

Parenting again when
you have a grandchild
with a disability

"I wish I
could just
be Grandma"




family fund
helping disabled children

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1. Introduction

Across the UK around 200,000 grandparents are again taking on the vital caring role in difficult family circumstances.

Nearly half of those grandparents are raising grandchildren who have multiple disabilities, long term conditions or a serious illness. These grandparents have already raised their own children, but due to the loss of a parent, or a family crisis, they have stepped in to pick up the reins and with it often the physical, financial and emotional challenges that come with being a parent.

Their struggle for information, services and money mirrors that of most parents of disabled children. These grandparents also face additional challenges relating to age, health, wider family pressures and greater isolation. Many of their stories are poignant and powerful and have until now remained largely untold.

In this survey, we asked grandparents who had received help from the Family Fund to speak freely about what it was like becoming their disabled grandchild's primary carer and about the help they needed. The report does not just contain statistical data but is filled with their voices. The chapter headings reflect real comments by grandparents from the survey.

One grandmother urged us simply, "Make them aware." The very high 65 per cent response rate to the survey reflects grandparents' intense desire for wider recognition, as does the fact that 93 per cent of respondents said they would be willing to be contacted for more information. It is important to the Fund that the vulnerability of grandparents is visible to policy makers and service providers. We do what we can and many of the 55,000 families we help every year with grants include grandparent carers.

We hope this report will help encourage policymakers to look at the additional support needed for grandparent carers. We thank every grandparent who took part. It has been a privilege to have a snapshot into their lives.

*Cheryl Ward
Development Director.*

Methodology

During 2010, the Family Fund sent out questionnaires to 500 grandparents who are the main carers for their disabled grandchildren and received usable responses from 324 (65 per cent). The questions were informed by earlier studies, notably one by Grandparents Plus (see Appendix C) and a pre-election survey by the Family Fund. Alongside statistical analysis, the focus of the research was on generating direct views from grandparents about the additional support they need to cope with the physical, financial and emotional challenges they face. In some cases, the free answers on the questionnaire were followed up by telephone discussions.



"Caring for a disabled child is a great strain on anyone. For a grandparent it is even more so. At a time when you are expecting to retire to a more relaxed and easy life, you are plunged into a myriad of tasks, which is fuelled only by your love for your charge."

2. Key findings

99%

of grandparents are bringing up their grandchild full time.

Of the respondents, 99% were bringing up their grandchild full time and 89% were providing more than 50 hours of care a week.

The grandchildren had a wide range of disabilities and conditions that provided great challenges.

- 84% had a developmental disability, such as an autistic spectrum disorder or a learning difficulty;
- 69% had an emotional or behavioural disability;
- 42% had a physical disability; and
- 30% had a sensory impairment (visual or hearing difficulty)
- 82% of the children had multiple disabilities and 41% had a long-term illness.

Grandparents can feel very isolated, a problem which is even more pronounced for lone grandparents. They welcome the idea of a network or a support group. And their age and state of health make things harder for them than for parents.

Against all this, many grandparents say that they would not change looking after their disabled grandchild for anything in the world.

We explore these findings briefly below and expand on them in more detail in the body of the report, where we also provide more space for the voices of grandparents themselves to be heard.

"I have two grandchildren with different needs. After ten years I sometimes wish I could be just Grandma but I love them dearly."

4 out of 5

need increased financial help.

Over 50%

have given up work or reduced their hours to care for their grandchild.

1 out of 3

need a break from caring.

1 out of 5

need help with the most basic of items.

4 out of 10

find it difficult to access information.

"We need financial help"

We know that disabled children cost at least three times as much to bring up as non-disabled children, and caring again for grandchildren at an unexpected time in their lives puts particular pressure on grandparents' finances. Four out of five say it has affected their financial situation.

Over half of grandparents have had to give up work completely or in a few cases reduce their working hours, resulting in a smaller income and pension. Meeting disabled children's additional needs can also prove expensive. Nearly half of grandparents have sought financial assistance to help with the extra costs. Over a fifth have both given up work and required financial assistance.

The Carer's Allowance is not adequate for grandparents caring for disabled children and it is not available to them if they receive other benefits (including a pension). Grandparents can often struggle to pay for the additional costs that arise from raising a grandchild with a disability. Many specifically raised a concern that foster carers receive better financial support and recognition than them.

"It is important to have some time away from home"

