



Family Poll March 2023
England, Scotland, Wales and Northern Ireland Findings



Family Fund
Helping disabled children



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

The data in this report comes from our quarterly Family Poll. The purpose of the poll is to better understand and track the needs and challenges families on low-incomes raising disabled children face.

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 13th March, 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 1,116 families across the UK.

- 778 families were in England
- 110 families were in Scotland
- 90 families were in Wales
- 138 families were in Northern Ireland





The UK Nations

In this iteration of Family Poll we were particularly interested in looking at how families are faring in each of the UK nations of England, Scotland, Wales and Northern Ireland.

This deck presents the same findings for each of the nations sequentially.





Contents

1. Profile of families who took part

The financial cost of caring

2. Reduced incomes

3. Access to other care

4. Increased and additional costs

5. Relying on benefits

6. Savings

The resulting financial difficulties

7. Going into debt

8. Going without

The impact on families

9. Disabled children

10. Non-disabled children

11. Parents and carers

12. Other needs



ENGLAND



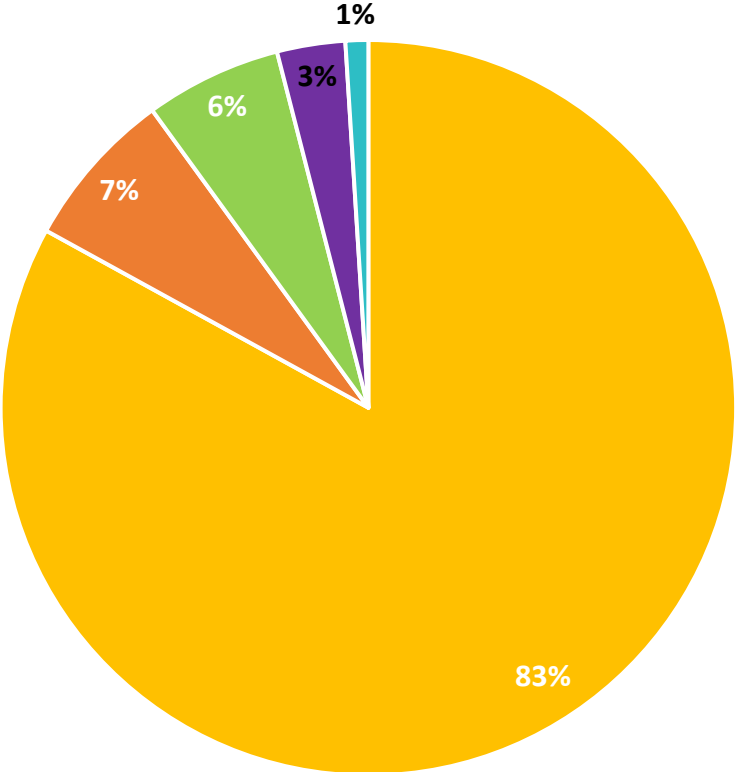
1. Profile of families

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

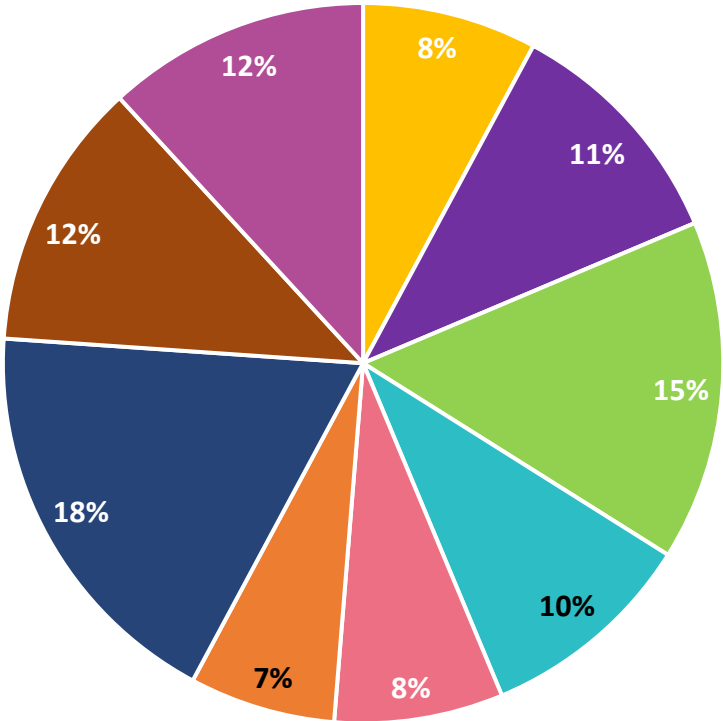


Who are the families who took part in Family Poll?

What is your ethnic group? [grouped] (n=778)



Which of the following regions do you currently live in? (n=778)

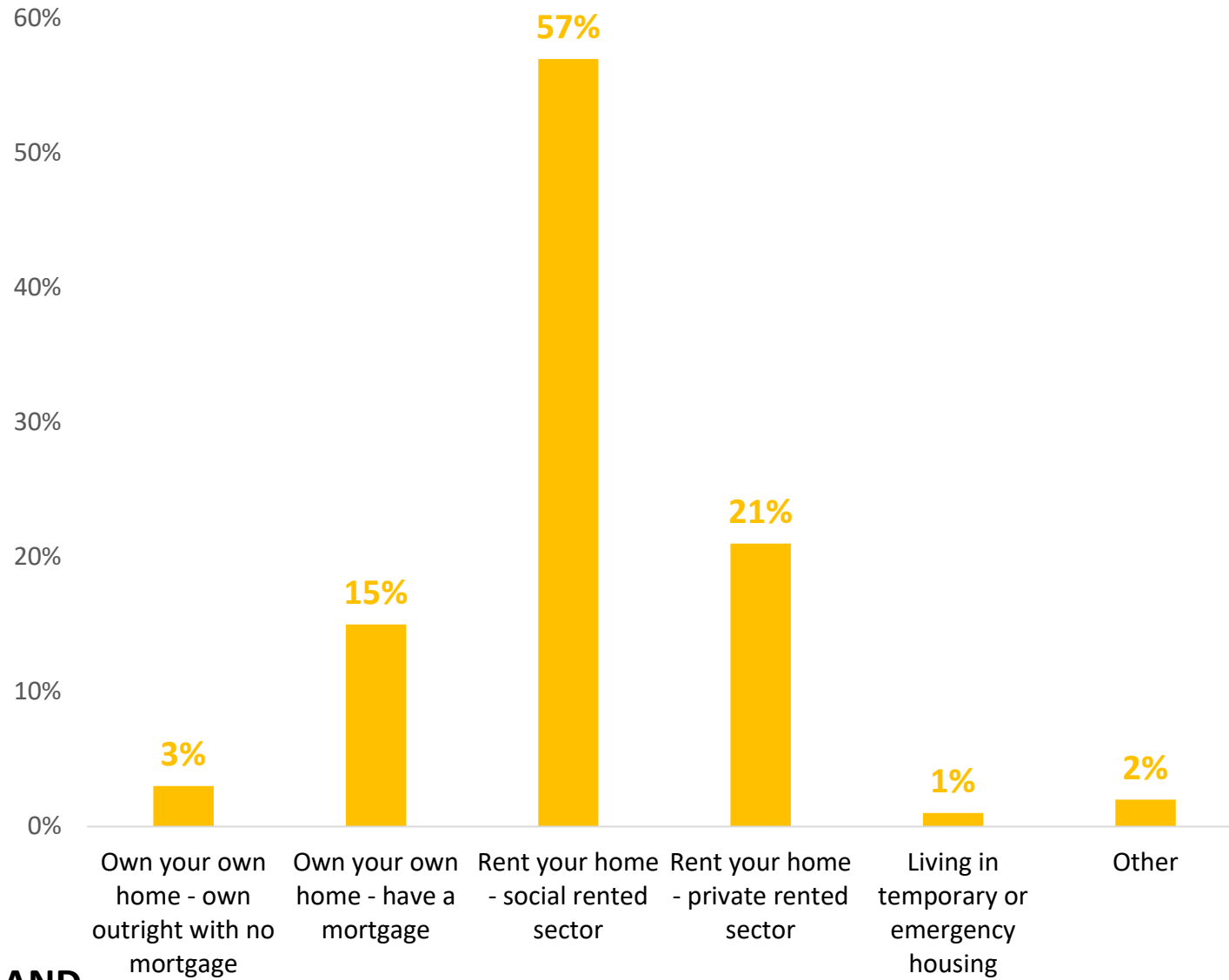


- England - North East
- England - Yorkshire & Humber
- England - North West
- England - West Midlands
- England - East Midlands
- England - East of England
- England - South East
- England - London
- England - South West

ENGLAND



Who are the families who took part in Family Poll?



ENGLAND

778

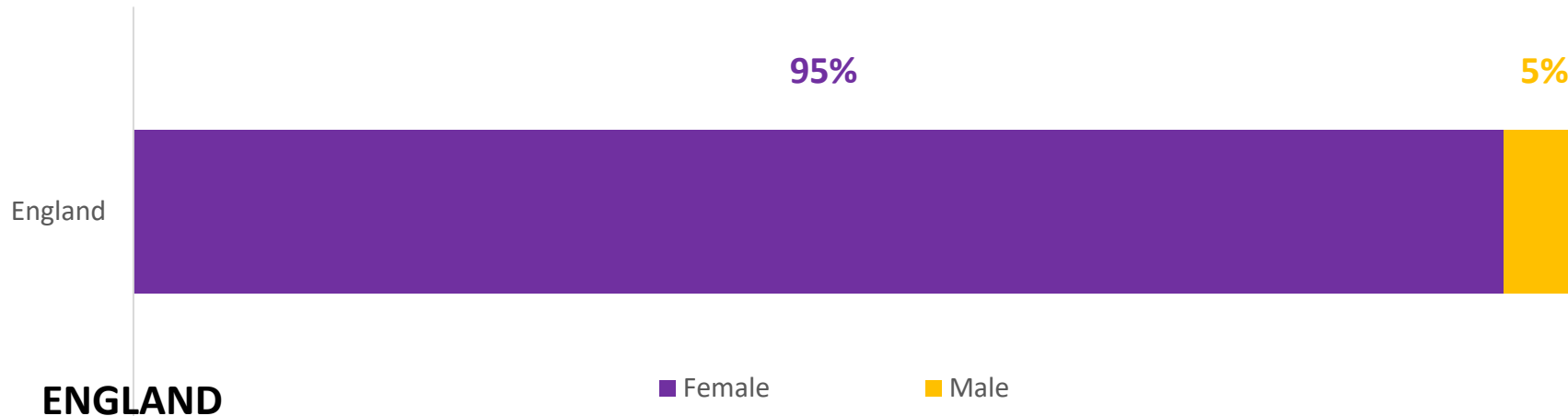
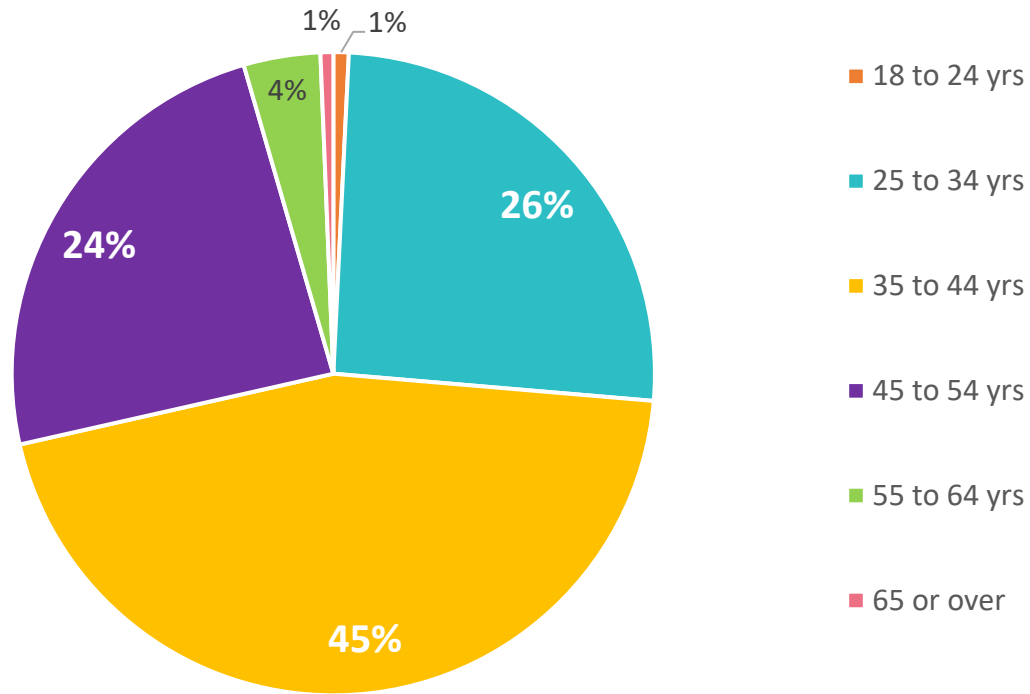
Responses from families in England

57%

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



Parents and Carers (N=778)



