



What makes my family stronger

A report into what makes families with disabled children stronger – socially, emotionally and practically



30 years of
strengthening
families with
disabled children

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Contents

Introduction	4
Summary of key findings	5
Recommendations	6
Who responded to the survey?	6
What makes my family stronger socially	7
Play	10
Stigma	12
Relationships	13
Sleep	14
What families say would make them stronger socially	14
What makes my family stronger emotionally	15
Being valued	17
Support from partner	18
Professionals	19
Seeing child reach full potential	20
Emotional support	20
What families say would make them stronger emotionally	21
What makes my family stronger practically	22
Short breaks	25
Childcare	27
Benefits	28
Education and communication	28
Bullying	30
Care package	30
Strong families	32
What families say would make them stronger practically	32
Conclusion	33



Introduction

“Me being the person I am makes our family stronger – or more accurately the person I’ve had to become. Without me, our family would disintegrate. I act as liaison, advocate, secretary, nurse, taxi, Physiotherapist, Occupational Therapist, Speech and Language Therapist, teacher for the blind. And I get no status in society for any of it.”

Parent of a disabled child

Introduction

Contact a Family is the leading UK charity working with families of all disabled children, regardless of the disability or condition.

Families of disabled children want to lead ordinary lives. However, they face practical, physical and emotional challenges over and above families with non-disabled children.

30 years on from when we first started supporting families with disabled children, we carried out research to find out their experience living in 2009, asking 615 families across the UK "what makes you stronger?"

Our research highlights that often the difficulties come from a lack of support from professionals and understanding from society. Most families have to fight for services that should be theirs by right to help their children and themselves overcome daily challenges and lead independent lives.

We asked families about their social, emotional and practical experiences of raising a child with a disability and there are three clear themes which come up time and again and which indicate the barriers standing in the way of families leading ordinary lives:

- Lack of services
- Attitudes towards disability
- Lack of support from professionals.

Thank you to all the families who took part in the survey for their comments and responses.

Summary of key findings

- Almost 70 per cent of respondents said that understanding and acceptance of disability from their community or society is poor or unsatisfactory.
- Over 60 per cent of families said they don't feel listened to by professionals.
- Over 60 per cent of families said they don't feel valued by society in their role as carers.
- Over 70 per cent of respondents said their child's access to play and leisure specifically for disabled children is poor or unsatisfactory.
- 50 per cent of families with disabled children said the opportunity to enjoy play and leisure together is poor or unsatisfactory.
- Vital support services such as short breaks, a key worker and childcare are unavailable to almost half of families
- Families biggest priorities for making them stronger –
 - They want more opportunities to enjoy play and leisure and want a real choice in the activities they can take part in.
 - They want to see their child reach their full potential.
 - They want a support package to meet their child's needs and flexible and regular short breaks.

Recommendations

- The Government should invest in a UK-wide campaign to raise awareness of the needs of families with disabled children.
- Everyone working in a public facing role in the UK should be given disability equality training. A priority should be given to health care professionals and staff working in leisure facilities.
- There should be stronger focus on disability awareness taught in early years and schools throughout the UK.
- The much welcomed and significant investment in short breaks services in England must be sustained and included in the next Spending Review.
- There must be fair access to short breaks for all families with disabled children and the use of eligibility criteria should not be used by local authorities as an excuse to limit access. There must be equality of short breaks services across the four nations.
- The Government must urgently commit to reviewing carers benefits and set a clear timetable for reform.
- To reduce the higher risk of poverty for disabled children, we urge the Government to undertake a Disability Living Allowance take-up campaign with a particular focus on ethnic minority families, whose take up of the benefit is particularly low.

Who responded to the survey?

This report describes the findings of an online survey hosted on the Contact a Family website in Spring 2009.

All respondents are family members caring for a disabled child aged between 0 and 19. Nearly all (613) are parent carers and two are other family members who look after a child with a disability.

- 22 per cent have a disabled child aged 0 to five.
- 52 per cent have a disabled child aged six to 12.
- 26 per cent have a disabled child age 13 to 19.

The families taking part in our survey have children with a range of disabilities and health conditions.

Throughout this report, we use the words 'disabled children' to describe children and young people aged 0 to 19 with a range of physical, learning, behavioural, sensory and communication needs, or complex health needs.

The comments in quotation marks featured throughout this report are all from the parents or family members caring for a disabled child, who completed our survey.



What makes my family stronger Socially

"We are stronger because we understand that she is not disabled by her condition but by the attitudes, policies and the surrounding environment."

Parent of a disabled child

Socially

Families with disabled children want to do the same things and go to the same places as other families. They want to see friends and family, enjoy time together, take part in fun activities and be accepted and included by their communities and society. They also want to be able to access the support designed to help families socialise, such as Children's Centres for young families. Basic needs such as a good night's rest and free time with a partner or spouse are also crucial to a good quality of life socially. Short breaks can give parents a rest and disabled children positive experiences away from home.

We asked the respondents about their experience of social and recreational opportunities. It is clear both from the figures and the comments that families with disabled children in the UK feel excluded from social situations that other families enjoy and there is very much a feeling of being on the outside looking in. It is not just about physical access, as families also feel excluded by other people's attitudes.

"We are stronger because we understand that she is not disabled by her condition but by the attitudes, policies and the surrounding environment."

"We have little social interaction due to a lack of money, a lack of opportunity and a lack of understanding from people that we meet."

Despite this feeling of exclusion, families show determination, resilience and creativity in finding solutions to getting out and about and enjoying time together. Some are faced with a fight to get involved in play and leisure activities where they are not initially welcomed or included.

"We are stronger because we spend so much time together and do everything as a family and don't let anything stand in the way of what we want to do. 'Have wheelchair, will travel' is our motto."

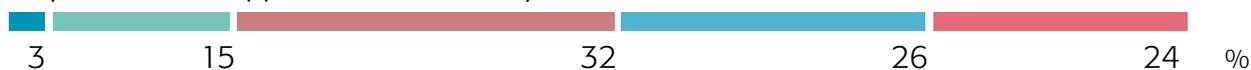
"I started a youth group, for disabled young people. I started a parent carers support group to meet other parents. Why do I have to do these things, why is there not something coming from the government to help us keep going?"

"Despite the fact that there are not many places to go with our disabled child where he can enjoy himself, we still try to have a good time, making the most of what is available although it is limited."

Socially what is your experience of the following?