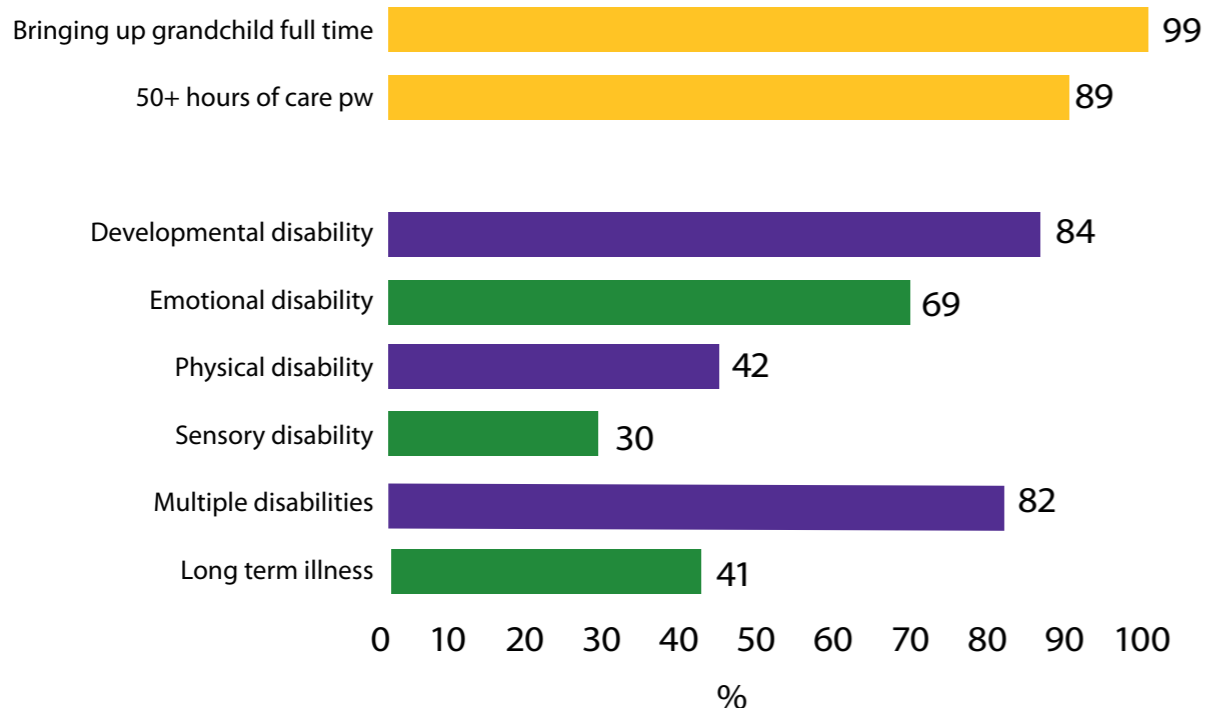
When asked what help would be particularly useful from the Family Fund, a third of grandparents said a short break or holiday. Nearly a fifth said help with the most basic of items such as a washing machine, clothing or furniture. Additionally, specialist equipment and driving lessons would make life easier. A relatively small grant amount can make an enormous impact on grandparents' ability to continue to care.

Grandparents talk about wanting their grandchild to have the same opportunities to have fun on holiday with their families as other children. Many children and grandparents have faced additional trauma, including the absence, perhaps through death, of the child's parent. Taking a holiday gives the whole family a chance to step out of everyday life.

Even more than a holiday away, many grandparents want some respite to give them a short break from caring.

"It is difficult to know what support is available"

At the time of taking on the care of their disabled grandchildren, grandparents – like parents – may have had little experience of disability and find themselves thrust into an alien environment. Four in ten have found it difficult to get the information they need on caring for a disabled child and nearly half have required help with this. Unlike parents, grandparents have to deal with the challenge of accessing information and support alongside the extra stress and anxiety resulting from the often traumatic change in family circumstances which has made them the main carer for their grandchild.



63%

rely on professionals.

“We are not recognised as carers by social services but we rely on their support”

Taking how they find out about the Family Fund as a proxy for how they find out about support in general, grandparents see professionals such as social workers or health visitors as their main source of information, with friends or relatives in second place and school or the internet ranking very low.

Yet many grandparents feel inadequately supported by social services and for some the Family Fund provides the only practical support they get.

1 out of 10

feel isolated and lonely.

“It can be very lonely”

Grandparents caring for disabled children have a particular problem with feeling isolated or lonely. One in ten respondents to the survey talked about this.

Many become isolated from their friends, who move in social circles that are unlikely to involve the full-time care of young children. They hugely miss the contact with their own peer group and the ability just to have some time off with friends or a partner. Their age also separates grandparents from other parents at their grandchildren’s schools.

Although the survey did not directly ask about their partnerships, many respondents mentioned the extra pressures facing lone grandparents. Some are on their own through the death of a partner while for others the strain of caring has resulted in the breakdown of their marriage or relationship.

Over 50%

want to be meet other grandparents to share their stories.

“A support group for grandparents would be ideal”

Given their difficulties with accessing information and services and their feelings of isolation, it is no surprise that nearly all respondents expressed interest in joining a network of other grandparents raising disabled grandchildren. Many spoke separately of their desire for a support group.

What they most want from a network are a regular newsletter and information about other support groups and carers’ organisations. Over half of those interested see it as an opportunity to meet other grandparents and share their stories and concerns.



Almost 6 in 10

have either a disability or chronic health condition.

“It can be a lot harder because of age and health”

Another challenge for grandparents who are parenting again later in life is that their health is likely to be less good than when they were younger. Many have age-related illnesses or other disabilities of their own. This often limits both their life and that of the children. In the survey, they talk about finding it challenging keeping up with young children, particularly those with behavioural difficulties.

Many grandparents also make it clear that their health has been further affected by the sheer, unanticipated effort of bringing up a disabled grandchild. They are at a stage in their life, too, where they may not be the carer just for their grandchildren but for a spouse, a parent or even their own disabled child as well.