73 %

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

47 %

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

36 %

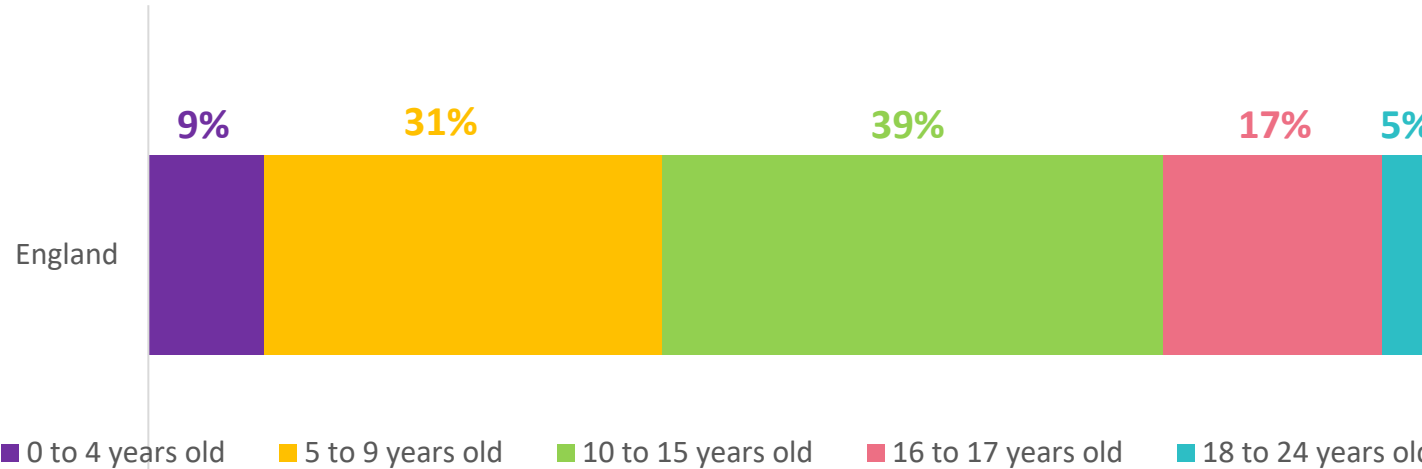
Of these said that their condition or illness **reduces their ability to carry out day-to-day activities**



Who are the families who took part in Family Poll?



1190+
Children with disabilities or serious illnesses



730+
Children without disabilities or serious illnesses

ENGLAND



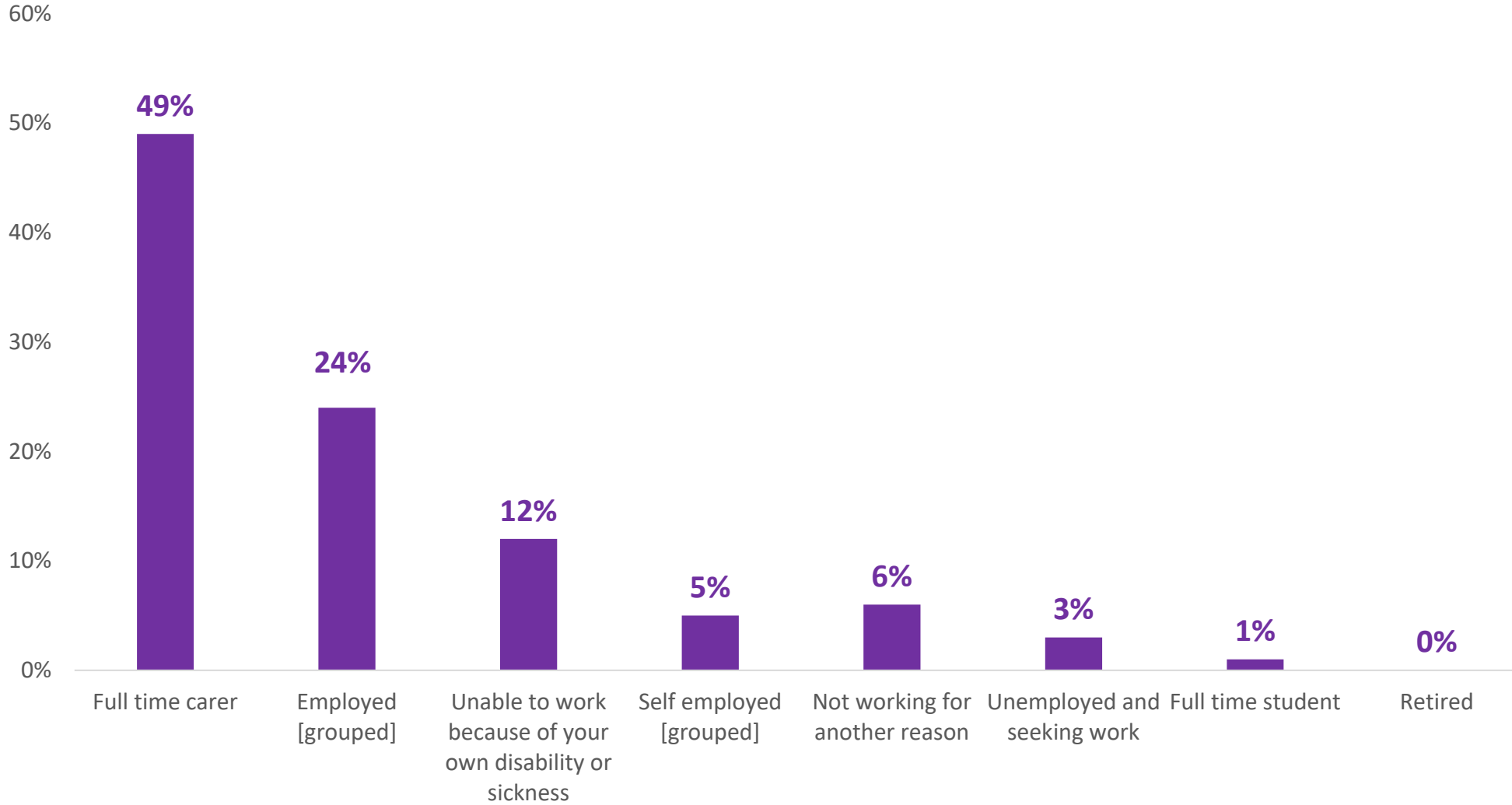
2. Reduced incomes

For many families raising disabled children, parents and carers' ability to earn an income is significantly limited by their commitment to caring for their child.



Working and caring

“Are you employed?” (n=778)



ENGLAND

£17,618

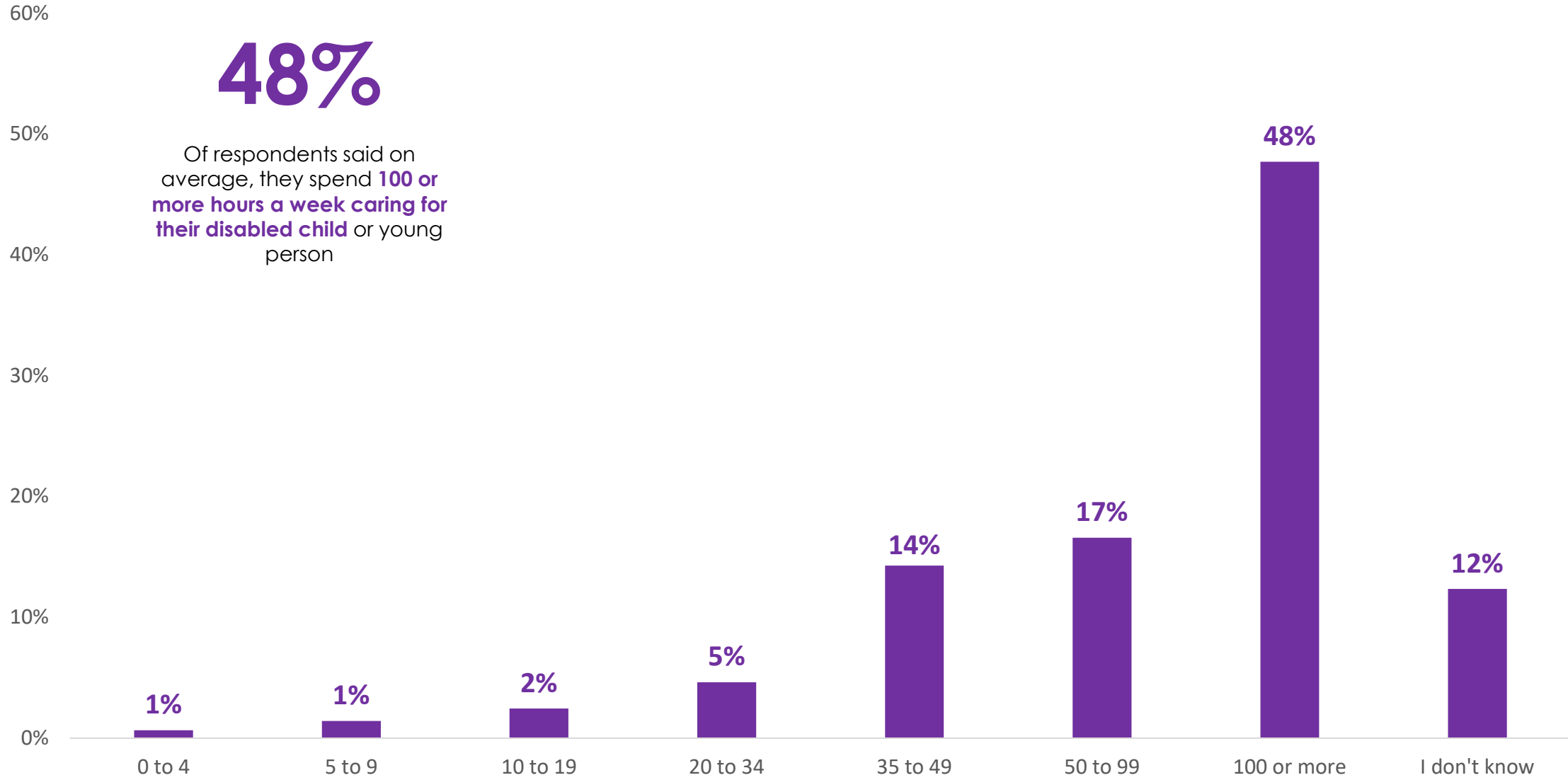
The mean **annual household income** reported by families (n=673)

£1468

The mean **monthly household income** reported by families (n=673)



“About how many hours a week, on average, do you spend providing help for or looking after your disabled child or young person?” (n=778)



48%

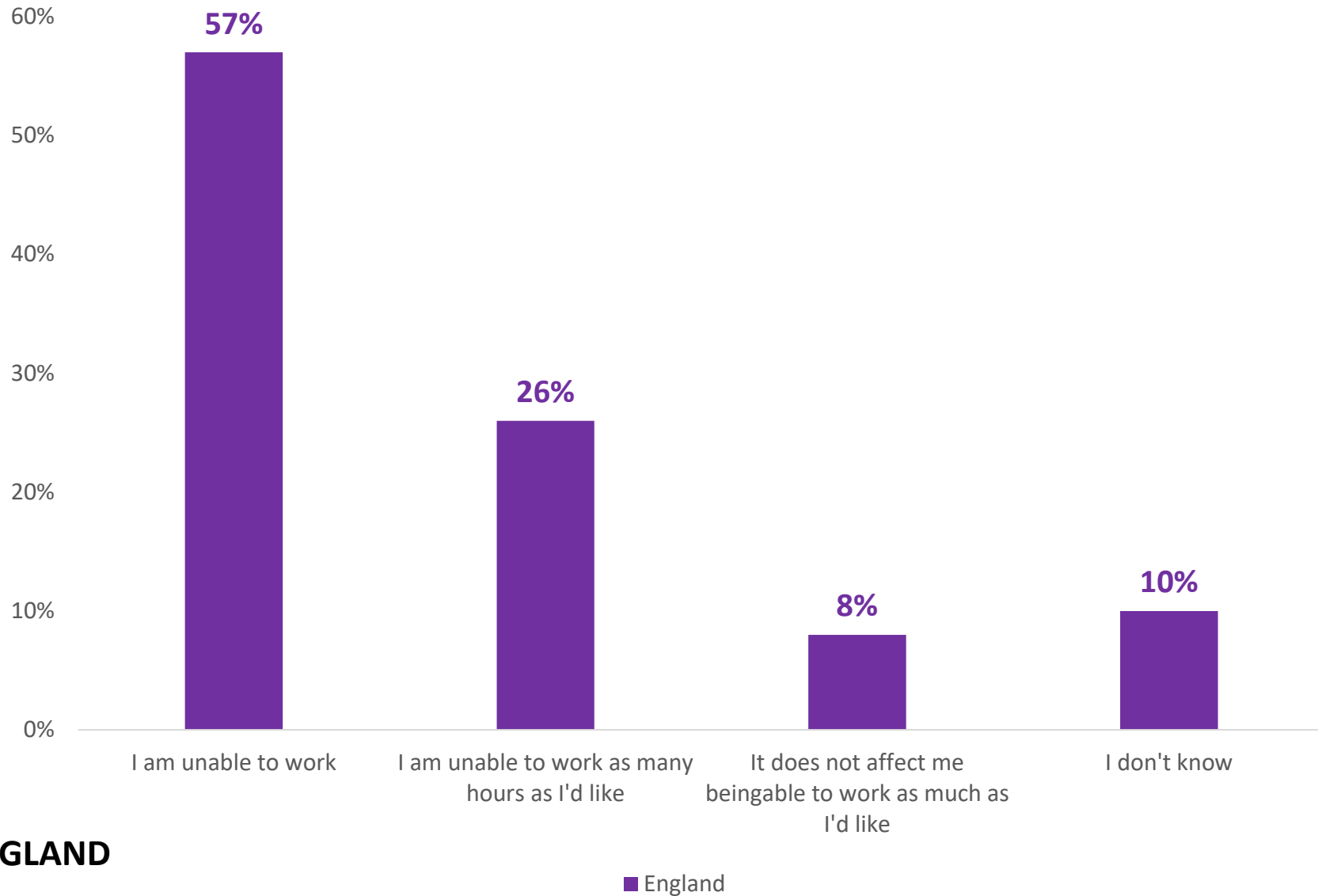
Of respondents said on average, they spend **100 or more hours a week caring for their disabled child** or young person