■ Excellent
 ■ Good
 ■ Satisfactory
 ■ Unsatisfactory
 ■ Poor

Play and leisure opportunities for family



Access to play and leisure specifically for disabled children



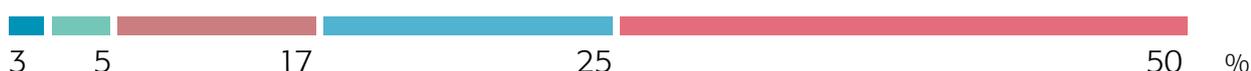
Social time with spouse/partner



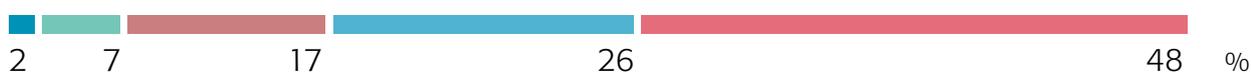
Access to Children's Centre



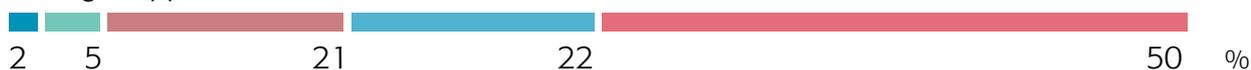
Childcare



Short breaks



Siblings support



Holidays



Linking with other families



A good night's sleep



Inclusion – understanding of disability



Percentage results have been calculated for each category according to how many said it was applicable to them.

“Inclusion is very important to us so we have worked very hard at making things easier for people to accept our family within our community. It would be really nice if someone could make it easier for us – if someone goes out of their way it can make a huge difference.”

“My child has a very active social life which is due to the support networks I have fostered and an attitude of he can do anything and go anywhere he wants to (my child is very severely physically disabled).”

“We don’t accept that she can’t join in with other groups for children and have in the past actively fought to get her involved.”

Play

The opportunity to enjoy play and leisure as a family with a disabled child is not easy with half of all respondents saying their experience was poor or unsatisfactory. Dissatisfaction with mainstream play and leisure opportunities centres around lack of accessibility, having to travel long distances to find something suitable, lack of facilities or changing rooms, lack of disability training among staff and disability awareness among other members of the public, lack of suitable transport to facilities and not having enough money to take part in recreational activities.

“We try really hard to be a ‘normal’ family doing ordinary things. BUT lack of facilities makes it difficult. There is no suitable swimming or parks nearby with accessible equipment. Our local cinema lift has been broken for five months.”

“Having access to places that fully understand about the amount of space required for people with complex needs would help make us stronger (e.g. space between tables in restaurants, changing rooms, bathrooms with changing beds).”

While 32 per cent of respondents said the opportunity to enjoy play and leisure as a family was satisfactory we believe this is not a reflection of the social activities provided by authorities, but rather from families’ determination and creativity in finding their own sources of entertainment and fun.

The Government has made a commitment to improve play opportunities for disabled children and young people in England through the Play Strategy.¹ There is now a duty on English local authorities to make play spaces accessible and fully inclusive for disabled children backed by £235 million of funding available 2008-2011. The funding will also be used for inclusion and equality training for play workers. The Play Strategy also sets out how disabled children should now get more say in the development and design of play spaces in England. From April 2009, there will be a new national play indicator, which will be informed by a TellUs survey finding out the views of children in England about the play provision in their area. An organisation with experience of working with disabled children has been recruited to ensure that their views are also gathered in the survey.

The Welsh Assembly Government (WAG) also has a Play Strategy and has committed £1.25 million for each of the next three years to help local authorities provide play opportunities for disabled children.²

In Northern Ireland, the Office of the First Minister and Deputy First Minister (OFMDFM) Children's Unit has issued a Play and Leisure policy statement which makes a commitment to take account of a range of vulnerable groups including disabled children in their plans to improve play and leisure.³

The new Early Years Framework in Scotland emphasises the importance of play in improving children's quality of life, including the need to remove barriers to play as a priority.⁴ But the absence of new funding for this framework raises doubts as to how much change can be delivered. Yet, the willingness of local authorities like South Lanarkshire to work with local parent carers on the accessibility of play areas promises to deliver real change in a short timescale.

We welcome the commitments to improve quality of life for children across the UK through play and leisure opportunities but emphasise this has to mean all children including those with disabilities. There needs to be consistency across the four nations in improving access to play and leisure for disabled children and there should be measures in place to check this is happening.

It is clear from the responses to What Makes My Family Stronger, the majority (73 per cent) of families in the UK are dissatisfied with their child's access to play and leisure specifically for disabled children.

"Socially we need somewhere for our daughter to go where she could be with other disabled youngsters. She gets fed up being around her family and enjoys the company of others, however when the school closes at the weekend, that's the end of it and she is bored."

1. Department of Children, Schools and Families and the Department of Culture, Media and Sport (2008) The Play Strategy, DCSF-00951-2008.
 2. Welsh Assembly Government (2008) We Are On The Way – A Policy Agenda to Transform the Lives of Disabled Children and Young People.
 3. Office of the First Minister and Deputy First Minister Children's Unit (2008) Play and Leisure Policy Statement.
 4. The Scottish Government and the Convention of Scottish Local Authorities (2008) Early Years Framework, ISBN 9780755957149.

Disabled children and their families should have a choice accessing mainstream or specialist play and leisure. Staff at mainstream leisure facilities should be better trained, qualified and confident in working with disabled children, and the design and provision of facilities should take into consideration the needs of children with disabilities. We believe that if this happened, there would be less demand for specialist provision.

Stigma

Many of the families' comments are about the lack of understanding around disability from members of the public and having to deal with people's stares and comments. Almost 70 per cent of respondents said that their experience of understanding and acceptance of disability from their community or society was poor or unsatisfactory.

Below are some of the answers to the question "What makes your family stronger socially?"

"Not having to apologise for having a child with a disability would make us stronger."

"When we do go out, we hold our heads up high. Disability is nothing to be ashamed or embarrassed about."

"Being able to just get on with it, put our shells on and not let other people's comments affect us, being able to switch off from them."

"We socialise with the people who can see a bit of what our situation might be like and who value our daughter and we have dropped contact with the people who can't or won't do that."

"Learning to deal with comments and stares you get from society about your disabled child and knowing that they are the ignorant ones, not your family."

"We have had to develop a very thick skin where outsiders are concerned. We are incredibly proud of our disabled child regardless of how difficult life may be."