“I would not change looking after her for anything”

Despite all the challenges, a lot of grandparents told us about their deep and reciprocated love for their grandchildren, their determination to see them achieve their potential and the sheer joy and reward of caring. “You do it because you love the child” said one.

3. Next steps

It is almost impossible to hear the grandparents voices in the report and remain unmoved. As well as providing new findings, this report supports previous research and continues to show the challenges facing grandparents taking on the role as parents to their disabled grandchildren.

The Family Fund urges national and local politicians, officials and professionals in social and health services to take action to help grandparent carers.

- 1. To relieve their extra financial hardship, review the benefits and allowances which grandparents raising disabled grandchildren are entitled to receive;**
- 2. To ensure they actually get the support they are entitled to, ensure more recognition by social services of grandparents who are their disabled grandchildren’s primary carers; and**
- 3. To ensure they can get a break/respite, take into account the particular needs of grandparents bringing up their disabled grandchildren when planning local short breaks provision.**

The Family Fund will listen to the voices in this report and will continue to do what it can by providing much needed grant help to make life easier and more enjoyable for grandparents and their grandchildren. We also support the call by Grandparents Plus that grandparents should receive a period of paid leave equivalent to adoption leave when they take on the care of a grandchild. Creating extra space to manage this upheaval becomes even more crucial when the grandchildren are disabled, as their conditions may be complex and considerable additional support in adapting to the change in carer may be required.

4. "We need financial help"

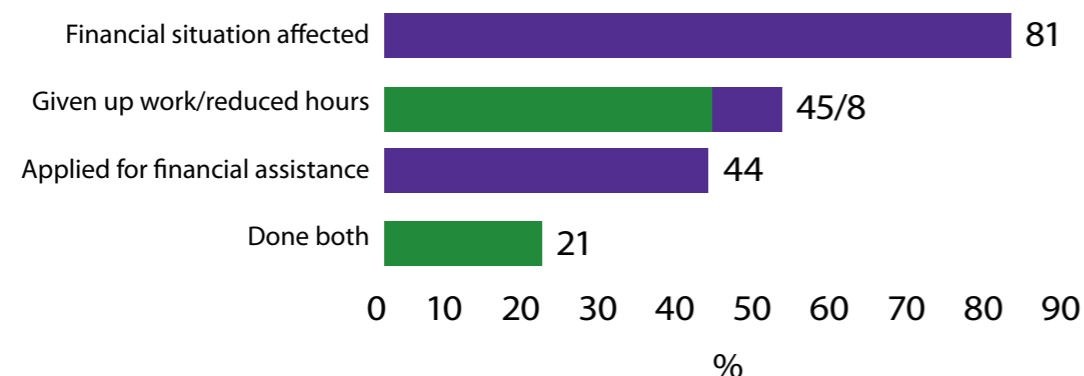
"We need financial help because he rips his clothes and bedding."

Four out of five grandparents say their caring responsibilities have affected their financial situation. We know that disabled children cost at least three times as much to bring up as non-disabled children, and caring again for grandchildren at an unexpected time in their lives puts particular pressure on grandparents' finances.

Over half have had to give up work completely or in a few cases reduce their working hours, and nearly half have needed financial assistance to help with the extra costs. Over a fifth have both given up work and needed financial assistance.

"When you're older it can be such a struggle, particularly financially."

The financial impact of caring for grandchildren



Working less means having to make a smaller income stretch further and having to rely on a smaller pension.

"As grandparents caring for our autistic grandson it has been difficult as I had to give up work completely due to D's care demands so our finances have suffered, also our pension. As we are not earning, we have had to use most of our savings for the extras."

"I am aware of what other parents receive. Since I reduced my hours I'm aware that my pension will also be reduced. It would be helpful if I could receive support from the government or any other source to top up my pension as I won't be able to."

"We are in our 50s and should be saving for old age. As it stands we are spending that on our grandson."

The nature of some children's disabilities also has an impact, with extra costs incurred because of travel to specialist appointments or damage to the home and possessions as a result of behavioural difficulties.

"We need money for things we can't afford to replace like broken doors, cut-up bedding and clothes and broken toys (theirs and other people's)."

"My situation is I need constant help due to behaviour causing a lot of destructiveness. I can't keep up with damages. Have to keep getting loans from the Social Fund."

The Carer's Allowance is not adequate for grandparents caring for disabled children and it is not available to them if they receive other benefits (including a pension).

"It is quite a strain on my husband and me. We have disability benefit for B and I have Carer's Allowance but it is still a tight stretch to keep up."

"I don't get Carer's Allowance because we get state pension. Family Fund has been the only help I've had since having my grandchild live with me 9 years ago."

"I am disabled myself so am living on Incapacity Benefit and Disability Living Allowance. I don't get Carer's Allowance because I'm on Incapacity Benefit."

"It is very hard financially as you nearly always have to give up work and as it's a relative you can't get any help with anything."

Grandparents can feel that financially and emotionally they do not receive the recognition of the huge caring role they have taken on. Many mentioned that foster parents receive generous allowances in comparison to them, although they may be providing just as much care.