ENGLAND

■ First adult

Caring

“Do your caring responsibilities for your disabled child or young person mean you cannot work as much as you would like?” (n=778)

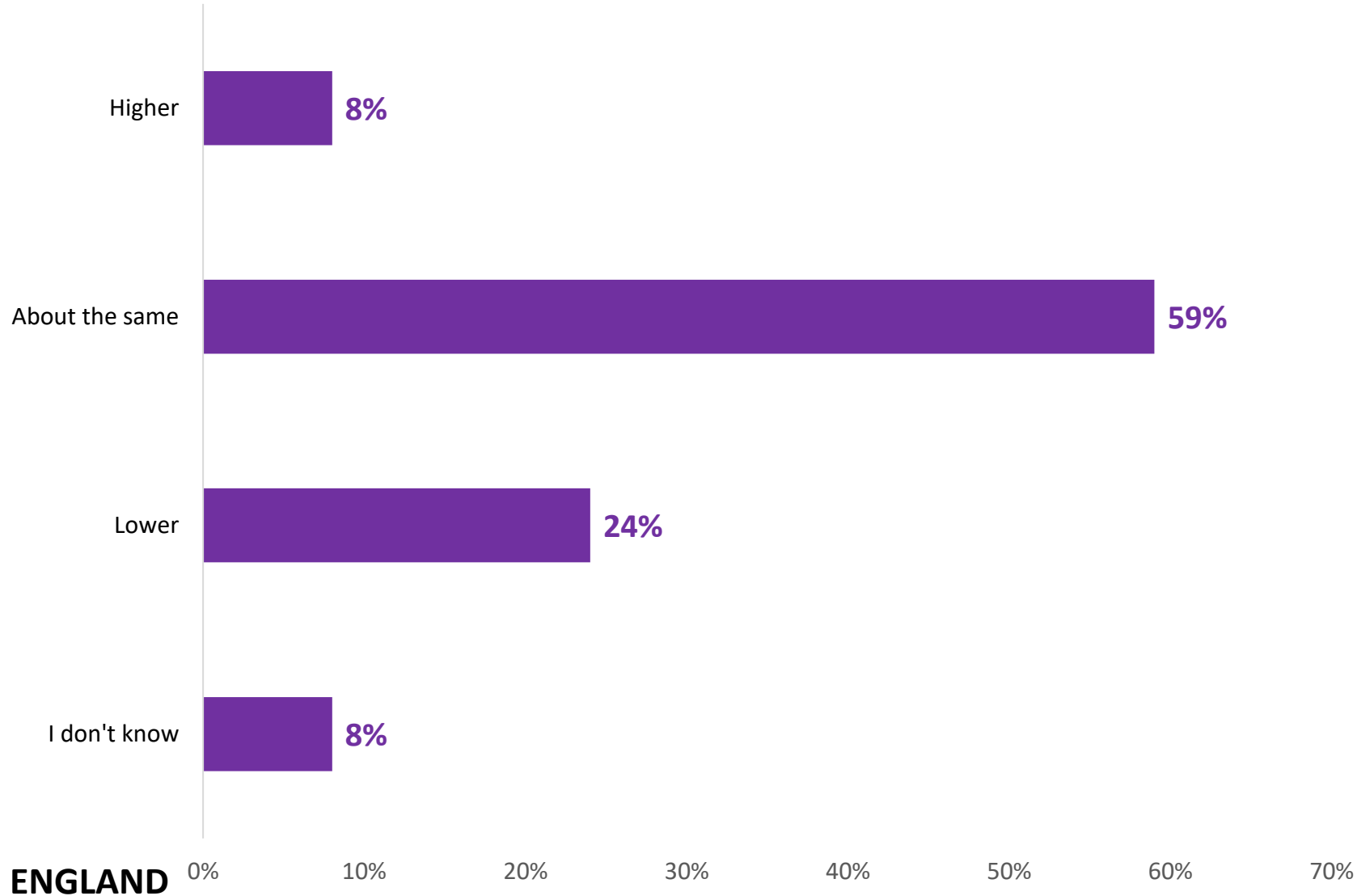


ENGLAND



Income

“Thinking about your current regular household income, would you say it is higher, lower, or about the same as he income you had 12 months ago?” (n=778)



44%

Of respondents who said their household income is lower because **they had to reduce their hours/stop working to meet the care needs of their disabled child or young person** (n=167)



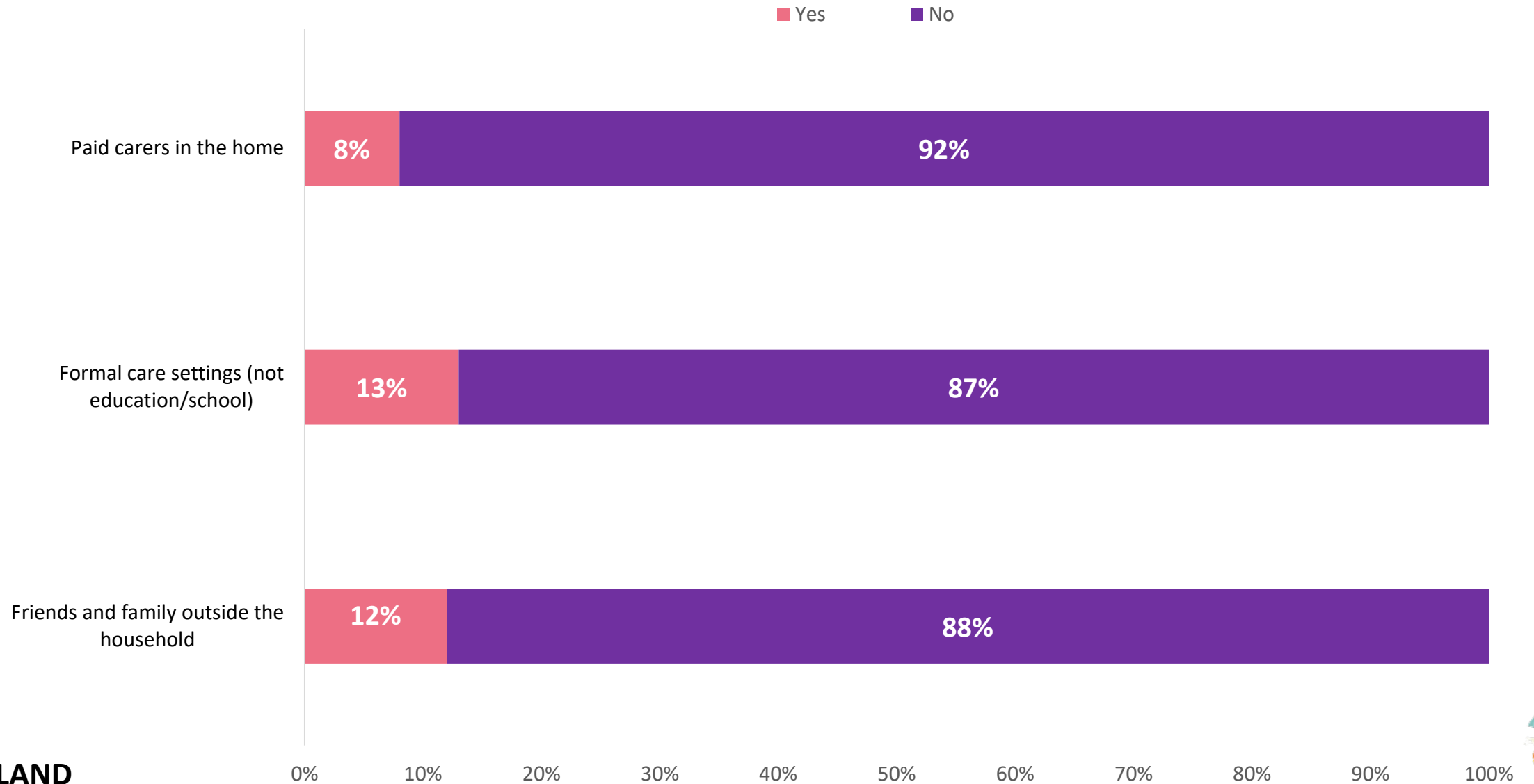
3. Access to other care

Even when families would like their child to be cared for by someone outside the household this isn't always available. This further limits their ability to earn additional income.



Access to care outside the household

“Are your disabled children cared for by the following?” (n=778)

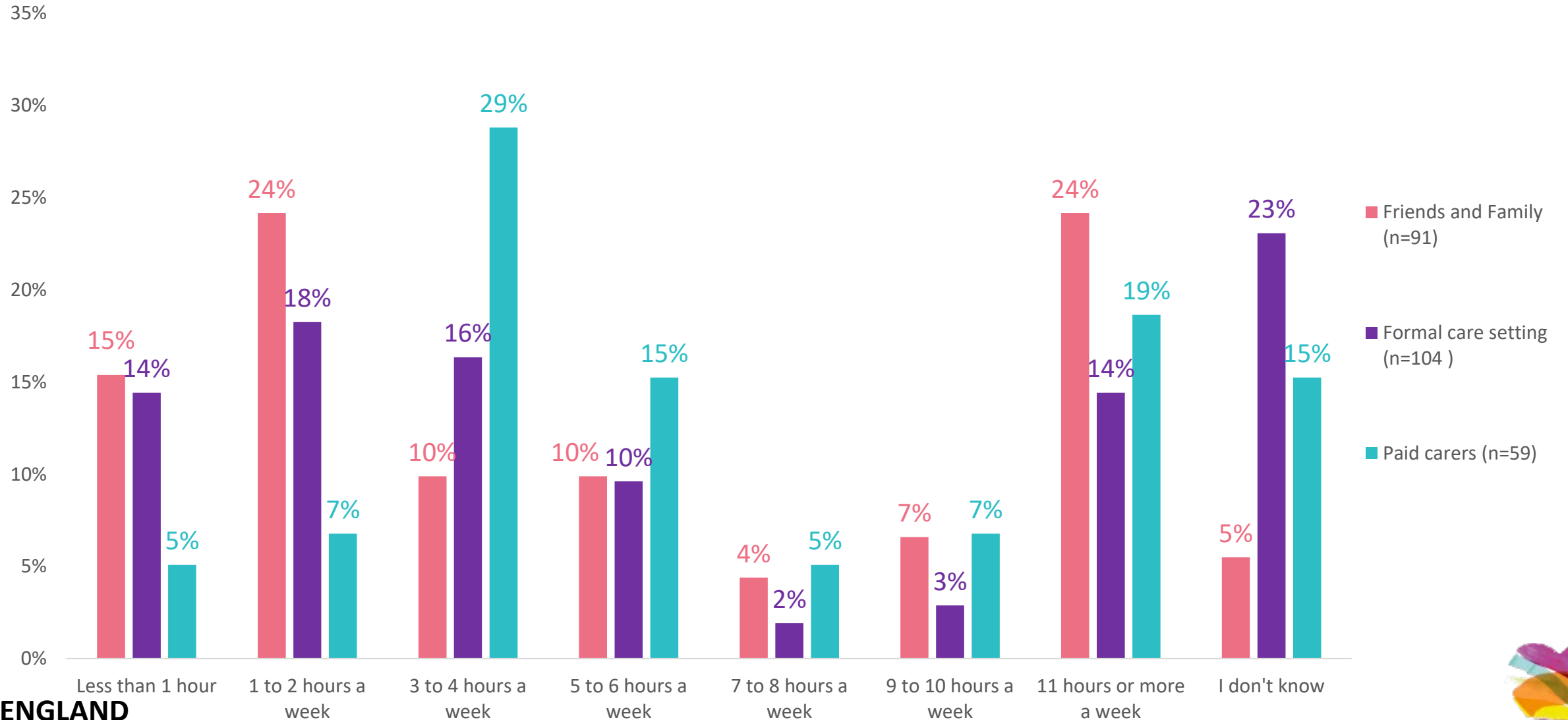


ENGLAND



Access to care outside the household

“On average, how many hours a week are your children cared for by the following?”