Under the Disability Discrimination Act 2005, local authorities and all publicly funded services in the UK have a duty to promote equality for disabled people. This includes eliminating harassment and promoting positive attitudes towards disabled children and young people.⁵

5. Department of Work and Pensions (2005) Disability Discrimination Act (DDA).

Everyone working in a public facing role should be given disability equality training. There should be stronger focus on disability awareness taught in early years and schools throughout the UK to promote positive attitudes throughout society.

We welcomed the Government's announcement that it intends to ban discrimination against carers by protecting people who are "associated with" someone who is disabled. The new protection will be included in the Equality Bill and follows a landmark legal case in 2008 in which Sharon Coleman, the mother of a disabled boy argued and won that she was treated less favourably in her workplace than employees whose children weren't disabled.⁶

Now employers have a responsibility to treat everyone equally and cannot refuse to employ someone because they are a carer. Protection in law from harassment and discrimination is key in ensuring parents are not excluded from the world of work, and are able to lead ordinary lives. However, there is still a long way to go in changing public attitudes towards families with disabled children.

Relationships

More than half of families who responded to our survey (55 per cent) said that the opportunity to spend time with their spouse or partner away from the role of caring is poor. Some children with disabilities require a significant amount of care and treatment day and night. As one parent is often unable to work, the other parent may work long hours to boost the family income.⁷ Many of the comments show that the demands of caring leaves very little time for each other and couples sometimes lead separate social lives because whilst one is caring, the other is snatching a couple of hours rest or time with other children. In some cases the parents have no social life at all. Research has shown parents with disabled children are more likely to experience a relationship breakdown than parents of non-disabled children.⁸

"It would be nice to have time with my husband as one of us is normally involved in caring to give the other a break. Good reliable childcare would allow us peace of mind to enjoy our rare time together without worrying about our son."

"We usually separate as a family where one parent goes with one child and the other with our disabled son, so they can both do their own thing."

Short breaks are key to making stronger couple and family relationships and preventing family breakdown. We urge Government to continue to invest in and ensure delivery of regular and flexible short breaks, to prevent families reaching crisis point and for some, family break down. Families with severely disabled children should have a legal minimum entitlement to short breaks.

6. Sharon Coleman v Attridge Law and Steve Law (2008) European Court of Justice.

7. One Plus One – Fiona Glenn (2007) Growing Together, or Drifting Apart? Children with disabilities and their parents' relationship.

8. Contact a Family (2004) No Time for Us – relationships between parents who have a disabled child.

Sleep

Families with disabled children often go without basic needs such as a good night's sleep. Almost 60 per cent of respondents said that their opportunity to get a good night's rest was poor or unsatisfactory. Parents often talk about being constantly tired and rundown and this can impact on their health and wellbeing and can lead to family breakdown.⁹ That is why short breaks are so vital to the health and happiness of families with disabled children because they give parents the chance to recharge their batteries and children the chance to experience social situations outside the home environment.¹⁰

"My basic needs are not being met – I don't get a good night sleep as my disabled child needs to be looked after during the night."

"Being able to have as many choices for leisure time as for those with children who are not disabled, and getting a good night's sleep for all of us would make me stronger. I have not had a full night's sleep for seven years and I am exhausted."

"If we were less tired we would be able to be deal with the social difficulties more easily. A tolerant and accepting society would help too."

We urge Government to continue to invest in and prioritise disabled children's services, particularly short breaks, to prevent families reaching crisis point and for some, family break down. Families with severely disabled children should have a legal minimum entitlement to short breaks.

What families say would make them stronger socially

In answering this question respondents could make multiple selections – they were asked for their top three:

1. Opportunity to enjoy play and leisure as a family	288	46%
2. Social time with partner/spouse away from caring	265	43%
3. Play days and activities specifically for disabled children	259	42%
4. Understanding/acceptance of disability from community/society	232	37%
5. A good night's rest	185	30%
6. Opportunity to enjoy family holidays	180	29%
7. Support for siblings	139	22%
8. Short breaks	119	19%
9. Opportunities to meet other families caring for a disabled child	47	7%
10. Access to local children's centre	34	5%

9. Contact a Family (2004) No Time for Us – relationships between parents who have a disabled child.
10. Mencap (2006) Breaking Point – Families still need a break, Mencap: London.



What makes my family stronger Emotionally

“We are stronger knowing that no matter how hard the struggle to have our child accepted (it is always an uphill struggle), we all pull together to make things happen. And we know our child is the best thing that has happened to the family and is loved and cherished just like our other children.”

Parent of a disabled child

Emotionally

Families with disabled children are often under emotional pressure. Finding out a child has a disability or health condition can be difficult and families are often trying to cope with a range of feelings as well as dealing with the physical demands of caring. Many feel isolated because they don't know anyone else in the same situation or who to turn to for support.

We asked the respondents about their emotional experience around raising a child with a disability and about the support that is available from within and outside of the family. It is clear both from the figures and the comments that families with disabled children in the UK generally feel supported by their family and friends but receive little or no professional emotional support.

"Knowing that was a tough day and it may happen again tomorrow but still we can do it as a family, makes us stronger."

"We are stronger because we know that we have to get on with it – we try to respect each other, learn from each other, laugh at one another and love one another. Oh, and on the odd occasion that we get a good night's sleep we do all the above, with value added."

Emotionally what is your experience of the following?



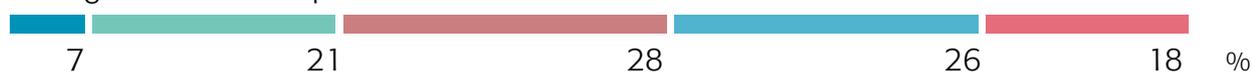
Sleep and opportunity to enjoy me time



Inclusion – understanding of disability



Seeing child reach full potential



Recognition of my value as a carer



Feeling listened to by professionals



Linking with other families



Percentage results have been calculated for each category according to how many said it was applicable to them.

Being valued

More than 60 per cent of families who completed the survey don't feel valued by society.

There are an estimated 6 million carers of both adults and children in the UK who save the economy £87 billion a year through their unpaid support.¹¹ A significant number are parent carers, as there are an estimated 770,000 disabled children in the UK.¹² People providing high levels of care are twice as likely to suffer from poor health than those without caring responsibilities.¹³ Their enormous contribution to society often goes unnoticed and this is a source of huge frustration for families.

“Feeling that all the hard work we put in is appreciated by the wider society would make us stronger. Not even my friends understand how hard I work. We have good quality of life because my extended family is so supportive, without this we would go under.”