"We know foster people who are paid £600 to look after two kids with no problems. We looked after two kids, one of whom is autistic and were given £40 per week tax credits with no help from social services"

"It is very difficult. Grandparents, apart from child benefit, child tax credit and free school meals, get nothing like foster parents get."

"The Government take full advantage of the fact that people like me will not allow their kith and kin to go into care. They are willing to pay foster cares and agency carers a fortune but keep family carers below the poverty line."



5. "It is important to have some time away from home"

"I have to apply to the Family Fund to go on holiday because I have only a pension and it is important to have some time away from home with my grandson."

Relatively small grant amounts can make an enormous impact on grandparents' ability to continue to care.

When asked what help would be particularly useful from the Family Fund, a third said a short break or holiday. Nearly a fifth said a washing machine, clothing, furniture, specialist equipment or driving lessons.

Grandparents talked about wanting their grandchild to have the same opportunities to have fun on holiday with their families as other children. We know that for a lot of families whom the Family Fund helps, being able to take a short break as a family and to participate in activities like other families is of huge importance. Many children and grandparents have faced additional trauma, including the absence, perhaps through death, of the child's parent. Taking a holiday gives the whole family a chance to step out of everyday life.

"Financial help with holidays is most important to our granddaughter. It helps her to get away from stressful situations."

"Going on holiday as a family gives my grandson everybody's attention and he has such fun being free from the medical side of things. For two weeks he is just like any other child."

"We can't afford a family holiday every year so we always apply for help. We need to go to a fully adapted holiday bungalow for this as I'm disabled myself and in a wheelchair."

Even more than a holiday away, many grandparents want some respite to give them a short break from caring. Yet their comments reveal that they are often not given information about relevant services such as Direct Payments or the range of short breaks that may be on offer locally.

"Grandparents would I'm sure be so grateful for some quality respite on their own. It's very difficult to make arrangements for this to happen. I have reached 60 and a week's respite away with my husband would be a dream come true."

"What I desperately need is some respite. Social Services can't really do anything in that respect because they say they haven't the funds."

"Lonely - can't get respite, have tried for eight years now. You are the odd one out. Don't have a social life. It has been so long now."

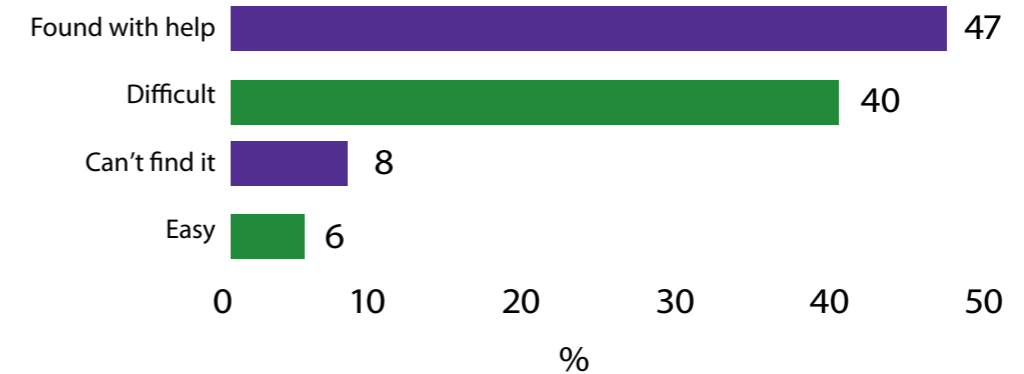
"We are able to get away on a week's holiday, usually with help from the Family Fund, and this recharges the battery again."

6. "It is difficult to know what support is available"

At the time of taking on the care of their disabled grandchildren, grandparents – like parents – may have had little experience of disability and find themselves thrust into an alien environment. Four in ten have found it difficult to get the information they need on caring for a disabled child and nearly half have only been able to do so with help. "It is difficult to know what support is available" is a typical comment.

Unlike parents, grandparents have to deal with the challenge of accessing information and support alongside the extra stress and anxiety resulting from the often traumatic change in family circumstances which has made them the main carer for their grandchild.

How easy is it to find information on caring for a disabled child?



"I find other carers tell me how much help they get, but I did not get much help for my grandchildren for years until my friend told me about the Family Fund. No one said anything to me about the other support I could get for my grandchildren. We have missed out on years of help."



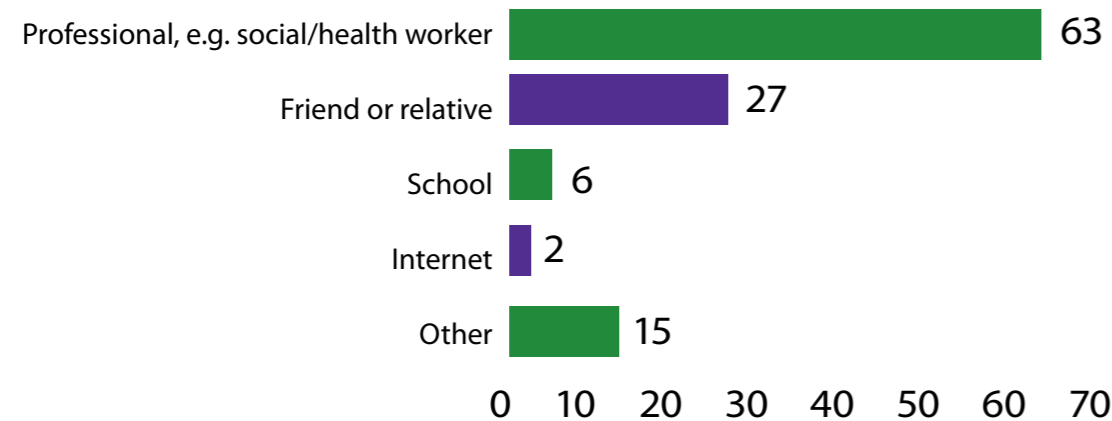
7. "We are not recognised as carers by social services"

"We are not recognised as carers by social services – just expected to do the job and get on with it."