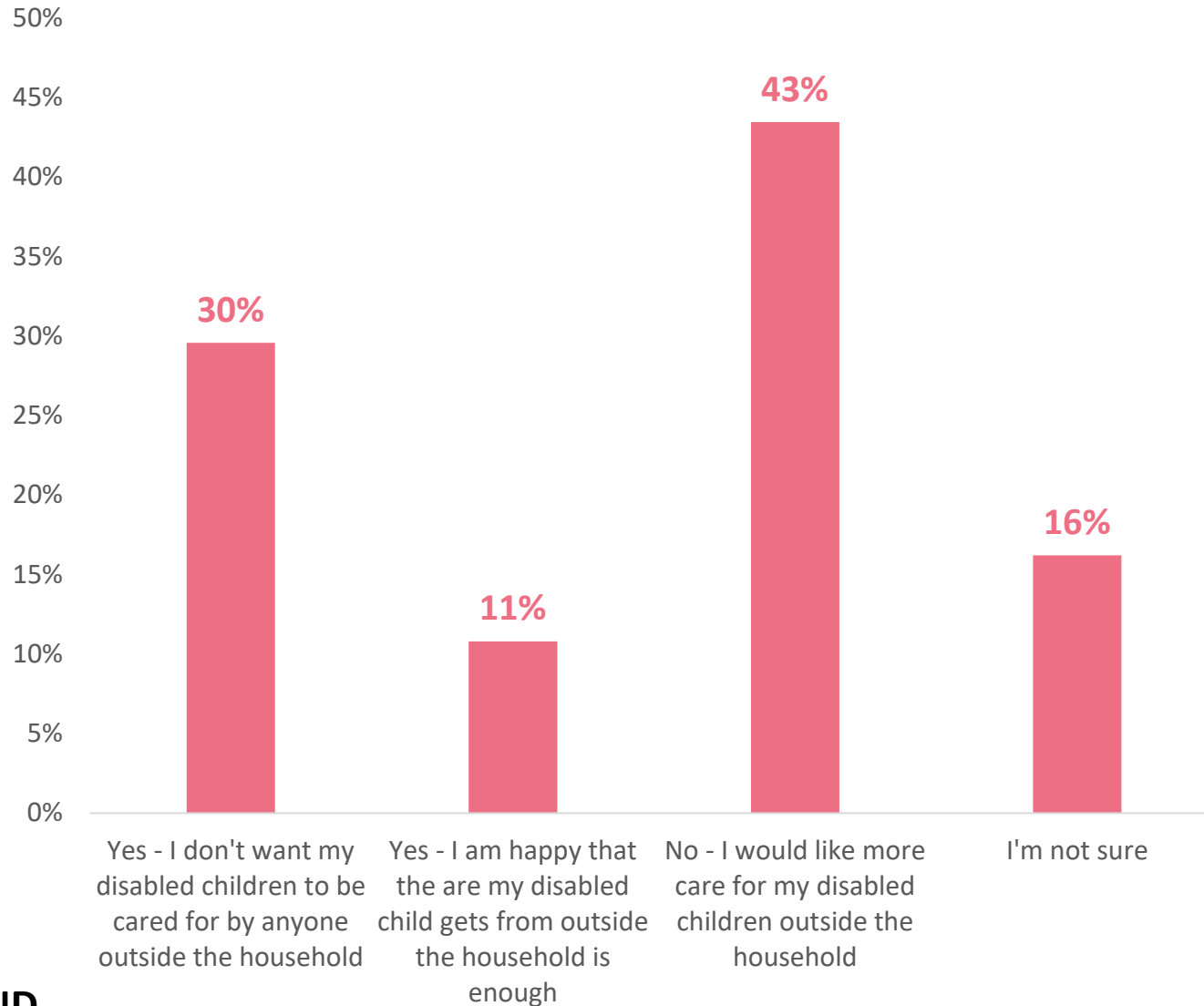


ENGLAND



Unmet need for care

“Do you have access to as much care (outside of school/education settings) from people outside the household as you would like for your disabled child?” (n=778)

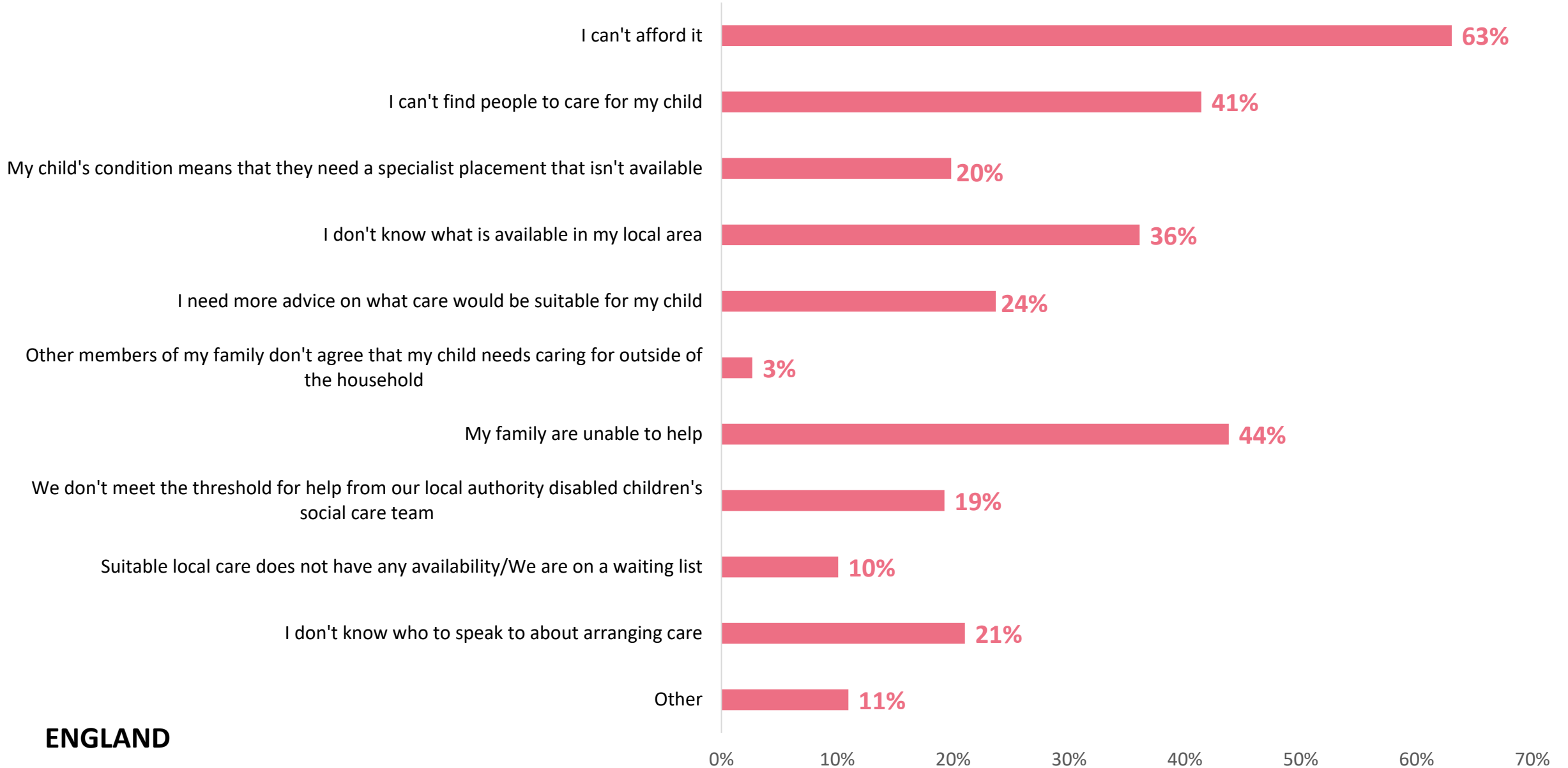


ENGLAND



Unmet need for care

Why are you unable to access as much care from outside the household for your disabled child as you would like? (n=338)



ENGLAND

Family's experiences of care outside the household

"It is difficult - especially when you don't have anyone who can care for them so you can have a break. It's difficult to look after myself and my mental health when I am constantly caring for a child with autism and his brother who is currently being assessed for a neurological condition."

"I love my children but would be nice to have a break once in a while"

"Most funding places need a professional's referral. Families like mine don't have the professional help As I can manage well in the home"

"Parents need all kinds of help not just financially. There isn't enough respite care for carers. Everything is online and sometimes you need someone to help point things out. Mental health for carers needs looking into and family outings to help."



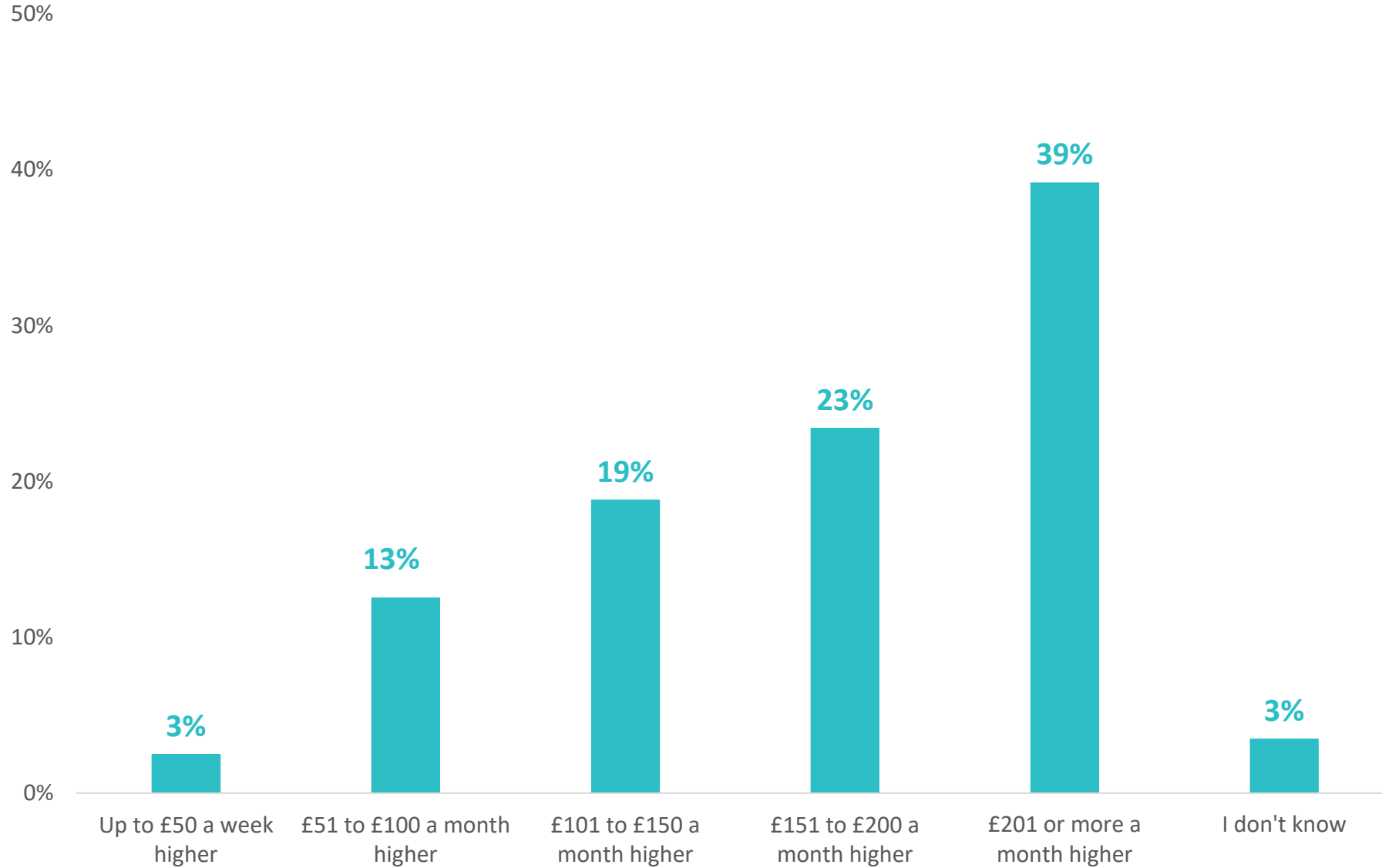
4. Increased and additional costs

Families raising disabled children face higher costs as a result of their children's disability which make them even more sensitive to the increasing cost of living. These increased costs include both additional items and increased costs of everyday items



Household Bills

“Thinking about how much higher your current regular household bills are compared to 12 months ago, which of the following describes the change?” (n=717)



