available.

### One-to-one support groups

We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

### Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

## Getting in contact with us

**Helpline 0808 808 3555**

Open Mon-Fri; 9.30am - 5.00pm

**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

**[www.makingcontact.org](http://www.makingcontact.org)**

Follow us on Facebook  
[www.facebook.com/contactafamily](http://www.facebook.com/contactafamily)

Follow us on Twitter  
[www.twitter.com/contactafamily](http://www.twitter.com/contactafamily)

Watch our videos on YouTube  
[www.youtube.com/cafamily](http://www.youtube.com/cafamily)

Registered Office: 209-211 City Road,  
London EC1V 1JN  
Registered Charity Number: 284912  
Charity registered in Scotland No. SC039169  
Company limited by guarantee  
Registered in England and Wales No. 1633333  
VAT Registration No. GB 749 3846 82





## Forgotten Families

The impact of isolation on families with disabled children in Scotland, Wales and Northern Ireland

### In Scotland,

148 families with disabled children in Scotland responded to our survey (13% of the total).  
70% said they experience poor mental health such as depression or breakdown due to isolation.  
51% felt so unwell they have asked their GP for medication or have seen a counsellor  
64% felt most isolated when their child was first diagnosed.

"I would love to be able to know that I could go anywhere with my son, because everywhere would be set up to cater for the needs of disabled people. My son is desperate to go to the local park and play with the other children but he can't because there are no disabled swings there. I hate walking past the park as he just cries, because he wants to go there more than anything. I dearly wish that I could walk past any park, see all the children playing and take my son in to join them."

"Other parents look at me differently so sometimes we don't go out the house, so the family has lost many of the normal day to day interactions. We are also restricted by all the appointments with the occupational therapist, orthopaedic surgeon, doctors etc rather than seeing friends. Giving up work has had a considerable impact on the family not just socially, but also financially"

As a result we are calling on the Scottish Government to ensure:

- funding to enable parents, carers and families to have a voice, as equal partners in making decisions about services that help them lead a more normal life and feel less isolated.
- funding and support to allow parents to act as volunteer parents so that they can develop peer support approaches to reducing isolation within their own communities, connecting families and sharing common issues and concerns.
- that services offered are responsive to changing needs, lead to the best possible outcomes and are delivered where possible within the home community, as recommended in the Doran Review.
- that carers, including parents of disabled children, are supported to manage their caring responsibilities with confidence and in good health, and to have a life of their own outside of caring as recommended in Caring Together, The Carers Strategy for Scotland 2010-2015.

## In Wales,

146 families with disabled children from Wales responded to our survey (12.7% of the total).

71% say they experience poor mental health such as depression or breakdown due to isolation.

48 % felt so unwell that they have asked their GP for medication or seen a counsellor.

60% felt most isolated when their child was first diagnosed

47% felt most isolated during school holidays.

“For the first few years, I felt very isolated, we were forced to move into a rural council estate with no amenities as our original house was too damp. Me and her father split up when she was 18 months old. I would try to take her to parent toddler things but we just didn’t fit in as the gaps between her and her peers grew bigger. She was unable to sit unsupported so couldn’t be on the same level as other children.”

“Cerebral visual impairment is a much misunderstood condition, and has resulted in a lot of self education. To have your baby and very young family to raise and having what seems like nowhere to turn for answers is very isolating.”

As a result, we are calling on the Welsh Government to commit funding to:

- the Early Support programme beyond March 2012.
- implement Section 25 of the Children and Young Persons Act 2008 to increase the duty on local authorities to provide short break services.
- enable health bodies to implement the Carers Strategies (Wales) Measure to provide effective information and support to carers including parents with disabled children to enable them to both continue to care and achieve a more normal life.
- ensure that parent carers have a voice and are partners in making decisions about services that help them lead a more ordinary and feel less isolated.

## In Northern Ireland,

47 families with disabled children responded to our survey (4% of the total),

81% said they experience poor mental health such as depression or breakdown due to isolation.

79% felt that a lack of support from statutory services caused their isolation.

79% felt most isolated when their child was first diagnosed.

“Gareth is an only child and despite the difficulties we love him dearly. We do worry about getting older and trust that we remain fit and able to care for him as long as possible. In relation to our own mental health, I think we have become used to living on the edge although we are aware that the stress is bound to take a toll. It is difficult to find ‘me time’ and we are not able to take part in family get togethers as Gareth doesn’t cope well with noisy voices or lots of people. I recently lobbied at Stormont to fight for retained funding for clubs for children and young people with special needs in our area but sadly it fell on deaf ears. Families were able to get a little respite while the club was held however the service sadly ended in March this year.”

We are calling on the Northern Ireland Executive via its Programme for Government 2011–2015 to make a specific commitment to improving outcomes for disabled children and their families by:

- funding a range of early intervention services such as short breaks and specialist family support to help families deal with the impact of caring for a disabled child on family life and minimise isolation and mental ill health.
- improving the provision of integrated and co-ordinated services across health, social care and education
- ensuring that parent carers have a voice and are partners in making decisions about services that help them lead a more ordinary life and feel less isolated.