

Family Fund Trust



Family Fund

Helping disabled children



Window to Our World:

Sharing experiences of
enjoying time together as
a family raising disabled
or seriously ill children
or young people

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What is Window to Our World?



A picture can be worth a thousand words and family photos capture treasured moments and the sometimes joyful, sometimes messy, reality of family life together. As part of Family Fund's 50th anniversary we invited families we have supported in recent years with a grant for a family break, day trip, or play/leisure equipment, to capture and share their personal moments together as part of our Window to Our World photo research project. The project aimed to showcase the importance of being able to take time to enjoy family life, and how support from Family Fund enabled families to do this.



At Family Fund, all of our work starts from the position that families are the experts in their own lives and our role is to listen so we can ensure that everything we do is underpinned by Family Voice. We do this by offering families a space and platform to share their stories and what is important to them. In our research we work hard to be a trusted friend to families by deliberately using less structured, more participative research methods. A participative research technique called photovoice was used in this project, in which participants are asked to share their experiences using photos of their choosing and then take part in an interview to share the stories behind the pictures. We chose the photovoice technique because it helps to address the power imbalance between people taking part in research and the researchers. This approach enables families to talk about the things that really matter to them and allows for richer, qualitative material from everyone taking part.

In our research report, we share with you personal insights and key themes from families on a low income raising a disabled or seriously ill child or young person across the UK in 2023, in the wider context of some of the other work that we do with families. Eighteen families have chosen to take part and explain more about their experiences of raising a disabled or seriously ill child or young person.

What do families want you to know?



We've grouped the insights shared by families into two key themes and from this suggested how we can all work together to enable families raising disabled or seriously ill children or young people to have the same chances as other families who are not raising disabled or seriously ill children or young people.

The challenges to enjoying family time

Going out and about whether on a big trip or just a trip to the local park was not easy for families. Some of the barriers to taking time to be together operate at a societal level in the way services and facilities are configured, such as accessibility of play equipment and playgrounds. Attitudes also formed a significant barrier with poor awareness of disabilities and conditions amongst the public, or outright discrimination and hostility making ordinary family activity feel risky. These experiences highlight why families value the support of grants from Family Fund, as wider society can feel unwelcoming and at times be outright hostile to families raising disabled or seriously ill children or young people.

Benefits of enjoying family time

Despite the wider disabling challenges that exist at societal level, families described how access to affordable family breaks and play equipment brought multiple and diverse benefits for the wider wellbeing of their disabled or seriously ill children or young people and other children in the family, as well as themselves as parent carers. Parent/carers emphasised that these benefits went far beyond the kind of experiences that any family might enjoy during a break or using play equipment because of the specific nature of the impairment or condition their child lived with and their wider experiences of being disabled by society.

Working together to make a change

Whilst each family's experience is unique, key themes emerged across the families' stories. As part of our responsibility to be led by Family Voice and break down the imbalance of power between researchers and participants in research, we want to ensure that the insights from families lead to real change.

We are therefore highlighting the following areas for action:

- Recognition of the wider benefits of play equipment.
- Wider recognition of the importance of inclusive play options in local communities.
- Better standard training for staff in the broad leisure sector about children and young people with disabilities and serious illnesses.
- Wider recognition by the general public of the challenges facing families raising disabled and seriously ill children and young people, and greater compassion in their interactions with other families.

We welcome conversations with partners, both new and existing, about how best to work together to make the change for families.

Meet the families

Before we move into the main body of the research, let's meet the families who took part in Window to Our World. This project would not have been possible without their help and support.



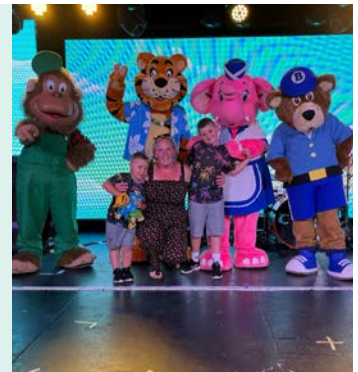
*"I'm **Zac** and I live in Edinburgh with my brother **Giovanni**, mum **Alessia**, and dad **Craig**."*

*"I'm **Max** and I live in Braintree with my sister **Katy**, mum **Carla**, and dad **Elliott**"*

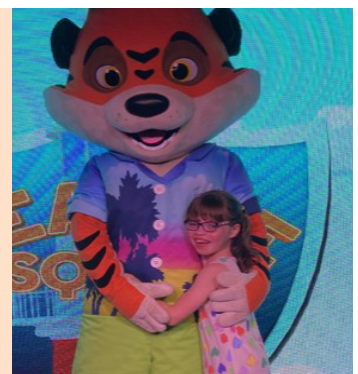


*"I'm **Jai** and I live near Stirling with my little sister **Hollie**, big brother **John**, big sister **Jordan**, and mum **Debbie**."*

*"I'm **Fletcher** and I live in London with my younger brother **Lowen**, mum **Debbie**, and dad **Stuart**"*



*"I'm **Hallie** and I live in Leicester with my sisters **Maisie**, **Trinity** and **Paige**, mum **Emma**, and dad **Simon**."*





*"I'm **Charlie** and I live in Darlington with my mum **Hollie**"*

*"I'm **Finley** and I live in Derby with my parents **Emma** and **Nat.**"*



*"I'm **Daniel** and I live in Glasgow with my mum **Jigjit** and dad **Paul.**"*