92%

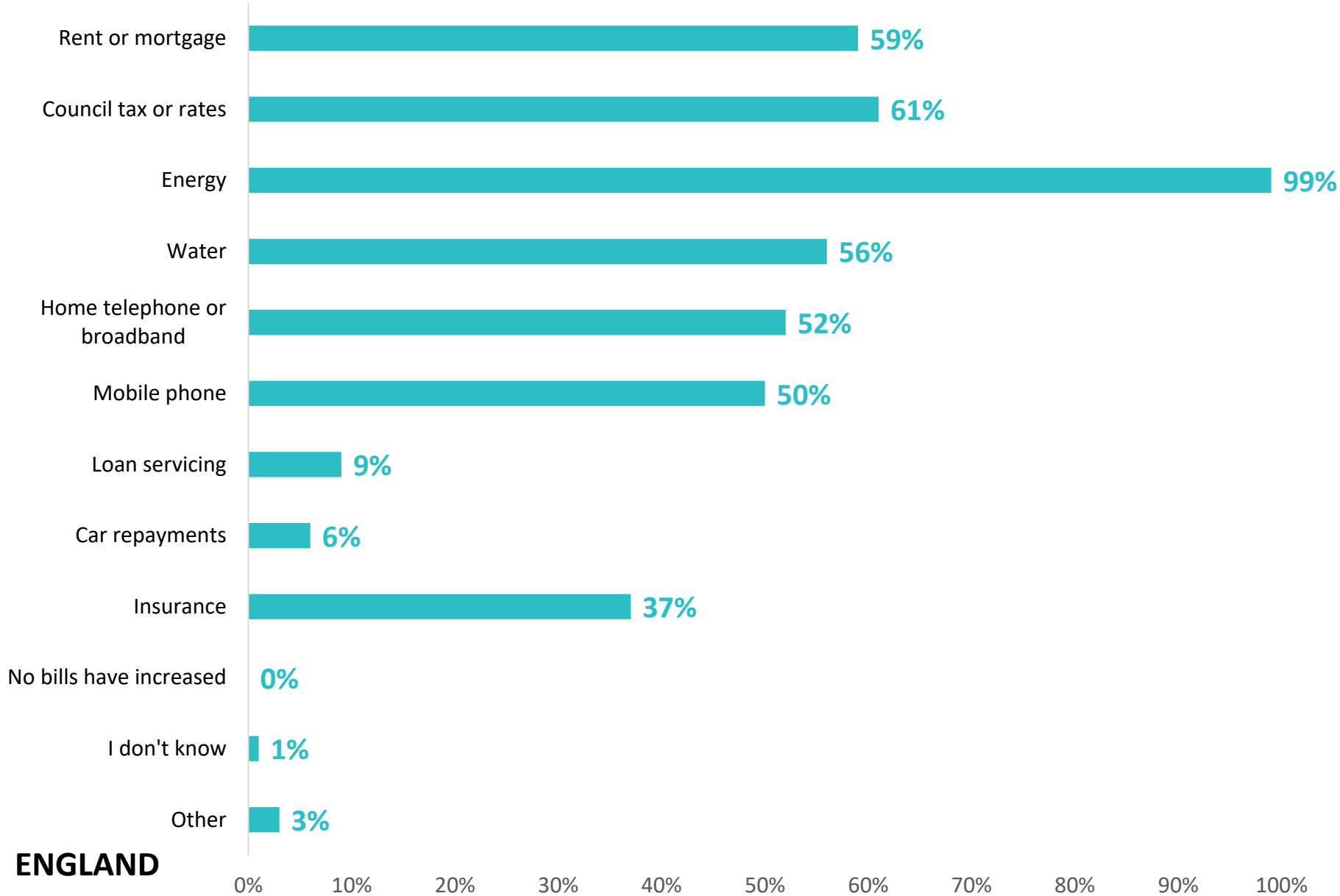
Of respondents said their current household bills are higher than 12 months ago (n=778)

ENGLAND

■ England

Household Bills

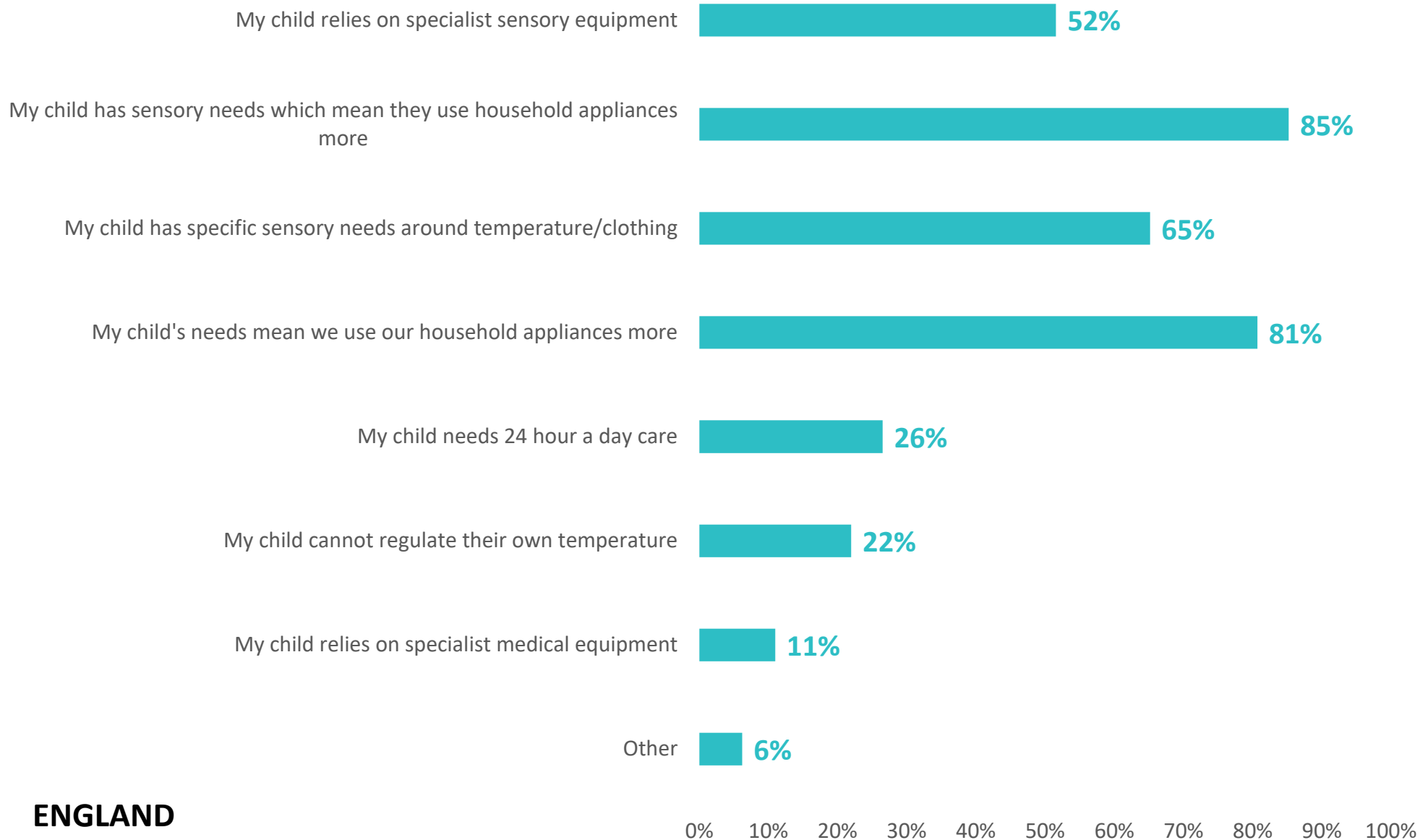
“Which, if any, regular household bills have increased compared to 12 months ago?” (n=1,028)



ENGLAND

Additional Costs

“What are the reasons that mean you have to use more energy than families raising non-disabled children?” (n=419)

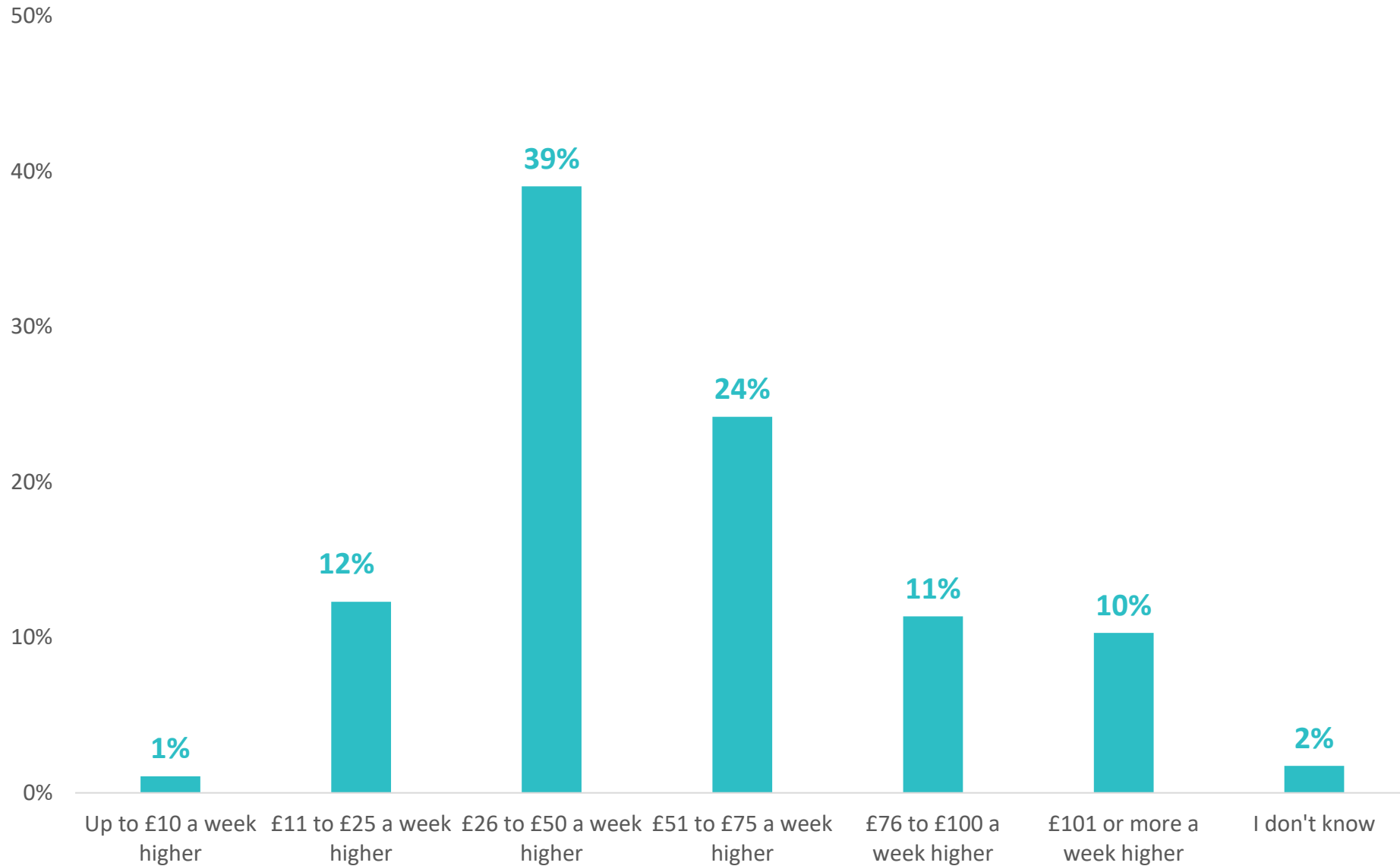


54%

Of respondents said they have to **pay more for energy** as a result of their disabled children's conditions or illnesses (n=778)

ENGLAND

“Thinking about how much higher your current weekly food shop is compared to 12 months ago, which of the following describes the change?” (n=748)