11. Dr Lisa Buckner and Professor Sue Yeandle - University of Leeds (2007) Valuing Carers – calculating the value of unpaid care, Carers UK.
 12. Social Survey Division of the Office for National Statistics (2002) General Household Survey.
 13. Carers UK (2004) In Poor Health – the impact of caring on health.

“Feeling valued and supported would make us stronger. An understanding that we are all doing the best we can, rather than feeling like we are all constantly failing.”

One of the main reasons cited by families with disabled children as making them feel undervalued by society is the amount of money they receive through Carers Allowance – just £50.55 a week. Many families with severely disabled children are providing round the clock care, but even when you work out Carers Allowance for a 35 hour week, it is equivalent to £1.51 per hour, well below the national minimum wage of £5.52 per hour. The Government has accepted that there needs to be a review of carers benefits but failed to set out any proposals in the National Carers Strategy published in 2008.¹⁴

Ministers have since failed to give any details about how and when the reform will take place. We urge Government to commit to reviewing carers benefits and set a timetable for reform immediately.

Support from partner

Despite the challenges of caring for a disabled child and the difficulty of parents spending free time together, two thirds of respondents said that the support they received from their spouse or partner was excellent or good (66 per cent).

“A good marriage, friends and financial security makes us stronger. My partner helps a lot in the house and does the main caring plus a job. But we ALWAYS worry about the future when we are unable to carry on caring – very stressful.”

However parents with disabled children are more likely to experience a relationship breakdown than parents of non-disabled children. A study of families in England and Wales found that 32 per cent of families with disabled children were single parent families, compared with 25 per cent of other families.¹⁵

“My husband left a year ago and this has left all of us emotionally raw. I have tried to keep it together for the children but this is hard with twin boys with autism and a daughter aged six.”

14. Department of Health (2008) Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own, DH 286149.

15. Lisa Buckner and Sue Yeandle – University of Leeds (2006) Managing More than Most: A statistical analysis of families with sick or disabled children, Ace National led by Carers UK.

"I am a single parent, and we are a close family. Support from family and friends keeps me going. I am determined to provide the best for my children."

Professionals

More than 60 per cent of families have a poor or unsatisfactory experience of being listened to by professionals. It is clear from many of the comments that families are constantly frustrated by professionals failing to understand their expertise in knowing and understanding their child's condition.

"It would be great if my daughter could reach her full potential, but this will only happen if professionals listen and act on my concerns. Parents are the ones who know their children best. It is impossible for professionals to have the insight necessary to help, if they don't listen."

"Being treated as a co worker or partner by professionals would make me stronger. And being recognised as an expert in their care: joint working to benefit all."

"We adore our child, appreciate what he is capable of and have acted in his best interests without worrying which professionals we upset in the process. If they can't see the child instead of the label, it's their problem, we'll go elsewhere."

A recent study by Mencap *Death By Indifference* concluded that there is widespread ignorance and indifference throughout the healthcare services towards people with a learning disability and their families and carers.¹⁶ The report says: "Parents and family members can often provide vital information that can help doctors and nurses to decide on appropriate treatments for people with a learning disability. But there appears to be a tendency among healthcare professionals to discount this information, or not even to consult family members in the first place. It is often assumed that they are over-emotional, irrational and uninformed."

It is clear from the comments left by families responding to our survey, they are frustrated not only by health professionals but also those in education and social care. They feel that their child's abilities are being dismissed because of their disabilities and this is preventing them from reaching their full potential.

16. Mencap (2008) *Death by indifference*.

Under Aiming High for Disabled Children (AHDC), the Government programme to transform disabled children's services in England, there is a Core Offer which sets out in one place a national statement of expectations for how disabled children and their families will be informed and involved.¹⁷ This should ensure better working relationships between parents and the services families use and will ultimately lead to services being built around the needs of disabled children and their families.

However, we need to understand if the Core Offer is being implemented so that we can hold local authorities and Primary Care Trusts (PCTs) to account. There is a new system to measure and compare the performance of each local authority area in England in providing disabled children's services.¹⁸ The national indicator (NI54) survey will gather parents experiences of disabled children's services locally and the extent to which these services are delivered according to Core Offer standards. However many parents don't know about the Core Offer standards so it is vital that Government and local authorities provide detailed information and guidance to parents, so that we get a clear picture of the standard of disabled children's services across England.

We hope that if the Core Offer initiative in England is successful it will be extended to other parts of the UK.

Seeing child reach full potential

There was a mixed response from families about their experience of seeing their child reach their full potential, with 56 per cent saying it was satisfactory or better and 44 per cent saying it was poor or unsatisfactory. Seeing their child reach their full potential was rated highly as a priority for families.

It is vital that disabled children are given the same opportunities as non disabled children to have fun, make friends and build relationships. It is equally vital that the education system provides the best education to meet each individual child's needs.

Families with disabled children have a right to fully participate in society and to expect and see their child reach their full potential.

Emotional support

Emotional support is generally found within the family or friend circle and this is viewed very positively. In contrast support from counsellors and other professionals is poor or unsatisfactory (65 per cent). It is unclear from the results whether this poor experience is due to a lack of availability rather than poor quality of service, but we know from anecdotal evidence that families have huge difficulty accessing emotional support from professionals.

"We've always had to manage on our own through some terrible times. We had no help then, so we don't need their help now. Sorry but after what we've been through, you tend to be a bit cynical."

17. Department for Children, Schools and Families (2008) Aiming High for Disabled Children – Core Offer.

18. Department for Children, Schools and Families (2008) Aiming High for Disabled Children – National Indicator 54.

Despite the emotional pressures, families show incredible resilience and what shines through most in their responses is the joy and inspiration they get from their disabled child. It is clear that families want to put their energy into enjoying life with their disabled child rather than fighting the system to get services.

“We are stronger knowing that no matter how hard the struggle to have our child accepted (it is always an uphill struggle), we all pull together to make things happen. And we know our child is the best thing that has happened to the family and is loved and cherished just like our other children.”

