



# Take a Break

*Scotland short breaks fund for carers of disabled children and young people*

## Outcome Report 2022/23



Administered by:



## Introduction

Take a Break is one of four grant programmes funded by Scottish Government's Short Breaks Fund. This programme supports unpaid carers of disabled children and young people under 21 years of age, who have complex additional support needs or serious or life-threatening health conditions to access a break from caring in a way of their choosing. Take a Break was set up and has subsequently been administered by Family Fund since 2011/12. Family Fund has 50 years' experience in providing grants and services to families raising disabled or seriously ill children and young people across the UK. Shared Care Scotland administers three Short Breaks Fund grant programmes: Better Breaks, Creative Breaks and Time to Live.

This report provides a review and analysis of the Take a Break programme for 2022/23. It presents the performance of the programme against its aims and also demonstrates how it aligns with the Getting it Right for Every Child (GIRFEC) approach to supporting children and young people's wellbeing. The report covers:

- Aims, outcomes and indicators
- Outcomes for carers
- Family-wide outcomes
- 2022/23 grant statistics
- Added value
- Summary of 2022/23
- Carers' stories





## Aims, outcomes and indicators

Family Fund is a UK wide charity providing grants to families raising disabled and seriously ill children and young people. We manage a range of grant programmes which support families across Scotland. Our vision is that families raising disabled or seriously ill children have the same choices, quality of life, opportunities, and aspirations as other families.

Family Fund administers the Take a Break grant programme, which is one of four grant programmes through which Scottish Government's Short Breaks Fund is distributed on behalf of Scottish Government.

Take a Break supports carers of disabled children and young people aged 0-20 years with complex additional support needs to take a short break, through the provision of a cash grant. The grant can be used flexibly to meet the particular requirements, interests and outcomes of the individual carer.

The programme supports the achievement of Scottish Government's strategic Health & Wellbeing outcome:

"People who provide care are supported to look after their own health and wellbeing."

It seeks to ensure that carers are more able to sustain their caring role for as long as they are able and willing to do and that all carers are more able to have a life alongside their caring role.

In 2022/23 funding for the programme was increased from £700,000 to £1.5 million and was open for applications from carers from 3rd May 2022 to 20th June 2022. The programme received 5,586 grant applications and we were able to award 4,641 Take a Break grants, including 1,604 to carers who had not previously received a Take a Break grant.



The agreed outcomes and indicators for Take a Break in 2022/23, and the results achieved, were:

## Outcomes for carers

Outcome	Indicator/s	Result	Related Carer Quotes
<b>All carers are more able to sustain their caring role for as long as they are able and willing to do so</b>	Percentage of carers reporting that the break has been beneficial for their health and wellbeing. Target – 85% plus	<b>94%</b> of Carers reported that the break had been beneficial for their health & wellbeing.	<p><i>“Has given us valuable time together as a family to nurture relationships and support mental health and wellbeing.”</i>                      Carer, Inverclyde</p> <p><i>“It has given me the much-needed respite, both physically, financially and mentally that I was in severe need of. It is an invaluable service.”</i>                      Carer, South Ayrshire</p>
	Percentage of carers who could not have afforded the break without a grant from Take a Break Scotland Target – 85% plus	<b>89%</b> of Carers reported that they could not have afforded the break without a grant from Take a Break Scotland. A further 10% were unsure if they could have afforded the break.	<p><i>“It gave us as a family time together, we were able to go away for a week that we wouldn't have been able to do without the grant. It really makes a difference. Thank you.”</i>                      Carer, North Lanarkshire</p> <p><i>“It's such a worthwhile thing you do to provide for families. Without this a lot would simply not get a break.”</i>                      Carer, North Lanarkshire</p>
		<b>97%</b> of Carers agreed that they were aware of why the Take a Break grant programme exists.	<p><i>“Thank you for giving us the opportunity to try out new experiences and stays that we not would have normally explored without the fund.”</i>                      Carer, Falkirk</p> <p><i>“The Take a Break Scotland grant allowed me as a carer to bring along an extra adult on days out to help look after my child. This meant I could sit with a coffee and watch my child play knowing they were safe.”</i>                      Carer, Fife</p> <p><i>“I was able to spend some quality one on one time with our eldest child and give him a new experience that made him feel special. It was so nice to have that opportunity for a treat out with our day-to-day life.”</i>                      Carer, Edinburgh</p> <p><i>“This is a fantastic resource that allows families who need their expenses in all kinds of additional ways to a typical family to give them the assistance to enjoy a family break and it is absolutely wonderful and required really as caring all the time is stressful and tiresome, so mini breaks are needed.”</i>                      Carer, North Lanarkshire</p> <p><i>“Allowing us to have a break away as a family together is so beneficial to us all and makes me more relaxed and confident in my caring role.”</i>                      Carer, Angus</p>