*"I'm **Stanley** and I live in Blackpool with my brother **Charlie**, mum **Rachael**, and dad **Stephen.**"*

*"I'm **Florence** and I live near Wrexham with my mum **Bethan** and dad **Kerry.**"*



*"I'm **Wyatt** and I live in Tredegar with my older brother **Lee**, mum **Kirsty**, and dad **Dean.**"*





*"I'm **Bonnie** and I live in Leeds with my **brother Bailey** and **mum Lauren**."*



*"I'm **Olly** and I live near Basingstoke with **mum Lily**."*

*"I'm **Amelia** and I live in Strabane with my **brother Jason**, **mum Natasha**, and **dad Darren**."*



*"I'm **Mia** and I live in Washington with my **brother Leo**, **mum Rebecca**, and **dad Massimo**."*



*"I'm **Ophelia** and I live in Troon with my **sister Lillith** and **mum Siobhan**."*



*"I'm **Jensen** and I live near Dewsbury with my **mum Sophia** and **dad**."*



Challenges to enjoying family life

At times family life can be challenging for all families, but for families raising a disabled or seriously ill child or young person there are additional challenges that they experience directly as a result of societal barriers and social responses to disabled and seriously ill children and young people. Some of these challenges are structural, some are attitudinal and all vary over time and place, but all the families we talk to, both in this project and our wider work, experience daily challenges to everyday experiences other families take for granted.

Access to accurate information

The needs of disabled and seriously ill children and young people make planning essential to successfully spending time together outside / away from the home. This includes negotiating a wide range of accessibility requirements, which will be unique to each family, and being able to check out details in advance:

“We normally have to do a bit of planning. It depends on where we’re going, if they’ve got a website. And if they’ve got a good section on it that tells you about accessibility and stuff, it’s quite handy that I can show [Fletcher], especially if there’s pictures and stuff that I can show.”

(Debbie, parent/carer of Fletcher)

The availability of accessibility information on attraction websites was considered by some parent carers to be a good indication of the degree to which these places might be able to accommodate their family's needs:

"If they've got sections on the website that are quite clear about disabilities - those are quite good. Whereas when it's quite vague you think 'well would you actually help?'"

(Hollie, parent/carer of Charlie)

Our Family Poll showed that only 26% of families said that they are able to get the information they need before deciding if a place is accessible to their child or young person before they go.

Additional costs for families with disabled and seriously ill children

One of the challenges facing families is the additional costs they face when paying for items. 38% of respondents to our Family Poll said that they pay £50 or more per play and leisure equipment item because of their child's illness or condition:

"Everything we need for children with extra needs is like twice the price of normal items. If you put autistic, or autism or special needs in front of something it's twice the price. It's crazy. Most of us have had to give up our jobs to take care of them."

(Kirsty, parent/carer of Wyatt)

The impact of the costs of items was reflected in some of the comments by families about being able to afford equipment for their children:

“Bonnie absolutely loves the great outdoors but our garden is ridiculously small and we just didn’t have the funds to be able to make this space suitable for Bonnie. As a low income SEND family it’s incredibly difficult to both meet your child’s need and actually be able to afford it at the same time so this was amazing for us.”

(Lauren, parent/carer of Bonnie)

Suitability of opportunities for spending family time together

The UK Chief Medical Officer has set out guidelines for the amount of recommended physical activity for children and young people. Our Family Poll, however, showed that 64% of respondents said their disabled or seriously ill child or young person did not have as many opportunities to take part in physical activity, exercise, and sport as they would like. Partly, this was about access. 61% of respondents to our Family Poll stated that providers of mainstream activities were unwilling to make adaptations to enable their child or young person to take part in outdoor and adventurous activities.

“Sometimes I think some of the environments are designed for neurotypical children actually, so as much as you would like your child to be included there are things they can’t really do ‘cos some places are far too noisy or crowded. Sometimes you used to be able to find friendly sessions for maybe sensory issues or children with additional needs but it’s very hard at the moment. So I don’t think that places are friendly and inclusive for everybody at the moment.”

(Alessia, parent/carer of Zac)

Families also talked about wider access to places to go on days out, including places to eat:

“People should be more accommodating to people with disabilities, extra needs, and then we would all feel a lot better about going out. And give people the chance to have a life. I think that’s the main thing I want to say is, I wish people would see that they need to have those things and the chance to have a life.”

(Kirsty, parent/carer of Wyatt)

As children get older there is less available for them. This partly related to accessible toilets and changing facilities for older children (Changing Places toilets), but also accessible play facilities as well.

“In play parks there’s not always disabled swings. Olly loves to be on a swing but unless it’s a big bucket swing or disabled swing, he can’t navigate an adult swing. He has to be in the baby one but the baby one is too small for him now. I feel in my head there should be disabled facilities in every single park in the UK, ‘cos there’s disabled children everywhere.”

(Lily, parent/carer of Olly)

A further issue was where options such as quiet sessions were offered at inconvenient times. Whilst families noted that businesses needed to maximise profits, they felt that the times offered didn't really work for families, or were restrictive in who could use them:

"Sometimes it almost feels like a token gesture. They do it at inappropriate times and not everybody can access it. They'll put criteria on things like places for children diagnosed with autism. Well that's fine for Charlie but what about others on the pathway? It doesn't mean you're not autistic. It's not as accessible as it should be."