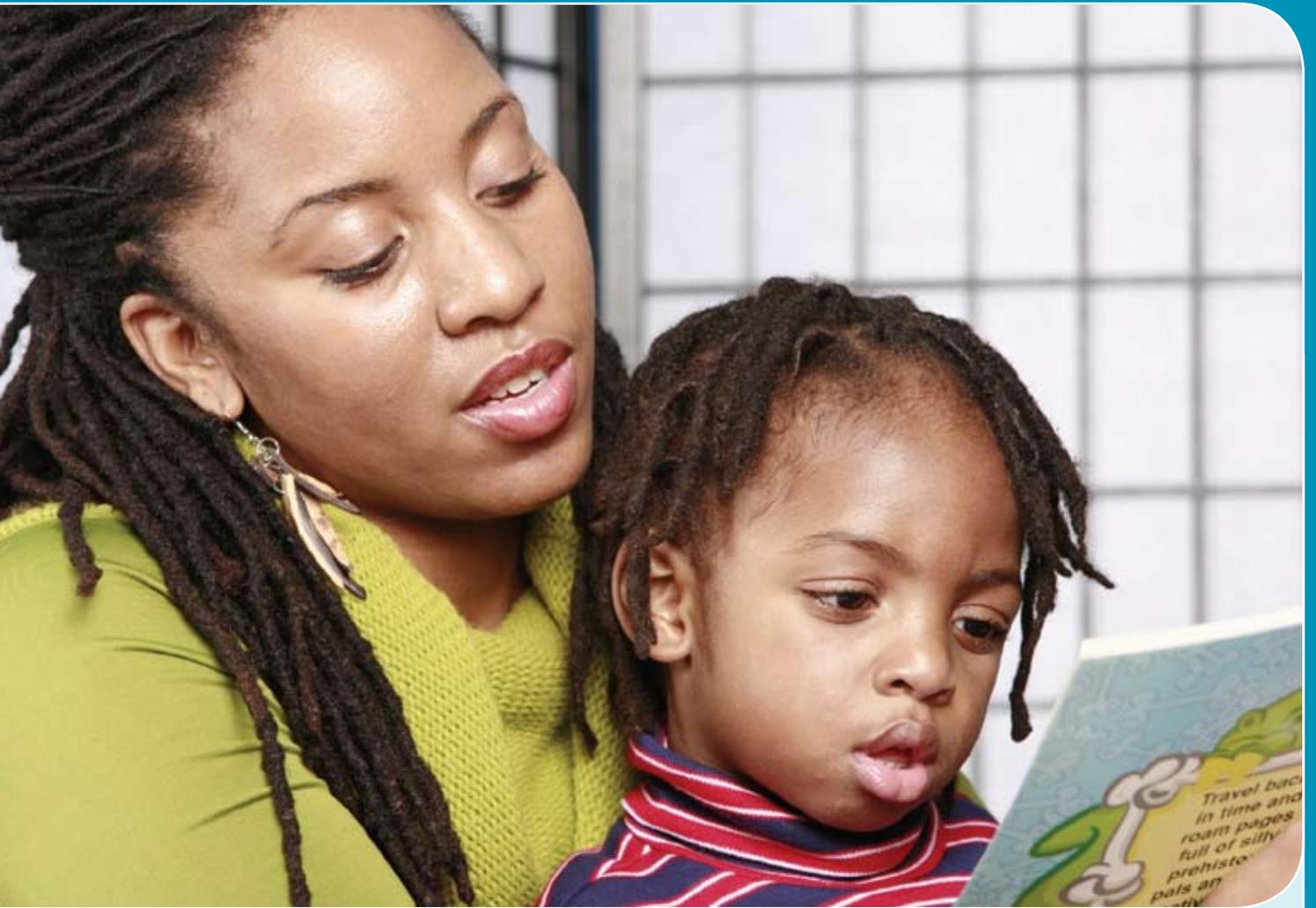
“The way that our son copes with his illness and seeing him achieve his potential in life, makes us stronger. He inspires us all and does not moan or get upset about his condition. He has just won the Children’s Champion award for helping other children. We are so proud of him.....”

“We are stronger because we know what is best for our child and her love and laughter carries us through. If she can get on with it, then so can we.”

What families say would make them stronger emotionally

In answering this question respondents could make multiple selections – they were asked for their top three:

1. Having a supportive relationship with my partner	325	52%
2. Seeing my child reach their full potential	295	47%
3. Recognition of my value as parent carer	233	37%
4. A good night’s rest and chance for ‘me’ time	214	34%
5. Having a supportive relationship with family	204	33%
6. Feeling like professionals have listened and understood	164	26%
7. Understanding/acceptance of disability from community/society	156	25%
8. Having a supportive relationship with friends	111	18%
9. Support from counsellors and other qualified professionals	107	17%
10. Talking to/sharing experiences with other families	33	5%



What makes my family stronger Practically

"I've got to the point of relying and depending on my family. As services are non-existent or my child does not meet a criteria. As a family unit it makes us stronger and united."

Parent of a disabled child

Practically

Families with disabled children often need practical support. Practical help can be anything from the personal care of a child in the home, to equipment to help in the care of a child, or benefits and financial assistance to meet the extra costs of raising a child with a disability.

We asked the respondents about their experience of the practical help available. It is clear both from the figures and the comments that the system continues to be under-resourced, services remain patchy across the UK and need far outweighs provision. This is leading many families to breaking point, worn out from the pressure of caring, unable to cope any longer and forced into considering making heartbreaking decisions.

“My position is unsustainable and because I am not receiving enough support I feel like I can’t go on and am considering giving up my son into care. Being with my son is intensive and I can’t go on doing 17 hours a day with only 3 hours a week help and no holiday.”

Many of the respondents’ comments give an insight into the difficulty of accessing practical help, which would enable families to lead the lives they want to lead. Most families talk of the stress and frustration that comes from having to fight for the smallest amount of support and it is apparent that those families less able to battle the system are particularly vulnerable.

“We have to fight for all our requirements including suitable education for my brain damaged child. There are barriers after barriers to overcome and no respite at all to speak of. Action is required to stop family break ups.”

“We have a common goal in getting the best for our son. Unfortunately this means a constant battle with ‘the system’. We feel like we are the first to ask a question when we clearly are not. Help and support is not offered it has to be fought for.”

“Currently we are satisfied with the services we receive eg short breaks but that doesn’t reflect the nightmare involved with fighting for them. We would be stronger if we didn’t have to fight for everything and made to feel difficult.”

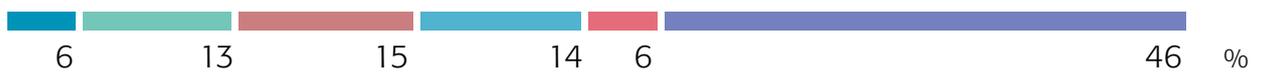
Practically what is your experience of the following?

