



Summer Fun - Physical activity, play and days out
Family Poll June 2023 –
UK Findings



Family Fund
Helping disabled children



Our purpose is to improve the lives of low-income families raising disabled or seriously ill children and young people.

Our mission is to provide items and services to all low-income families in the UK raising disabled or seriously ill children, that they could not otherwise afford or access, and that help improve their quality of life, realise their rights, and remove some of the barriers they face.

Our vision is that all families raising disabled or seriously ill children have the same choices, quality of life, opportunities and aspirations as other families.





Methodology

This report is the findings of the Q1 2023-24 Family Poll. In a break from previous Family Polls we have themed this edition around physical activity, play, days out and short breaks. Family Fund grants are often used by families on items to help with physical activity, play, days out and short breaks so we wanted to get 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. As a thank you for their participation, participants were offered the chance to enter a draw for a £100 Argos voucher.

The initial invitation was sent out on 16th June, with a follow up three days later to recipients who hadn't opened the email.

This resulted in an achieved sample size for this poll of 1224 families across the UK.





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8. Experiences of discrimination

Family wellbeing

9. Wellbeing of disabled children
10. Wellbeing of non-disabled children
11. Wellbeing of Parents and carers



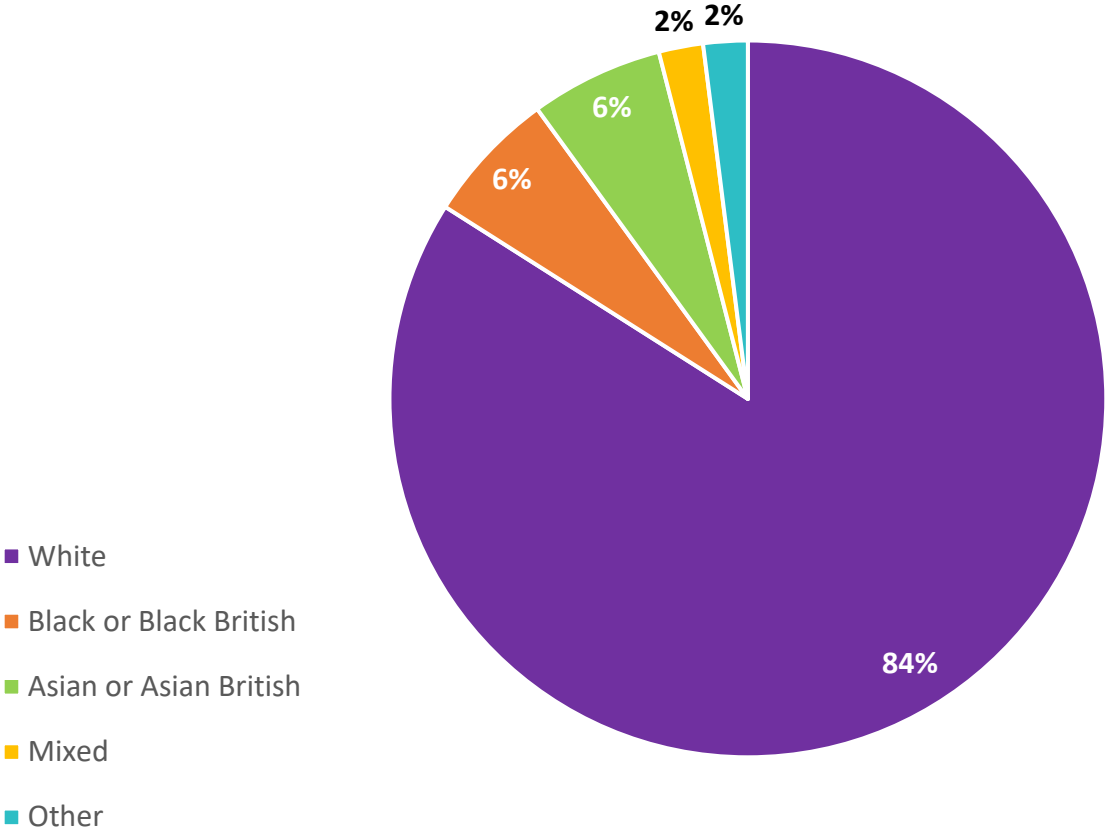
1. Who took part

Families who took part in Family Poll are a cross section of the families Family Fund works with

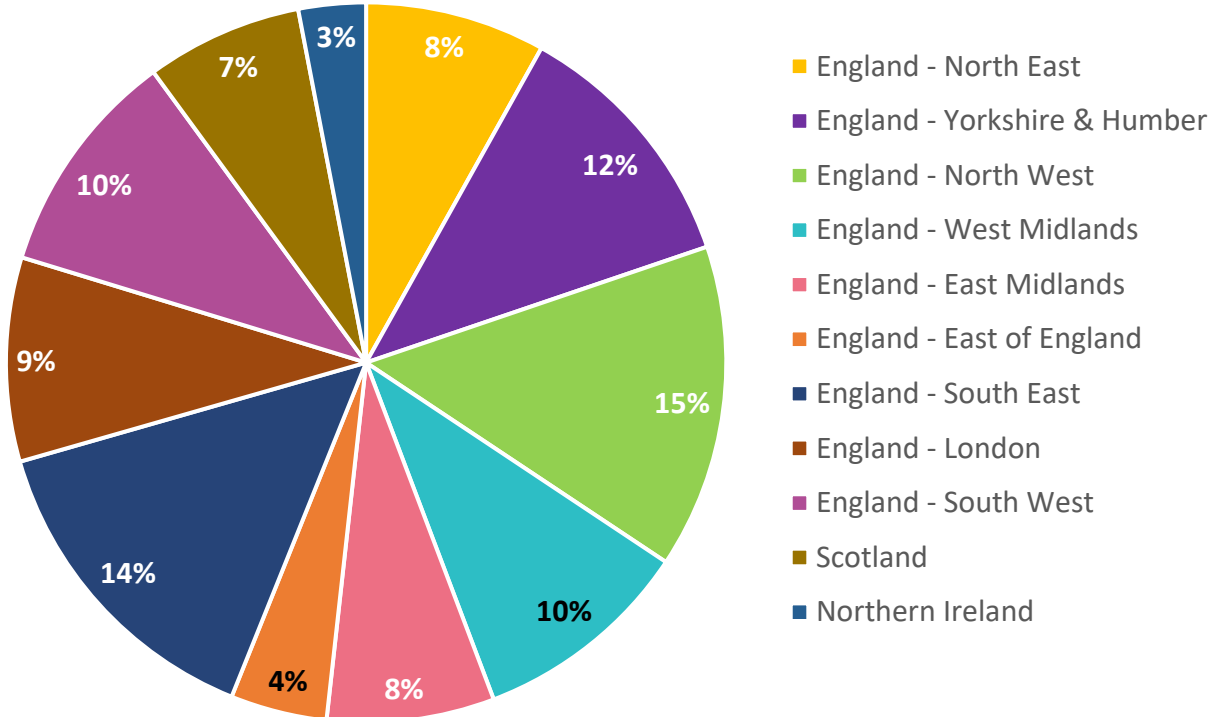


Who are the families who took part in Family Poll? (N=1,224)

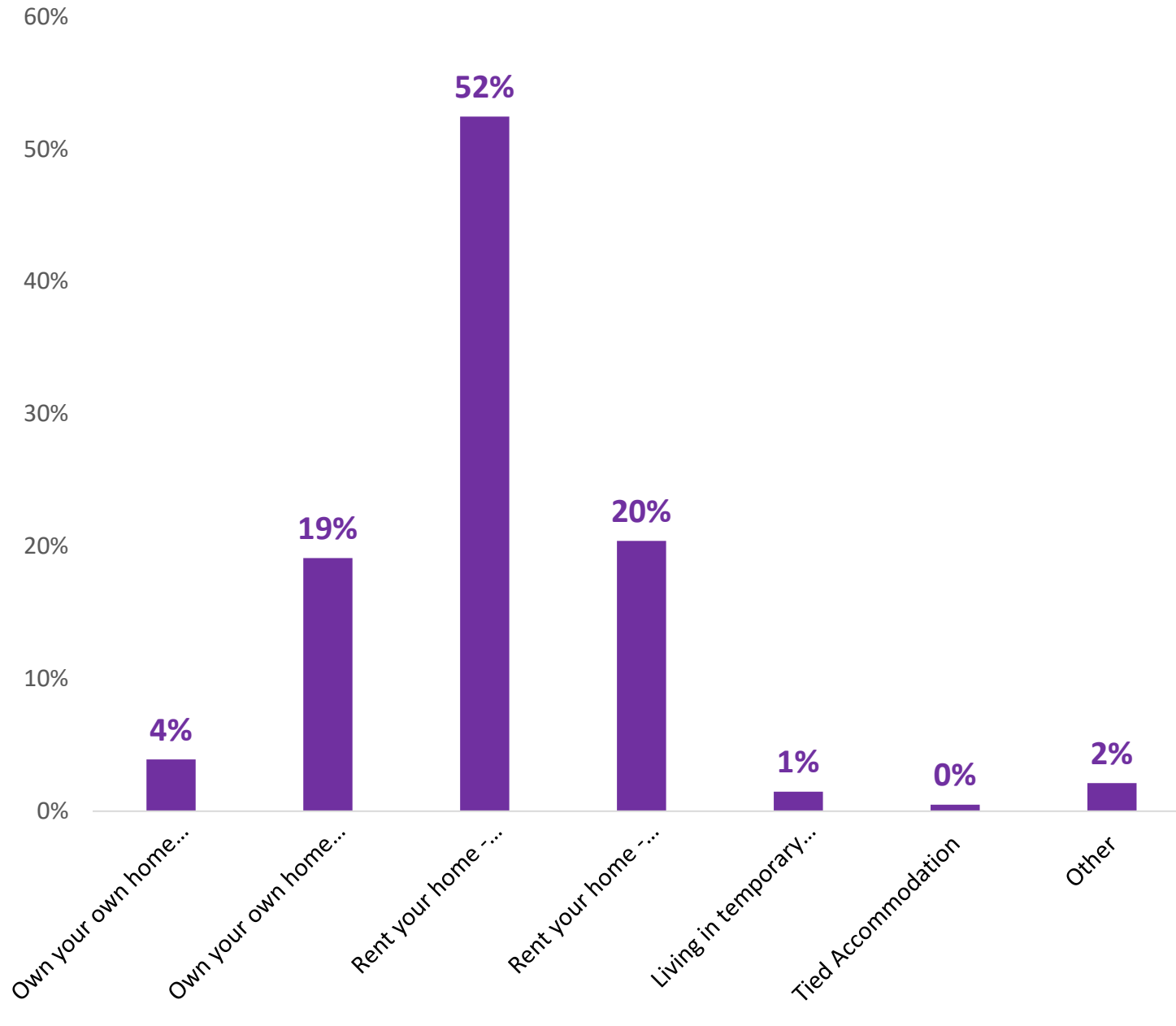
What is your ethnic group? [grouped]



Which of the following regions do you currently live in?



Who are the families who took part in Family Poll?



1,224

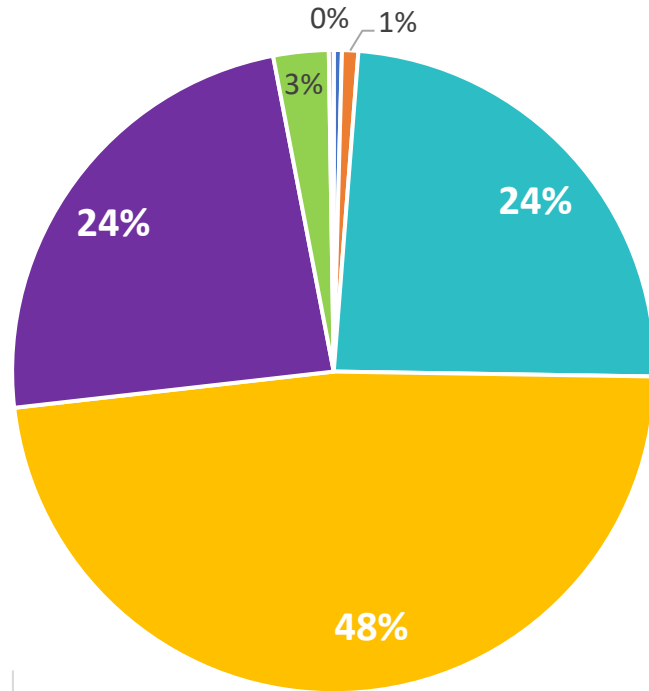
Responses from families

40%

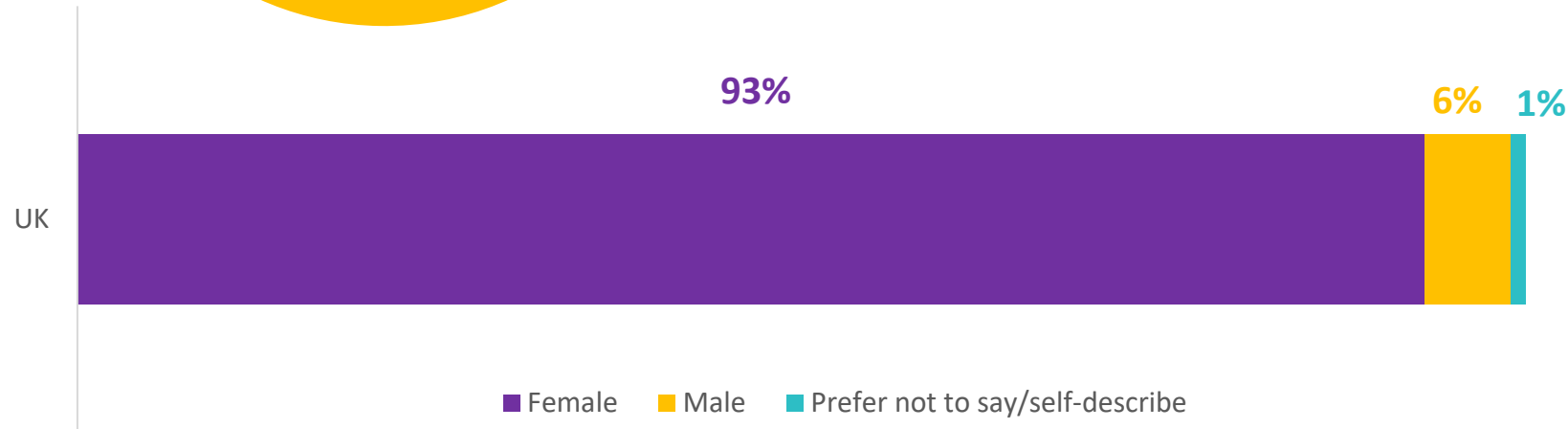
Of families that responded were **single adult households**



Parents and Carers (N=1224)



- 18 to 24 yrs
- 25 to 34 yrs
- 35 to 44 yrs
- 45 to 54 yrs
- 55 to 64 yrs
- 65 or over



■ Female ■ Male ■ Prefer not to say/self-describe

71 %
Of respondents were the **sole main carer for the child/ren**

51 %
Of respondents **have a long-term physical or mental health condition or illness**

41 %
Of these said that their condition or illness **reduces their ability to carry out day-to-day activities**



Disabled or Seriously ill children and young people



■ Female ■ Male ■ Prefer not to say/self-describe

1730
Children with disabilities or serious illnesses



■ 0 to 4 years old ■ 5 to 9 years old ■ 10 to 15 years old ■ 16 to 17 years old ■ 18 to 24 years old

1153
Children without disabilities or serious illnesses



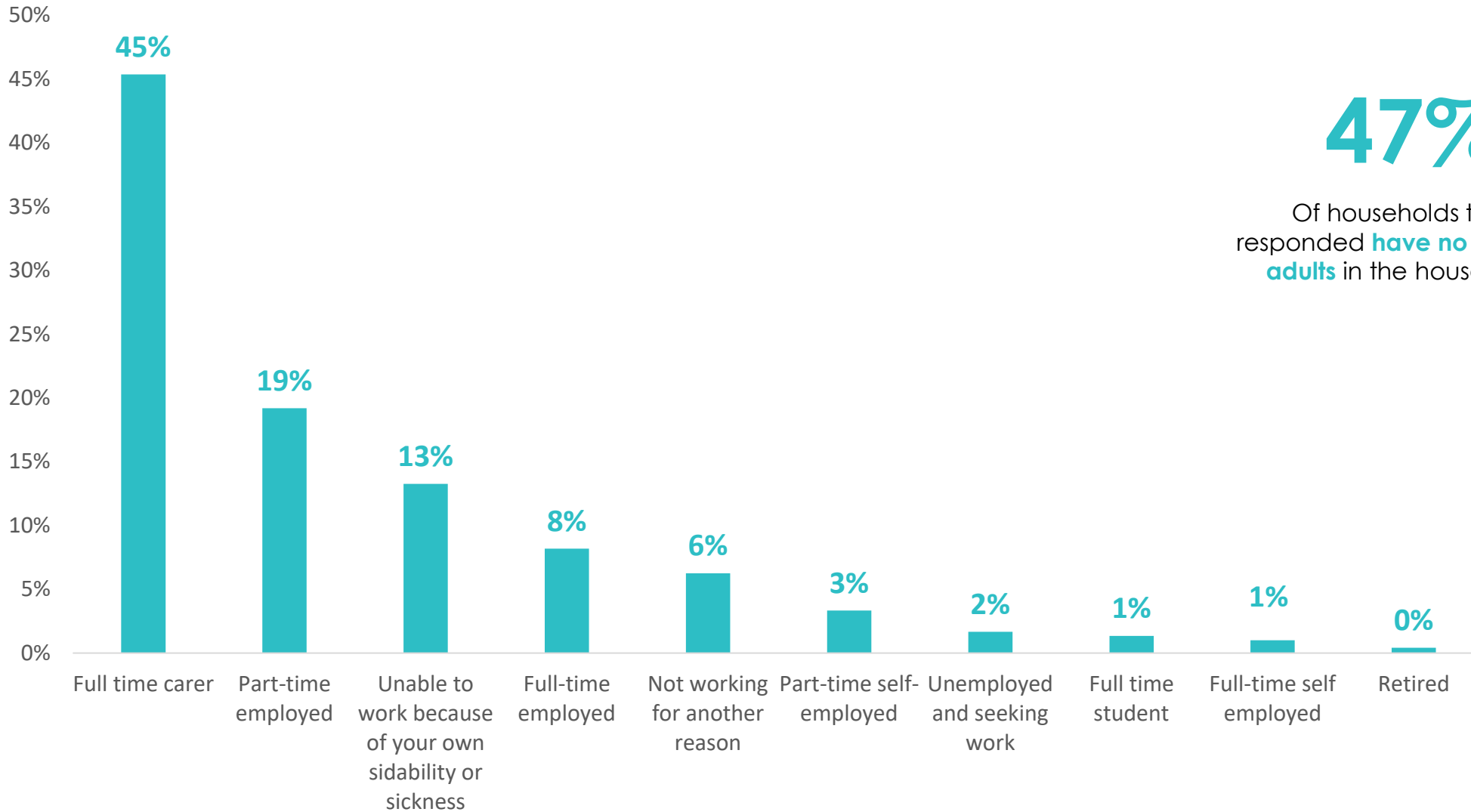
2. Working and caring

For many families raising disabled and seriously ill children and young people their caring responsibilities can mean that it is challenging to work.