Taking how they find out about the Family Fund as a proxy for how they find out about support in general, grandparents see professionals such as social workers or health visitors as their main source of information, with friends or relatives in second place and school or the internet ranking very low.

"Sometimes I do feel isolated because social services have never got involved, so I've never had help."

How did you find out about the Family Fund?



Yet many grandparents feel inadequately supported by local agencies. They want and need recognition of their caring role by local authorities and social and health services.

"He needs care 24/7. I do feel I am left unsupported by support agencies because he is related to me and I feel if I was not related, support would be given more freely."

"There is a rollercoaster of emotions, sometimes good and sometimes far from good. The intensity of demands leaves you drained both from the child's needs and the various agencies who quite often fail to communicate effectively with each other."

"There is far too much papering over the cracks and a deep lack of commitment by agency workers."

"I have gladly raised my grandson for 17½ years – he has autism. I did all the fighting and struggling to get his needs met and succeeded. I am now in my 60s and would like to do something for myself but it is impossible as my grandson has to be included in everything I do. As there is no support available for us, after years of doctors and of school trying to get us a social worker to provide us with some form of respite, I was finally allocated a social worker in September 2009. As of yet no one has contacted me despite several calls from myself and school."

"I suggested a grandparents' club for people like myself in my area to a social worker once. She laughed loudly and said, 'What you want, go and do yourself.' I could not at the time as husband had just left, wasn't up to it."

For some grandparent carers, the Family Fund provides the only practical support they get.

"The Family Fund have been brilliant. They are the only help I have received since my grandson came to live with me over ten years ago."



8. "It can be very lonely"

"You're quite isolated as other people don't understand your child, they think that they are just being naughty. You have to give all of your attention and time to the children."

Grandparents caring for disabled children have a particular problem with feeling isolated or lonely. One in ten respondents to the survey talked about this.

Many become isolated from their peer group, who move in social circles that are unlikely to involve the full-time care of young children. They hugely miss this contact and the ability just to have some time off with friends or a partner.

"It's difficult when networking, socialising. My friends are older and their activities are different to ones that they used to do when bringing up their families."

"My own peer group has grown-up children, so I am excluded from doing things with them as the activities, eg holidays and socialising, don't include young children."

"Very lonely and also not recognised. Unable to express my feelings to mates my age."

Their age also separates grandparents from other parents at their grandchildren's schools.

"It is rare when you go to school to see another grandparent regularly, the age difference is huge. To make friends with my granddaughter's friends' parents is hard, you just tend to end up isolated from the rest."

"I find that I am quite isolated at times and don't really fit in with other parents because of the generation gap."

"Things like schoolwork and parent meetings are daunting because you get out of the way of these things."



"I lost friends when I became a parent again and it can be very lonely."

9. "Lone grandparents can need as much help for a happy life"

"I am on my own with my grandchildren and they all need help. I would love to be told about more help for them. Lone grandparents can need as much help as others for a happy life."

Although the survey did not directly ask about their partnerships, many respondents mentioned the extra pressures facing lone grandparents.

"I am on my own and have been for last four years as I lost my husband. It is very hard for me to find any funds for my grandson for things like holidays, washing machine, dryer etc."

"As a single grandparent, help with holiday costs are important because I feel it is important for my child and me to have a break from home."

Some are on their own through the death of a partner.

"It is a child that needs a lot of my time. She's the one that's kept me going since I lost my husband so we are both a comfort for each other."

"As a widow it is exhausting and I have four grandchildren, three of which have severe behavioural difficulties, although despite this being hard I wouldn't change anything."

"I hit a lot of red tape and ended up bankrupt as at the beginning I had just lost my husband and knew nothing or what I could claim for."

For others, the strain of caring has resulted in the breakdown of a marriage or partnership, creating additional stress and exacerbating the need for support.

"It is very isolating and exhausting. My marriage has ended because of the stress and it is very difficult financially to be able to do things now that I have to rely on benefits."



"Sometimes it is very hard and tiring as I have no other help at all. My 16-year marriage ended."