Outcome	Indicator/s	Result	Related Carer Quotes
<p><b>All Carers are more able to have a life alongside their caring role</b></p>	<p>Percentage of carers reporting that they were able to do activities with their children that they wouldn't normally do together. Target – 80% plus</p> <p>Percentage of carers reporting that they feel better able to balance their caring responsibilities with their other responsibilities. Target – 30% plus</p>	<p><b>94%</b> of carers reported that the grant provided opportunities for them to do activities with their children that they wouldn't normally be able to do together.</p> <p><b>82%</b> of carers reported that, following their break they felt better able to explore and maintain opportunities outside of their caring role.</p> <p><b>82%</b> of carers reported that following their break, they were better able to balance their caring responsibilities with their other responsibilities.</p>	<p><i>"It gives us a chance to relax and have time to enjoy ourselves without money pressure and do things we wouldn't normally do."</i></p> <p><i>"I used my take a break fund for gym and swim membership so I can exercise more and take a break from my carer duties. This has helped me tremendously - both my mental and physical health."</i> <b>Carer, Aberdeenshire</b></p> <p><i>"Take a break grant has allowed us to have family days out where we may not have financially coped with in the past. This resulted in us spending quality time together and better understanding some struggles and needs that weren't being met before."</i> <b>Carer, Aberdeen</b></p> <p><i>"The Take a Break Scotland grant allowed me to take two days away from my caring responsibilities and spend time with friends just being myself. I came back feeling refreshed and more like myself than I did before the break."</i></p> <p><i>"This is a fantastic resource that allows families who need their expenses in all kinds of additional ways to a typical family to give them the assistance to enjoy a family break and it is absolutely wonderful and required really as caring all the time is stressful and tiresome, so mini breaks are needed"</i> <b>Carer, North Lanarkshire</b></p>

## Carer Outcomes

94% of 2,059 carers said that the grant had benefitted them. 82% said that they feel better able to explore and maintain opportunities outside of their caring role as a result of their grant.

*“Giving carers a break is the best thing you can do for the family as a whole. When we use it for a few days away, it lets us come back refreshed, knowing we can tackle anything that comes at us. It’s hard, caring constantly, caring more for someone else than you do for yourself. There’s very few times where you stop and think about yourself or what you’d like to do, take a break gave me that time.”*

*Carer, Glasgow*

## Family Wide Outcomes

We asked carers to tell us what the biggest difference the Take a Break grant made to their family. Carers told us it was important to have something to look forward to as a break from the normal routine and spend time together as a family.

*“Fantastic night away as a whole family, fun at a show and food treats, could not afford without grant, this day and night also allows us to mentally and physically improve our mental health, keeps us positive and something nice and special to look forward to which is a huge positive thing for us as a family.”*

*Carer, Edinburgh*

*“Our oldest got to have a break from all his appointments and therapy and enjoyed being a kid spending time with his family.”*

*Carer, South Ayrshire*

Carers felt that Take a Break grants provide a valuable opportunity to do activities with their disabled children that would otherwise be inaccessible.

*“It gave us the opportunity to have a break away from home in a safe adapted environment where she could access places she would not normally have been able to access like the beach.”*

*Carer, Fife*

*“It’s given us a space to relax without having to find childcare which is obviously difficult. It’s also allowed us to engage in a physio like activity with my son without him becoming overstimulated and having a meltdown in an unsafe situation.”*

*Carer, East Ayrshire*



Take a Break grants helped carers to feel like they were able to care better for their child and offer opportunities that they could not normally offer.

*"Take a break has been great to get away for a few days as a family, when we are away, we are more relaxed and can do more as a family and this helps us relax and feel less guilty about not doing activities."*

*Carer, Midlothian*

*"Being able to take my children away as a lone parent of disabled children has made me feel like a better parent that can give my children these experiences."*

*Carer, Fife*

*"It has given me the opportunity to take the children to visit their family and get some much-needed relief and support to look after them."*

*Carer, South Lanarkshire*

Take a Break grants also enabled families to do things together that were financially otherwise out of reach.

*"The grant gave us a break that we could not have afforded on our own. It was lovely to get away from the house and break from the routine and be together as a family."*

*Carer, Argyll and Bute*

*"This grant allowed us to come together as a family unit and spend much needed time in the outdoors doing things I couldn't financially commit to before."*

*Carer, Aberdeen*



## Children & young people's wellbeing outcomes

### Included

Of the 1,216 responses, 53% of carers indicated that, as a result of their Take a Break funded break, their disabled child was more included.