■ Excellent
 ■ Good
 ■ Satisfactory
 ■ Unsatisfactory
 ■ Bad
 ■ Unavailable

Short breaks



Childcare



Education



Equipment



Employment



Benefits



Support package



Home adaptations grant



Information



Key worker



Linking with other families



Percentage results have been calculated for each category according to how many said it was applicable to them.

Short breaks

Short breaks, formerly known as respite care, can be sitting services, befriending services, youth clubs, play schemes, the use of outreach workers to stay with the child or take them out and overnight stays with carers or in care homes or hospital. Research shows short breaks are one of the most effective ways of improving the quality of life for disabled children and their families.¹⁹ However our research shows they are unavailable to 41 per cent of families. Where short breaks are available, they generally have a positive impact on making families stronger (41 per cent rated short breaks satisfactory, good or excellent) and the respondents' comments reflect this also.

“Short breaks make it possible for my partner and me to reconnect and remember why we got together in the first place. That was before caring for our children became the overwhelming focus of our family life.”

“The access to monthly short breaks makes us stronger because the rest of the family can do things that otherwise are inaccessible to us while caring for our disabled child.”

“In short – respite care has made my family stronger. I couldn't function without it and would have probably had to put my twins into care.”

We were surprised to see such a large number of respondents say that short breaks were not applicable to them and we believe this figure could also include those who don't have access to short breaks and therefore felt unable to comment, rather than they were not needed. It is also possible that poor information about the variety of short breaks available means a number of families don't feel they are applicable to them.

The comments make clear that dissatisfaction with short breaks services centres around lack of availability and flexibility and the difficulty of having to travel long distances to access them.

“Short break services need to become more widely available and flexible to suit families needs rather than the family fitting into the short break services that currently exist.”

There has been significant Government investment in short breaks services in England under the Aiming High for Disabled Children (AHDC) programme. It is very

19. Parliamentary Hearings on Services for Disabled Children (2006) Full Report.

early days for the programme and there are some good models of practice already emerging. However there is still a long way to go before a consistent, sustainable service is established that works for all disabled children, particularly those with the most complex needs.²⁰ There is also concern that the investment in short breaks is properly spent, particularly in relation to the funding announced as part of £340 million given to Primary Care Trusts (PCTs) in England to improve disabled children's services which has not been ringfenced.²¹

In addition to extra funding for short breaks, the Children and Young Persons Act creates a new duty on English local authorities to provide short breaks by law from 2011.²²

We call on Government to sustain the investment in short breaks services beyond the current Comprehensive Spending Review.

Disability campaigners in Wales and Scotland were angered and disappointed that around £55 million extra funding made available to improve services for disabled children, particularly around short breaks, has not been used for this purpose by the Welsh Assembly Government (WAG) and Scottish Government.²³

WAG's programme to improve outcomes for disabled children in Wales – We are On The Way – does include £1 million for each of the next three years to help Welsh local authorities increase short breaks provision for disabled children.²⁴ Contact a Family as members of the Disabled Children Matter Wales campaign group welcomed the funding but expressed disappointment that it did not match our call for more substantial investment – at a level we believe is needed to transform services for disabled children in Wales.

In Scotland, the Scottish Government has committed to providing an additional 10,000 weeks of short breaks per year by 2011, has provided local authorities with an additional £4 million to achieve this and is currently reviewing the carers' strategy in Scotland. As part of For Scotland's Disabled Children campaign group we continue to work to promote better outcomes for families and to promote good practice in service design and delivery.

In Northern Ireland, the need for short breaks exceeds provision.²⁵ Legislation introduced by the Department of Health, Social Services and Public Safety (DHSSPSNI) contains recommendations to develop a model of service which supports children and their families at home. We believe the problem lies in the lack of implementation of the policies and recommendations. There is a Northern Ireland Government target to provide 200 new or enhanced short breaks packages to benefit 400 children by 2011 but we would like greater commitment to help families with disabled children and will be campaigning as a member of the Children's Disability Strategic Alliance for that.

We urge the devolved governments in Scotland, Wales and Northern Ireland to prioritise disabled children and their families including further funding to be made available in

20. Every Disabled Child Matters (2009) Short Breaks Tracking Interim Report.

21. Department of Health (2009) Healthy Lives, Brighter Futures: The strategy for children and young people's health. The strategy confirmed funding available to Primary Care Trusts (PCTs) to improve services for disabled children – £310 million investment in short break and community equipment and wheelchair services from 2008-2011 and £30 million for children's palliative care. This investment has not been ringfenced. Every Disabled Child Matters is campaigning to ensure the money is spent on its intended purpose and has written to each PCT asking that this happens and is asking its supporters to do the same. Secretary of State for Health, Alan Johnson and Secretary of State for Children, Schools and Families, Ed Balls have also written to each PCT stressing the importance of spending the extra investment on its intended purpose.

22. Children and Young Persons Act 2008.

23. There was a Barnett consequential with funding announced under Aiming High for Disabled Children which meant £34 million extra funding for Scotland and £23 million extra for Wales. While it is completely up to the devolved governments how to spend the money there was disappointment WAG and the Scottish Government missed the opportunity to transform disabled children's services.

24. Welsh Assembly Government (2008) We Are On The Way – a policy agenda to transform the lives of disabled children and Young People.

25. Department of Health, Social Services and Public Safety (DHSSPSNI) (2007) Family Policy Unit Consultation.

the next Spending Review to ensure a real transformation of services to improve the lives of often vulnerable children and their families.

Childcare

Our research found that childcare is still unavailable to a large proportion of family respondents (46 per cent). The comments make clear that parents have little choice of childcare options, it's too expensive and often unreliable.

“It would be good to be able to pay the bills without worrying who has my son while I am at work and how quickly the child minder is going to break down again.”

Childcare gives parents the opportunity to take up employment, which can help families lift themselves out of poverty. Childcare can provide a valuable break for parents caring for a disabled child and gives children the much needed opportunity to make friends and have fun. Finding the right childcare is a challenge for all families but for parents with a disabled child this is even more problematic.²⁶ Families with disabled children pay five times more towards childcare costs.²⁷

Despite the much welcomed Childcare Act 2006 (England and Wales) introducing specific duties on local authorities to provide more childcare places for disabled children, there is still a shortage of places.²⁸

To address some of these problems Aiming High for Disabled Children has allocated £35 million to improve childcare provision for families with disabled children in England. This money is currently funding 10 English local authorities to pilot accessible forms of childcare through the Disabled Children's Access to Childcare (DCATCH) project.²⁹ The pilots are focusing on childcare for those disabled children who are currently least likely to be able to access services, including older children and children with complex needs. Projects include training childminders and nursery workers on how to care for and educate disabled children and encouraging university and gap year students to take on caring roles. If successful, the programme could be rolled out across England.