Employment status

“Are you employed?” (n=1,199)

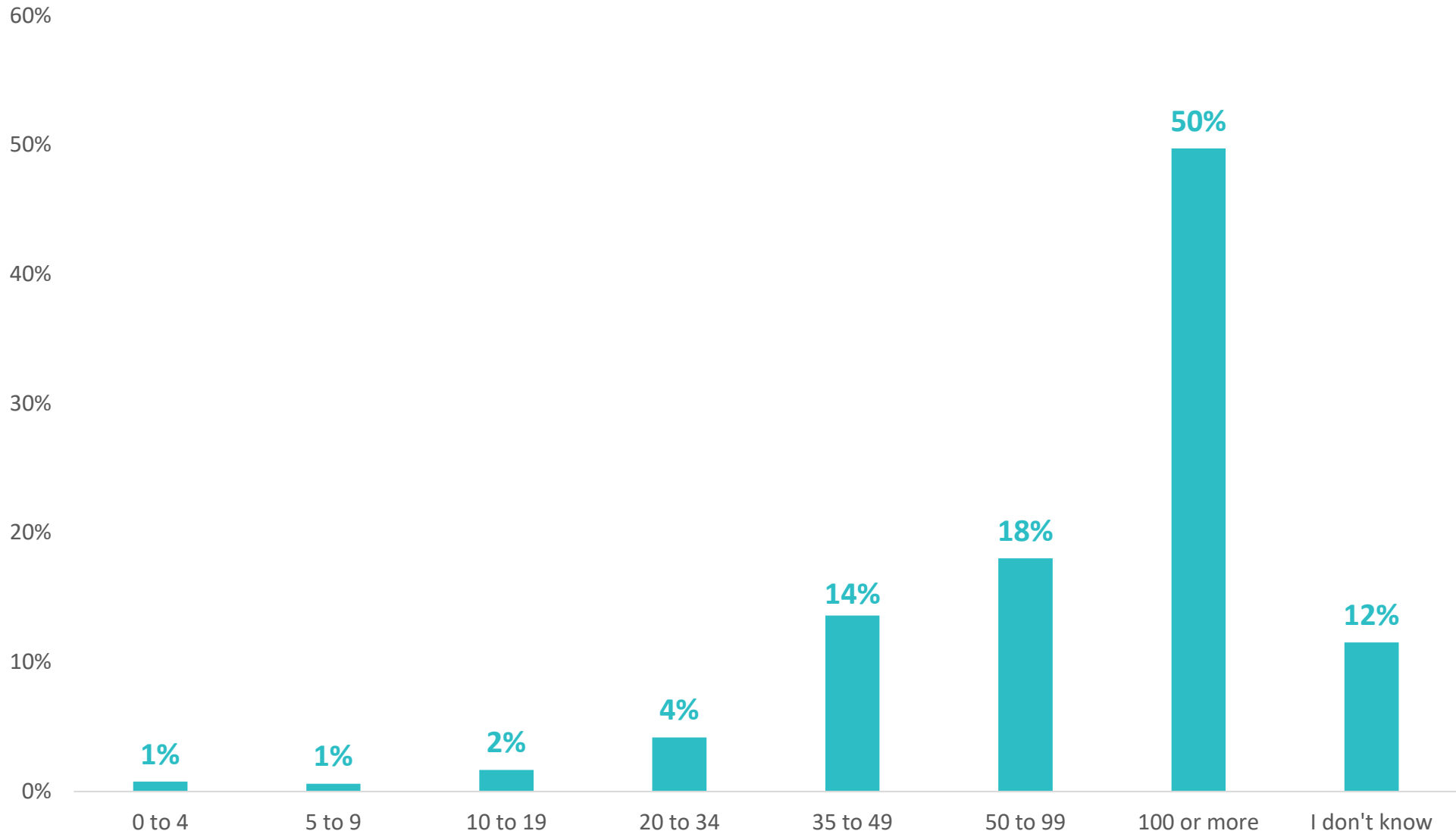


47%

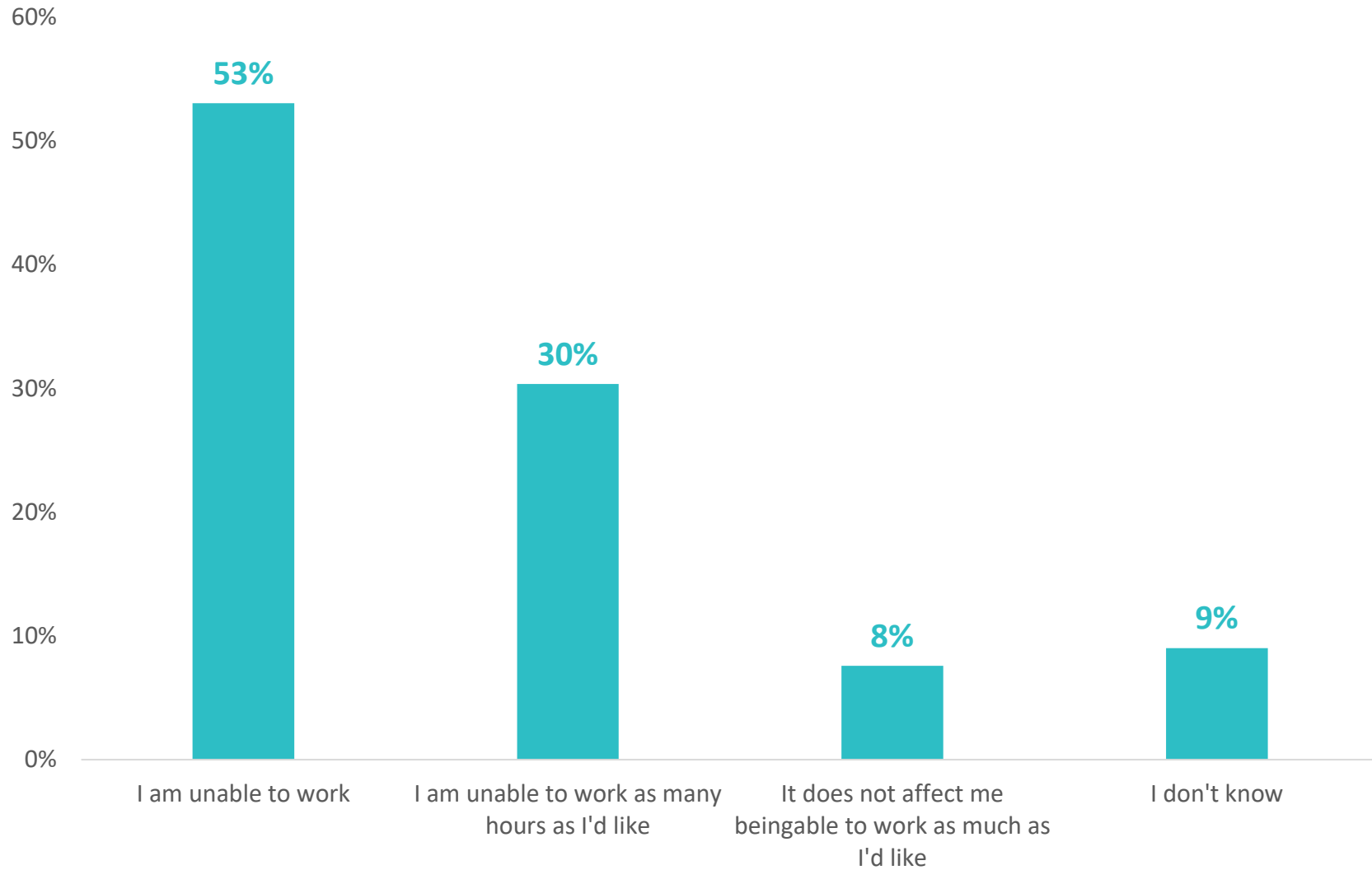
Of households that responded **have no working adults** in the household



“About how many hours a week, on average, do you spend providing help for or looking after your disabled child or young person?” (n=1,199)



“Do your caring responsibilities for your disabled child or young person mean you cannot work as much as you would like?” (n=1,199)

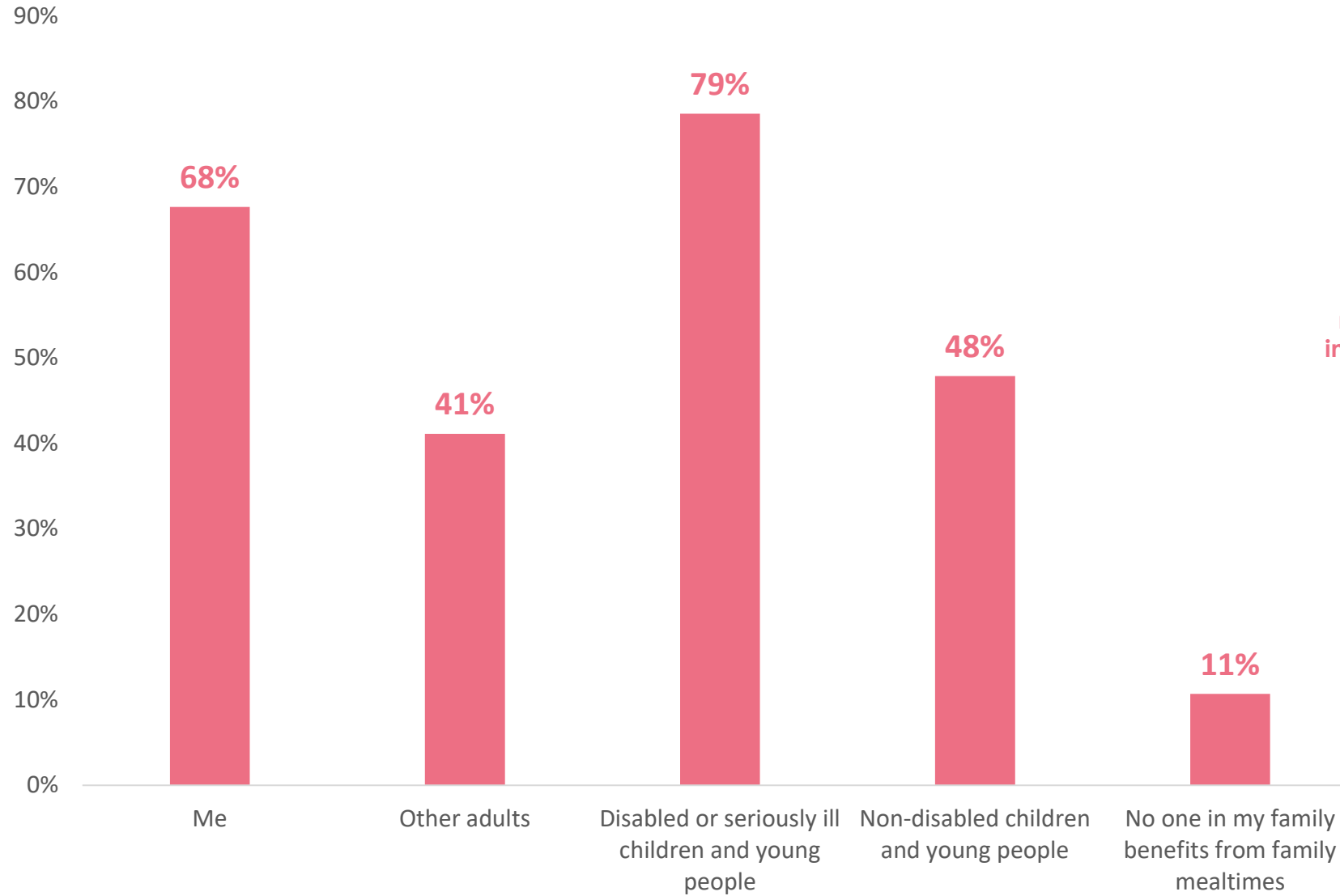


3. Family Mealtimes



Family Mealtimes

“Do you think family mealtimes are important for the wellbeing of: (n=1,199)



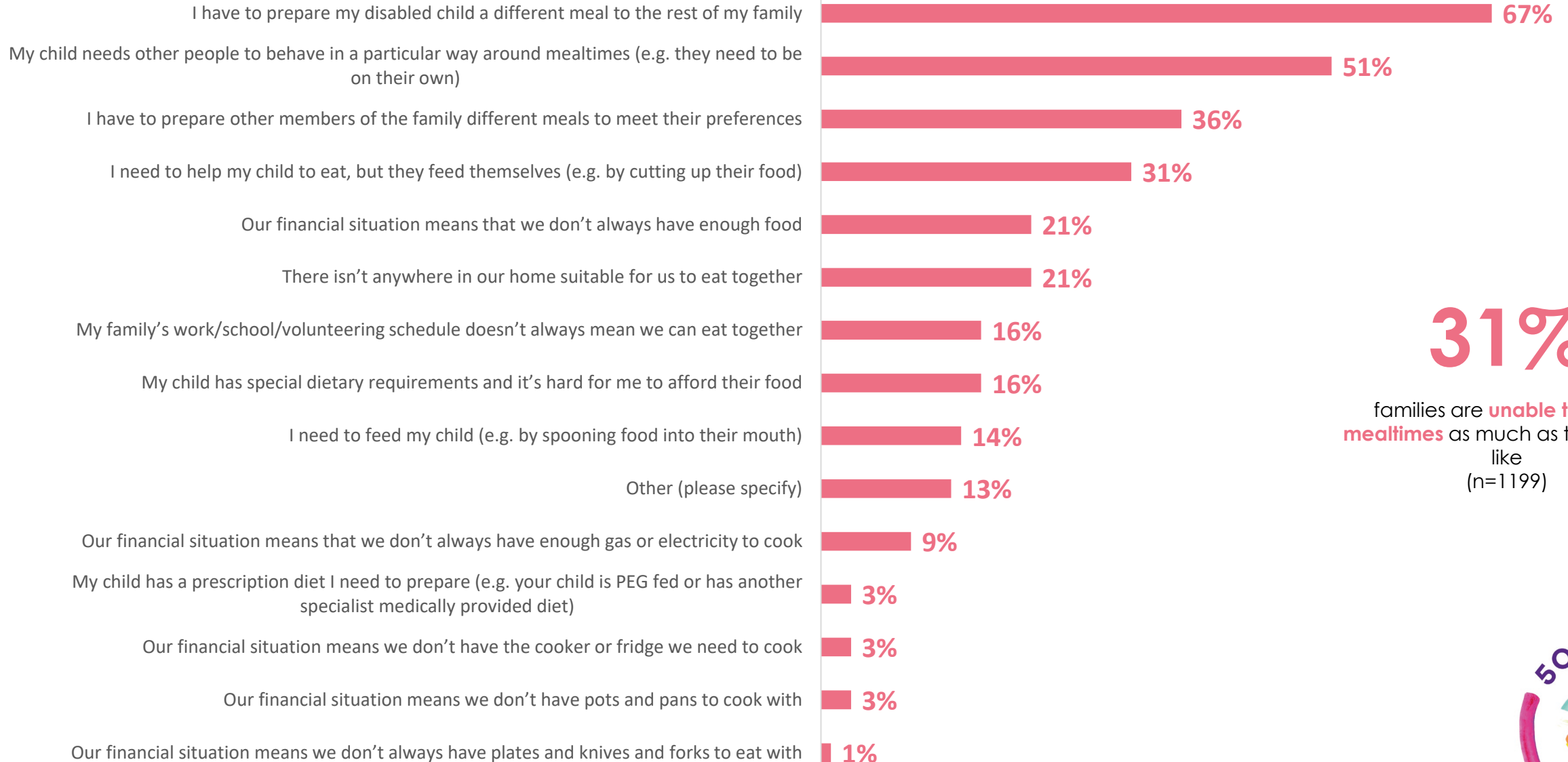
71%

families report that **family mealtimes are extremely or very important** for them and their family (n=1,199)



Family Mealtimes

“Why are you not able to enjoy mealtimes as much as you would like?” (n=373)



31%

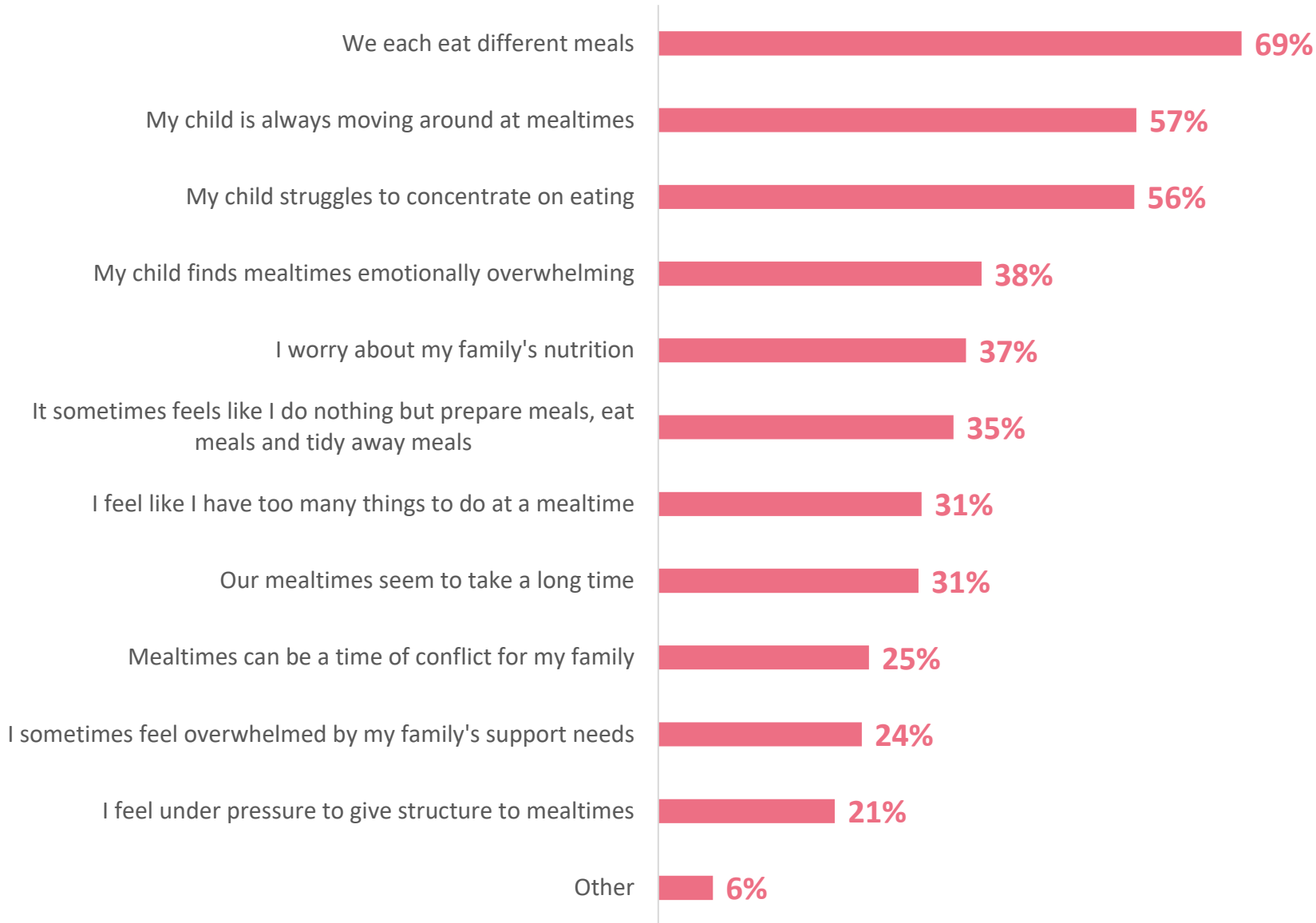
families are **unable to enjoy mealtimes** as much as they would like
(n=1199)



Family Mealtimes

“Why do you find mealtimes tiring or stressful for you?”

(n=816)



68%

Of parents/carers find mealtimes stressful or tiring (n=1,199)



Why are mealtimes important to your family?

"It's where we are all together talking about our days or having a giggle and we can be together without one of them running around or wanting to go do a different thing."

"A time to share our concerns what has made them happy/sad today, do they feel we could do anything different."

"A chance to provide the children with a place and time they feel included and valuable."



Mealtime challenges

“My child is very picky with food. I have to make sure she eats regularly. I have a carer who cooks for us as I can't so mealtimes are very important.”