*"This meant that we could safely take my child out as we could use the grant to pay for days out for us and also someone else to accompany us. It makes a massive difference to us as a family and meant my child was included where maybe not usually. It took the pressure off from myself for once."*

*Carer, Edinburgh*

*"It helped us have a well needed family break away together and spend more time doing things we all enjoyed as a family. It also made my children feel more included in getting to pick what fun activities we could do on our break away."*

*Carer, Inverclyde*

*"My son felt included on our holiday and was participating in games and dances with the entertainment crew and other children, which meant I was able to have a break for a bit."*

*Carer, Fife*

*"Our son was diagnosed with Asperger's aged 6 and has struggled in education finally stopping attending school altogether. This has had a massive effect on maintaining friendships, but he attended a gaming tournament with the money we received from TABS. He loved this experience and felt "included" and he hopes to go again next year. This is fantastic to hear as he very rarely leaves the house apart from dental appointments etc."*

*Carer, Falkirk*

### Active

From 1,216 responses, 49% of carers indicated that, as a result of their Take a Break funded break, their disabled child was more active.

*"Our break gives us the opportunity to spend time together as a family away from our day-to-day routines. It allows us to escape the city and enjoy time outdoors being active - as we take our breaks off peak season, we are able to access activities etc. whilst they are quiet."*

*Carer, Glasgow*

*"This allowed outdoor play equipment to be purchased so my daughter could play safely in more age appropriate and height appropriate equipment allowing her to make the most of the garden and keeping her active and calm as she loves being outdoors and using swing and slide."*

*Carer, Fife*





## Nurtured

Of the 1,216 responses, 44% carers indicated that, as a result of their Take a Break funded break, their disabled child was feeling more nurtured.

*"The grant helps me be able to take my daughter places that I might not be able to afford to go to and to see her be happy and enjoy herself is wonderful. It makes me happy to see her so happy."*

*Carer, Glasgow*

*"This grant was invaluable. I was able to take my son and his sister to days out that I couldn't previously afford. New experiences that I am keen for him to have so he doesn't just repeat the same thing at home. By getting out and doing fun things, it's helped reduce his anxiety to engage in these experiences and it's been fantastic that we were able to do it all 3 of us, as a family. I am extremely grateful for the support my family have been given and, for that, I thank you very much."*

*Carer, Falkirk*

*"The take a break grant helps our daughter so much as she finds secondary school extremely challenging and her anxiety and depression has been so bad these past three years since the pandemic and this affects us all as a family as myself (her mum) gets really anxious as well continually worrying for her. Getting away my husband, myself and daughter helps us have time away together where we can relax, spend time and reconnect as a family unit again as my elderly mother now lives with us now as well so it's lovely to focus on our daughter and do and go places which she enjoys and without the grant we couldn't afford to otherwise and appreciate the help we have received so very much."*

*Carer, Aberdeenshire*

*"I have been able to spend time with my son doing things that particularly interest him that I otherwise would have had to financially sacrifice other things to be able to do so."*

*Carer, East Ayrshire*

## Achieving

29% of 2,059 carers indicated that, as a result of their Take a Break funded break, their disabled child was achieving more.

*"Being able to participate in activities with my child has reminded me how amazing they are and how much they have achieved, we had fun together. Attending a disability holiday facility was safe and fun."*

*Carer, North Lanarkshire*

## Healthy

Of 1,216 responses, 25% carers indicated that, as a result of their Take a Break funded break, their disabled child was healthier.

*"It helped me spend quality time with my children doing fun things rather than just a caring role. It helped fund days out during the holidays to help my children have fun, get stimulated, get healthy exercise. It helped us more than words can explain."*

*Carer, Aberdeenshire*

## Safe

17% of 2,059 carers indicated that, as a result of their Take a Break funded break, their disabled child was safer.

*“My son climbs a lot and being able to do this safely at home means the family can relax together more as my sons needs can be met more effectively at home than they were previously.”*

*Carer, Aberdeenshire*

“Applying for a take a break has been simple and straight forward. It enables us to pay towards a holiday we otherwise couldn’t afford, it gives us peace of mind knowing my children are safe and have privacy it helps us relax and connect as a family.”

*Carer, North Lanarkshire*

## Respected

Of the 1,216 responses, 11% of carers indicated that, as a result of their Take a Break funded break, their disabled child was feeling more respected.

*“It was able to let me take my child away on a trip that was more suited to him, he was able to do things his way and burn up some energy. Also, he felt included & respected as an individual.”*

*Carer, Glasgow*

“Bringing the family together and taking the stress off the daily grind of everyday life. Achieving new experiences making them feel confident.”