(Hollie, parent/carer of Charlie)

Societal-level challenges to enjoying family life: feeling excluded

The single biggest theme from families who took part in Window to Our World was experiencing a lack of understanding and often outright hostility as they tried to enjoy themselves as a family. Places where any family should be able to relax, enjoy themselves and have fun could be marred by the negative reactions of people around them. Families talked about feeling judged, being stared at, people making negative comments, or worse, people using slurs.

Most of us take for granted that we can step outside our homes and spend time with loved ones without attracting negative comments or behaviour from people around us. This is often not the experience of many families with disabled or seriously ill children or young people, however. Our Family Poll showed that 94% of families reported that they've experienced a negative reaction to their disabled or seriously ill children when on a family break or day out. Shockingly, perhaps, respondents in our Family Poll reported that they were more likely to

experience a negative reaction from adults than they were children. The damaging impact on families is again reflected in our Family Poll. 57% of families stated that they sometimes or often avoided going on family breaks or days out because they were worried about other people's reaction to their child's disability or serious illness. 15% said they always avoided going out on short breaks or days out for this reason.

"You should be able to go anywhere with a child without having people judge you. When a child is in discomfort rather than looking, judging, either help, or be part of understanding. It's hard to explain because to us it's still raw, we're still understanding. Like it's heart breaking for us, having to watch her go through the meltdowns and it's more heartbreaking having people looking at you."

(Natasha, parent/carer of Amelia)

"If they just read up or realised that not everyone's the same. Even neurotypical people aren't all the same. And some children have sensory problems or processing disorders so if you read up on those things and then you educate your own children/family on it, then hopefully it'll start to get easier for people. Rather than me having to go 'I'm sorry 'cos it's this', or 'I'm sorry he can't understand'. Because that's mostly what I say. And why should I? I don't know why I should be sorry for it. I'm not sorry."

(Kirsty, parent/carer of Wyatt)

Feeling excluded by not being included

Sometimes being excluded was not necessarily a result of active hostility or negativity, but from carelessness and a lack of awareness and appreciation of how to fully include disabled or seriously ill children and young people. This is structural rather than active discrimination, but it had an impact on the ability of families to enjoy time together and compounded families' experiences of active hostility and exclusion.

There were very mixed experiences of interactions with venue staff as part of days out or family breaks. Some families described very positive experiences from staff members, including instances where individuals had gone 'above and beyond' to offer support. Just over a third of respondents to our Family Poll, however, reported experiencing a negative reaction from staff at the place they visited. A couple of families noted that their experience of repeated visits to the same venue depended on whichever member of staff happened to be on duty at the time. This point suggests that greater consistency could be achieved through better training:

"A lot of staff are just young people which is fine, but they don't get the training. Like the leisure centre staff, a lot don't have SEND training. So having that as part of core training. It doesn't have to be in depth - but just having a good awareness, especially working in a public facing role. Just make things easier so you don't feel as if your being watched. Tiny little things like that would make a massive difference."

(Hollie, parent/carer of Charlie)

Another family said that they had attended an awards ceremony on a holiday park where certificates were handed out. However, the ceremony was ableist and only rewarded children who had succeeded at a particular activity. This family reflected on the need for a more inclusive approach:

Emma: *“Just to consider that children don’t have to be the best of the best to get rewarded. They still need to be rewarded so that they can gain confidence.”*

Nat: *“for participating... have a bit more inclusion.”*

Emma: *‘like sports days at school. Rewards for effort instead of just winning. Simple stuff like that would make a big difference to a lot of children.’*

(Emma and Nat, parent/carers of Finley)

There was an awareness by some families that their experiences on a daily basis did not necessarily reflect the rhetoric around public awareness of disability:

“I think people are really good everywhere about speaking about inclusion, being accepted, but then there isn’t enough awareness that behaviours can come at any time. Speaking from my experience I don’t think people are ready to accept somebody is different. It feels like you need to fit into this society, group of people, whatever. But then it is not possible for them to fit in. And why should they, because people want to be accepted for what they are.”

(Alessia, parent/carer of Zac)

For some families whose children had non-visible disabilities or serious illnesses there was a tension around whether or not to share their child's disability or serious illness, for example by means of a sunflower lanyard:

Emma: *"We should probably get him one of the sunflower lanyards or something, but we've always been of the stance that we don't want people to treat him differently cos of that either".*

Nat: *"It's a fine line between making people aware but not changing their behaviour too drastically either. Because you see us there in the street and he's there on his bike in front of us, it appears like there's nothing going on. But what they don't see is all the little micro managing that we have to do behind the scenes. And you're prepared, or preparing for anything that could happen at any given time. You're constantly..."*

Emma: *"You're on edge all the time."*
(Emma and Nat, parent/carers of Finley)

"like one time Max was in the buggy with the green lanyard...He won't put it round his neck, so he was just holding it, playing with it, and some old man he walked up to us and he was like (mimics staring down at Max and then hostile staring at C), 'why are you giving him a lanyard, he don't need a lanyard'."