10. "A support group for grandparents would be ideal"

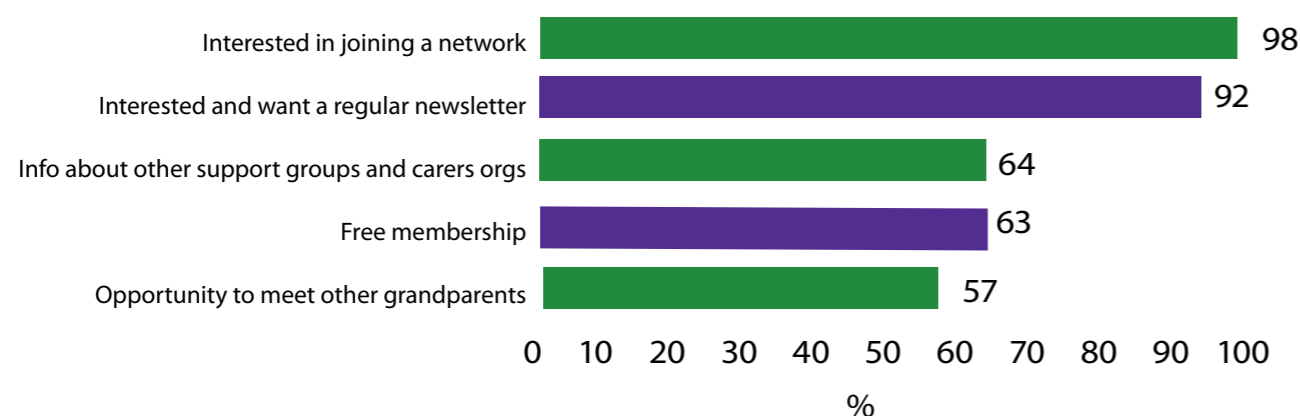
"A support group for grandparents would be ideal if the child has a disability. I get no respite or support from anywhere. I have raised my grandson from birth to 17½."

"I'd like to get to know other grandparents who are in the same circumstances we are in."

Given grandparents' difficulties with accessing information and services and their feelings of isolation, it is no surprise that nearly all respondents expressed interest in joining a network of other grandparents raising disabled grandchildren.

Nearly all of those interested in a network would want it to issue a regular newsletter, and almost two-thirds would want it to provide information about other support groups and carers' organisations. Over half of those interested see the network as an opportunity to meet other grandparents. Perhaps as a result of most grandparents' low incomes, the idea of free membership is popular.

Interest in grandparents' networks



Besides supporting the idea of a network, many grandparents spoke separately of their desire for a support group.

"I'd like to get to know other grandparents who are in the same circumstances as we are in. To have someone other than professionals to speak to on a regular basis. A list of what we can ask help for sent to us more often."

"I enjoy meeting other grandparents/parents/carers in school and leisure activities. I feel that if there were more opportunities to meet others in similar circumstances then this would be beneficial to all concerned."

"There should be more support for children with ADHD like support groups. I attend a three-month appointment for medication; other than that there's nothing to help me or my grandchild."

11. "It can be a lot harder because of age"

"I am now 70 years old. Support from children's services is getting less, never much in first place. No respite, nothing, am so tired."

"It can be a lot harder because of age plus I have a lot of health problems of my own."

Another challenge for grandparents in parenting again later in life is that their own health is likely to be less good than when they were younger. This often limits both their life and that of the children. They talk about finding it challenging keeping up with young children, particularly those with behavioural difficulties. Their health can also be further affected by the sheer, unplanned-for effort of bringing up a disabled grandchild.

"Most carers can struggle, but when you're older it can be harder due to your own health problems."

"The fact that we have already brought up a family means we're both financially and emotionally drained and not getting any younger. Our health is also affected."

"Our oldest daughter passed away from deep vein thrombosis and so it was sudden. We took on her three children, one who is disabled. It has now been 12 yrs since this happened and still hard as we are getting older and find it hard to be running around 24/7."

"My grandson is 17 years now and getting very frustrated at not having a job. He is having driving lessons but I cannot afford many lessons, so this is frustrating for me as I'm too old and sick to get a job to try and help him."

Grandparents are at a stage in their life where they may not be the carer just for their grandchildren but also for a spouse, a parent or even their own disabled child.

"S can't stand and is in a wheelchair. He is now 18 and at college three times a week. His mum died ten years ago at the age of 32. His dad, my son, has had several strokes and is also in a wheelchair. It's been really hard."

"I care for a husband, he is disabled, and a granddaughter, she is disabled."

"Caring for him is a full-time occupation as he needs constant watching. It can be wearing at times as my husband is disabled and I am not very fit."

Grandparents may also have age-related illnesses or other disabilities of their own.

"I also support my mother aged 88 and am disabled myself."

"I suffer from severe osteoporosis, have had numerous spinal fractures and sometimes feel I could do with help myself."

"Because my grandson has ADHD and Hyperkinetic syndrome, he has really violent temper tantrums. Also I suffer spondylosis of the spine."

12. "I would not change looking after her for anything"

"It is hard work but I would not change it for the world looking after her. She's the one that's kept me going since I lost my husband so we are both a comfort for each other. I would not change looking after her for anything."

"Frustrating, lonely, funny, rewarding, a roller coaster of a ride. Not what we expected in our 60s, but we love her to bits."

At the same time as speaking frankly and movingly about the great pressures and challenges of raising a disabled grandchild, a lot of grandparents told us about their deep and reciprocated love for their grandchildren and the sheer joy and reward of caring for them.

"It is as much rewarding as it can be tiring but I would not change it for the world. I love my grandsons and God willing will always be there for them as long as they need."