*Carer, Argyll and Bute*

## Responsible

Of the 1,216 responses, 10% of carers indicated that, as a result of their Take a Break funded break, their disabled child was more responsible.

*“Allowed my child to express herself and practice integration with other children her age. This gave me joy and took the pressure off me.”*

*Carer, Perth and Kinross*

“The grant allowed our daughter a degree of independence. She was able to go somewhere different with a friend (and their two Carers) explore a different town, where they had an over-night stay in a hotel and also visited a safari park. She is a teenager who benefits from getting away from home (like others of her age) and having some fun. As parents we were able to go for a meal and attend the theatre together when she was away.”

*Carer, Edinburgh*





## 2022/23 Grant Statistics-

A total of 4,641 grants were provided to support unpaid carers of disabled children and young people with complex needs to access a short break.

### Applications received

Total Applications	5,586
First time applications	2,180
Repeat applications	3,406

### Grants made to carers

Total grants	4,641
First time applications	1,604
Average grant value	£290.99
Total grant spend	£1,350,239

### Age of child

Age at application	No of children
0 to 5	768
6 to 10	1,943
11 to 15	1,971
16	288
17	260
18+	185



## What did carers need the most?

1. Breaks away **3,856**

*"The ability to take my daughter away for a break was incredible. She seems to learn and come on so much more when it's one to one time away from home, so this was perfect. Thank you so much."*

**Carer, North Lanarkshire**



2. **379** Outings and days out

*"It has allowed us to have days out and spend quality time together, we don't have spare money ever so this was great to have fun as a family and get away from the house."*

**Carer, Perth & Kinross**

*"Given me the opportunity to provide a piece of equipment - i.e., an electric trike - which makes a huge difference to my son's motor skills, ability to get around, have fun and meet people."*

**Carer, Perth & Kinross**



3. **82** Outdoor play equipment



4. **58** Camping equipment

*"I was able to purchase new camping equipment for our family, so we have had a few weekends away, seeing different places, enjoying time together outdoors."*

**Carer, Midlothian**

5. **42** Membership fees

*"Our grant was for a Swim Membership for myself and my daughter. We now go twice a week and spend quality time together, improving our relationship. Also helps with our health and wellbeing."*

**Carer, South Ayrshire**



## Reach to Carers

Family Fund's existing reach to parent carers across Scotland and our network of relationships across Scotland's local and national voluntary and statutory sectors supports the delivery of Take a Break.

In 2022/23 we undertook a range of activity to help us reach carers throughout Scotland, including those who had not previously applied but would be eligible to do so. We were grateful for the support of many local and national organisations/networks including Fife Voluntary Action, Aberdeenshire Voluntary Action, Living well East Ayrshire, The Children & Young People's Palliative Care Network, Children in Scotland, Govanhill Community Development Trust and the National Carer Organisations who responded to our requests to share information about Take a Break with their staff teams and potentially eligible carers for example via their social media platforms and bulletins.

A press release sent out with emphasis on Edinburgh City, Aberdeenshire, Aberdeen City, Perth and Kinross, Dundee City, Renfrewshire, Fife and East Lothian, where proportionally low applications had previously been received, secured coverage in local press publications including The Arran Banner, Ellon Times, Barrhead News, Linlithgow Gazette and the Milngavie and Bearsden Herald.

In 2022/23 we able to undertake face to face activities again. As such, we were able to promote Take a Break to carers attending Family Fund's Information and Support Day in Glasgow and to organisations attending our workshop at SCVO's The Gathering for the Third Sector across Scotland.

We were also grateful for the support of Buchanan High School and SENSE Scotland who invited us to participate in their information events in North and South Lanarkshire and North Ayrshire.

**In May 2022, Family Fund also hosted two webinars which provided an opportunity for carers of disabled children and young people throughout Scotland to learn more about some of the grants, information resources and support available to enable them to have a short break. These were supported by Shared Care Scotland and two parent carers who shared their experiences of Take a Break, other short breaks provision and why short breaks matter.**