“It's rare that we do this as he doesn't sit for long periods of time and gets irritable and upset.”

“We rarely are able to have family mealtimes because my disabled children can't cope with it.”



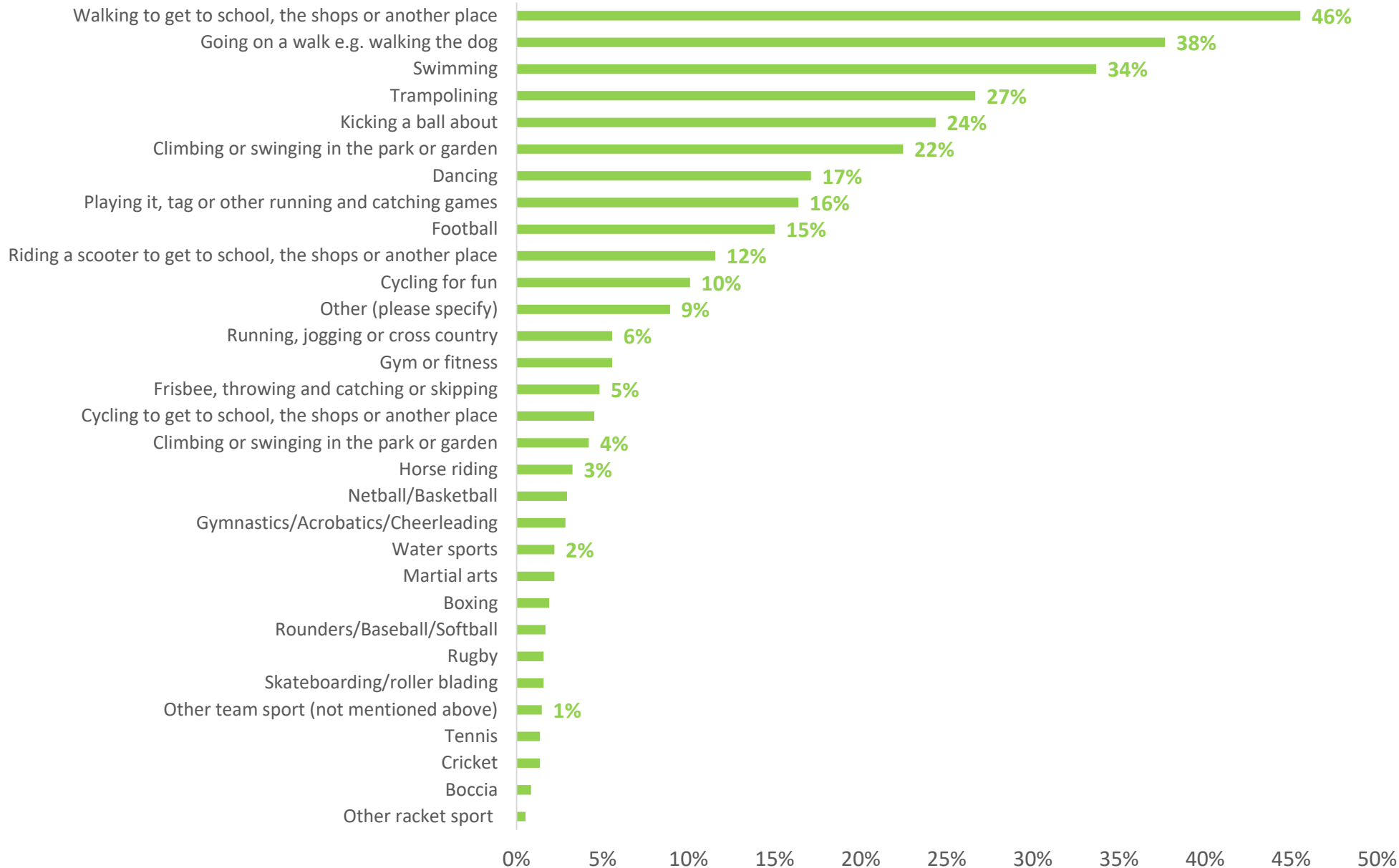
Summer Fun – Physical activity, play and days out

4. Taking Part in Physical Activity



Physical Activity

“Which of these has disabled or seriously ill child or young person done in the last seven days?” (n=953)



21%

Of respondents said that their child is able to **take part in physical activity, exercise or sport** (n=1,199)

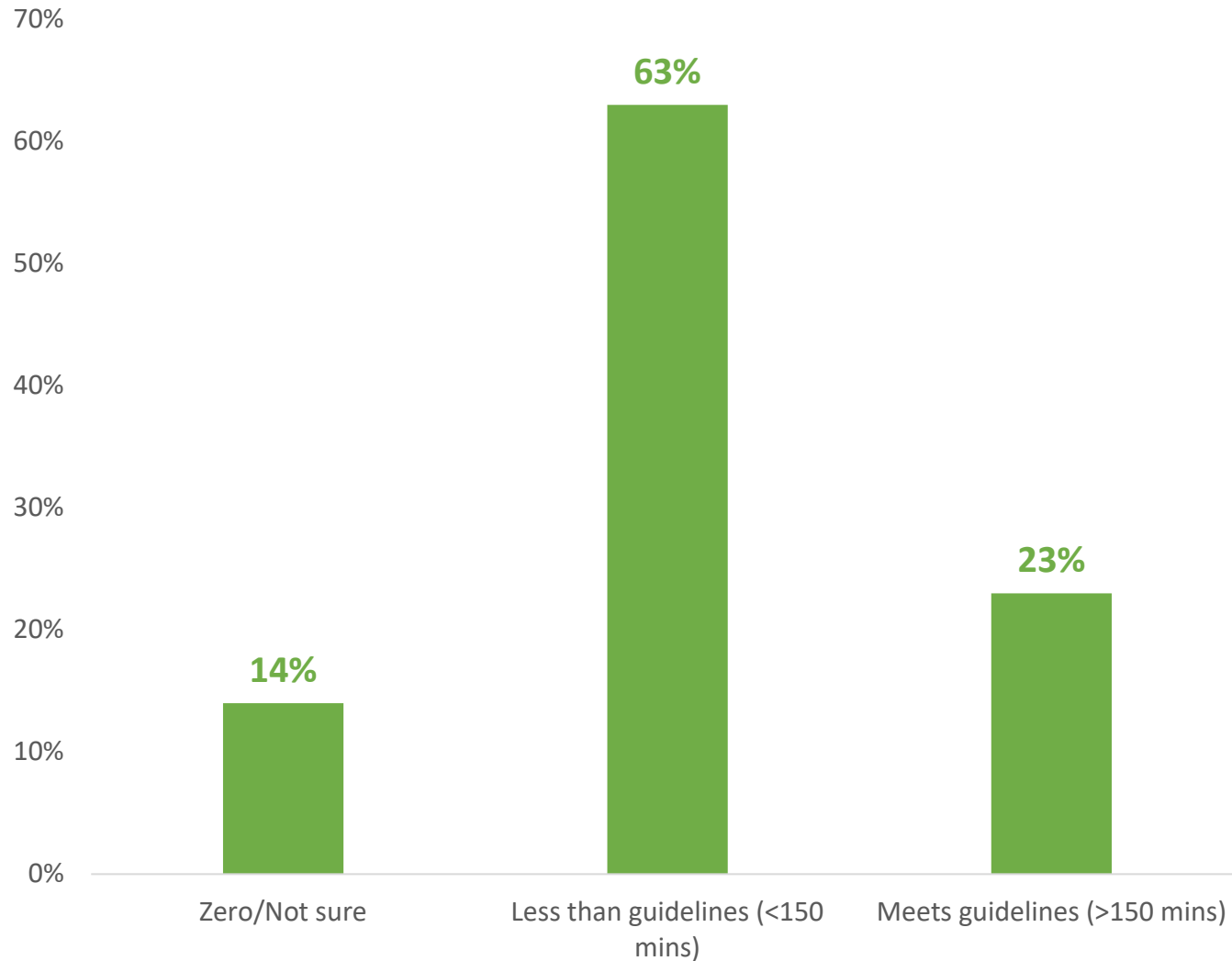
69%

Of respondents said their disabled or seriously ill child or young person **taking part in physical activity, exercise or sport is important/extremely important** (n=1,199)



Physical Activity

Children who meet the definition of physically active



44

Average number of minutes of physical activity children took part in per week (n=953)

“The Chief Medical Officer’s guidelines recommend doing **150 minutes** or more of moderate intensity equivalent a week.”
- Sport England



Physical Activity

“Why do you think your disabled or seriously ill child or young person is unable to access as many opportunities to take part in physical activity, exercise or sport as you/they would like?” (n=606)



64%

Of respondents said their disabled or seriously ill child or young person **does not have as many opportunities to take part in physical activity, exercise and sport** as they would like (n=953)

When we talk about “accessible”, we mean having the range of facilities that meet your particular disabled or seriously ill child or young person’s needs to enable them to fully take part. This includes things like wheelchair access, hearing loops and quiet spaces etc.



Family's experiences of taking part in physical activity

"[Child] suffers with too much anxiety to partake in group activity, and social anxiety going out the house to partake in 1-2-1 activity, also lack of money for 1-2-1."

"There is never anywhere local to offer these types of things, so you give up looking."

"My child needs 1:1 support to access any activity and this isn't provided, or it costs too much."



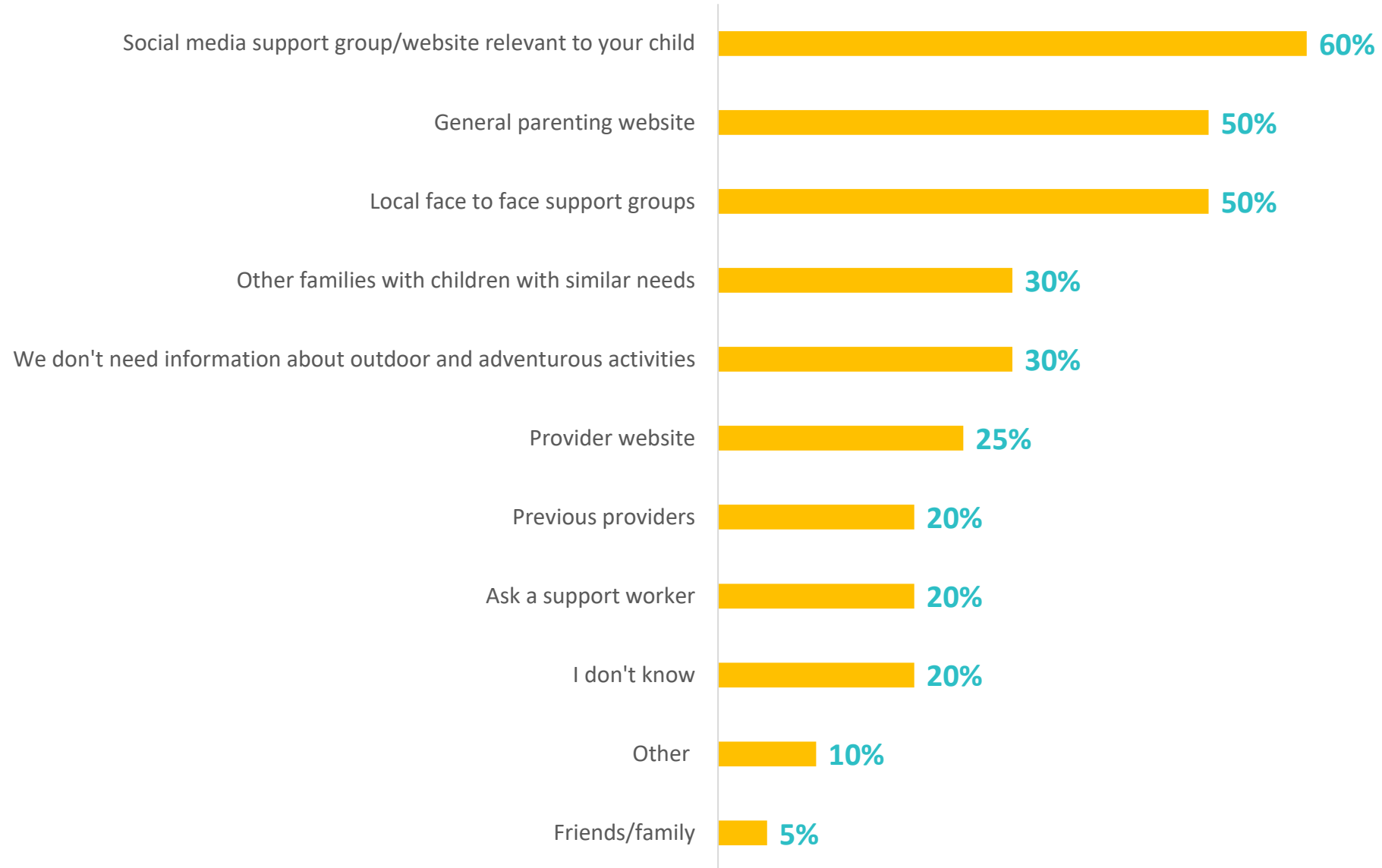
Summer Fun – Physical activity, play and days out

5. Outdoor and adventure activities



Outdoor and Adventure

“Where would you look for information about outdoor and adventurous family activities that would be accessible to your disabled or seriously ill child or young person?” (n=953)



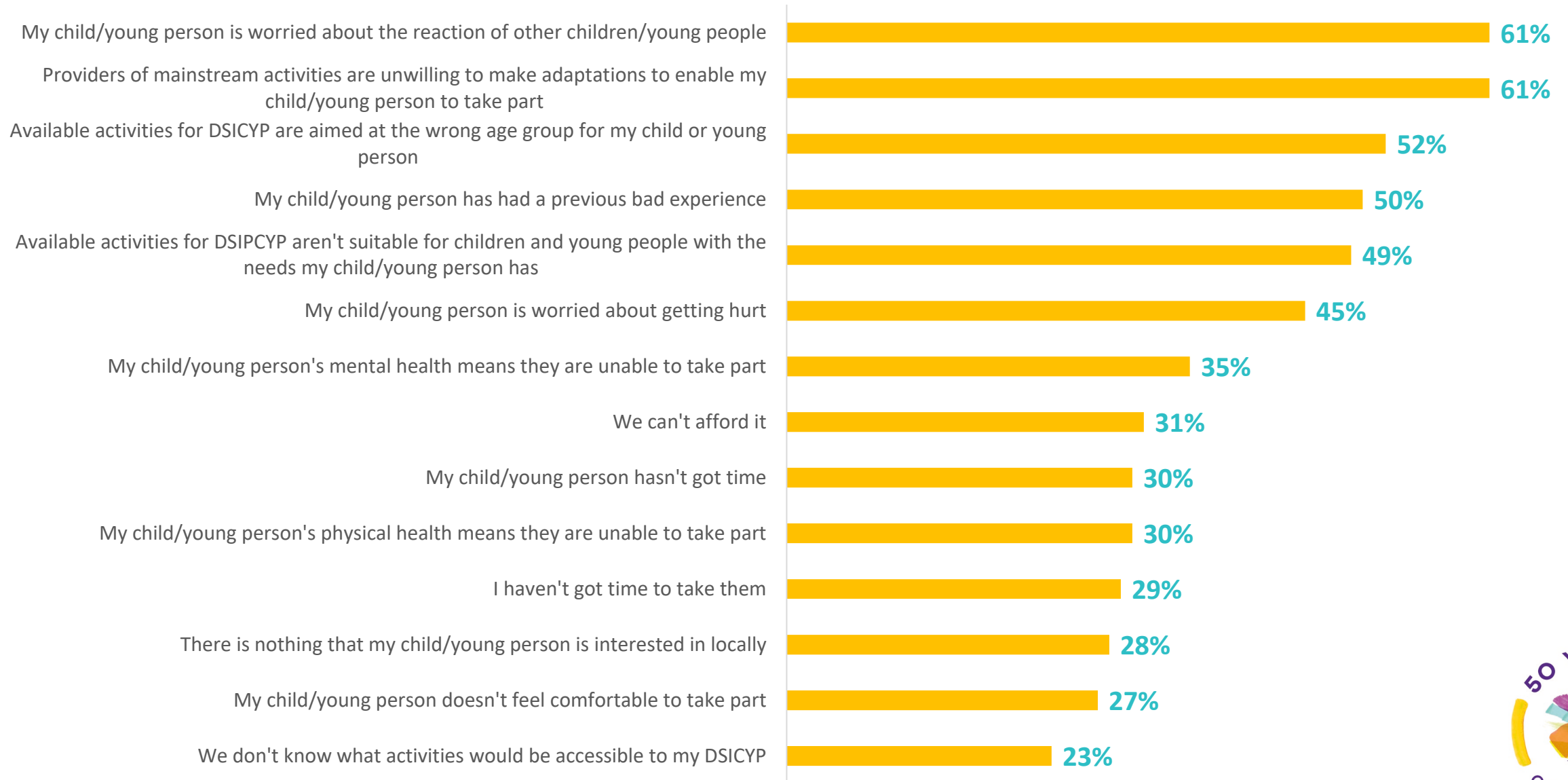
68%

Of respondents said they **are not able to take part in as many family outdoor and adventurous activities** as they would like (n=953)



Outdoor and Adventure

“Why do you think your family is unable to take part in as many outdoor and adventurous activities as you would like?” (n=767)



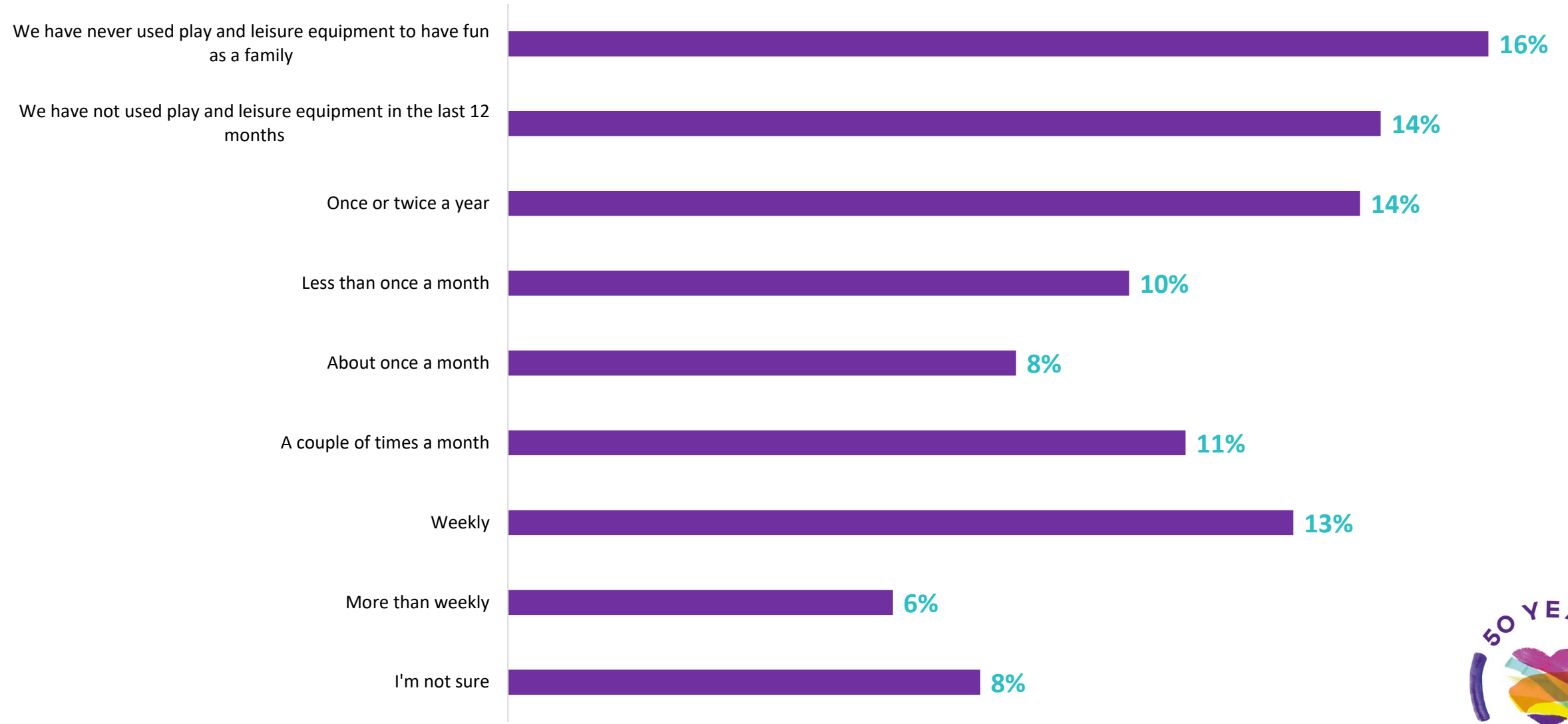
Summer Fun – Physical activity, play and days out