ENGLAND

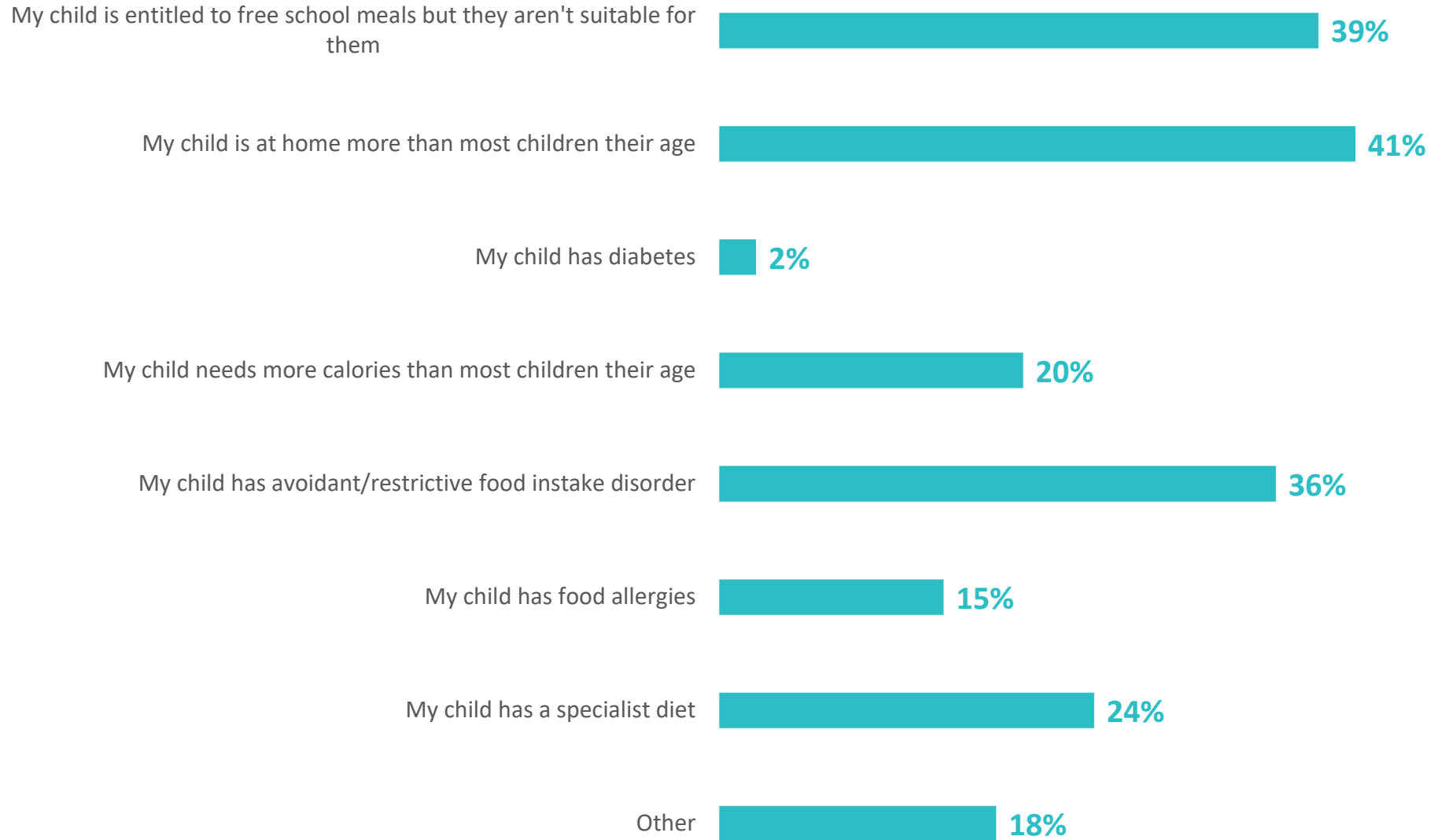
96%

Of respondents said their weekly food shop is higher than 12 months ago (n=778)



Additional Costs

“What are the reasons that mean you have to spend more on food and groceries than families raising non-disabled children?” (n=542)



73%

Of respondents said they have to spend more on food and groceries than families raising non-disabled children (n=778)

ENGLAND

0% 10% 20% 30% 40% 50%

Family's experiences of needing to spend more

"The energy prices are shocking and for families like mine who rely on electricity to use tablets to help communicate or for any other equipment to keep them safe and well I feel there should be extra support. Also my child had ARFID and we all eat different and with the prices of food my bill has nearly double and due to stock issues my daughter has nearly been hospitalised as the 1 drink she will drink goes out of stock all the time and I travel 30/40miles a day til I find it or she refuses to eat and drink."

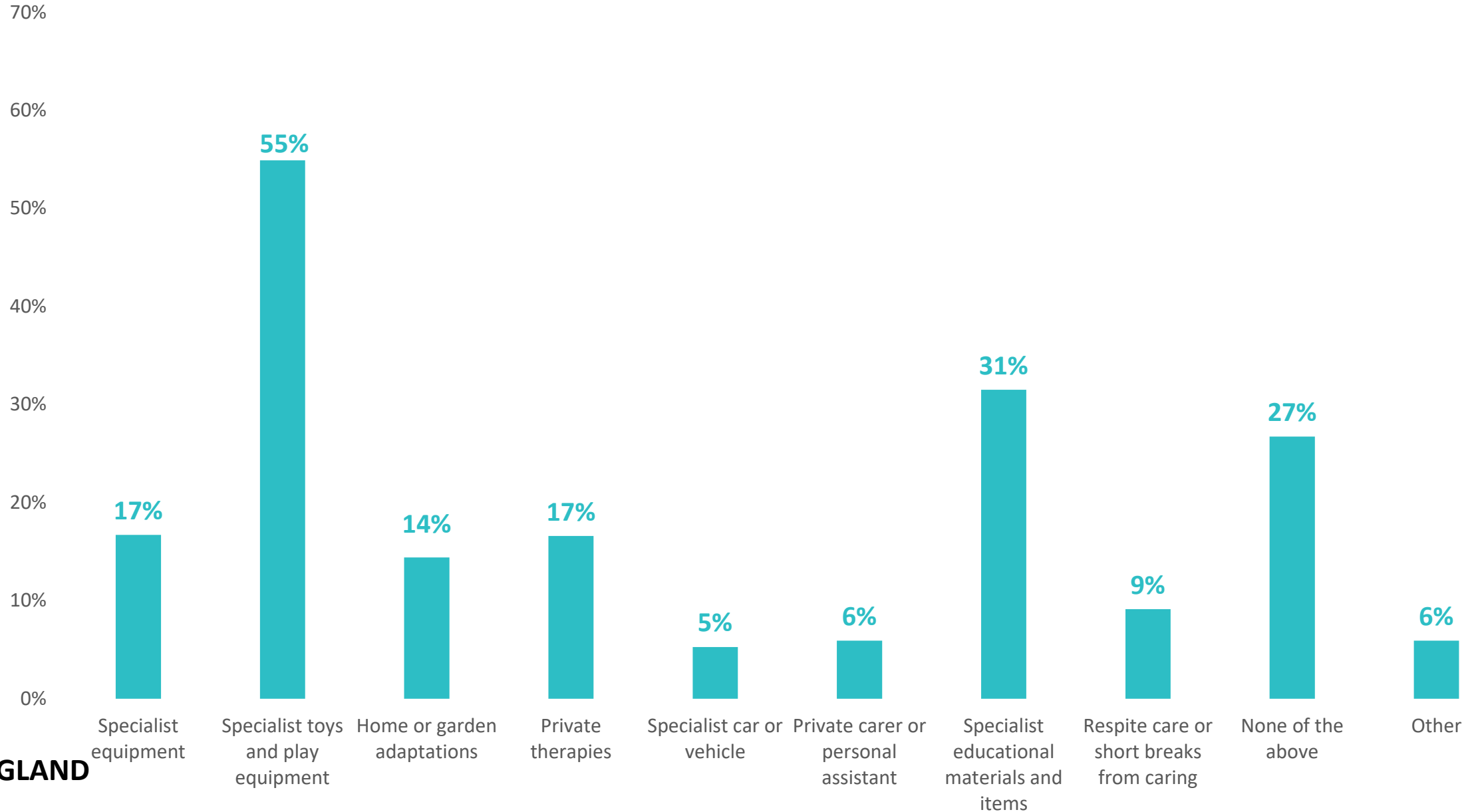
"Not enough finance to pay for how much special food or heating"

"The cost of living has affected us so much due to the high cost of specific food and energy"



Additional Costs

“As a result of your disabled children’s conditions or illnesses, have you had to buy any of the following specialist items and services using your own money?” (n=778)



ENGLAND

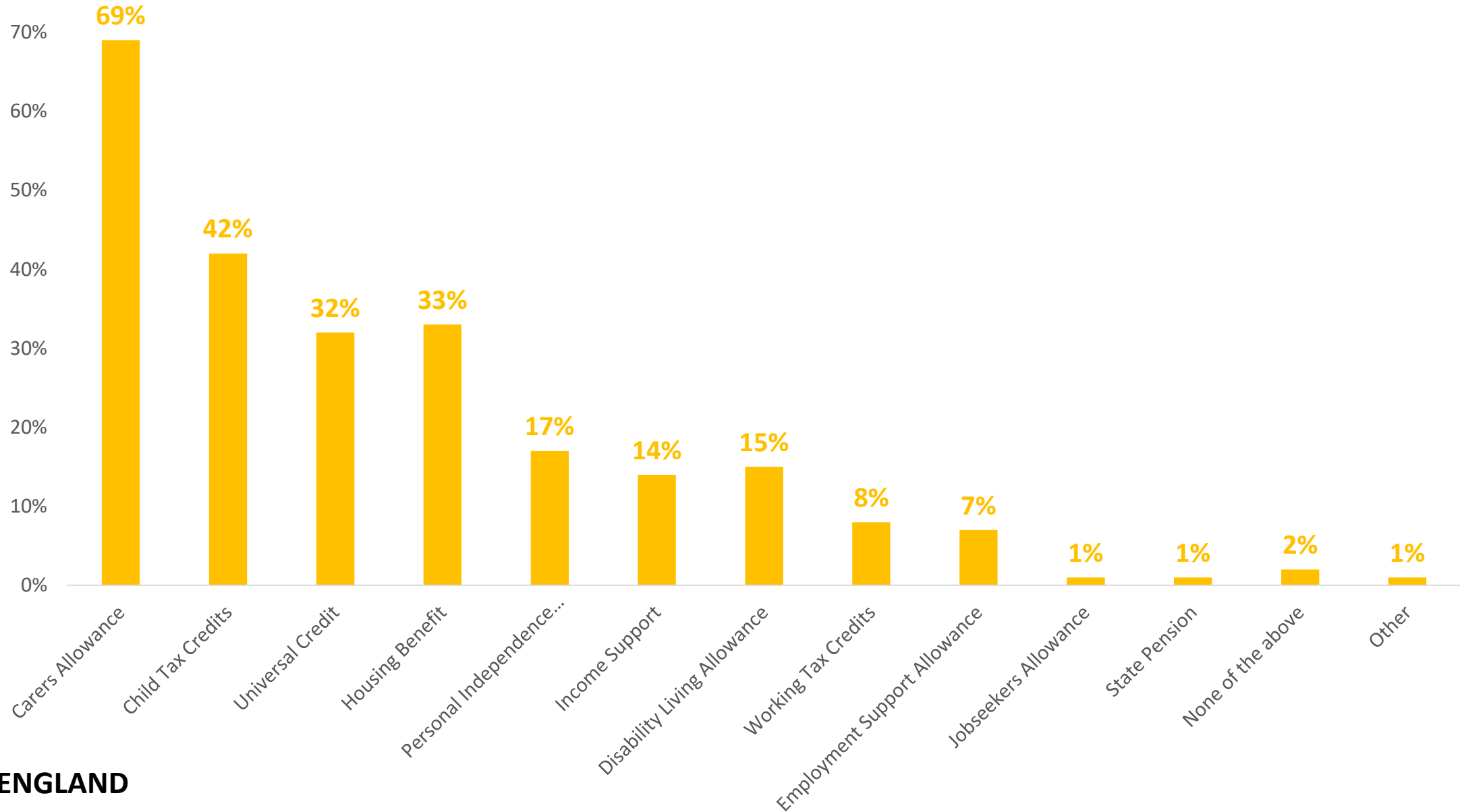
5. Relying on benefits

The vast majority of families have to rely on state benefits for at least some of their income.



Benefits families receive

Which benefits do one, or more, adults in your household currently receive? (n=778)



ENGLAND



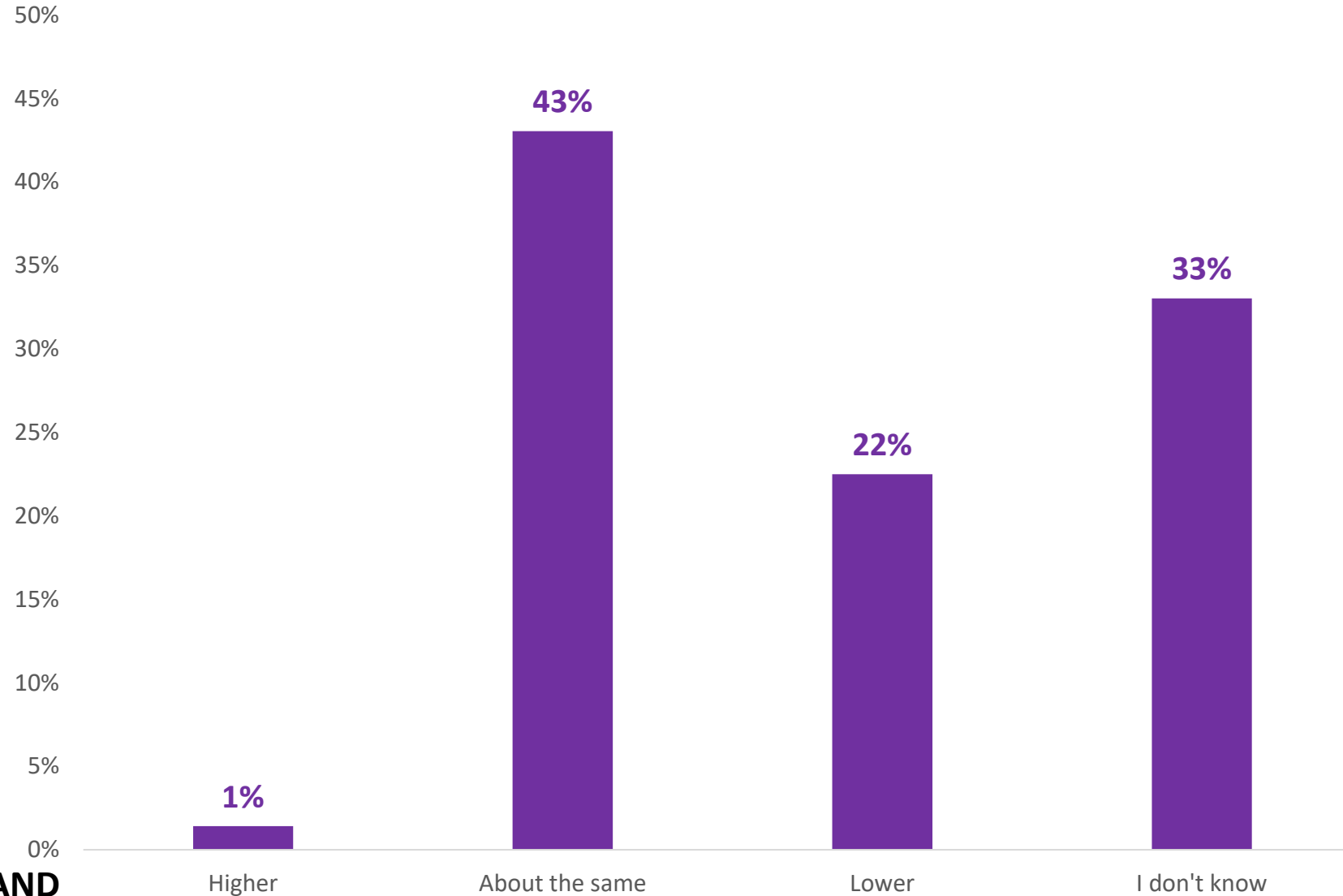
6. Savings

Families are in a financially precarious position with many having very limited access to savings and relatively small unforeseen costs being enough to cause significant financial distress