There is also a childcare affordability pilot scheme for London aimed at helping families with disabled children with the cost of childcare.³⁰ The scheme is paying an increased level of the childcare element of working tax credit to eligible low income families with disabled children.

The Scottish Government published its Early Years Framework in 2008 to support parents to access employment, including the provision of flexible and affordable childcare.³¹ We emphasise that the particular needs of families with a disabled child must be addressed. In Northern Ireland, there has been no priority given to childcare provision for disabled children.

26. Every Disabled Child Matters (2006) *Between a Rock and a Hard Place*.

27. Every Disabled Child Matters (2006) *Between a Rock and a Hard Place*.

28. Daycare Trust (2009) Childcare costs survey. Half of Family Information Services (FIS) in England and Wales that responded to the survey reported that there was not enough childcare provision in their area for disabled children.

29. Department for Children, Schools and Families (2008) *Aiming High for Disabled Children – Disabled Children's Access To Childcare projects*.

30. Department for Children, Schools and Families (2005) *Ten Year Childcare Strategy: choice for parents, the best start for children*.

31. The Scottish Government and the Convention of Scottish Local Authorities (2008) *Early Years Framework*, ISBN 9780755957149.

If successful, we want DCATCH and the affordability pilots to be rolled out across the UK and we urge the devolved governments in Scotland, Wales and Northern Ireland to learn from and fund similar initiatives. We believe these initiatives will give parents more control and choice getting childcare which will help them to access employment and lift families out of poverty.

Benefits

Positively, more than 70 per cent of families said they were satisfied or better about the benefits and financial assistance they receive for their child and themselves. However research shows families with disabled children are more likely to be living in poverty than other families.³² It may be that the majority of respondents are accessing support services and getting all the financial help they are entitled to.

It costs three times more to raise a child with a disability.³³ Disability Living Allowance (DLA) is the main benefit for disabled children designed to cover direct extra costs such as such as equipment and transport.

We welcomed the Government's announcement in the 2009 budget that they will pay an extra £100 per year for disabled children and £200 per year for severely disabled children to Child Trust Fund payments. This significant investment in the future of disabled children shows that the Government recognises they and their families are particularly vulnerable to living in poverty. However, the Government also needs to consider the financial circumstances of families with disabled children now and ensure we lift these families out of poverty.

To reduce the higher risk of poverty for disabled children, we urge the government to undertake a DLA take-up campaign with a particular focus on ethnic minority families, whose take up of the benefit is particularly low.

Education and communication

It is encouraging to see that more than 60 per cent of families said that they were satisfied or better with the education their child was receiving. However, it is apparent from the comments that many families have had to struggle to reach that point.

"Having fought the education system which was a huge struggle, life is much better now that my son is getting a suitable education that meets his needs. Many families still have not got this."

"Having the right education would make our family life less stressful – unfortunately we've had to fight for EVERYTHING. My son is autistic and non-verbal and we've fought for Speech and Language Therapy and there's no choice of schools locally!"

32. Department of Work and Pensions (2006-7) Households Below Average Income found that the risk of living in poverty for families with disabled children has increased from 20-25 per cent making disabled children at greater risk of living in relative poverty than non-disabled children.

33. Barbara Dobson and Sue Middleton (1998) Paying to Care: the costs of childhood disability, Joseph Rowntree Foundation.

Parents tell us of the huge difficulties they experience getting the right education to meet their child's needs, including getting a statement of special educational needs from their local authority. There is also a serious shortage of trained professionals such as Speech and Language Therapists even for those children who have speech and language as a statement of need.

Some parents of disabled children are so concerned and frustrated about the education their child is receiving from the authorities that they remove them from school all together and educate them at home.

“Since removing my child from school to home educate, we have worked together more and been able to deal with issues as and when they arrive.”

At present there is an inquiry set up by Government to investigate ways to improve parental confidence in the Special Educational Needs (SEN) system in England.³⁴ The Lamb Inquiry's early findings, published in December 2008, led to the Government announcing measures to improve SEN in English schools. These included a £31 million scheme to raise expectations and outcomes for children with SEN and £7 million to strengthen support for pupils with SEN, including strengthening school leadership and improving online reporting for parents. And in 2009 the Government made a commitment to improve interaction between parents and schools, to strengthen the accountability system and to look at Ofsted's inspection arrangements with a view to placing a greater focus on SEN and disability.

Following the Berrow Review 2008 which looked at services for children with speech, language and communication needs in England, the Government published its plan Better Communication which we hope will lead to improved services and increased support for children with these needs.³⁵

The situation in Scotland is different: the SEN framework was changed into one which supports all children with additional support needs in 2004. That Act is currently being amended and a review of the Code of Practice which guides local authorities in implementing their duties and responsibilities to disabled children and their parents has been promised.³⁶ Since 2003, over £86 million has been allocated to local authorities to meet the needs of the new framework, yet many are still battling the system to have their child's needs, and therefore their child's educational potential, fulfilled.

The Welsh Assembly Government (WAG) has allocated £5.1 million over three years for Unlocking the Potential of Special Schools. This programme aims to support an inclusive education system in Wales, ensuring that wherever possible and appropriate pupils' needs are met within their local mainstream school. However, it also ensures that if specialist provision is required it is of the highest standard.³⁷

34. Brian Lamb (2008-9) The Lamb Inquiry was established as part of the Government's response to the House of Commons Education and Skills Committee Report *Special Educational Needs: Assessment and Funding*. The inquiry has been tasked with investigating a range of ways in which parental confidence in the SEN assessment process might be improved.

35. John Berrow MP (2008) The Berrow Review of services for disabled children and young people 0-19 with speech, language and communication needs.

36. Education (Additional Support for Learning) (Scotland) Act 2004.

37. Welsh Assembly Government (2005) *Unlocking the Potential of Special Schools*.

In Northern Ireland, the Special Educational Needs and Disability Order 2005 provides better rights for disabled children to attend mainstream schools and sets out new duties on schools and boards to improve provision for disabled children and protect against discrimination³⁸. However, the lack of resources, adequate planning, participation and support has resulted in disabled pupils being placed in mainstream schools that are ill prepared to meet their needs.