(Carla, parent/carer of Max)

Interconnected family characteristics and multiple discrimination

Although many families discussed negative reactions from people around them in response to their child's disability, experiences of other forms of discrimination were reported as well. These multiple experiences of discrimination sometimes intruded into time spent together as a family. One parent carer was very conscious of how their identity could shape their child's experiences of other people as they got older. They discussed how they were trying to promote their child's independence in the context of their ethnicity.

Another family talked about the level of masking they undertook as parent carers in relation to their own experiences of conditions and mental health. They also discussed the experience of being doubly judged, or of attracting negative attention because of their sexual identity:

"I think we mask a lot socially when we're out because we have our own things going on. But when you put that together...and we also have the added aspect of the looks we get for being gay. We get people giving us a lot of funny looks or passing comments...so we also get the pressure of that. Like you feel definitely a lot like when people are looking, it's just not nice. And you add them all together and it is like a pressure cooker."

(Emma and Nat, parents/carers of Finley)

Whilst these challenges are not within the capacity of Family Fund to solve, we are committed to being led by Family Voice and are aware that we can use our platform and networks to raise awareness of these challenges. We are committed to playing our part in the movement to challenge societal and social discrimination against all families raising a disabled or seriously ill child or young person.

Benefits of family breaks and play equipment

Quality family time together

Non-stop caring responsibilities can mean families struggle to be able to spend quality time together and make precious memories. Enjoying time together is a normal part of family life, and every family enjoys themselves in their own unique way. Family time isn't a 'nice to have', it's essential. Whether on a family break, a day trip or just being able to be together at home away from the routine, being given a grant which supports quality family time can be a lifeline.

The science of child development emphasises the importance of developing a relationship between children and parent/carers that moves beyond functional caregiving and encompasses play¹. From birth, the importance of parent/carers playing with children in a developmentally appropriate way is associated with positive outcomes for disabled or seriously ill children². Indeed, for disabled or seriously ill children the importance of parent/carer and child interaction, and wider social inclusion and interaction and participation is particularly important for positive developmental outcomes³.

1 World Health Organization (2012). Early childhood development and disability: A discussion paper.

2 National Research Council (US) and Institute of Medicine (US) Committee on Integrating the Science of Early Childhood Development. From Neurons to Neighborhoods: The Science of Early Childhood Development. Shonkoff JP, Phillips DA, editors. Washington (DC): National Academies Press (US); 2000. PMID: 25077268.

3 Aslam, A. (2013). The state of the world's children 2013: children with disabilities. United Nations Children's Fund (UNICEF).

There is extensive evidence elsewhere that caring for disabled or seriously ill children or young people takes a physical and mental toll on parent carers^{4 5}. One of the strongest protective factors for good mental health and coping ability of parents of disabled and seriously ill children and young people is social support^{6 7 8}. As such, family time also has benefits for parents and carers. As well as the benefits to parent/carers' own mental wellbeing of being able to spend time with friends and family, there are benefits to children when their caregivers are refreshed and resilient in terms of the care they can offer them⁹.

The importance to both parents/carers and children of taking time together as a family, doesn't mean that all families have equal opportunities to enjoy family time. For families with disabled or seriously ill children, there can be particular reasons why spending time together is more challenging than for families with a non-disabled or seriously ill child or young person. We support families on a low income because we know the acute challenges for families of combining caring responsibilities and paid work, further compounded by the disability premium they face day in, day out. All of this adds up to significantly reduced opportunities to spend quality time together.

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- 4 [The Caregiver Health Effects of Caring for Young Children with Developmental Disabilities: A Meta-analysis | Maternal and Child Health Journal \(springer.com\)](#)
 - 5 [Healthy Parent Carers: feasibility randomised controlled trial of a peer-led group-based health promotion intervention for parent carers of disabled children | Pilot and Feasibility Studies | Full Text \(biomedcentral.com\)](#)
 - 6 [Frontiers | Interventions and strategies to improve social support for caregivers of children with chronic diseases: An umbrella review \(frontiersin.org\)](#)
 - 7 [Healthy Parent Carers: feasibility randomised controlled trial of a peer-led group-based health promotion intervention for parent carers of disabled children | Pilot and Feasibility Studies | Full Text \(biomedcentral.com\)](#)
 - 8 [Interventions to Improve the Mental Health of Mothers of Children with a Disability: Systematic Review, Meta-analysis and Description of Interventions | SpringerLink](#)
 - 9 [Maternal and child factors associated with the health-promoting behaviours of mothers of children with a developmental disability - ScienceDirect](#)

Families described the things that really mattered to them and how getting a grant from Family Fund for a family break, day trip, or play/leisure equipment enabled them to flourish:

"Family Fund has been a massive help; brought us together as a family. Family time is important."

(Sophia, parent/carer of Jensen)

For all the families we spoke to being able to spend time together making memories was incredibly precious:

"I've chosen this photo because it just shows all three of them taking a moment to look at the ocean and to take it all in."

(Debbie, parent/carer of Fletcher)



When she sees the Center Parcs sign it's sort of 'yessss' (does a fistpump). She knows where she's going. She knows the thing for 'get in there'. A good time had by all. 'Cos it looks like we're enjoying ourselves. The face says it all there really doesn't it. The enjoyment. She looks like she's having a nice time. Yeah - we've got there."