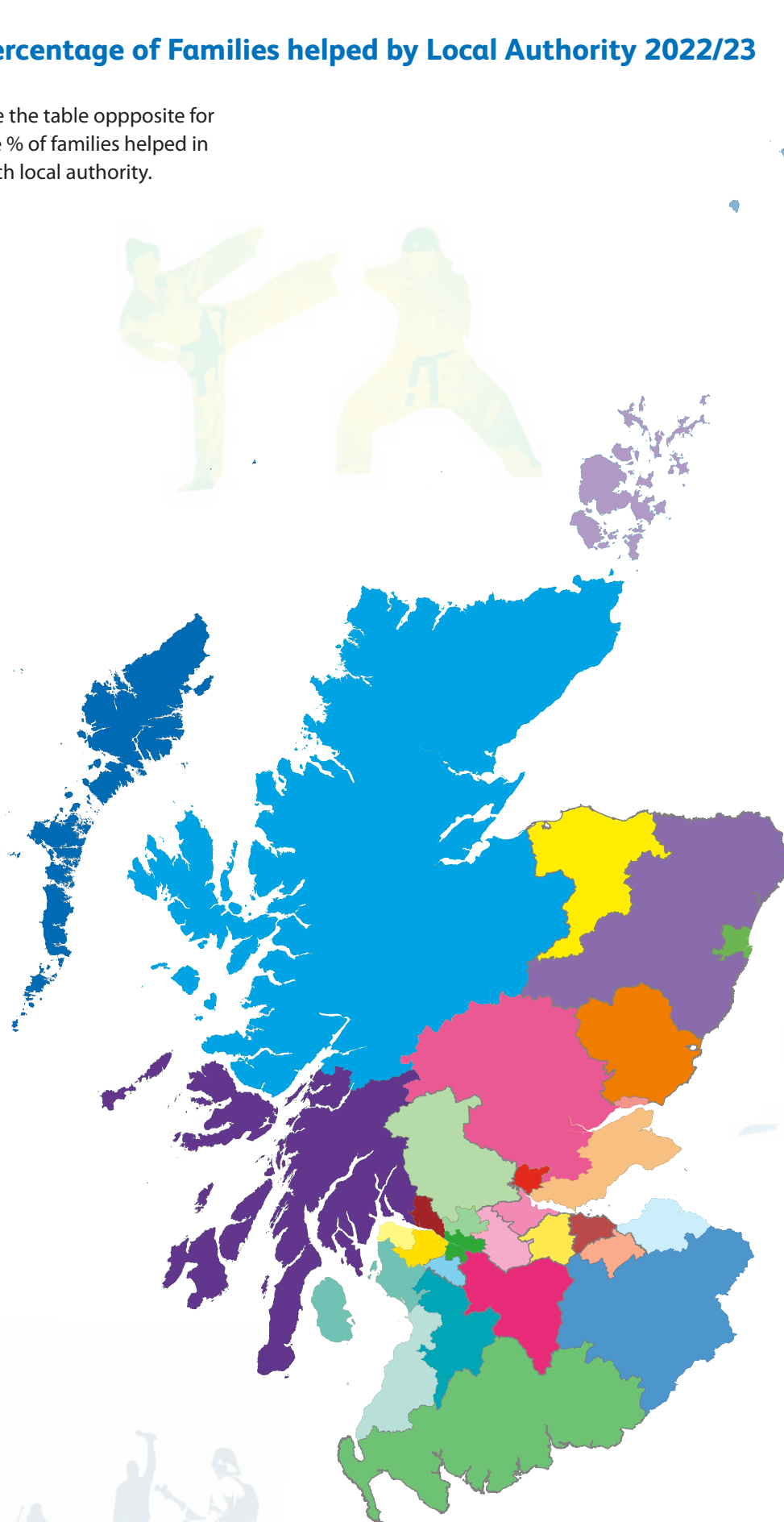
## Percentage of Families helped by Local Authority 2022/23

Scotland	% of families helped in 2021/22	% of families helped in 2022/23
Aberdeen City	2.7%	3.1%
Aberdeenshire	3.4%	3.7%
Angus	1.9%	2.1%
Argyll and Bute	1.3%	1.2%
City of Edinburgh	6.6%	6.0%
Clackmannanshire	0.8%	0.8%
Comhairle nan Eilean Siar	0.1%	0.1%
Dumfries and Galloway	2.2%	2.4%
Dundee City	1.6%	2.3%
East Ayrshire	2.9%	2.4%
East Dunbartonshire	2.0%	1.4%
East Lothian	1.3%	1.4%
East Renfrewshire	2.2%	2.2%
Falkirk	3.7%	3.4%
Fife	5.8%	6.2%
Glasgow City	14.1%	14.2%
Highland	3.9%	4.2%
Inverclyde	2.6%	2.1%
Midlothian	2.7%	2.5%
Moray	1.4%	1.8%
North Ayrshire	2.1%	2.7%
North Lanarkshire	10.0%	10.0%
Orkney Islands	0.1%	0.2%
Perth and Kinross	1.6%	2.7%
Renfrewshire	2.5%	2.8%
Scottish Borders	1.6%	1.7%
Shetland Islands	0.3%	0.2%
South Ayrshire	1.6%	1.8%
South Lanarkshire	9.7%	8.1%
Stirling	1.2%	0.9%
West Dunbartonshire	2.4%	1.7%
West Lothian	3.9%	3.6%
Total	100.0%	100.0%



## Percentage of Families helped by Local Authority 2022/23

See the table opposite for the % of families helped in each local authority.