6. Play and leisure



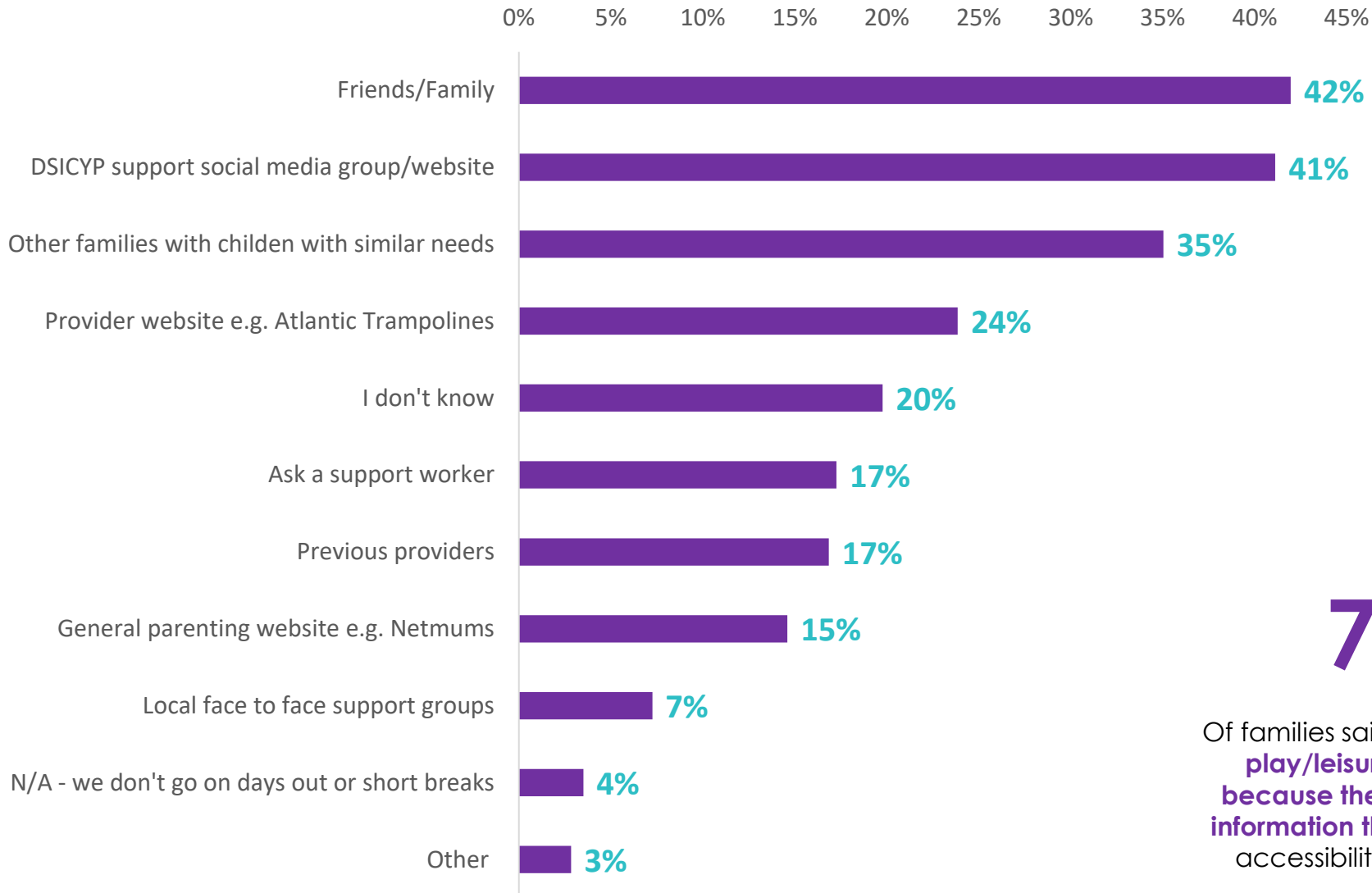
Play and leisure

How often in the last 12 months have you been able to use play and leisure equipment to have fun with your child? (n=1199)



Play and leisure

Where would you look for information about play and leisure equipment that would be accessible to your disabled or seriously ill child or young person? (n=1199)



26%

Of families said they **are able to get the information they need** before buying or using play and leisure equipment buying

25%

of families said they just **have to hope for the best** before buying

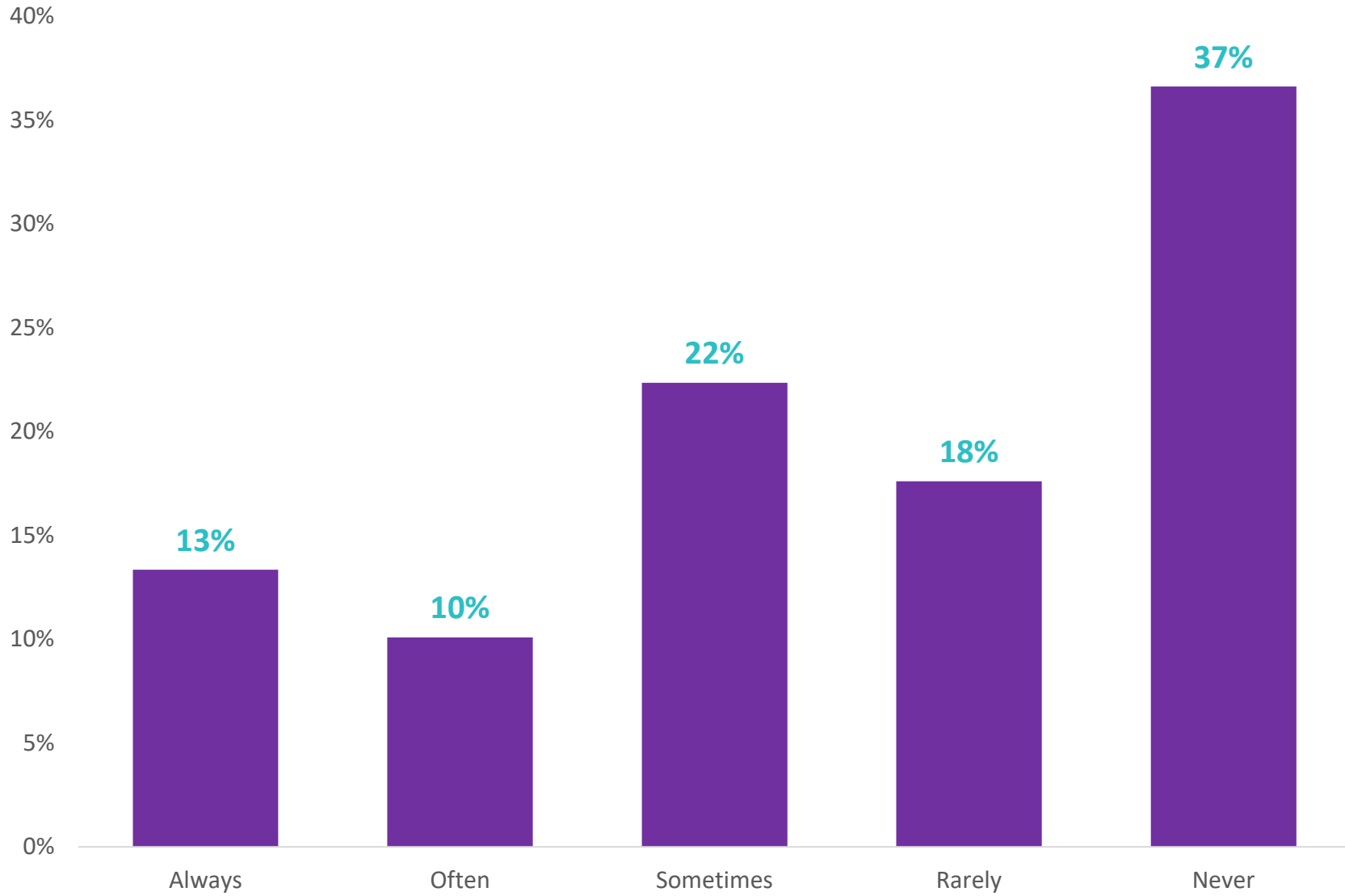
7%

Of families said they **don't buy play/leisure equipment because they can't get the information they need** about accessibility to their child



Play and leisure

Do you think you ever have to pay more for play and leisure equipment as a result of your child's illness or condition? (n=1199)

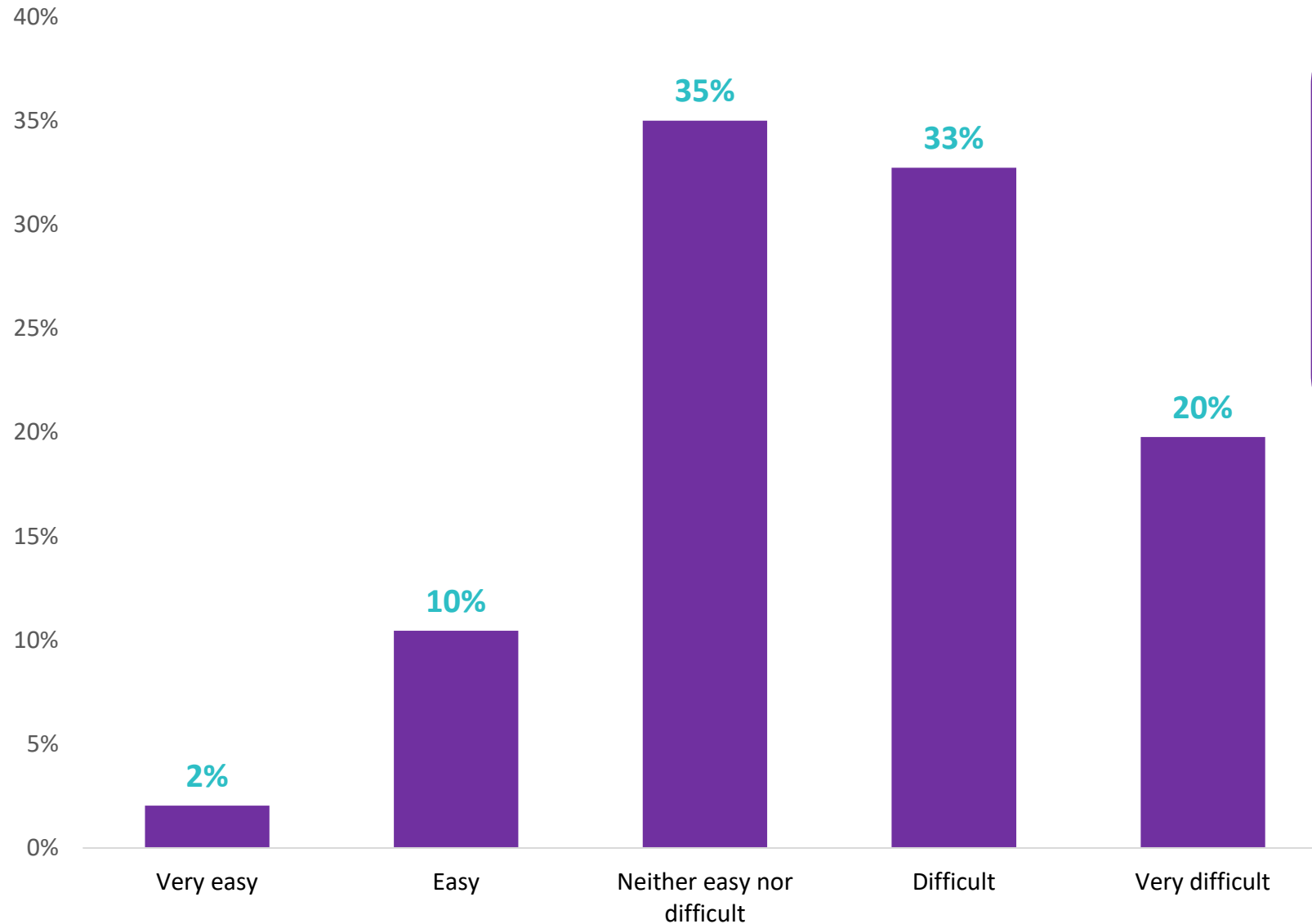


38%

Of families said they **pay £50 or more per play and leisure equipment item** as a result of their child's illness or condition (n=760)

Play and leisure

How easy is it to find play and leisure equipment suitable for the different needs of each of your disabled or seriously ill children or young people? (n=440)

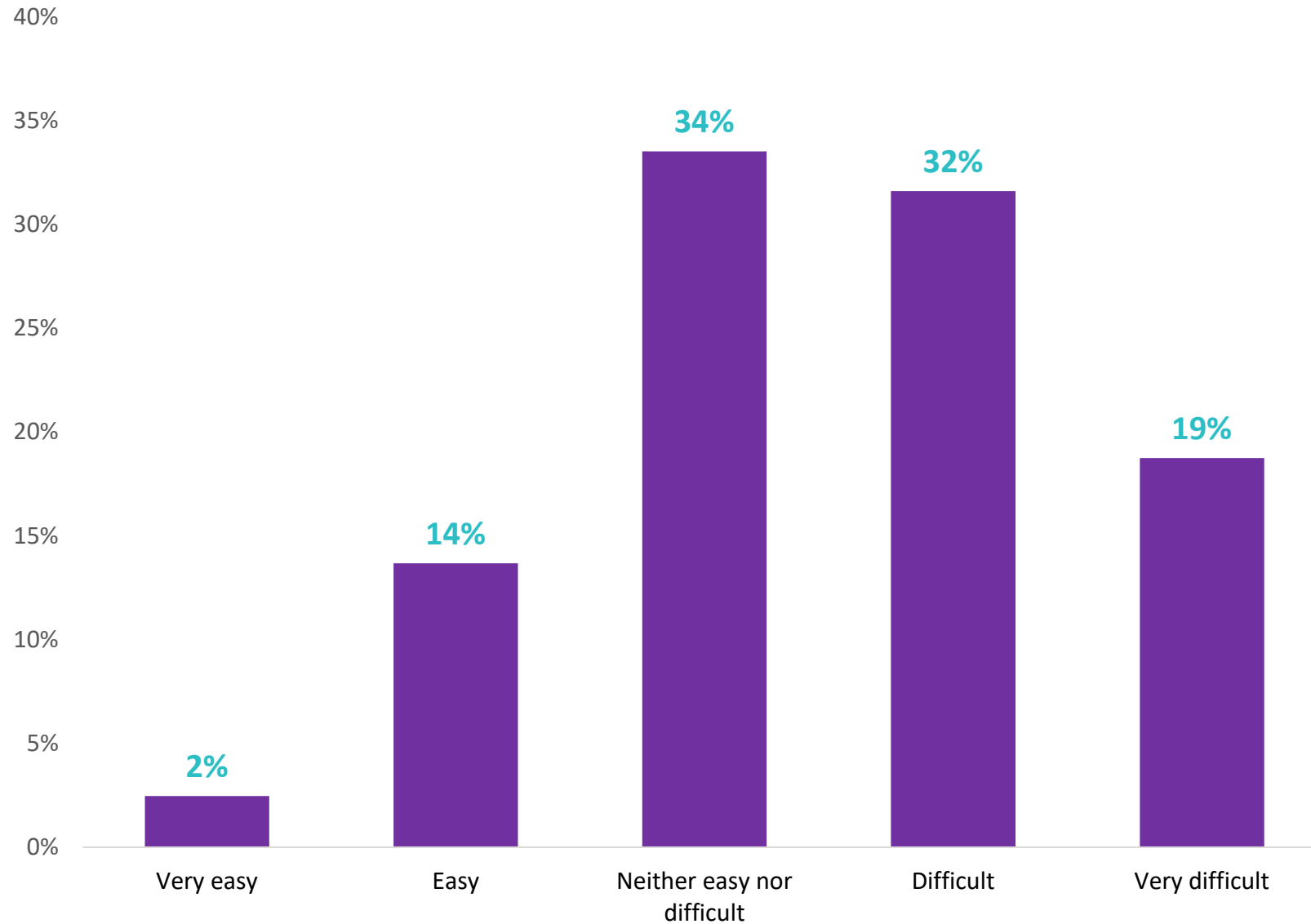


“We have to make sure it is the safest option available. My son has a high pain threshold and doesn’t realise when he is seriously hurt. We have to try and limit this by buying extra secure items and making sure that they are well built to last.”