(Rebecca, parent/carer of Mia)



Some of the families felt that their photos captured a moment in time when everything fell into place, when otherwise they may find days out stressful:

“The pictures were almost a symbol of our memories together, like finally together. Because usually we go places and we don’t seem to enjoy them most of the time because we are too stressed to. So this time was more about us as a family enjoying something that we all really loved to do.”

(Alessia, parent/carer of Zac)



“Hallie doesn’t particularly like sand, but at that time she was loving it. We asked Hallie to scare the seagulls away, and with this job that she was given she was distracted from her sensory issues. Hallie was in her element. She spent all day running up and down the beach scaring the seagulls. Hallie was having a very happy day, a lovely family moment that we will remember.”

(Emma, parent/carer of Hallie)



Affordability of family breaks and play equipment

However, for many of the families these opportunities were not something that could be taken for granted, as affording the costs of going away or getting play equipment and meeting daily living costs were a struggle. Grants from Family Fund gave families a chance to spend time together, which for many families would simply not have been possible otherwise:

"It was obviously the contribution to the holiday. That helped, because with the cost of living and things it was a massive struggle. And just to get that enjoyment back in our lives. And to put a smile on Jensen's face. That's what mattered. And he did. Every photo he was so happy, and it was really brilliant."

(Sophia, parent/carer of Jensen)



"I think without having that trampoline it probably would have caused a lot more behaviours in the regard to his PICA and a lot more behaviours physically because he's not getting right physical input that he needs to be able to function. I think if I hadn't got (the trampoline) through you guys I probably would be in debt right now, because of having to try and borrow money to be able to get things like that. So it was either choosing between my bills or buying him things that can help him."

(Lily, parent/carer of Olly)



Family breaks or day trips give the whole family opportunities outside of their daily routines and experiences. It isn't always possible, however, for families with neurodivergent children to predict how their child will feel about visiting a new place. The needs of families with a neurodivergent child are often not considered by destinations. One parent/carer, Hollie, described her experiences:

"I'll look for discounts 'cos quite often families like ours, you'll get there and then you'll have to come home after an hour. And you don't want to pay £80 for a day. And I have to stick by his side and it's not like I'm utilising the park...and we end up having to leave early or you don't get the full day there."

(Hollie, parent/carer of Charlie).



For many families with a disabled or seriously ill child, routine in their daily lives is very important for coping and functioning. When this routine is taken away during school holidays the value of time away as a family sometimes comes to the fore, as with this family:

"Having a full week at home can be very, very intense. To have that 24/7. So I think being in a different place, it's just the load is lessened, if that makes sense. So for us it's nice to take up the holiday."

(Emma, parent/carer of Finley)



Opportunities for time with wider family

Families also valued being able to spend time with family and friends while they were on holiday. One family described how going away as a wider family meant they could spend time together in a way that was not possible at home:

“my mam and dad are always in work and don’t get to spend time with Wyatt, because he can’t go to them on his own. He couldn’t handle the separation or being in a different place. So it was lovely that they got to spend time with him. So we watched films in the caravan together. And we went and got a take away and a film, so there’s all those things as well as going to the beach. So it all added up!”

(Kirsty, parent/carer of Wyatt)



Time with wider family was not just an opportunity for shared experiences. It also offered an essential network of support for parent carers. Another parent carer noted just how important it was that she could spend time with her wider family during their family break. This parent carer was a lone parent with two children with different disabilities, and described the challenge of finding things on days out that both children could enjoy at the same time. Our Family Poll showed that 62% of families found it either difficult or very difficult to plan family breaks that are suitable for the different needs of each of their disabled or seriously ill children or young people:

"It was brilliant because my eldest daughter was there. My big sister came as well. So I had the two of them to help. I get stressed and panic about things. And she is 'well we'll just take it one step at a time'. And if it's me before I go I'm thinking 'if I take them here is this going to happen'. I'm thinking of things before we're even there, so I can prepare myself for how to deal with them. So it is easier when I've got support."

(Debbie, parent/carer of Jai)



Our Family Poll showed that 79% of families said that they would like to spend more time on days out and short breaks with family and friends. One of the main reasons given by families in our Family Poll as to why they could not spend time with family and friends on holiday was the cost involved. A grant from Family Fund can help with this.

Making family memories wasn't confined to short breaks and trips outside the home, with families also using a Family Fund grant to take the opportunity to make family memories at get togethers at home. For one child, having a hot tub provided a focus for spending time with wider friends and family, but also enabled him to forget daily worries:

"On a weekend it's what's important. Obviously my family are working and I don't work cos I care for Jensen. So on a weekend it's nice when we're all together. Brings us all together, and we can talk about what we've been doing all week, and it's just laughter and smiles, just brilliant. Wouldn't change it for the world. Family time is important. But also if there's been bad days at school that takes it away for him."

(Sophia, parent/carer of Jensen)



Another family discussed how play equipment enabled their child to enjoy sharing activities around their home, as well as helping to meet her natural inquisitiveness:

“She likes going up to the washing machine, and get up to the TV and stuff like that... she loves to open and close the doors. She definitely has a Fear Of Missing Out (FOMO). She’s nosy. She likes to know what’s going on!”