### Added Value

We always look for opportunities to expand the help provided to those supported by Take a Break and aim to provide wider support to carers raising disabled or seriously ill children and young people across Scotland. Additional support provided via our wider charitable activity in 2022/23 includes:

- Family Fund's First Contact Team (FCT) received approximately 11,584 calls from carers in Scotland.
- Family Fund's FCT have provided 348 carers in Scotland with information and support.
- Family's Fund's FCT have provided 40 carers in Scotland with HMRC Tax credit support (Child Tax Credit).
- 6,593 families were helped with 8,690 grant items via Family Fund's main Scotland grant programme.
- 135 disabled young people in Scotland, aged 18-24, received grant items via our 'Your Opportunity' programme.
- 24 grants in Scotland have been provided with Family Fund Mobility Support (Funded car leases, in conjunction with Motability).
- 1,033 grants in Scotland were provided via the Children in Need Emergency Essentials Programme.

### Summary of 2022/23

In 2022/23, carers of disabled children and young people were still striving to recover from the detrimental impacts of the Coronavirus pandemic, which were being compounded further by rising household costs. As such, Scottish Government's increased investment in the Short Breaks Fund was timely and welcome. This investment saw funding for the Take a Break programme increase from £700,000 to £1.5 million, thereby enabling Family Fund to award 4,641 grants, including 1,604 grants to carers who had not previously received a Take a Break grant.

Our survey findings clearly demonstrate the need for Take a Break grants to support carers of disabled children and young people to be able to afford a break which meets their individual needs, circumstances, and desired outcomes. They also demonstrate the benefits of this provision in relation to carers being better able to have a life alongside their caring role and be as physically, mentally, and emotionally well as they can be. Take a Break grants can also be used in ways which support the wellbeing of disabled children and young people, for example through accessing activities and opportunities which their parent carer might otherwise be unable to afford. For example, of the 1,216 responses, 53% of carers indicated that, because of their Take a Break funded break, their disabled child was more included. At a time when parent carers are themselves increasingly experiencing loneliness and social isolation, such support is vital for them to feel supported in their dual role of parent and carer.

Despite the significant increase in funding, we still received more applications from eligible carers than we were able to support with an award in 2022/23. We know this led to disappointment for some carers and we continue to provide ways for families of disabled children and young people to share their experiences, so they can influence lasting change on issues that matter to them such as support for carers.







## Carer's Stories

# Laura's Story

### Background

Laura is mum to eleven-year-old Oscar who autistic and has Developmental Co-ordination Disorder (DCD). She lives in Edinburgh with her partner Jason and two children. Laura explains, "Oscar was diagnosed with autism at the age of four. He also has a recent diagnosis of DCD, previously known as dyspraxia. When Oscar was younger, he had speech and language delay so that put us on the path of finding the autism diagnosis."

As a result of Oscar's conditions, he can feel stressed and overwhelmed at times. Oscar has hyperacusis which means he's sensitive to loud noises. A sensory overload is often the cause for a lot of his meltdowns, so he uses ear defenders when we're out and about, to help him cope with loud sounds. With Oscar's DCD diagnosis, we also have to physically support him with brushing teeth, washing hair, and getting changed.

When Oscar is feeling overwhelmed, he will shout and become angry. He is very aware of his behaviour and after he's calmed down, he will often feel regret and upset about his behaviour, so it's a bit of a vicious cycle. It's hard for us to deal with it but we try to let him know that it's not his fault."

Laura says, "Our home is quite calm and relaxed since that's what Oscar needs after being at school. In order to manage meltdowns, we ensure we stick to a routine. A lot of preparation goes into getting Oscar ready to go somewhere. We have to tell him exactly what we're doing and sometimes show him YouTube videos of where we're going."

Laura adds, "Jason and I don't get much respite. If we're lucky we get one night a year to ourselves. With that being said, being a parent to a child with a disability has made us more patient and flexible. I'm someone who likes their own routine but since I've had to care for Oscar, a lot of that has gone out of the window as I have to look after his needs first. I've learnt to go with the flow. In recent years, I have been diagnosed with autism, and Jason with ADHD. I think that helps with looking after Oscar, as it feels more natural to us."