Families should have a choice of where to send their disabled child to school depending if mainstream or special education better suits their child's needs. They have a right to see their child reach their full potential. We urge all local authorities throughout the UK to provide disability training for staff in mainstream schools and further education colleges and ensure specialist provision is of the highest standard to ensure every disabled child is able to reach their full potential.

Bullying

More than 10 per cent of families who completed the survey said they had a bad experience with their child's schooling. Some of the comments suggest that bullying was a factor.

"I had to be self reliant and take responsibility for my child's education by home educating him from the age of 10 rather than letting him suffer from the daily physical and verbal abuse in a mainstream school who didn't/couldn't understand his special needs resulting in him suffering from clinical depression."

Disabled children are more vulnerable to bullying. Research suggests that disabled children are three times more likely than their peers to be bullied.³⁹

Care package

Worryingly, more than 60 per cent of families questioned said that the overall support package to meet the needs of their child was unsatisfactory, poor or unavailable.

"I feel stronger now that we are home from hospital after spending the last two years in waiting for a care package"

"I've got to the point of relying and depending on my family. As services are non-existent or my child does not meet a criteria. As a family unit it makes us stronger and united."

The support services a family should expect for their child and themselves can include home help, occupational, social, cultural or recreational activities, assistance to have a

38. The Special Education Needs and Disability (Northern Ireland) Order (2005).

39. Council for Disabled Children (2006) *Safeguarding Disabled Children: A Resource for Local Safeguarding Children Boards*.

holiday, advice, guidance or counselling and travel assistance as well as equipment for the child, adaptations for the home and benefits to meet the extra costs of raising a disabled child.

However, in reality there is a tiny proportion of families who are receiving regular support from social services. Both the figures from the survey and the comments from the respondents show overwhelmingly that the system is under-resourced and strict eligibility criteria is used by local authorities, leaving very vulnerable families to fend for themselves. Only one in 13 families with disabled children receives a regular support service of any kind from their local authority.⁴⁰

“We get little or no support from outside agencies. Instead our family is strong because we work together to assist our son. Both my husband and I but also the extended family (grandparents aunts/uncles and godparents) have all supported us in a practical way.”

“We have been told my son is not disabled enough to warrant extra help even though at times I feel we are at breaking point!”

“My daughter never gives in and always smiles – that is what makes us stronger. Her smile is enough to make anyone strong and keep going. Social Care direct are no help, we do not merit an assessment, apparently she is not disabled enough although we get higher rate Disability Living Allowance.”

Parent carers often miss out on a carers assessment because the duty to inform carers of their right to an assessment is sometimes not happening. Also local authorities operate different eligibility criteria to determine access to disabled children’s services.

Assessments should be needs-led and not based on services already available. We would like to see better information and greater transparency about the carers assessment.

A High Court ruling in March 2009 means that limiting access to disabled children’s services can be unlawful.⁴¹ The judge in the case *JL and LL v Islington London Borough Council* stated that the law governing eligibility criteria for local authorities is complex, and stated the need for guidance for local authorities, which would ensure the role of eligibility criteria is better understood.

The new system to measure and compare the performance of each local authority in England in providing disabled children’s services will be based on parental experiences and should help to hold local authorities and Primary Care Trusts to account and ultimately improve services.⁴²

40. Commission for Social Care Inspection (2005).

41. *Sharon Coleman v Attridge Law and Steve Law* (2008) European Court of Justice.

42. Department for Children, Schools and Families (2008) *Aiming High for Disabled Children – National Indicator 54*.

Strong families

Overwhelmingly, what comes through repeatedly from the comments of those families who completed the survey, is a sense they are on their own, forced to be wholly self-reliant because of little or no help from outside sources. For some families, this experience has made them more determined but for others it is pushing them to breaking point. It is also clear that there are many incredibly inspirational people out there who are making an enormous contribution to society but get no recognition for their achievements.

“Having always looked after our son as a family with no help or support has enabled us to share the easy, hard, good and sad moments. The more we struggle, the more we appreciate each other.”

“Determination makes my family stronger – determination to find out what we are entitled to in the way of financial and practical support, and determination to have fun in spite of our problems.”

“If I didn’t push my way through the bureaucracy of authorities for support and services, we would have nothing – so I guess the answer what makes our family strong is ME and knowing my children deserve everything I can do for them.”

“Watching your new born child fight for life for weeks and pull through with problems that will last her whole life. She’s still alive!!! That’s what makes us strong. But we get no help to stay strong. Stop playing with our emotions and help us!”

What families say would make them stronger practically

In answering this question respondents could make multiple selections – they were asked for their top three:

1. A support package to meet my child’s needs	336	55%
2. Short breaks – regular and reliable	329	53%
3. An education to meet my child’s needs	308	50%
4. Benefits	166	27%
5. Childcare	158	26%
6. Key worker	119	19%
7. Information about my rights and entitlements	100	16%
8. The opportunity to work	97	16%
9. Linking with other families in similar situation	94	15%
10. Equipment	80	13%
11. Home improvement grants such as DFG	58	9%



Conclusion

Conclusion

Families with disabled children face enormous challenges. While many show resilience, imagination and great strength in attempting to overcome these challenges, they are being pushed to the brink having to fight each step of the way. Then there are those who simply cannot cope any longer and are at breaking point.

Our research shows that the difficulties for families with disabled children come mostly from outside of the family circle – a lack of support services, attitudes towards disability and a lack of support from professionals.

These are all things that can and must be changed and there have been some steps towards improving the situation for families with disabled children. However, there is still a long way to go to ensure families with disabled children are recognised for the enormous contribution they make to society and that they have the access to support, understanding and services they need to allow them to lead ordinary lives.

The Government must continue to invest in disabled children's services and must sustain the investment in short breaks in the next Spending Review. Short breaks are the most effective way to give parent carers a well earned break and disabled children the chance to enjoy positive experiences outside of the home. This can ultimately lead to stronger families who stay together and are more able to lead ordinary lives.

We believe the Government should invest in a campaign to raise awareness of the needs of families with disabled children and disability and equality training should be given to all people working in a public facing role. This coupled with more focus on disability awareness in schools and early years, would lead to greater understanding and acceptance of disability in the UK. Only then will families with disabled children feel fully included in society and be able to lead ordinary lives.

Thank you to all the families who took part in the survey for their comments and responses.

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 gives 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 site 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 1000 conditions and related support. Each entry provides an overview of the condition with details of support groups where available.

One-to-one support

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.

Contact a Family is a national registered charity, founded in 1979, providing advice information and support to families with disabled children.

Getting in contact with us

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