Play and leisure

How easy is it to find play and leisure equipment that your disabled and non-disabled children can enjoy together? (n=731)



7. Days out and short breaks

Families share their experiences of days out and short breaks

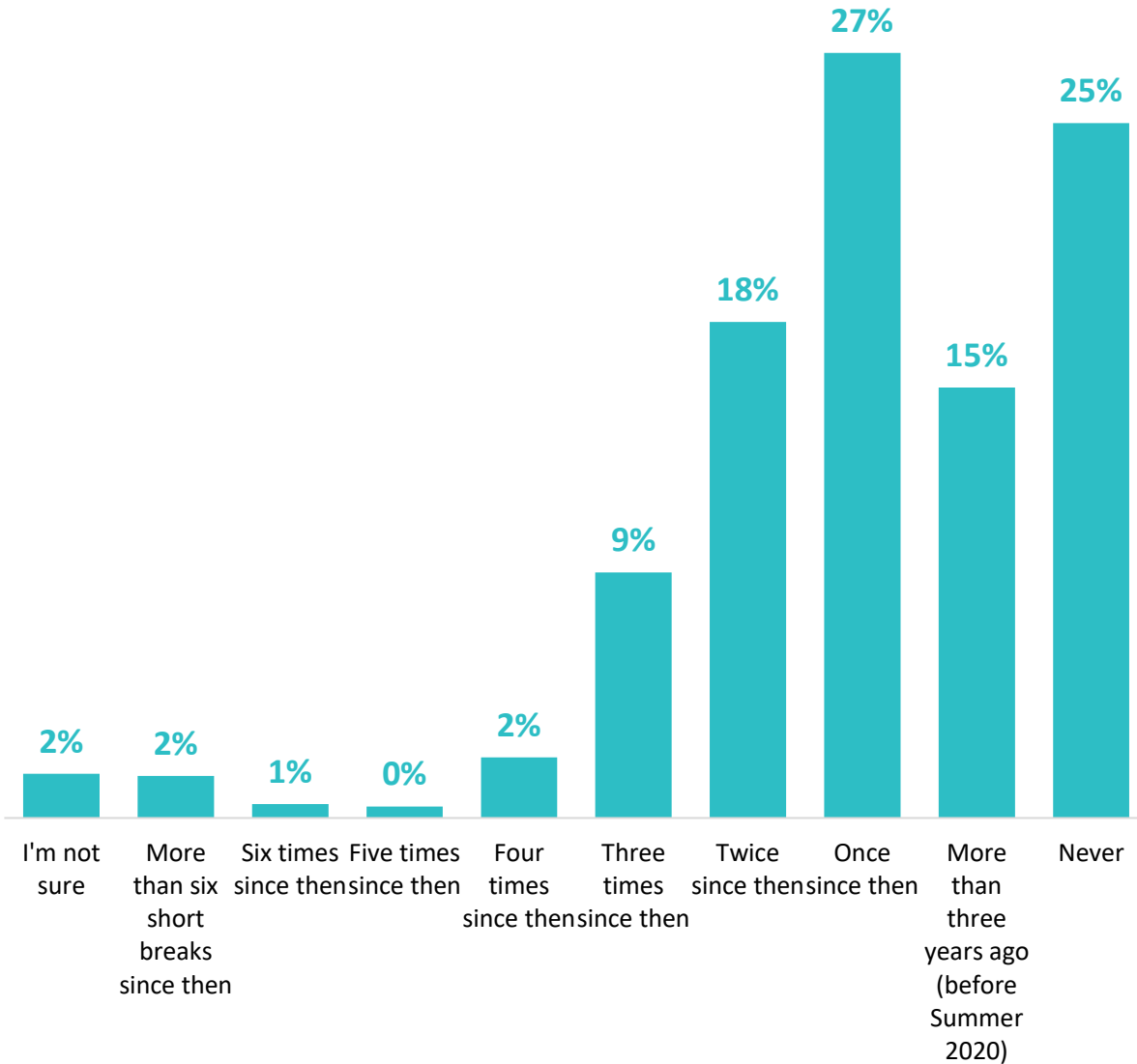


Short breaks and days out

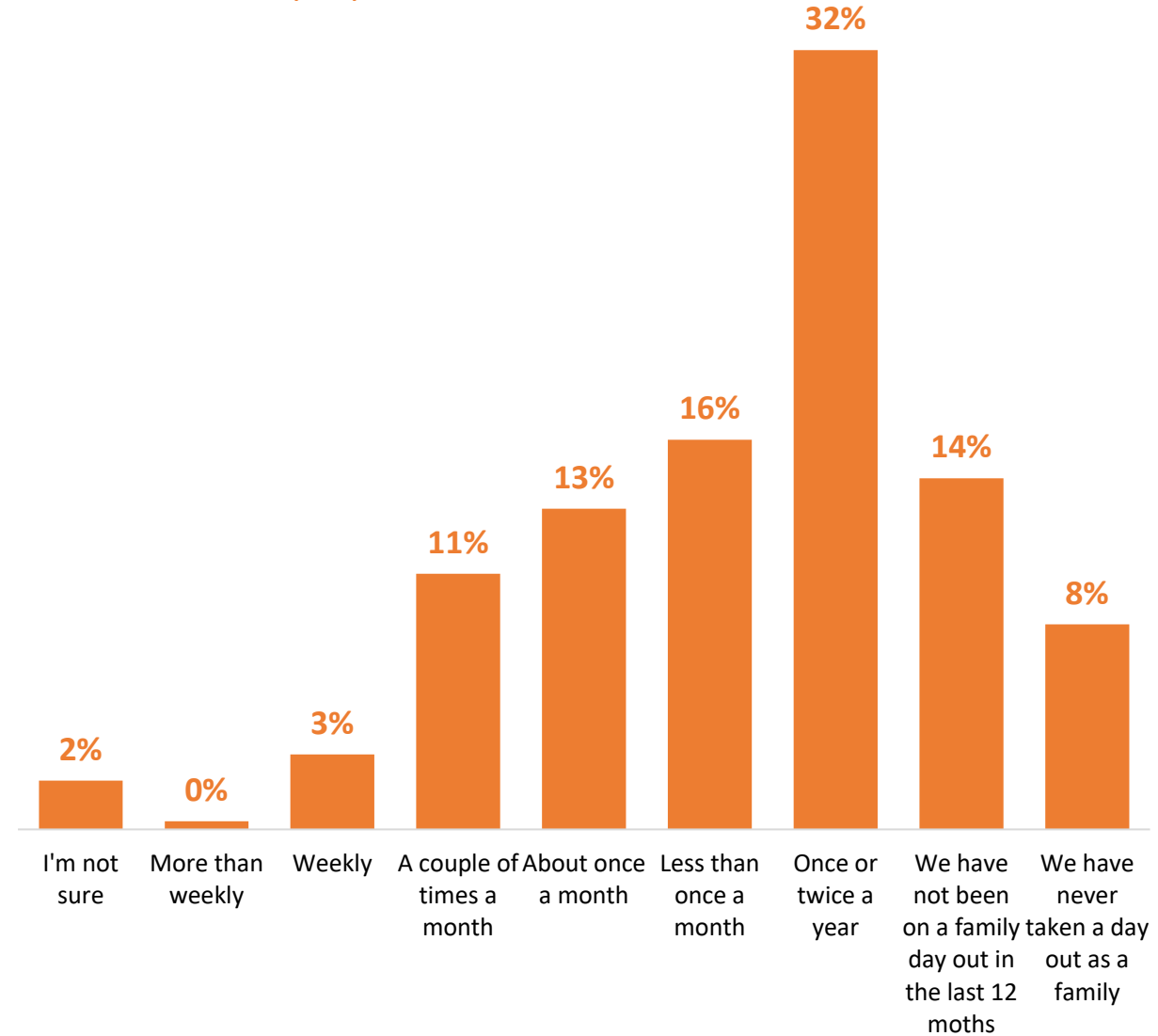
“How often do you take day trips or short breaks as a family?”

(n=1199)

Short breaks in the last three years

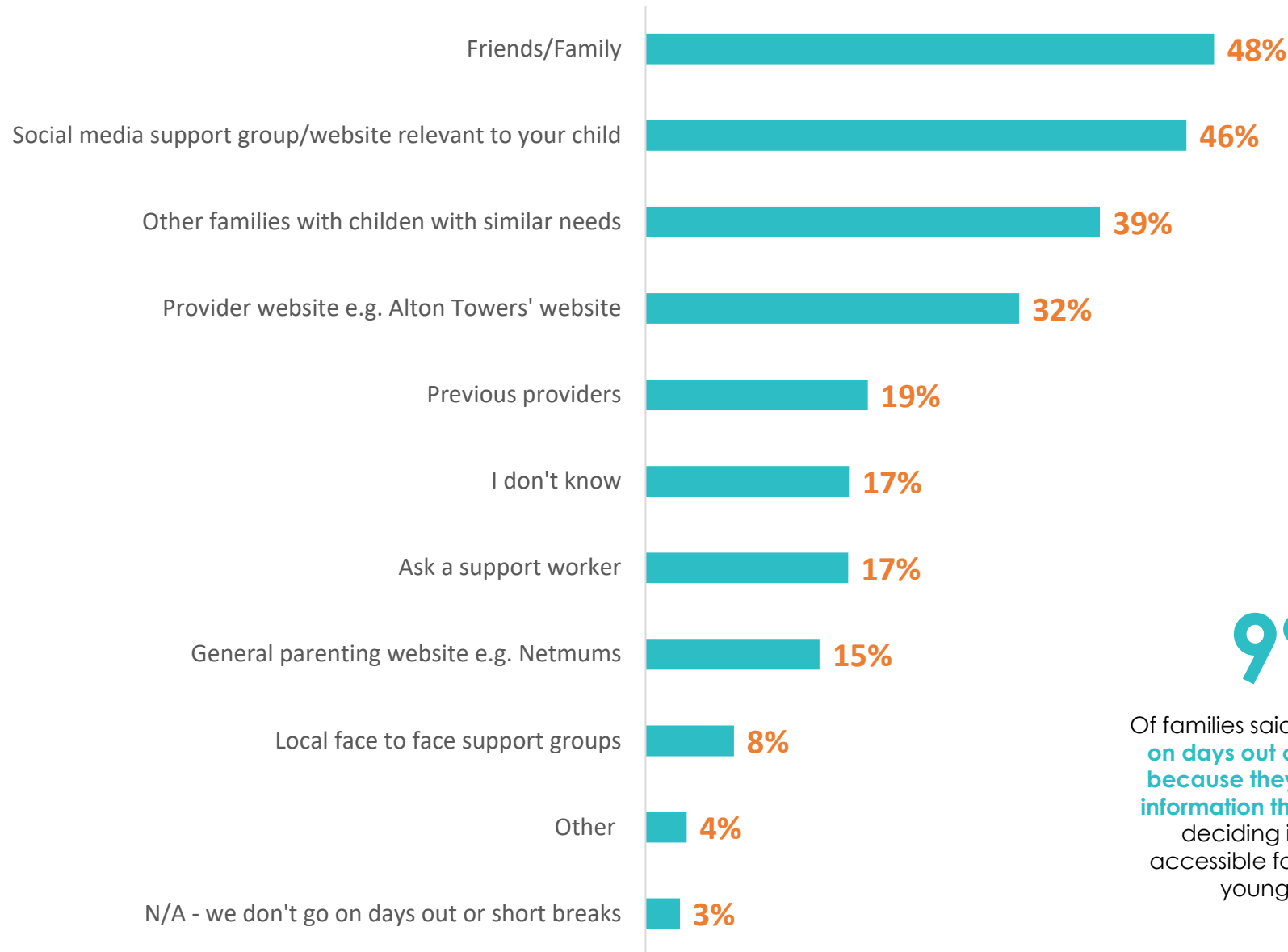


Family days out in the last 12 months



Days out and short breaks

“Where do you find out if a day trip or short breaks is accessible to your family?” (n=1199)



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

18%

Said they can't get the information they need, **and just have to hope for the best when deciding** where to go for days out/short breaks

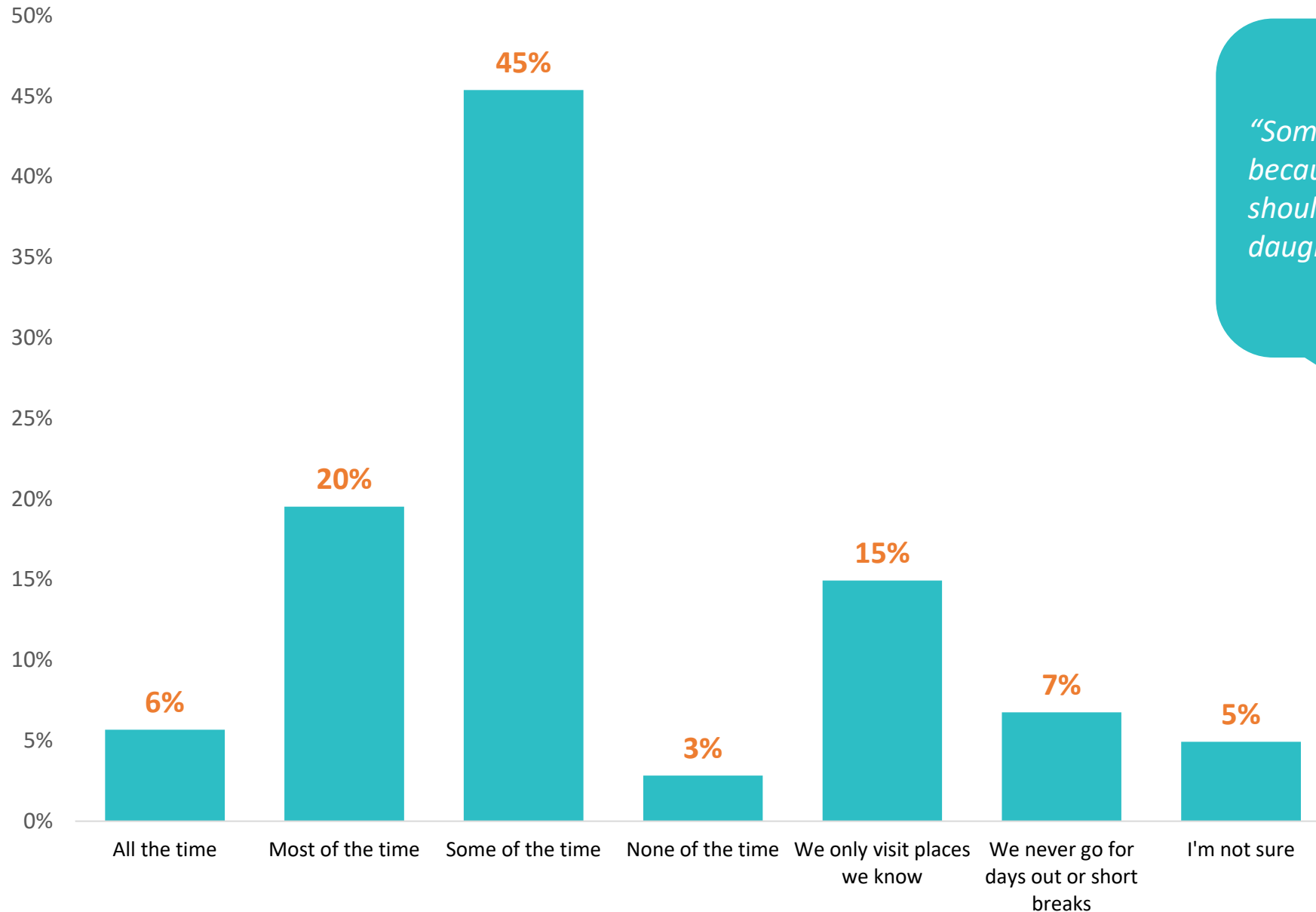
9%

Of families said they **do not go on days out or short breaks because they can't get the information they need** when deciding if a place is accessible for their child or young person



Days out and short breaks

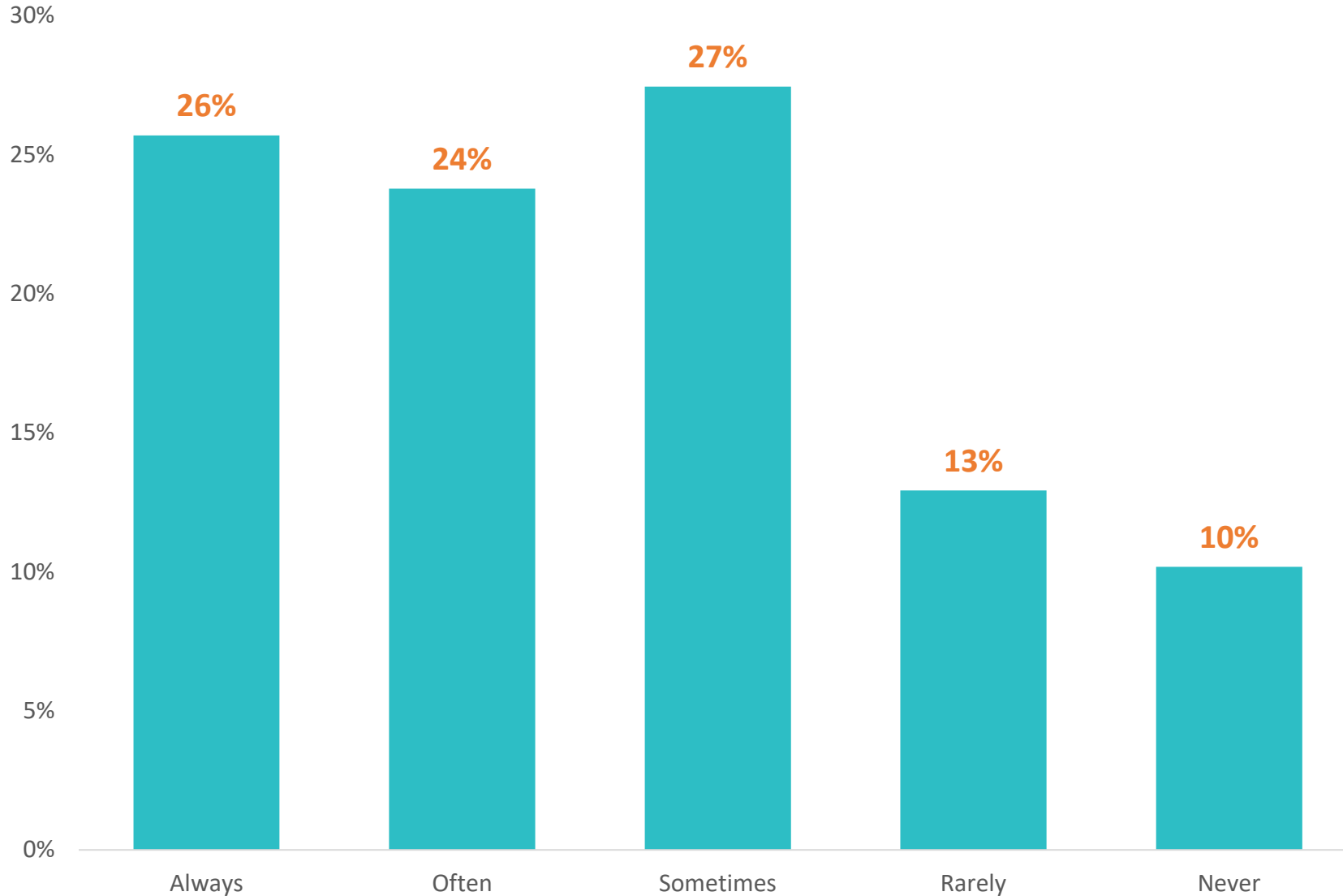
“When you are visiting a new place for a day out or a short break, how often do you feel that it is accessible for your child?” (n=1199)



“Sometimes it's not clear, that because I'm a carer if I should or should not have to pay to help my daughter on some things.”