"My granddaughter has lived with me since the day she was born due to her mother being unable to look after her. I love her as if she was my own daughter."

"It can be very hard but the love you get back makes up for it all. I have had M all his life and I look on him as my child."

"J has made a huge difference to my life. I gave up a lot, but I have never had any regrets. She is so lovely. Hard work at times but a hug and 'I love you' say it all."

The ferocity of grandparents' love and support and their determination to battle to ensure their grandchildren achieve their full potential are very evident.

"Hard work! No life of your own – on call 24 hours a day BUT every achievement however small, keeps you going. And of course we love them!"

"I have had a hysterectomy due to cancer, six weeks of radiotherapy, five days a week but God gave me the strength to continue caring for him. He is a wonderfully blessed child and I'm glad that I have made a difference in his life. I know he is safe, clean, protected from harm and abuse, he has a happy house, he gets loving tender care and that has made it worthwhile."

"There have been a lot of sacrifices made in order to look after my grandchild, however it has been so worthwhile and we love him very much and he is a great child."

"You do it because you love the child."



Appendix 1 – The survey questions

Grandparents were asked these questions.

1. Are you a grandparent raising a grandchild with a disability?
2. Please can you tell us more about the disability affecting your grandchild/grandchildren – please tick all that apply.
 - Do they have a physical disability?
 - Do they have a developmental disability (such as an autistic spectrum disorder) or a learning difficulty?
 - An emotional or behavioural disability?
 - A sensory impairment? (visual or hearing difficulty)
 - A long-term illness?
 - Or does the child or young person you care for not have a diagnosed disability?
3. How many hours of childcare per week do you provide for your grandchild?
 - 20-30
 - 30-50
 - 50+
4. What type of care and support do you provide?
 - Regular overnight care
 - Bringing up grandchild full-time
 - Financial support
 - Practical and emotional support
 - Support at health and educational appointments for child or siblings
5. Has your financial situation been affected by the care you offer?
6. If you answered Yes to question 5, can you tell us in what way your finances have been affected?
 - Had to give up work
 - Had to reduce working hours
 - Had to return to work to cover caring costs
 - Had to apply for other financial assistance to cover costs
7. How did you find out about the Family Fund?
 - Friend or relative
 - Professional worker
 - Internet
8. Is the assistance you need from the Family Fund different to other parents or carers? Can you please explain what help would be useful from the Family Fund? (Open-ended response)
9. How easy or difficult is it to find the information you need to provide care for your grandchild?
 - Easy
 - Found it with help
 - Difficult
 - Can't find any of the information I need.
10. Would you be interested in joining a network of grandparents who are raising their grandchildren? If so would the following be helpful?
 - Regular newsletter
 - Free membership
 - Information about other support groups and carers organisations
 - The opportunity to link up with or meet other grandparents
11. The Family Fund and Grandparents Plus might be interested in finding out more about the needs of Grandparents to develop their services in the future. Would you be willing for us to contact you for more information?
12. Is there anything more you would like to tell us about what it is like caring for a grandchild with a disability? (Open-ended response)

Appendix 2 – Grandparents Plus survey

The findings of this survey align closely with those of a report by **Grandparents Plus**.

In October 2010, under the title *Family and Friends Care – “What if We Said No?”*, **Grandparents Plus** published a survey of the experience of grandparents undertaking the care of their grandchildren, disabled and non-disabled alike.

Of the 255 of the “family and friends” who responded, half (48%) were looking after at least one child with special needs or a disability. Almost all (96%) were grandparents, with the rest being great-grandparents, aunts, uncles or friends. For our purposes, we refer to all respondents as grandparents below.

48%
*were looking after
at least one child
with special needs
or a disability*

A key finding of the Grandparents Plus survey was that those caring for their grandchildren were similar to other grandparents in terms of age or occupational grade but were likely to be poorer because they had given up work or reduced their working hours. They were also more likely to be in poor health, with six in ten having a chronic health condition or disability such as arthritis, high blood pressure or anxiety/depression.

Nearly nine in ten respondents (88%) were under the age of 65 and four in ten (42%) were under 55. Over eight out of ten (83%) were women.

Nearly four in ten (38%) had been looking after their grandchild or grandchildren for more than five years and almost as many (36%) had been looking after them for between two and five years. For just under half (47%), this was because of parental drug or alcohol abuse.

The children looked after ranged in age from 0 to 18, with two-thirds aged between 3 and 11.

Financial challenges

A key finding of the survey was that most grandparents exist on low or very modest incomes compared to the average household income of approximately £500 a week, including benefits and after tax. Two-thirds (65%) have a household income of under £300 a week, with a third (32%) having an income of under £200 a week.

Half (52%) are in work or have a partner who works, while more (57%) have given up work or reduced their hours to take on the care of their grandchild.

It is perhaps no surprise that two-fifths (41%) describe themselves as “struggling” financially, with half (49%) just “coping”. Only one in ten describes themselves as “comfortable”.

Many are experiencing loss of income and/or financial hardship and feel they should be entitled to a grandparents’ financial allowance. Those receiving discretionary local authority allowances are vulnerable to cuts in children’s services as local authorities may have to focus resources on meeting their statutory obligations, rather than making discretionary payments.