"It was a nice way to spend time together in a relaxed environment. Oscar is not normally a chatty person, so it was great to have lots of opportunities to engage with him. It felt like a treat that we don't often get. The whole experience was really good!"

## Take a Break Scotland

Laura's family has received support from the Take a Break Scotland scheme: *"We were granted a break away. Oscar and I used the grant to visit York. We did consider going on a family trip somewhere, all four of us, but decided against it as we thought that Oscar could do with a break away from his little brother for a while. It was lovely to spend some time with Oscar.*

*We got the train down to York and stayed in a hotel, which Oscar and I absolutely loved! Oscar really likes history, so we took a tour of the city and had a pizza in the evening. It was a fun break away and nice that we could do it without saving up.*

*Although Oscar was still with me, it did feel like a treat for myself and a break away from day-to-day life. It was a nice way to spend time together in a relaxed environment. Oscar is not normally a chatty person, so it was great to have lots of opportunities to engage with him. It felt like a treat that we don't often get. The whole experience was really good!"*

## Laura's Story





# Leona's Story

## Background

Leona lives in Dundee with husband Paul and six-year-old daughter, Elena. Elena has diagnoses of Down's syndrome and autism. Leona recalls, "Within the first 24 hours of Elena being born she was diagnosed with Down's syndrome. A day later, Elena was also diagnosed with a congenital heart defect which led her to undergo heart surgery at nine weeks old. Three years later, Elena was then diagnosed with autism. Nowadays, Elena continues to wear nappies, day and night, and she is completely non-verbal, so uses an Augmentative Communication device to help her communicate."

Learning about Elena's conditions came as a huge shock, since we completed all the tests during pregnancy without any worries. It was a difficult time for us. Elena went into heart failure at five days old, we were in and out of hospital, Elena was being tube-fed, and getting sicker every day until her heart operation. I had to take a career break for the first five years of Elena's life due to her 24/7 medical needs."

Now that Elena is older and attending school, Leona is able to return to work part-time. Leona says, "Elena attends a SEN hub within a mainstream school. She's in a classroom with five other children and really enjoys school. Since Elena struggles to sleep through the night, she mostly sleeps in my room with me, and her poor sleeping pattern has a knock-on effect with our family. Paul has to sleep in the spare room to ensure he has a good night's sleep for work, and sometimes I go to work on two hours sleep which can be difficult."

Leona explains, "We don't receive any respite. Childcare is difficult, due to Elena's complex medical needs. We do receive some support from Elena's grandparents, but it gets harder as they grow older. If me and my husband are socialising, we have to do it separately. We can't ever go out together. We've never had a night away or gone out for a meal just the two of us. Elena's needs are so much that she requires one of us to be there for her the whole time."

Leona adds, "Elena has a good character, she's fun and a thrill-seeker. She rarely has any meltdowns, despite not being able to communicate certain things, which can be frustrating for her. Being a parent to a child with a disability has taught me to be more empathetic and patient."



"The break away grants create a sense of relaxation which allows us to feel more refreshed as we go back to our caring responsibilities."



## Leona's Story

### Take a Break Scotland

Leona has been supported by the Take a Break Scotland scheme for several years. The family has been granted breaks away allowing them to attend a wedding, go on a weekend break and most recently, visit a Haven holiday site. Leona says, *"The on-site swimming at Haven was brilliant! There were water slides which all three of us could go down together. We get on a lot better as a family when we're away from the stress of home life. The break away grants create a sense of relaxation which allows us to feel more refreshed as we go back to our caring responsibilities."*

The family also previously used the scheme for some outdoor play equipment for Elena. Leona says, *"The swing and climbing frame we were granted have been a great addition to our garden. Not all parks are accessible for children with conditions like Elena's. It's really good that she can go out into the garden and we're able to assist her. The equipment helps with her sensory needs and allows her to calm down. The equipment also means that we can sit out in the garden, relaxed, knowing Elena is enjoying herself in a safe environment."*

*Family Fund and the Take a Break Scotland scheme have been amazing. It has really helped us for many years. It's been absolutely fantastic, with the number of different things we've been able to use it for. Also, the application process is really easy and straightforward. It's not as daunting as some other forms that we've had to fill out."*



## Nicola's Story

### Background

Nicola lives in Lanarkshire with her nineteen-year-old daughter Libby, thirteen-year-old son John and their grandmother. Libby has a diagnosis of autism, learning and behavioural difficulties, and partial chromosome deletion disorder.