“How often do you have to spend more on a day out as a result of your child’s disability or illness” (n=1199)



£17.85

Average amount more paid for a day out by families

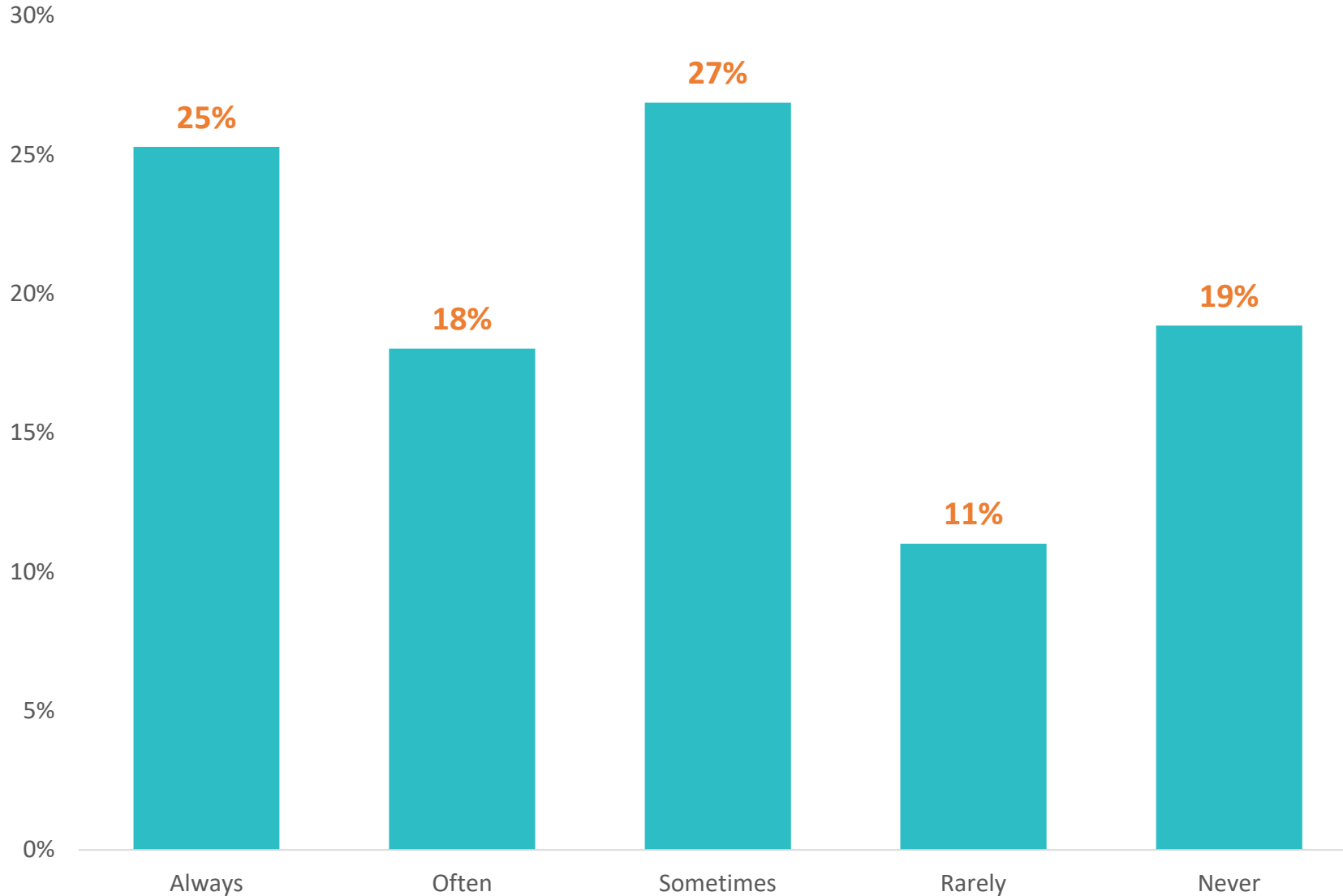
38%

Of families said that they pay **more than £30 more per day out** as a result of their child's illness or condition (n=1078)



Short breaks

“How often do you have to pay more for a short break as a result of your child’s disability or illness” (n=1199)



£85.50

Average amount more paid for a short break by families raising a seriously ill or disabled child or young person

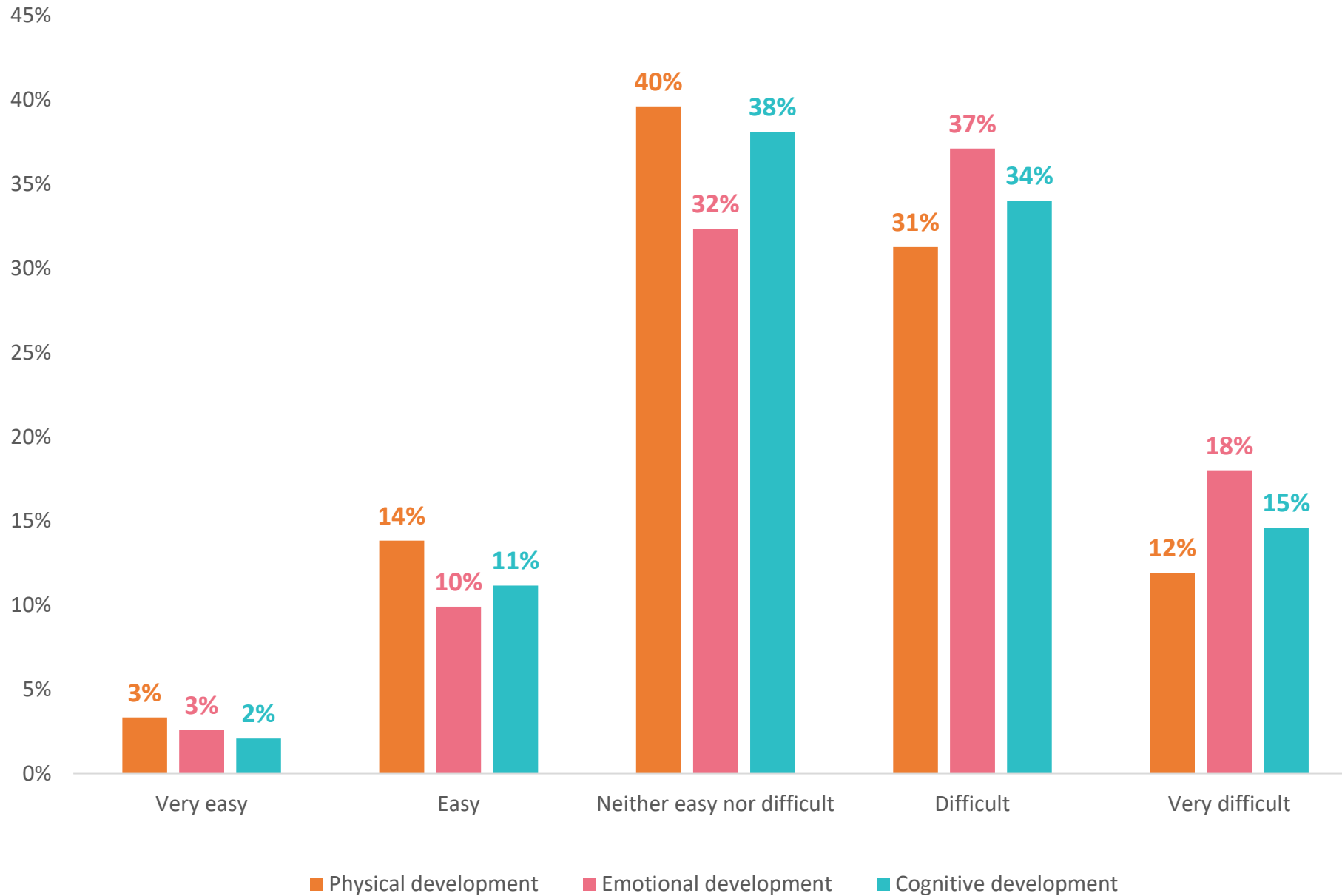
44%

Of families said that they pay **more than £150 more per short break** as a result of their child's illness or condition (n=973)



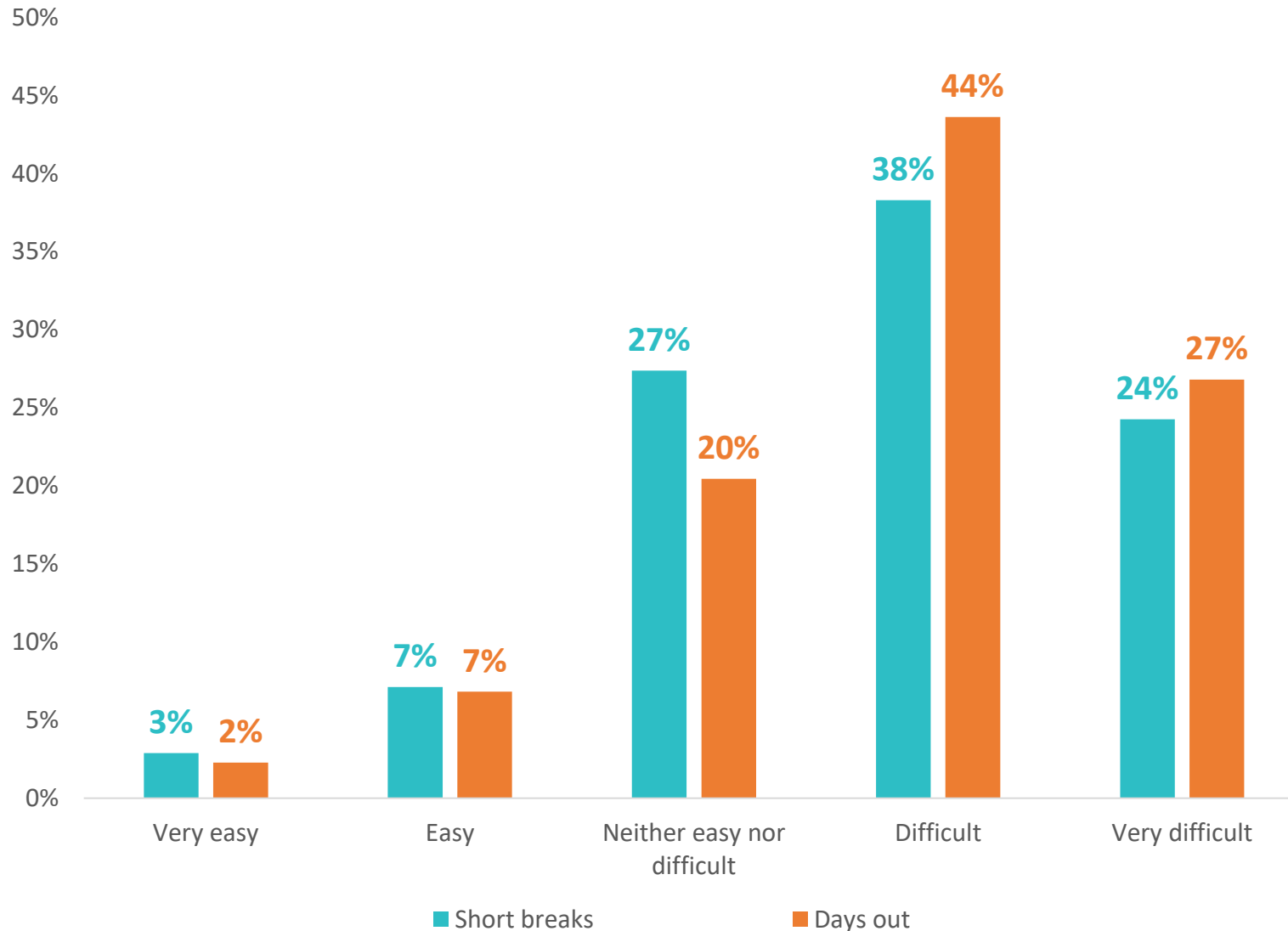
Days out and short breaks

“How easy is to find short breaks and days out which are suitable for your child’s development?” (n=1199)



Days out and short breaks

“How easy do you find it to plan days out and short breaks that are suitable for the different needs of each of your disabled or seriously ill children or young people?(n=449)

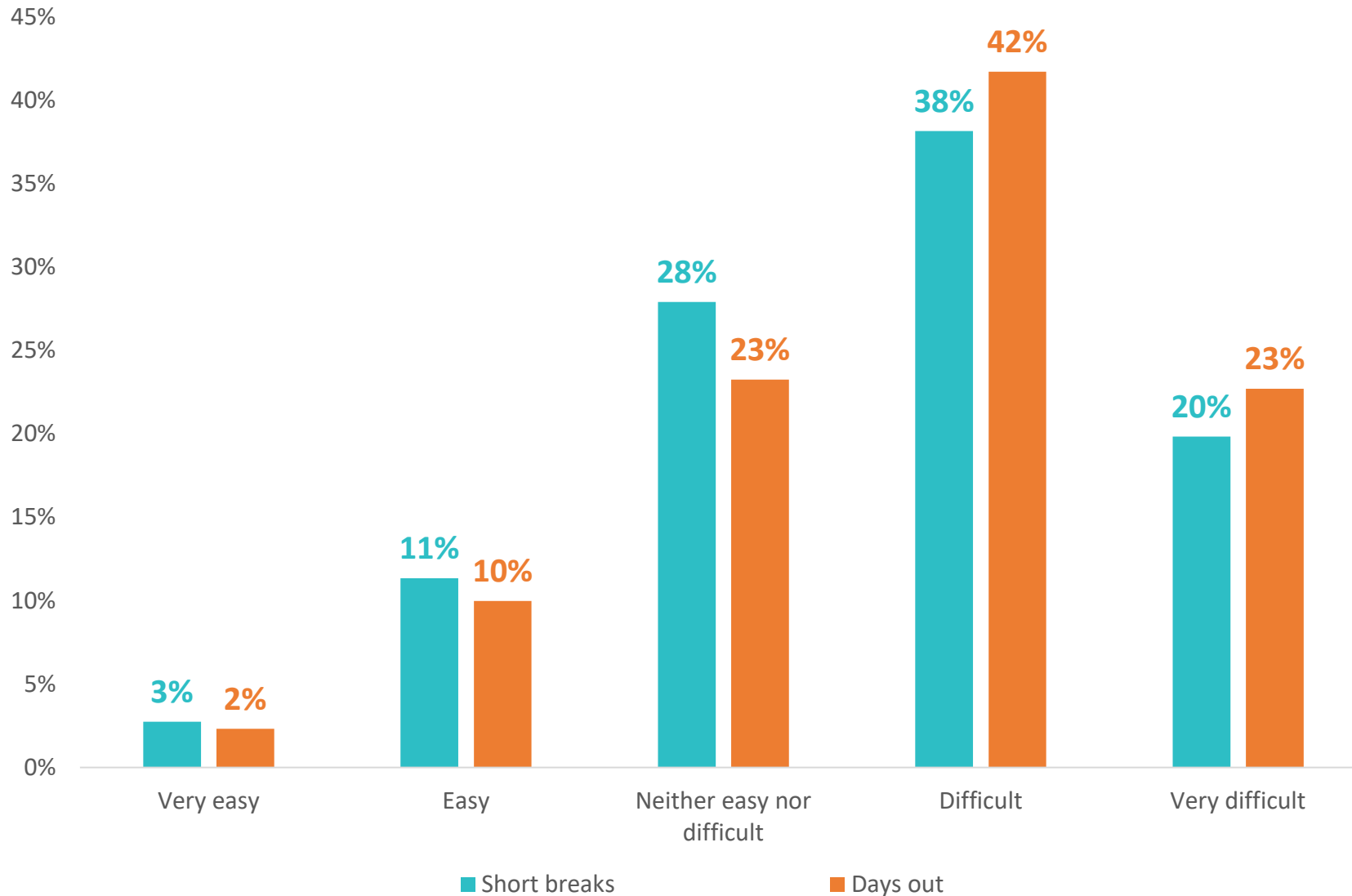


“It's difficult to enjoy these things when your children require constant supervision, and you are unable to relax.”



Days out and short breaks

“How easy is it to find days out and short breaks that your disabled and non-disabled children can enjoy together?” (n=731)

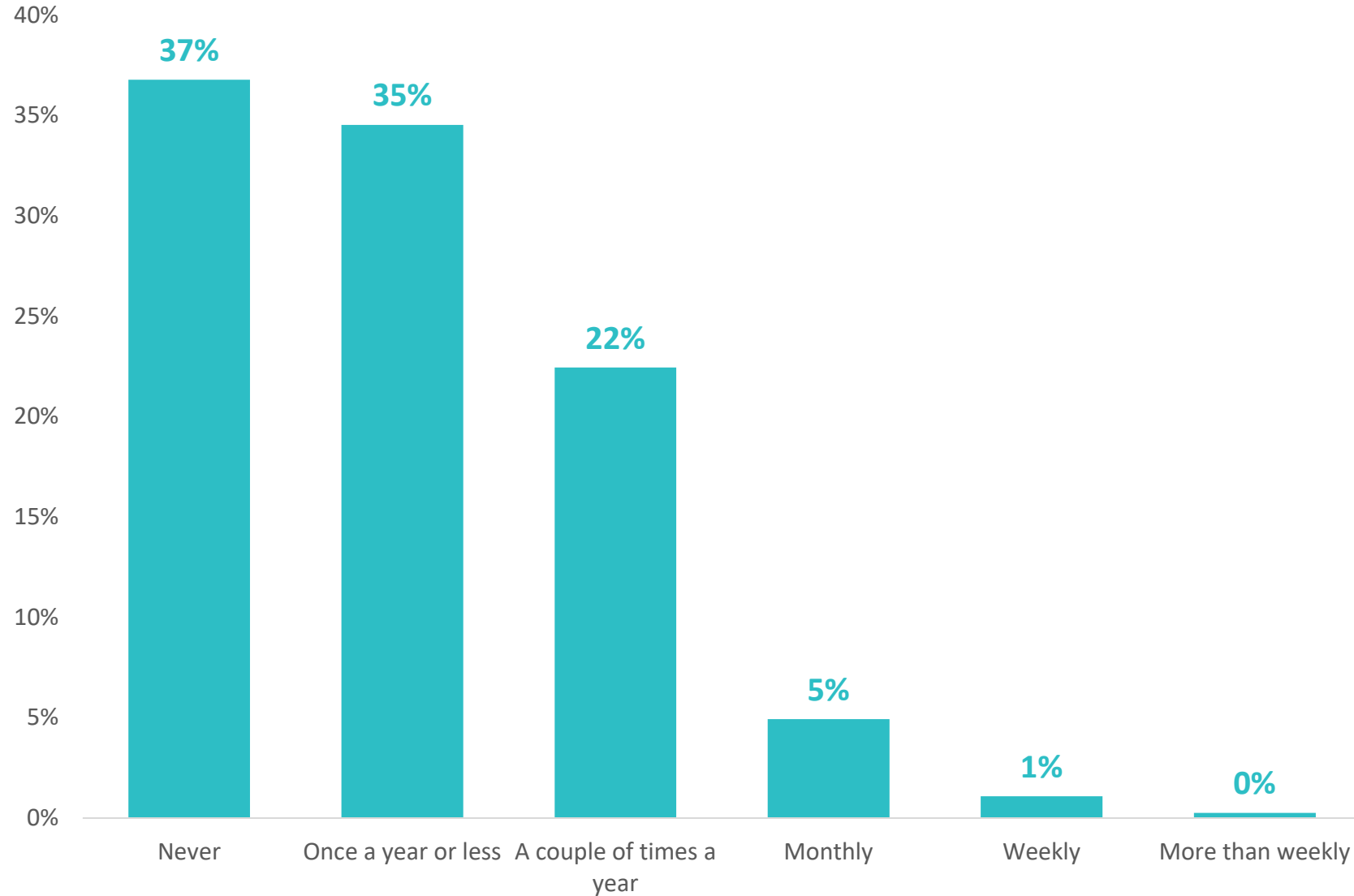


“I take my children out during school time for ease of access to places so not so busy as he doesn't do well with noise etc, meaning I end up with additional costs from school also for taking not just him but his brothers also.”