Nearly nine in ten (86%) receive child benefit and seven out of ten (72%) also receive child tax credits. These may be the only support they receive from the state for taking on the care of a child, even though many of the children would otherwise be in local authority care. A small number (7%) receive nothing for looking after their grandchild, not even child benefit.

One in three grandparent carers cites welfare benefits as a main source of income, and one in four (27%) relies on the basic state pension. Only just over a third (36%) gets an allowance from their local authority for looking after their grandchild/children.

Grandparents raising their grandchildren rely on benefits more than other grandparents do. A third (33%) receive council tax benefit, which is one and a half times the number (22%) of households in the general population who do. One in five (22%) gets housing benefit, which exceeds the national average of 18%. Against a national household size of 2.4, at least one in ten grandparent carers is living in a household of five or more people, and eight in ten live in households of three or more. Four in ten are looking after more than one child.

They are thus likely to be disproportionately affected by welfare benefit changes, which will impact most on larger households. Single carers will be particularly hit, as they are more likely to be in receipt of welfare benefits, including housing benefit.

Lone grandparents

Around four in ten (41%) grandparent carers are single (living without a partner), compared to a quarter (24%) of all 45- to 64-year-olds. Of these, 99% are women.

Lone carers are more likely than grandparent couples to give up work (36% compared with 28%) and to depend on welfare benefits. 48.5% get council tax benefit (versus 33% of grandparent couples), and 37% receive housing benefit (compared with 22% of couples).

Six out of ten (59%) of all grandparent carers say they feel less isolated thanks to their membership of the Grandparents Raising Grandchildren Network.

Health and well-being

Six in ten (60%) grandparent carers have either a disability or chronic health condition, arthritis being the most common, followed by high blood pressure. Almost half (47%) of their partners have a chronic health condition or disability and one in ten (10%) grandparents is also caring for a partner.

Three in ten (30%) have a disability or health condition that has a moderate or severe impact on their ability to carry out everyday tasks and activities. However virtually none (1.8%) receives help from adult social services on account of this.

Social services

A third of grandparent carers are currently in touch with children’s social services, while a further half say they have had contact in the past. Of these, only a third (32%) say they got what they needed while over two-thirds (68%) say they did not.

As a result, almost two-thirds (63%) describe themselves as “very dissatisfied” or “dissatisfied” with social services or social workers, with fewer than one in three (29%) being “satisfied” or “very satisfied”.

What grandparent carers want

Survey respondents were given the opportunity to say in free text what they would find helpful.

Most want more financial support for the children they are looking after. They also want access to free legal advice and to other sources of information and help.

Three in ten would like respite care (short breaks). Two in ten would like help from a volunteer, for example to assist with shopping and babysitting.

Conclusions from Grandparents Plus

Grandparents Plus wants policymakers to take the steps needed to ensure that grandparent carers can enjoy the following:

1. Recognition for the vital role they play in looking after vulnerable children and keeping them out of the care system: as a minimum they deserve to be counted;
2. Respect and support from service providers, including legal advice when needed and information about financial and other support they may be able to access.
3. Protection from the impact of welfare reform and cuts to local authority children's services (which may hit grandparent carers particularly hard, especially those outside the care system), coupled with the introduction of a national allowance for grandparent carers who look after a child for more than 28 days;
4. Better access to services for grandparents and the children they care for, including respite care/ short breaks, peer support groups and family group conferencing; and
5. A period of paid leave equivalent to adoption leave when they take on the care of a child: this would give them time to manage the upheaval in their lives while keeping their job and would reduce the number that feel they have to give up work.



Appendix 3 – About us

This report has been undertaken by the Family Fund with the support of Grandparents Plus.

The Family Fund

Across the UK each year, the Family Fund helps 55,000 low-income families with severely disabled and seriously ill children and young people aged 17 and under to have choices and the opportunity to enjoy ordinary life. As the country's largest charitable grant-giver to disabled children, the Family Fund provides £33 million in grants for things that make life easier and more enjoyable, such as washing machines, fridges, clothing and bedding, computers, much-needed family breaks, driving lessons, hospital visiting costs and sensory equipment.

A registered charity, the Family Fund receives virtually all its funding from the four UK governments. It operates extremely efficiently and passes on 91p to families for every pound of funding it receives.

See www.familyfund.org.uk



Grandparents Plus

Grandparents Plus is the national charity which champions the vital role of the UK's 14 million grandparents and the wider family in children's lives, especially when grandparents take on the caring role in difficult family circumstances.

Grandparents Plus campaigns for change so that grandparents' contribution to children's wellbeing and care is valued and understood. It provides evidence, policy solutions and training so that grandparents get the services and support they need to help children thrive. And it builds alliances and networks so that grandparents can have a voice and support each other, especially when they become children's full-time carers.

See www.grandparentsplus.org.uk



The Family Fund Trust for Severely Disabled Children.

Private company limited by guarantee. Incorporated in England and Wales. Registration no. 3166627. Scottish charity no. SC040810.
Registered charity no. 1053866. Registered office: Unit 4, Alpha Court, Monks Cross Drive, Huntingdon, York YO32 9WN.



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