(Kerry, parent/carer of Florence)



Keeping children healthy and happy

As well as giving opportunities for families to spend time together, grants from Family Fund helped to keep children healthy and happy, which had wider impacts for the whole family in terms of reducing the stressfulness of family life. The benefits of having play equipment include not only an opportunity for fun, but also a way to get exercise, as well as a way to self-regulate. Self-regulation is the things we all do to manage our emotional response to daily life, and for disabled or seriously ill children and young people access to opportunities to self-regulate safely can make a huge difference to day to day life as often self-regulation can be a struggle. One parent carer discussed the benefits of having a trampoline and other exercise equipment for her son:

“His stamina has got better. And he gets supervision on it, but he can go out on it after school jump on it and (a) get some of the energy out and (b) it builds him up.”

(Hollie, parent/carer of Charlie)



"He really enjoys it. He knows that it makes him feel better. And now that we've had it a bit of time, he knows when he feels like that he can get the ball out, cos it helps him. Obviously it took a bit of teaching, but now he knows. Some days he won't use it 'cos he doesn't need it. Some days it'll be his blanket, other days it'll be the bar."

(Hollie, parent/carer of Charlie)



Some children living with disabilities or serious illness have very specific needs about physical activity, and being able to regulate themselves using equipment provided by Family Fund was vital:

"He has sensory processing disorder and he needs physical movement at all times. Or a big chunk of physical movement. So as long as he's got that physical activity it can enable him to regulate his sensory needs, to then go about his daily tasks or daily routine. He tends to go on the trampoline in the morning before breakfast so that he can then get that sensory input so he can sit down and have breakfast."

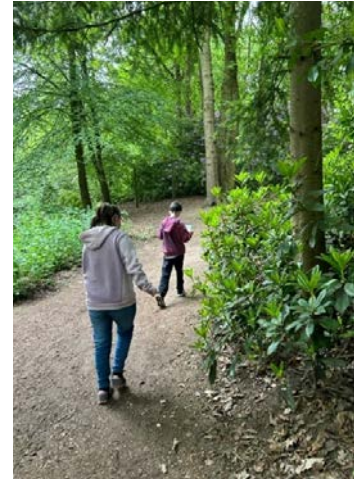
(Lily, parent/carer of Olly)



For many disabled and seriously ill children access to the natural world is an important source of interest, enjoyment and enables children to self-regulate. For many families, their grant from Family Fund gives them the opportunity to explore nature.

"She loves all the animals. She knows where we're going. She likes the swimming, so she likes the subtropical paradise. Being out and about. She likes to be able to feed the animals and feed the squirrels. So we take masses of monkey nuts with us. Feeding the ducks. Feeding them from her bedroom window so she could watch them."

(Rebecca, parent/carer of Mia)



In particular access to safe water play and swimming is valued by families:

"As long as he's out, in nature. He likes to go to farms and country parks.. And water. He's obsessed with water. So anything that involves splashing, running water he's obsessed with."

(Lily, parent/carer of Olly)



A grant from Family Fund can help a family to access opportunities that are key in enabling children to be healthy and happy, but which because of the wider barriers that families face could otherwise be limited.

Parent/carer wellbeing

A number of parent carers reflected on their own experiences of family breaks, and their own sense of wellbeing:

"I think it was just to show our family. How Wyatt is, all the things he's interested in. What makes him happy, and that keeps us happy then as a family. Because when he's happy and enjoying himself, we get to be happy and enjoy ourselves. We spent most of the time on the beach. We made sandcastles. Dean made a bowls court...we've got bowls and he marked out the area and we played that as a family, while Wyatt went off with my father to look for crabs. And it was nice because we weren't spending money, we were just spending time together."

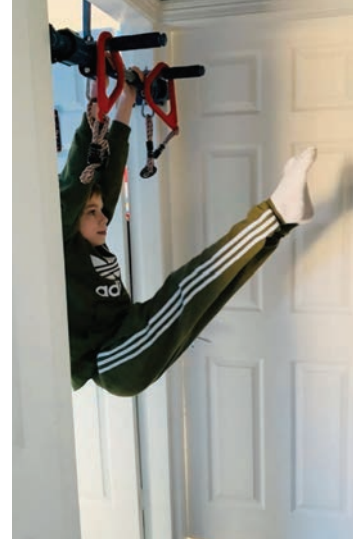
(Kirsty, parent/carer of Wyatt)



Parent carers also discussed their sense of how their wellbeing might have been impacted had they not been supported by the grant:

"I think things would still have been quite stressful... whereas now I can distract and redirect when he does - sometimes he still does try and climb on the doorframes - but I can say no, go and use your bar. And he will. Whereas before when we didn't have an alternative he would get really frustrated and obviously I would get stressed thinking I can't find a way to calm him down."

(Hollie, parent/carer of Charlie).



A safe space for play

For some families the nature of their child's impairment or conditions meant that it was not safe for them to socialise and play away from their own homes. Having access to play equipment in their own garden or backyard meant that children had a safe space for play:

"Ophelia, 13, suffers from a rare brain disorder called Bilateral Perisylvian polymicrogyria as well as multiple other disabilities which means that for her own safety, she cannot go out and play with friends and therefore having a safe garden with toys for her to play on is very important..... As you can see from the photos and her smile... she loves the trampoline and it has made a HUGE difference to our lives!!"