Nicola recalls, *"Libby was diagnosed with autism at the age of five. When she was 12, she was then diagnosed with learning and behavioural difficulties. A couple of years later, she had some blood tests done which discovered that she was missing a part of a chromosome. This led to a diagnosis of partial chromosome deletion disorder. Throughout her life, Libby has always been in special education. She's now at specialist college which she attends to study life skills."*





Generally speaking, Libby is a happy wee soul who loves to sing. People are often shocked that my daughter has autism since it's rare in girls and she gives good eye contact, which isn't the usual stereotype that society has for autism.

Changes to routine can be stressful for Libby. We have to make sure that we prepare her as much as possible for new situations. If we go out somewhere then I have to let her know in advance and we use calendars so she can visually see the plan for the days ahead. Essentially, we try to make sure things are the same as much as possible, for as long as possible. If she becomes overwhelmed and has a meltdown, then time-out and sensory rooms work really well, to calm her down."

Nicola says, "I have to make sure that Libby's food is on time and that I'm able to support her with washing, dressing, and hygiene. Also, when we're out and about, I always have to keep a watchful eye on her. I wouldn't be able to send her down to the local shop unsupervised, as I would be able to do with my younger son John without a problem.

I don't get much respite from my caring responsibilities. It's only when Libby is at college or out with her support worker that I get some time to myself. Additionally, looking after Libby can be difficult for her brother John, since a lot of my attention is focused on her."

## Take a Break Scotland

The Take a Break Scotland scheme, administered by Family Fund, has supported Nicola on several occasions by providing a break away.

Nicola says, "We've received three Take a Break Scotland grants over the years and have used all of them to visit Haven Seton Sands Holiday Park. Libby absolutely loves Haven! It's her favourite place in the entire world. The staff are amazing with her and we enjoy swimming and walking on the beach.

Even though Libby was with me, it still felt relaxing and a break for me, away from day-to-day life. We often plan our trip to coincide with my sister's family so that we all get to spend time together. If I need some time to myself then my sister will be able to look after Libby.

Family Fund and the Take a Break Scotland scheme is an amazing service. I tell everyone about it, including social workers. It's been a bit of a lifesaver! It's great to have a break away and not have to worry about the financial burden."

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# Sarah's Story

## Background

Sarah lives in Glasgow with her partner Daniel and their four-year-old son Nick.

Sarah explains, "Nick was diagnosed as autistic just after he turned four years old. The nursery suspected this a couple of years before that, but the assessment process took a while. Nick is a very happy, cheeky, adventurous and sweet child. He does have issues with emotional dysregulation and anxiety, but when we're able to adjust the environment and care for his needs he's a lovely boy.

Nick is nonverbal which can be frustrating for him at times. He also has sensory difficulties around noise, especially high pitch sounds such as crying or screaming, so busy and unpredictable environments can be difficult for him.

At home, Nick is an only child so we're able to accommodate the whole house around Nick's needs. He also has additional learning difficulties which are still being investigated, so teaching him basic skills, such as putting rubbish in the bin, can be challenging for Nick to learn. We have to support him with getting changed because he can be quite sensitive to clothing, and he doesn't have a sense of danger, so we keep an eye on him. A lot of our time is taken up with supporting Nick with the basics so it can be quite exhausting for us. On top of that, Nick has a sleep disorder, so his sleeping habit is unpredictable and broken, which in turn makes us feel even more tired."

Sarah says, "Caring for a child with additional needs can be very expensive. I buy lots of clothes for Nick hoping that it'll fit his needs but sometimes he won't ever want to wear them. Similarly with foods, Nick will only eat certain foods so new foods may go to waste if he doesn't like them. Specialist sensory equipment also costs a fortune. Caring for Nick is challenging and expensive. We're either working or looking after Nick, so we don't get any respite."

## Take a Break Scotland

Sarah and her family have been supported through the Take a Break Scotland scheme: "The grant allowed us to take a holiday that we would otherwise not have been able to afford. Before I had Nick, I used to love spending time in nature, hiking, and camping. But since having Nick it hasn't been possible. It was absolutely amazing for me to receive the grant and have the opportunity to be outside of the city for a few days. It made me feel relaxed and like my old self again. Coming from Glasgow to a calm environment in nature was fantastic!

I think Nick really enjoyed the break as well. Before that, he didn't like being in nature because he preferred being around vehicles, but since the trip he's been keen to explore nature. It's now been possible to take him on little walks. I could also tell that being in a quiet place made Nick more relaxed, with less going on. The grant also did him a lot of good.

The Take a Break Scotland scheme is a great initiative. As a family we're barely getting by financially and it seems like we're excluded from a lot of other support, so being included with the grant has been great. As a parent it feels bad not being able to offer your child the holidays that other children get, so being able to take Nick camping, and to a cottage, means a lot to us."

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