Days out and short breaks

“How often are you able to enjoy short breaks or days out with family who do not live with you or friends?” (n=1199)



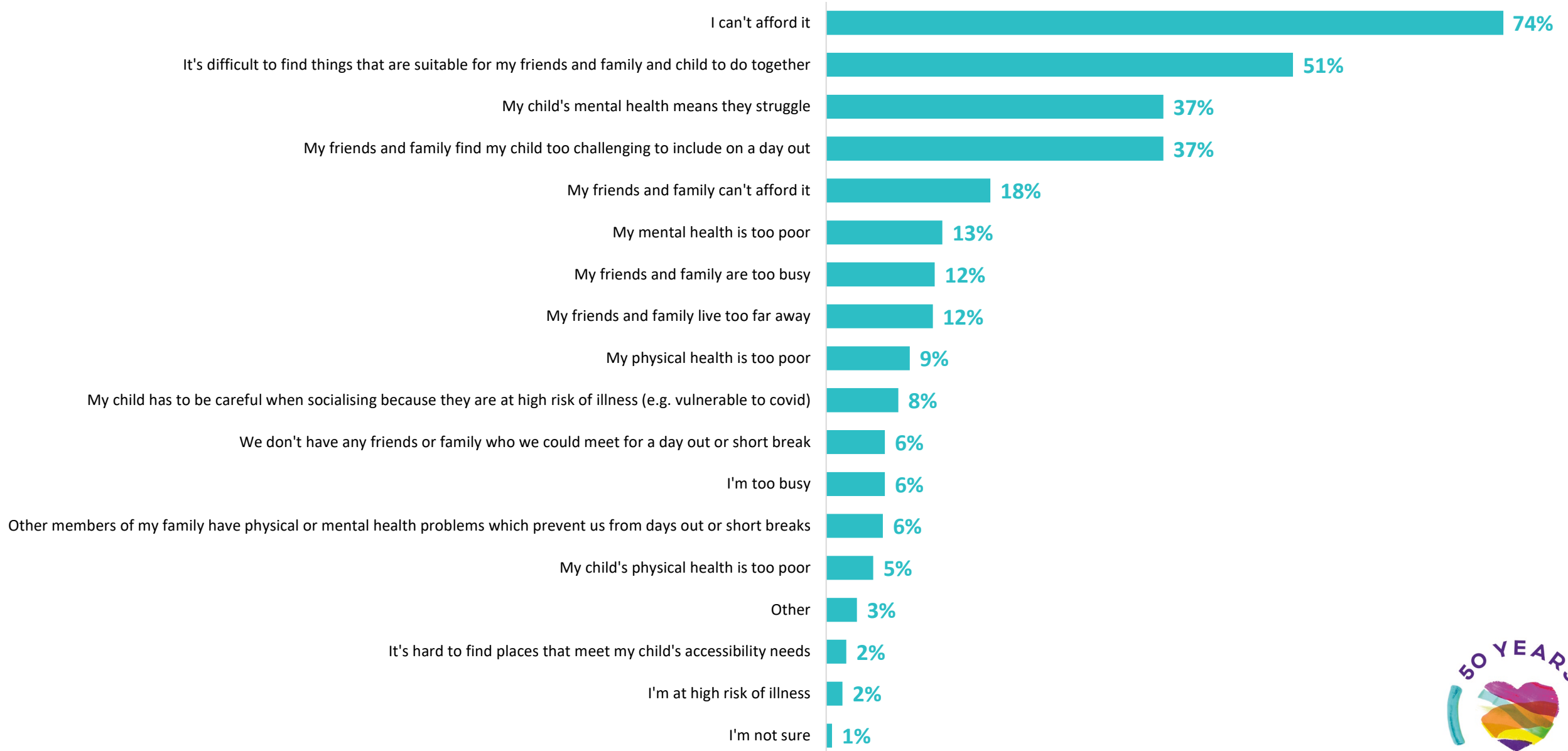
79%

Of families said that they would like to spend more time on days out and short breaks with family and friends



Days out and short breaks

“Why are you unable to go on days out or short breaks with friends and family who do not live with you” (n=953)



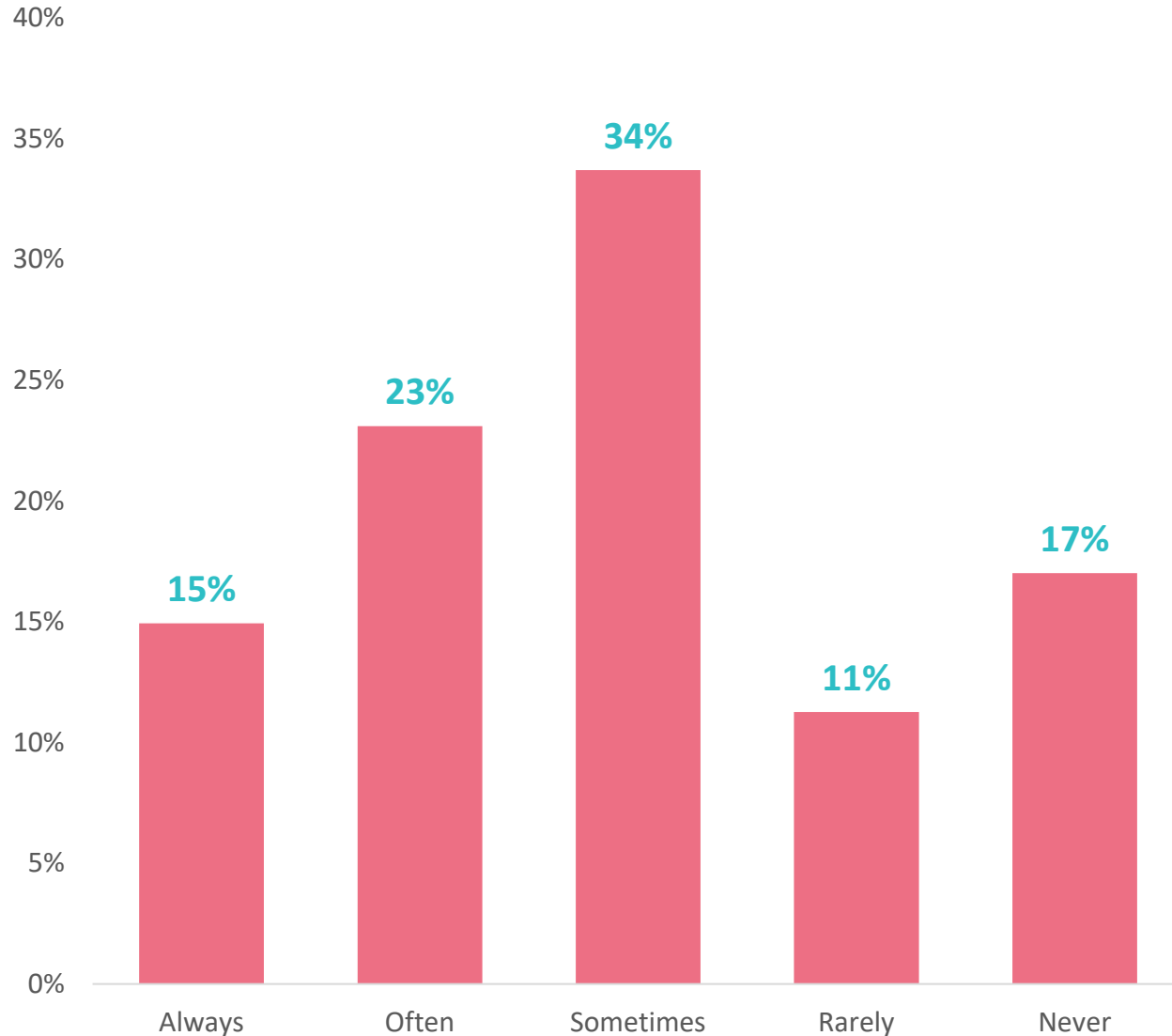
8. Experiences of discrimination

Families share their
experiences of discrimination



Experiences of discrimination

“Do you ever avoid going on short breaks or days out because you are worried about other people's reaction to your child's disability or serious illness?”: (n=1199)



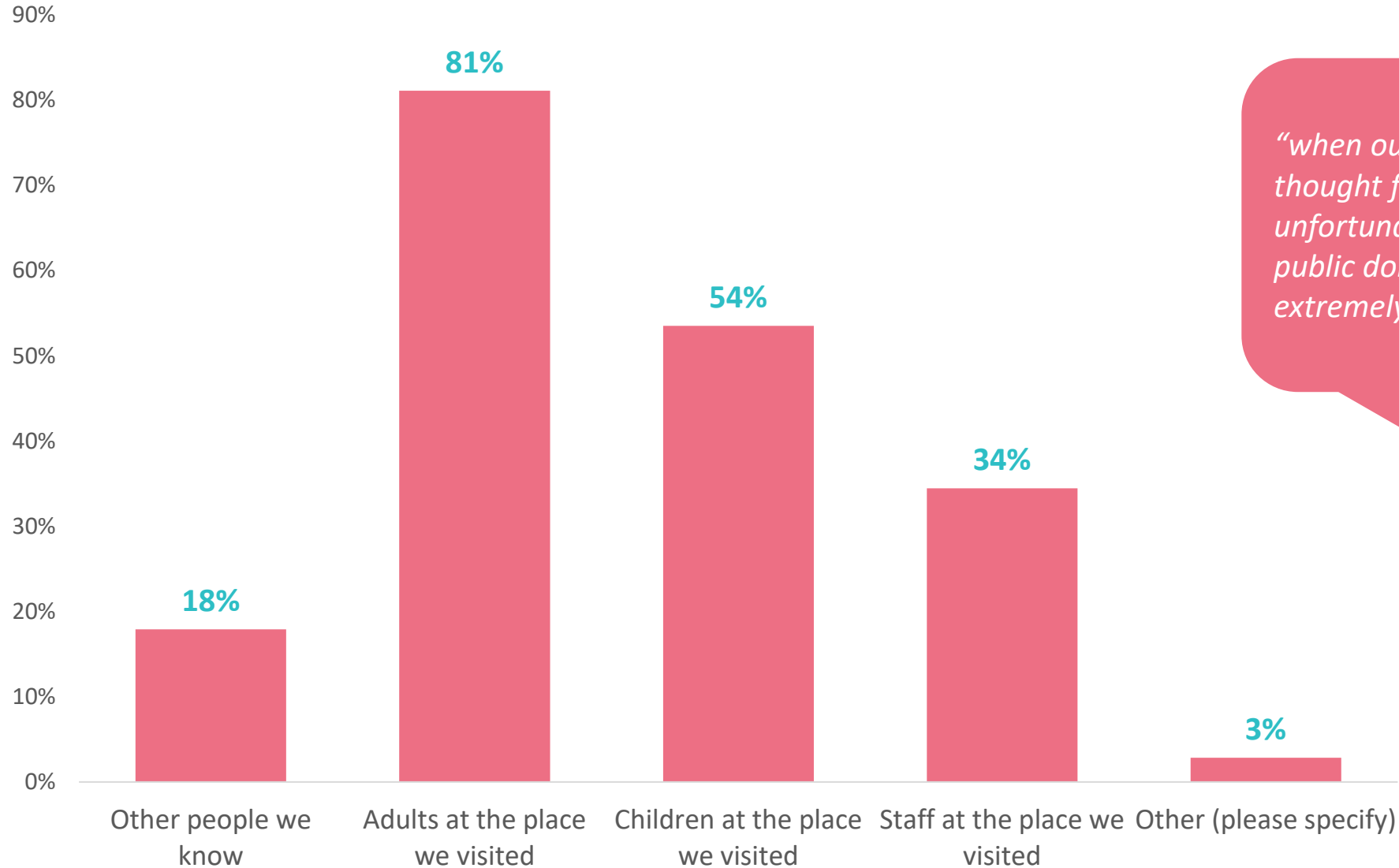
94%

Of families report that **they've experienced a negative reaction to their disabled or seriously ill children** when on a family break or day out (n=1123)



Experiences of discrimination

“Who did you experience a negative reaction from?”:
(n=1199)

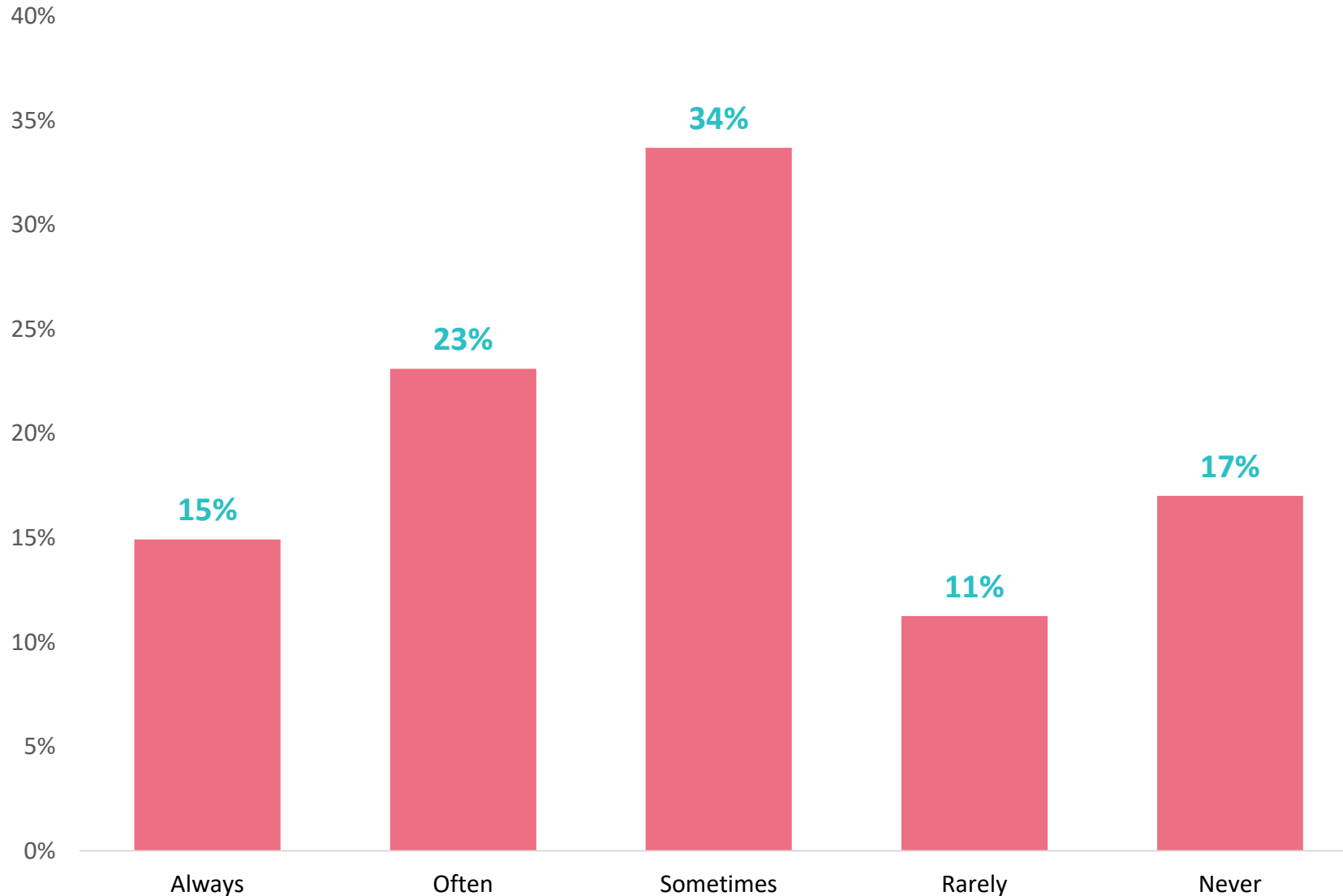


“when out, places do not provide thought for disabled children. And unfortunately, other members of the public don't either, making it extremely difficult.”



Experiences of discrimination

“Do you ever avoid going on short breaks or days out because you are worried about other people's reaction to your child's disability or serious illness?": (n=1199)



87%

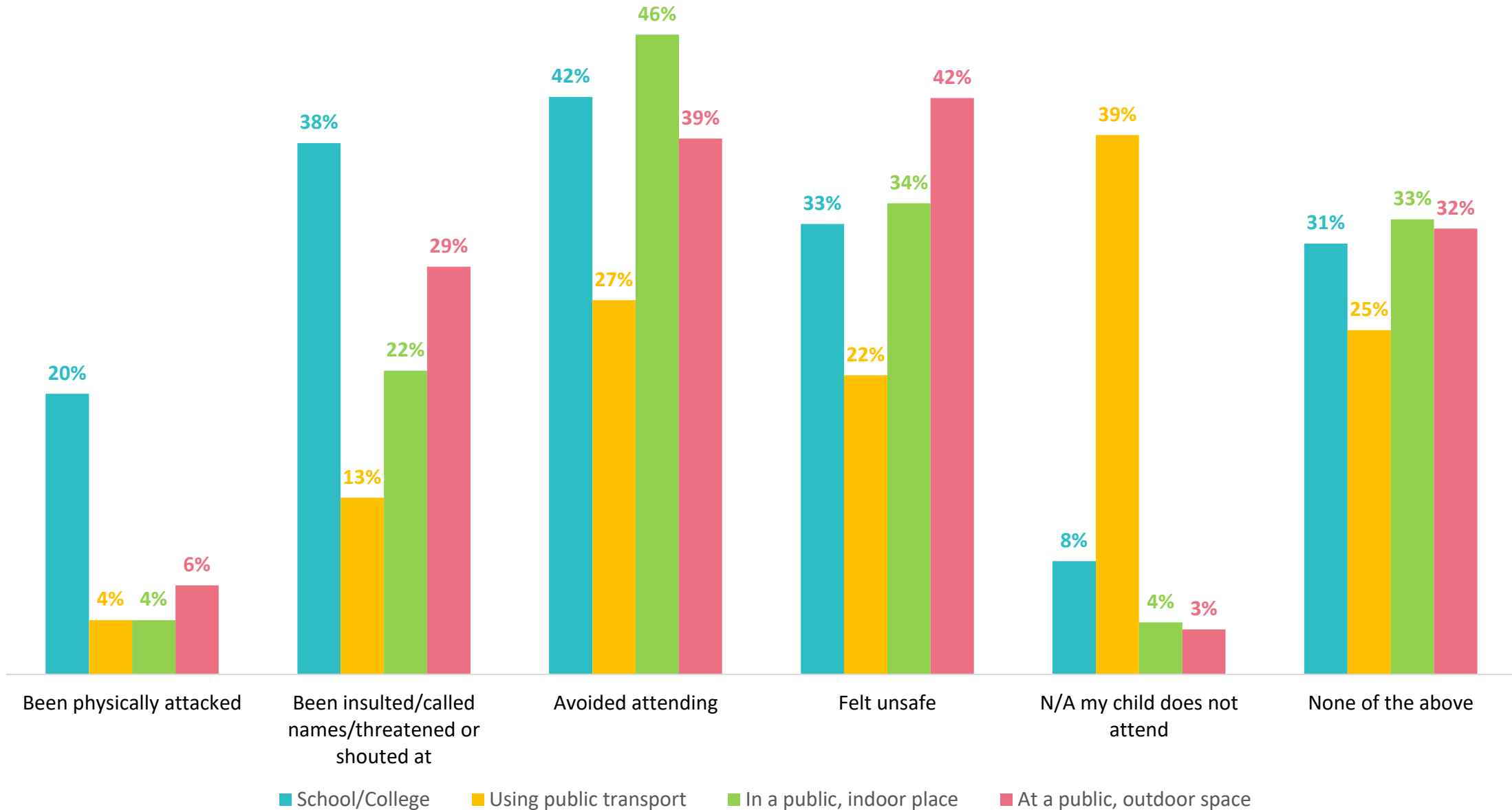
Of families report that **other people's behaviour or attitudes towards their children affects what they do as a family** when on a family break or day out (n=1199)

“I have a high level of anxiety about how my child will cope and how others will view my child's behaviour.”



Experiences of discrimination

“As a result of their disability, have you ever been concerned that your disabled or seriously ill child or young person has:” (n=1199)



Experiences of discrimination

"My youngest child has autism and Tourette's. Their tics have drawn comments, staring, laughing etc from other people."

"Everyone stares and starts judging us and he causes a scene so it's easier to buy it quick and get out."

"In public we can feel people looking at us and judging our behaviour and nowadays we do not apologise and that has been a big deal."

"My youngest has quite an unusual dress sense and has often had things shouted or been laughed at in the street."