(Siobhan, parent/carer of Ophelia)

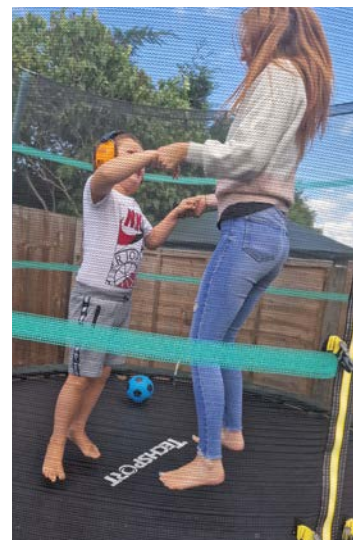


In addition to providing a chance to self-regulate, families also described wider wellbeing benefits especially including opportunities for meeting and making friends in a safe way:

Another family echoed the importance of play equipment for meeting and making friends in a safe way:

"How long have we had it now, over a year now and it's still used daily. All the street kids come out and all the street kids play. It's created a lot of new opportunities for him. They are really good with him. He doesn't really engage with them on the trampoline, but he'll bounce around while all the kids are there. It's more me and Katy he'll take our hand and that's when he'll want us to bounce."

(Carla, parent/carer of Max)



Family bonding

For many families raising disabled or seriously ill children and young people, sibling relationships can often feel strained, as sometimes children struggle to understand the needs of their disabled or seriously ill sibling. The opportunity for siblings to spend time together either on family breaks and day trips or sharing time together on play equipment was valued:

“The last photos are Max and his sister Katy! Katy has always struggled with the fact that Max didn’t play or interact with her like all her friends’ younger siblings. The trampoline started bonding them together. He has a real soft spot for his sister now and loves having a bounce. But...because of the trampoline bonding it now has progressed even further with them playing little games together outside of it! They’ve just started playing hide and seek and they have a lovely bedtime routine where they sing ring o round a roses together. For us it’s amazing to finally see a brother sister relationship, I never thought it would happen.”

(Carla, parent/carer of Max)



The role of play equipment in enabling a deeper relationship wasn't limited to siblings, and also encompassed wider family members:

"My nephew and Wyatt are the same age, there's seven weeks between them, and I have a niece who is eight and another nephew who's one they come up and play with him on the swing set. They get to play together, in the garden. And he's a different child then to what we see when we take him anywhere else. He interacts with them and tries to speak to them. His speech is very little, but he does try. He feels more calm and not so anxious. They are still children themselves and they have got some understanding. They know that Wyatt's not the same as them, and they are really good with him."

(Kirsty, parent/carer of Wyatt)



Given the important role of play equipment in encouraging family bonding, we also asked families through the Family Poll how easy it was to find play and leisure equipment that their disabled and non-disabled children can enjoy together. Just over half of families responding to this question said they found it either difficult or very difficult. The specialist suppliers used by Family Fund allow families to make a choice from a wide range of play equipment that is suitable for children with disabilities and serious illnesses and overcomes some of this challenge in finding equipment to enable important family bonding.

Families also discussed balancing or juggling the needs of different family members, including making sure that siblings could enjoy time on holiday or using play and leisure equipment at home:

“Rather than him missing out, I made sure he got the best out of it too. Wouldn’t have been fair with it being his holiday as well. Me and my husband kind of took turns...”

(Natasha, parent/carer of Amelia)



Building confidence and independence

Disabled or seriously ill children and young people are on a developmental journey as much as any other child, but may need a bit of extra support. Grants from Family Fund have been instrumental for many families in supporting the development of their disabled or seriously ill child's independence - and importantly, the child's confidence in their independence. One family described how her Firefly Scoot enabled their daughter not only to help develop her motor skills, but also to use other play equipment like a sand table:

"It gives her more independence. It gives her a headstart as to what a wheelchair would be like, with the wheels and be able to move round independently. It's a good steppingstone for when she comes out of her buggy to her adapted wheelchair."

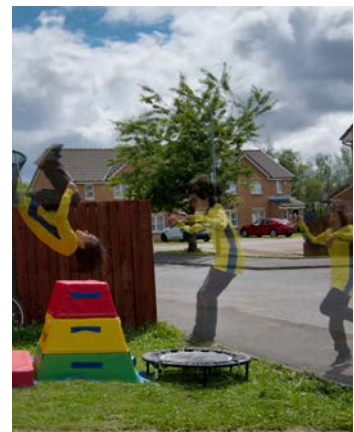
(Kerry, parent/carer of Florence)



Being away on family breaks could also help promote confidence and independence. One family discussed how they were helping their teenage son make the transition towards adulthood. They used some of the money granted for a family break to help build their son's financial awareness, and to pay for entry fees to venues such as museums, joining the National Trust and shopping while they were away. They had also separately used a grant to buy equipment at home to enable their son to develop his interest in parkour, again supporting confidence and independence:

"And so he's changed an awful lot with his independence and what we've allowed in the last year. And he's more familiar with the area ... just last year he got a Bank card as well, but that's about trying to ... it's for me, trying to let him have that independence, but also to test that independence and how he copes."