Family savings

“Thinking about your current household savings and investments, would you say they are higher, lower, or about the same as your household savings and investments 12 months ago?” (n=778)



ENGLAND

79%

families report that they have **no savings** or investments



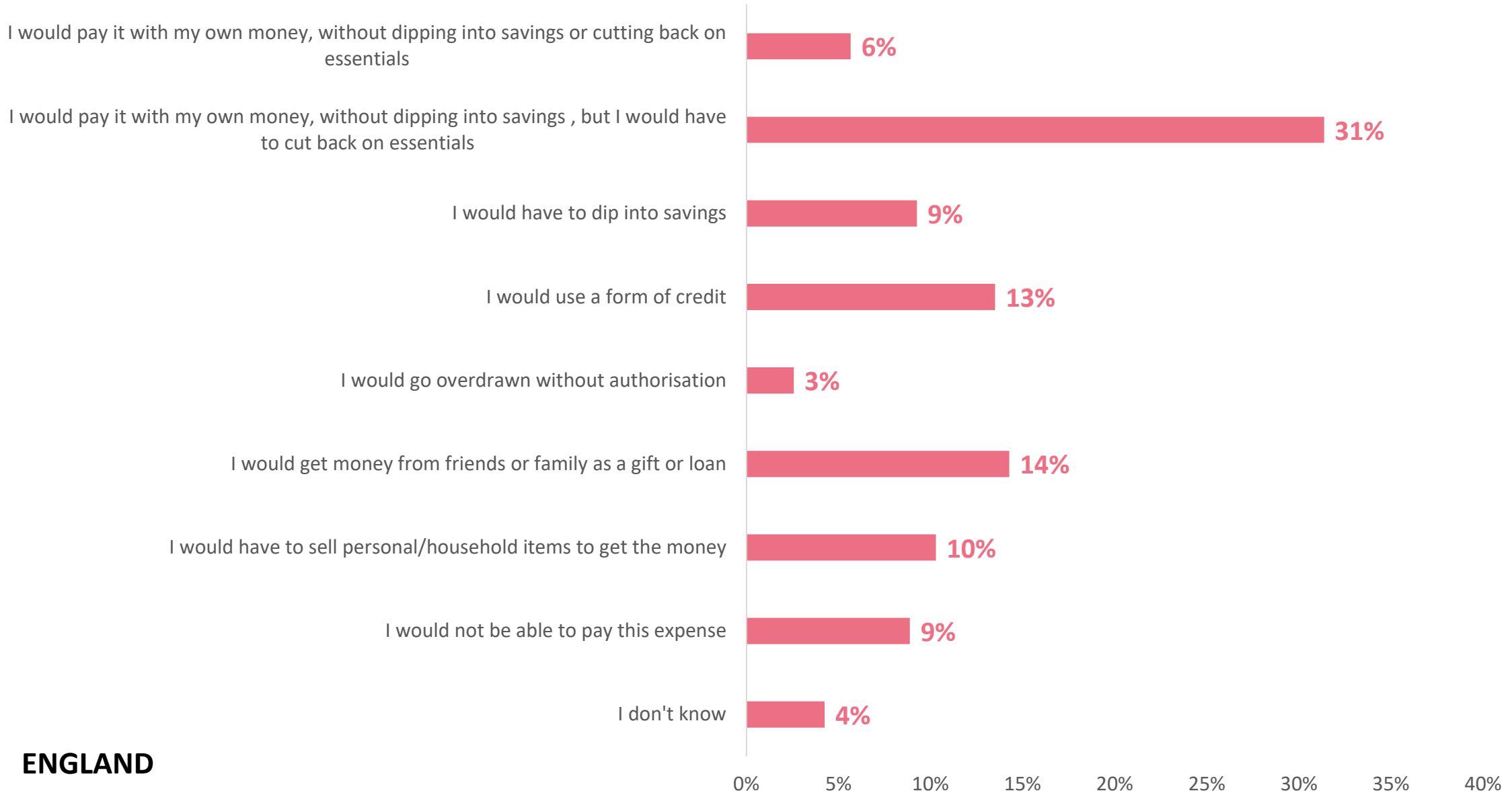
7. Going into debt

Where families cannot make any further cut backs, they are often forced to go into debt to pay for essential items and bills.



Trying to financially cope

“Would your household be able to pay an unexpected expense of £200?” (n=778)

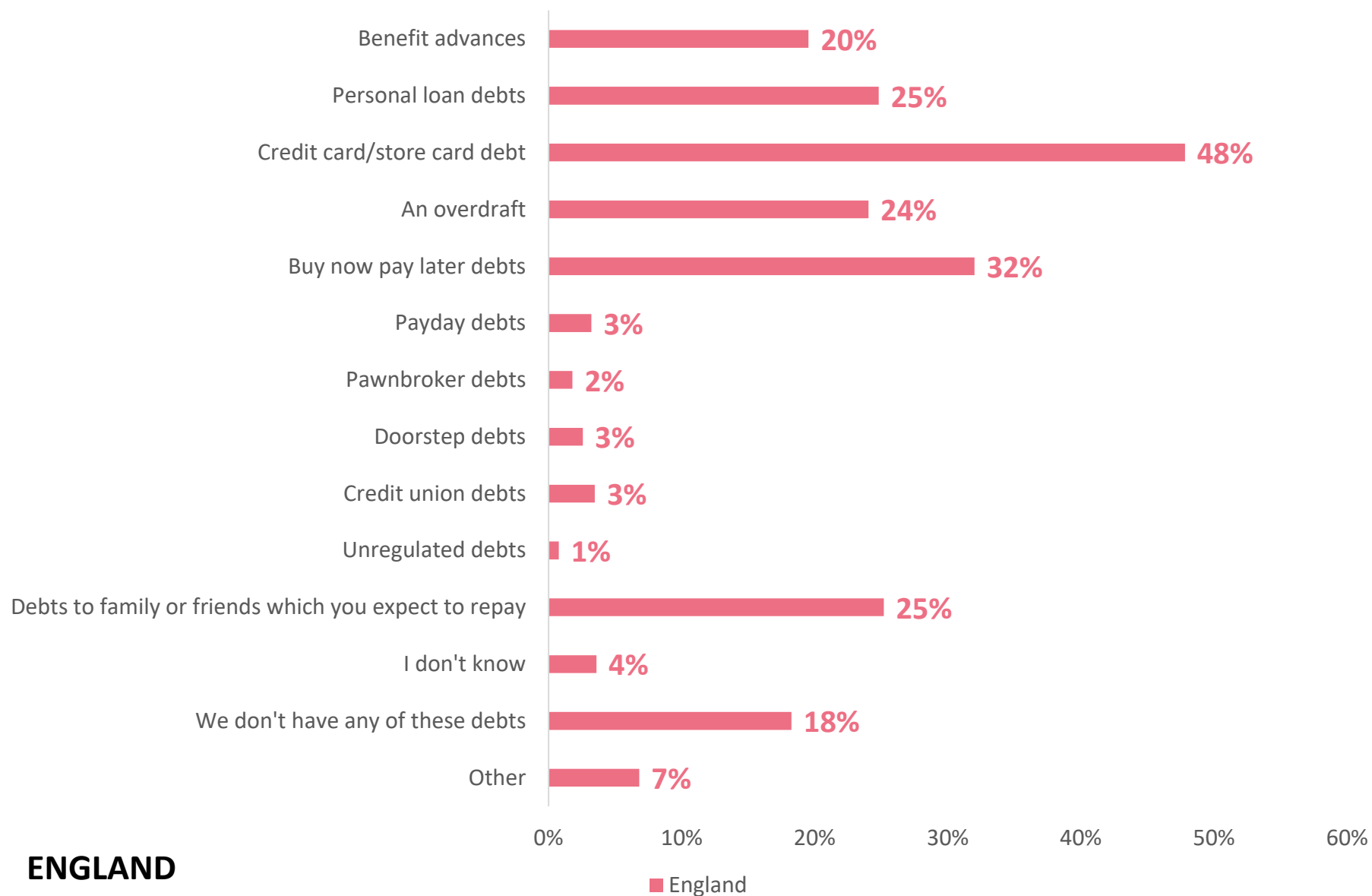


ENGLAND



Going into debt

“Do you have any of these debts?” (n=778)



86%

families report that **keeping up with the repayment** of their debts is a difficulty or burden.

45%

families report that it's fairly or very likely they will need to borrow more money or **go further into debt in the next six months**

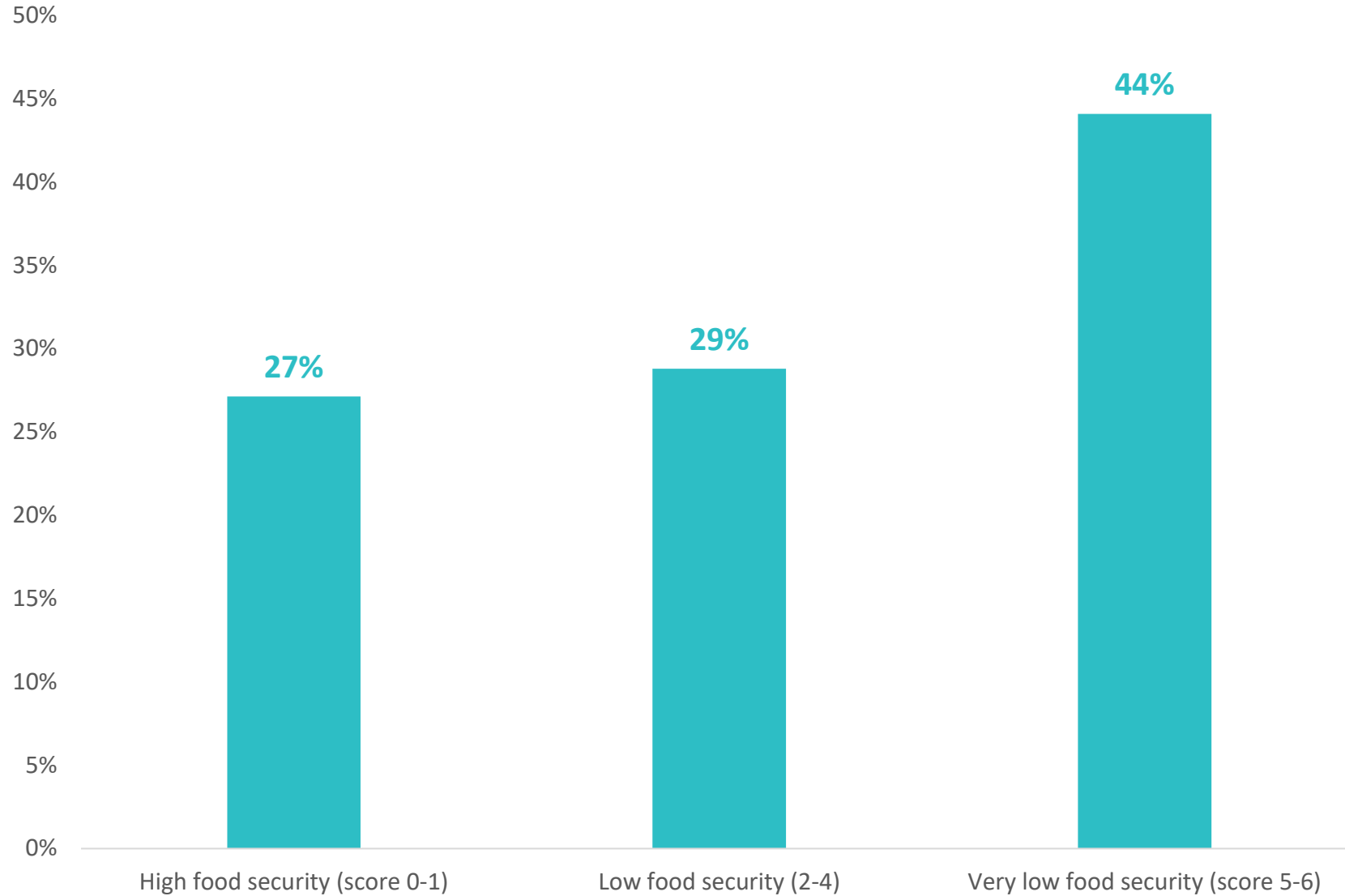


8. Going Without

As a result of the challenges families face working and the extra costs in bringing up a disabled child, families often find themselves having to go without necessities