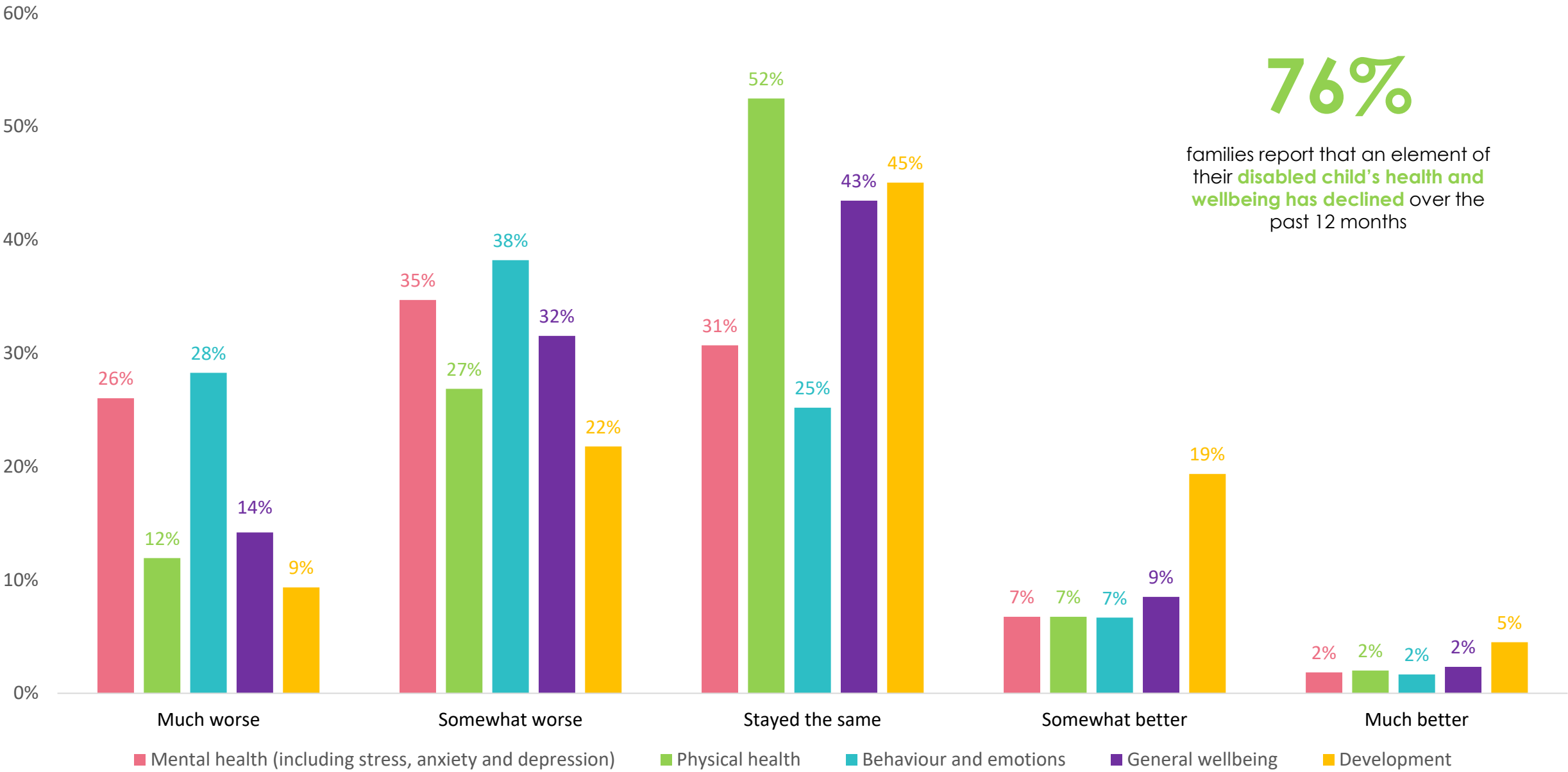
9. Disabled children

We ask how children's health and wellbeing has changed over the last 12 months



Wellbeing of disabled children

“How would you say the following as changed over the past 12 months for your disabled children and young people?” (n=1199)



76%

families report that an element of their disabled child's health and wellbeing has declined over the past 12 months

Wellbeing of disabled children

“She could not cope with the school environment, it was too overwhelming meaning she was unable to learn. Bullying and social anxiety led to trauma and mental health issues. Now home educating and things so much better for us all as a family .”

“My youngest child has been out of education for 2 years and the LA have failed to provide funding for education or a school place. Missing 2 years of secondary school has had a massive impact on the physical and mental wellbeing my child”

“To see him happy being the way that he is and to see him progress as he grows brings me all the happiness that I need.”

“My son has ADHD /ASD and takes everything literally, so if playing football, he doesn't understand why people break rules, and it would get him into arguments. He also doesn't understand team member's frustrations at his level of understanding rules, is slow and really isn't interested in winning as much as they are. This often results in melt downs, withdrawals from the activities as it affects his wellbeing .”



10. Non-Disabled children

We ask how non-disabled children's health and wellbeing has changed over the last 12 months

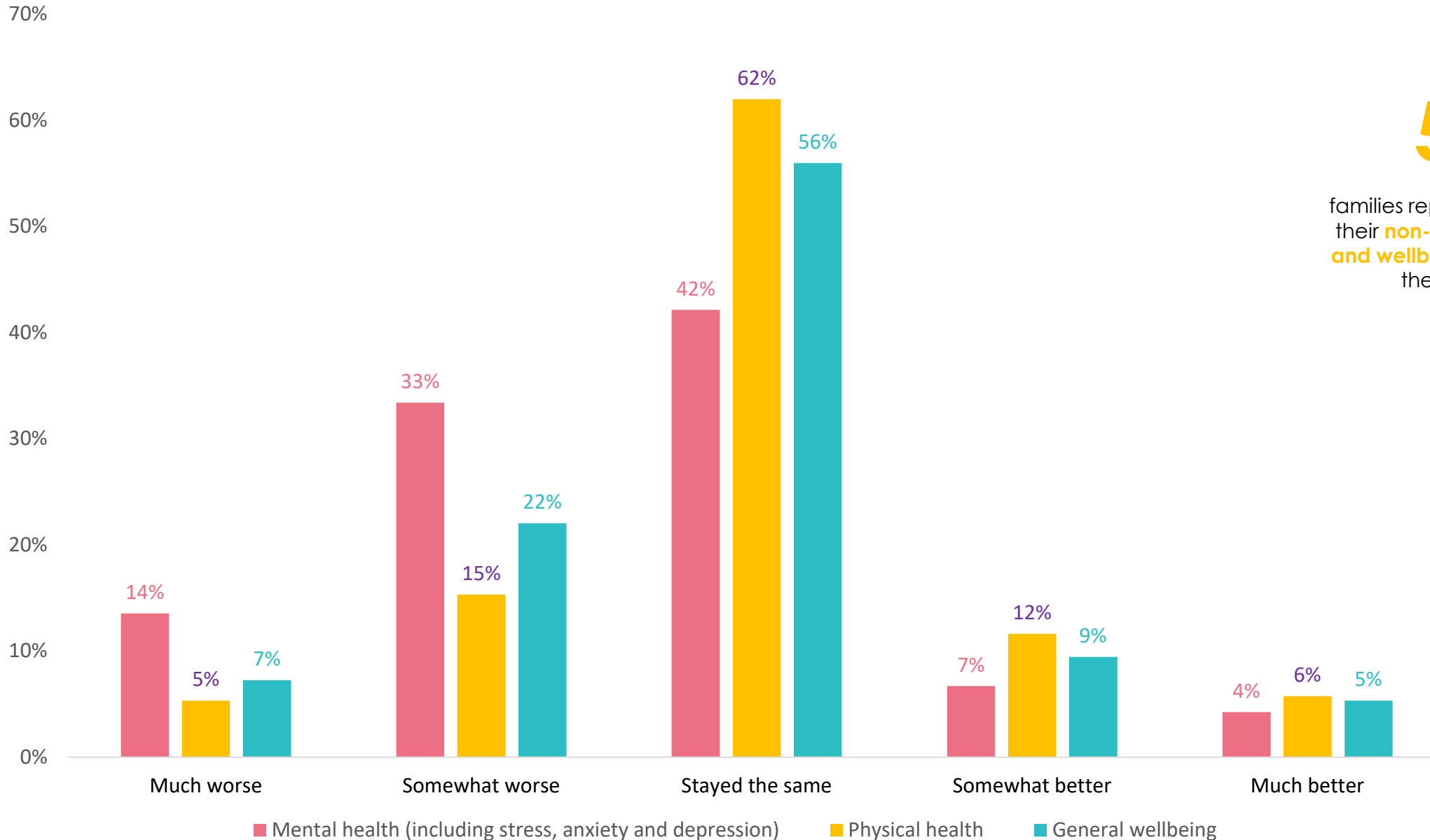


Wellbeing of non-disabled children

“How would you say the following as changed over the past 12 months for your non-disabled children and young people?” (n=731)

50%

families report that an element of their **non-disabled child's health and wellbeing has declined** over the past 12 months



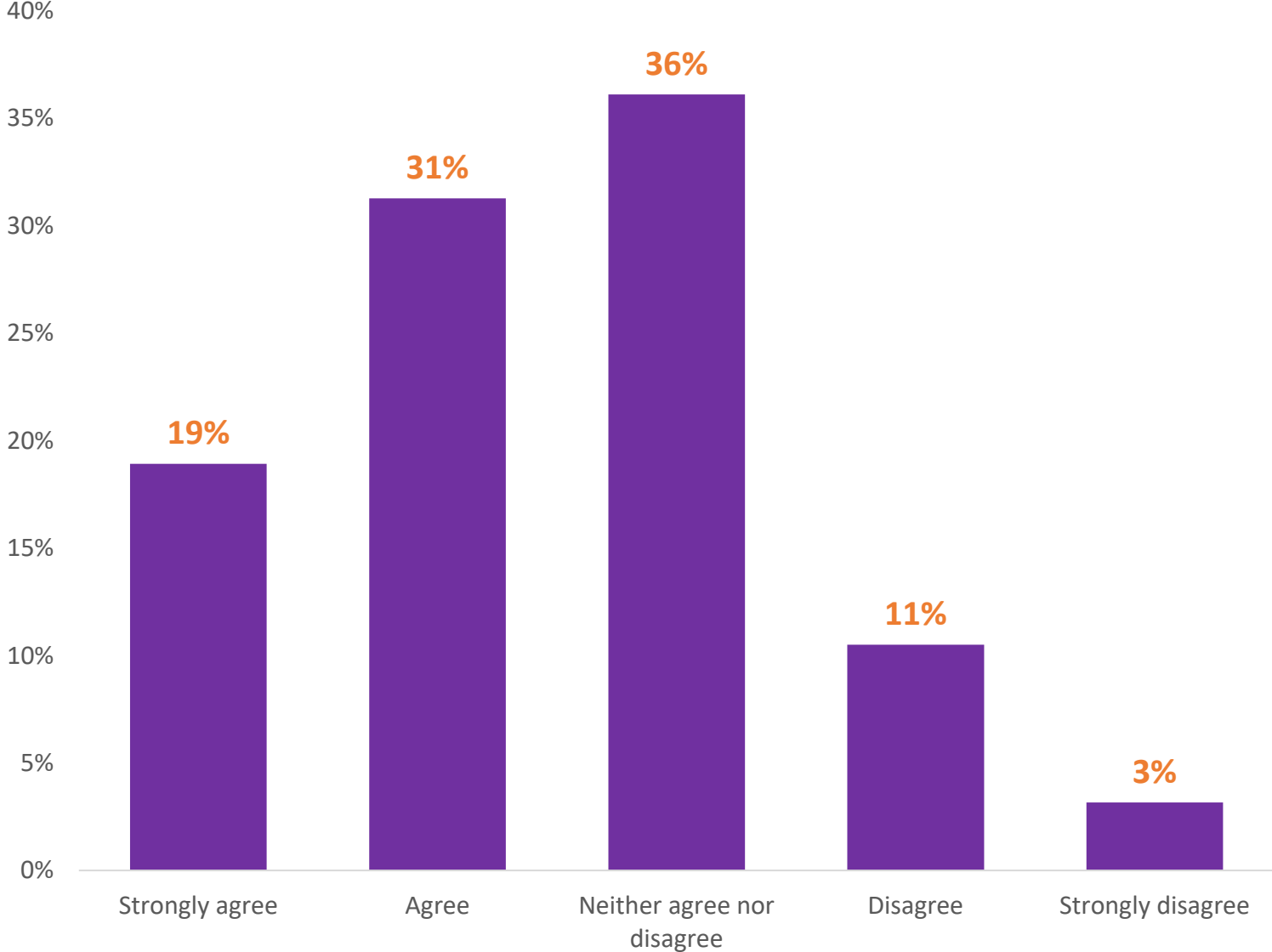
11. Parents and carers

Many parents and carers
have poor wellbeing across a
range of dimensions



Impact on parents and carers

“Do you think you have been treated worse than other people as a result of your child's disability or serious illness?” (n=1199)



Impact on parents and carers

Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale)
(n=1199)

42%

Low wellbeing (adjusted score
of less than 19.5)

High wellbeing 35

6.81

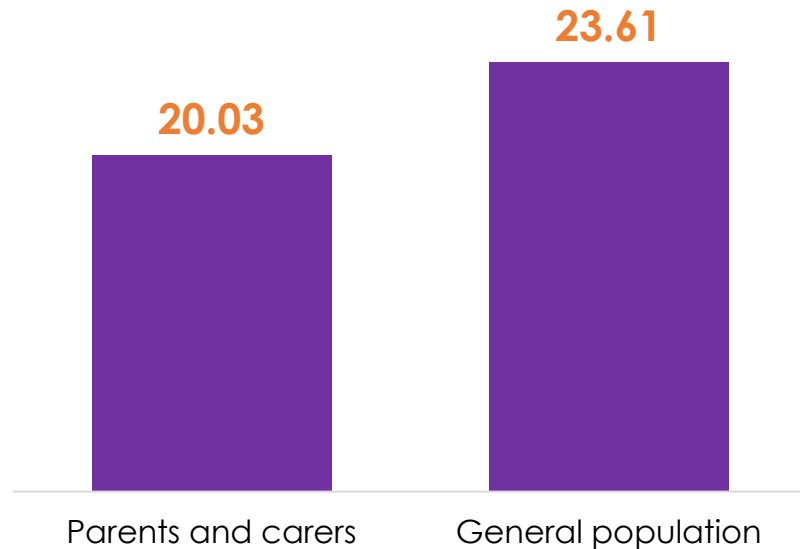
Mean UCLA Loneliness Score

26%

Registered an **extremely high loneliness** score equal to 9
(maximum)

26%

Probable depression (adjusted
score of less than 18)

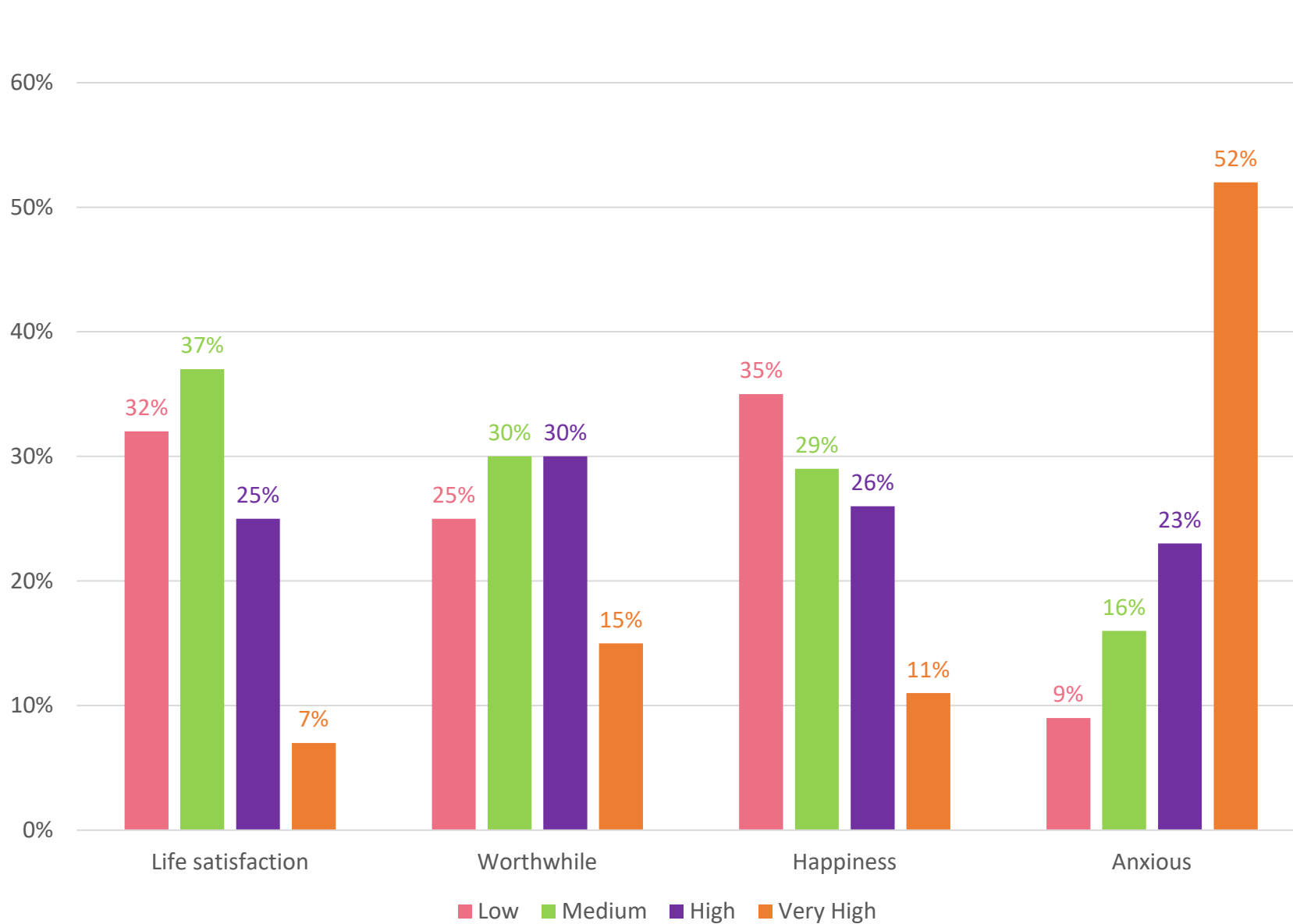


Low wellbeing 7



Impact on parents and carers

ONS Wellbeing Scale (n=1199)



Medium
Average Life satisfaction score

Medium
Average Worthwhile score

Medium
Average Happiness score

Very High
Average Anxiety score



Parent's experiences of the impact of caring

"As a parent I am absolutely overwhelmed with caring for 2 special needs children, I wish I could have a job and a life outside of the 4 walls."

"I think the world of a carer can be lonely. Nobody really understands, it's a constant battle and it's draining. I love my kids but wish things could be better for both of them sometimes. Just this week alone we've had hospital appts every single day."

"There is very little respite locally for disabled children to access meaning as parents we are lacking in sleep/rest."

"Being a single parent, I feel like I never ever get a break. I worry constantly and never have time to myself."



Parent's experiences of the impact of caring

"I feel so isolated and alone. I try my best for my children but really worry about the future and how I will cope."

"I've been a carer for over 22 years for 3 of my children. It's been a struggle and I've not been able to get a job or have respite due to mainly being a single mum."

"It's very isolating as a single parent. I had to give up work to look after him. The demands means very limited social life, no opportunity for a relationship, and your life revolves round your child. It's very rewarding and I wouldn't change him for anything, but it can be tough. "



Other family needs – access to services

“Services are being cut and this is having a huge impact on support for families and children.”

“Being aged 16 we find it difficult to access services. A lot of the time we find that he is too old to access any of the children’s service (for example mental health support) yet he is too young for the adult services.”

“There isn’t any one person to go to for support. You’re passed around the different services and years later you’re still in the same position after trying and fighting for so long.”



Other family needs - education

"I wouldn't change my son to the world. I would however change systems. He is due to start school in September and still haven't started any transition process into his new school."

"More practical support is needed in our education system. It's hard to bring all suggestions practically into the classroom. Particular modern technology, white boards, iPads etc are missing in our schools, also the training given to use them is not provided."

"[We] found out last Monday my son's school is closing this July and there isn't another one that can meet his needs so all very bleak right now."

"We have been seeking a special needs school for our son for over a year, There are not enough schools available that are within distance, can meet needs and have available space."



Other family needs – transitions to adulthood



“Our child was 16 before we got any support and a PA to take him out once a week. Our child is now 18. The transition to adult services is terrible, the transition from paediatrics to adult consultant is still ongoing. There is no transition plan, 1 minute you have a team of 5 people in paediatrics then you are transferred to adult consultant with no support at all.”

“No matter how much we ask social care for help all we get is “no funding” and are told things will get worse as he gets older as there is even less help in adulthood.”



Contact us

If you are interested in finding out more about this research or sharing the findings, please get in touch with either our research or partnership teams:

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Family Fund

Helping disabled children

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