(Jigjit, parent/carer of Daniel)



Another family described how they had used a grant from Family Fund to go away for the first time as a family, and how this experience had enabled them to see new possibilities. They had seen a new side to their son as he tried things for the first time. This had given them confidence to build on this experience and go away again:

"I didn't have someone to tell me it'll be OK. It was just kind of 'this is your life – now deal with it'. And now it's like 'this is our life and this is what we're going to do with it'. When people ask us about Family Fund and we can say well we've experienced it and because of them we went on our first ever holiday with Stan."

(Rachael, parent/carer of Stanley)



Conclusions and next steps

Every family's story is unique, but there are key themes which emerge from the stories that families shared through Window to Our World.

The benefits to disabled or seriously ill children, and their siblings and parents/carers, of being able to spend family time together are significant, and a small grant can have a ripple effect through an entire family. Families shared things that really mattered to them that were reflected in the photos they had sent and as part of wider experiences when they are out and about. Being able to share time together on family breaks, day trips and also around the home using play equipment enabled families not just to survive but to thrive.

In order to enable even more families to thrive we suggest the following areas of action:

- Recognition in funding of the wider mental and physical wellbeing benefits of play equipment, including safe play in home environments, opportunities for self-regulation and a way to break down social isolation.
- Families had limited options available to them in their surrounding areas for play, and commented on the limited availability of accessible play equipment. In 2022 there was a Joint Children's Play Policy Forum and UK Play Safety Forum Position Statement to support those involved in play spaces, playgrounds and adventure playgrounds in the UK in making these facilities more accessible and inclusive. Each of the national governments in the UK have considered issues around playground accessibility (see for example, The Disability Unit's current consultation on playground accessibility) but more focus and dedicated resource is required to move this work forward. Family Fund supports Scope's 'Let's Play Fair' campaign. However, families' comments went wider than this to include access in the public realm to facilities such as Changing Places.

- Staff at venues and destinations could really help to make or break a day out or visit. Families highlighted very variable experiences, including sometimes inconsistent reactions from staff at the same destination. Although plentiful guidance is available, families' experiences highlight the need for a universal basic level of training. Family Fund is working alongside researchers to bring the evidence to providers we work with in the leisure industry, and supporting the researchers to share their evidence with policy makers.
- Perhaps the most important impact on families' experiences was the attitudes of people around them. Families reported on the limited public awareness of the wide range of issues and challenges facing families, including how disability is understood in relation to invisible disabilities. Families also emphasised the poor wider understanding of neurodivergence. This issue is not new, and has been reported elsewhere as a policy driver, but its resilience in public perceptions points to the continued and ongoing need for action to bring about behaviour change at the scale required to have a meaningful impact on families' lives. Family Fund is working alongside McCain in a corporate partnership which aims to increase public awareness of how families who don't have a disabled or seriously ill child or young person can support families who do.

The findings and learning points from this report pose a question for us: How can Family Fund best work alongside others to push for change? We welcome an ongoing dialogue with partners, new and existing, to identify how we can work together to enable families to exercise their rights to be able to enjoy family time together and visit accessible play and facilities that are inclusive of their needs.

Please get in touch with us at partnerships@familyfund.org.uk or research@familyfund.org.uk

Appendix One: Methodology

The project aimed to showcase the importance of being able to take time to enjoy family life, and how support from Family Fund enabled families to do this. A research technique called photovoice was used in which participants are asked to record and share their experiences using photos and then take part in an interview.

Families who had received funding for a family break, day trip, or play/leisure equipment were invited to share photos of their experiences of enjoying time together as a family. Families were recruited through invitations via social media, and direct invitations to families who had already given their consent to be approached to participate in research. The project reflected a range of families across the spectrum that Family Fund works with (such as geography, child's disability, ethnicity, and family make-up). Eighteen families shared photos, with sixteen taking part in an interview (and two families sending comments via email).

Families were either sent a disposable camera or elected to use their own cameras. The families were then invited to take part in an interview to discuss their photos and wider experiences of family breaks and days out. The interviews were also an opportunity for families to talk about what really mattered to them and how they could be better supported to thrive. The key element of this approach was that participants were able to frame their experience and tell their own story through their photos, and about what is important to them. The interviews were undertaken in families' homes, over the phone or on Teams.

A qualitative analysis was undertaken of the families' interviews to identify the key themes that emerged from the conversations. Quotes are used to illustrate the main points that families discussed. All the families gave their consent to take part and share their stories and photographs. The project was a joint effort across Family Fund to enable families to take part and share their photographs, stories, and experiences safely.

The data in this report was supported by statistics from our quarterly Family Poll. The purpose of the poll is to better understand and track the needs of families on low incomes raising disabled children, and the challenges they face. The Q1 2023-24 Family Poll asked about physical activity, play, days out and short breaks and provided an insight into how raising a child or young person with a serious illness or disability impacts on being able to take part in these activities. Families were eligible to participate if they had not received a grant from Family Fund in the previous 12 months and had not been invited to take part in Family Poll in the previous 12 months. A random sample of eligible families were invited to take part, with a sample size for this poll of 1224 families across the UK.





Family Fund

Helping disabled children

find us:




Family Fund
4 Alpha Court
Monks Cross Drive
Huntington
York YO32 9WN

talk to us:

Telephone: 01904 550055
Fax: 01904 652625
Email: info@familyfund.org.uk

online: www.familyfund.org.uk

community:

 facebook.com/familyfund
 @familyfund
 @family_fund