U.S. Household Food Security Survey Module: Six-Item Short Form Food Security Scale (n= 766)



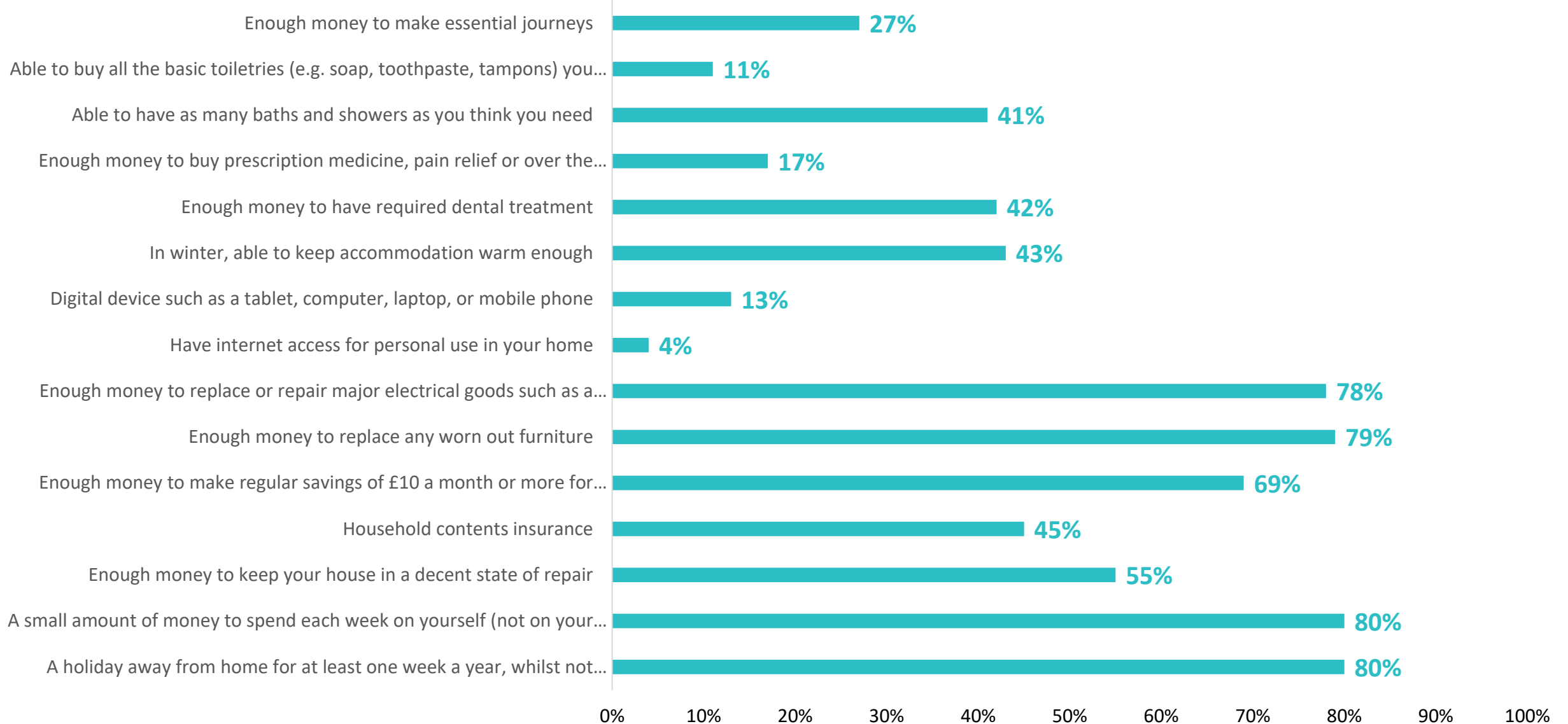
30%

families report that they have had to use a food bank in the last 12 months because there wasn't enough money for food



Going Without – Parent/Carer

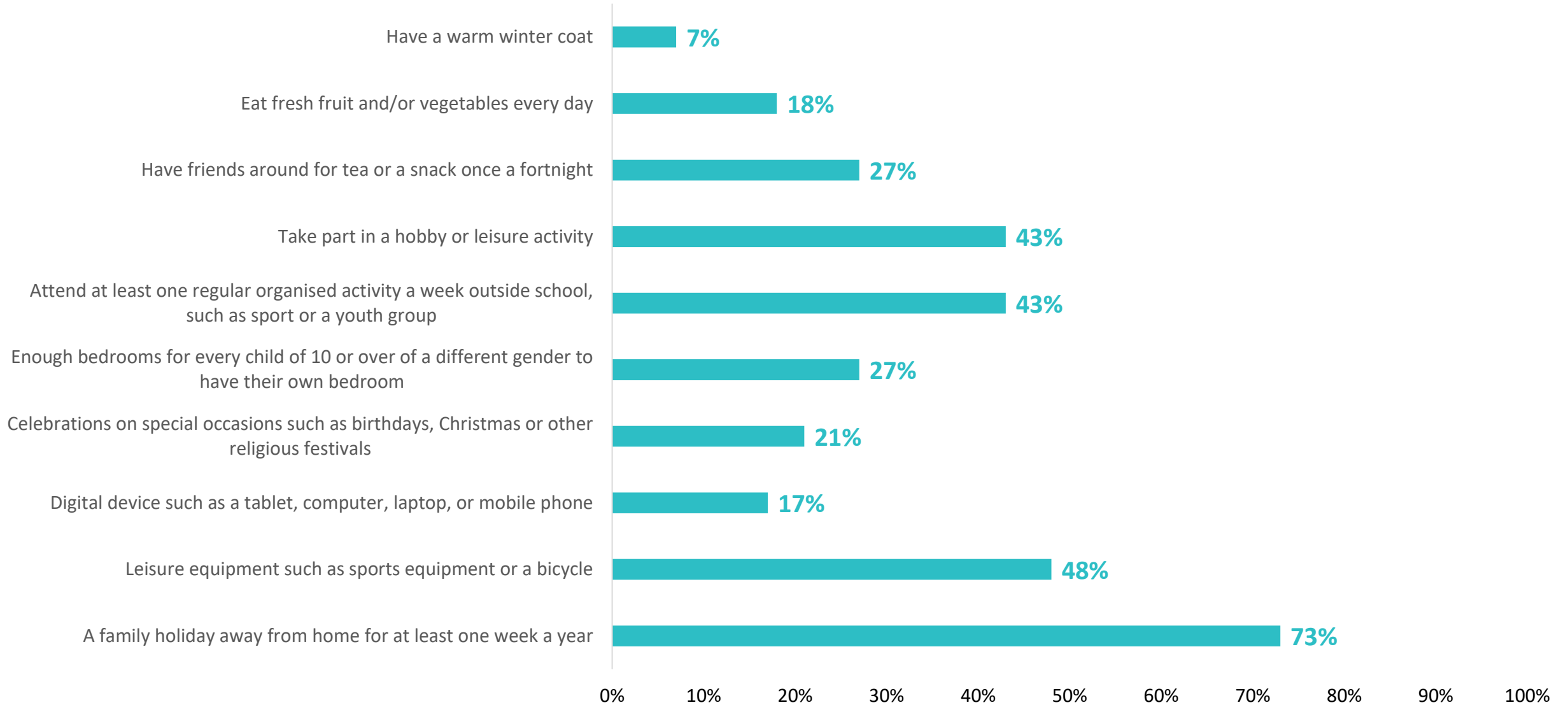
“We can’t afford this” (n=778)



ENGLAND

Going Without – Disabled Children and Young People

“We can’t afford this” (n=778)



ENGLAND

9. Disabled children

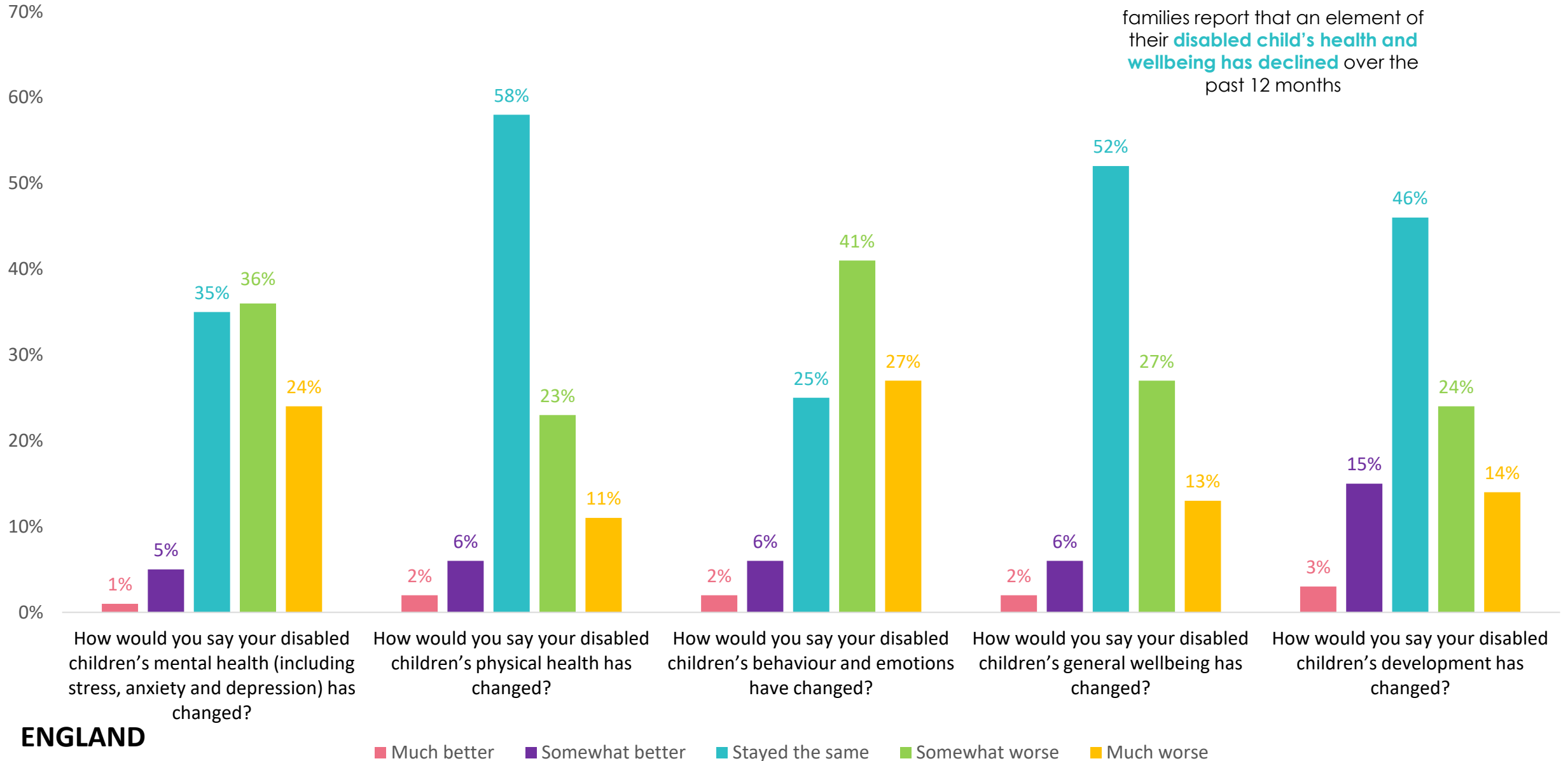
The situation families find themselves in has a negative impact on the health, wellbeing and quality of life of disabled children.



78%



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



ENGLAND

■ Much better ■ Somewhat better ■ Stayed the same ■ Somewhat worse ■ Much worse

Disabled children's wellbeing

"There is a lack of mental support for children when dealing with trauma. It was very shocking that there's nothing available for a child who's been in a road traffic accident but there is support for an adult"

"Mental health help for children is non-existent, especially for disabled children"

"How tiring meltdowns become when they are constant, and consistent. How our lives changed as a family after having covid, which really affected us, and disrupted my son's mental health."

"My son is not able to get the support he needs when I'm crying out for it"



10. Non-Disabled children

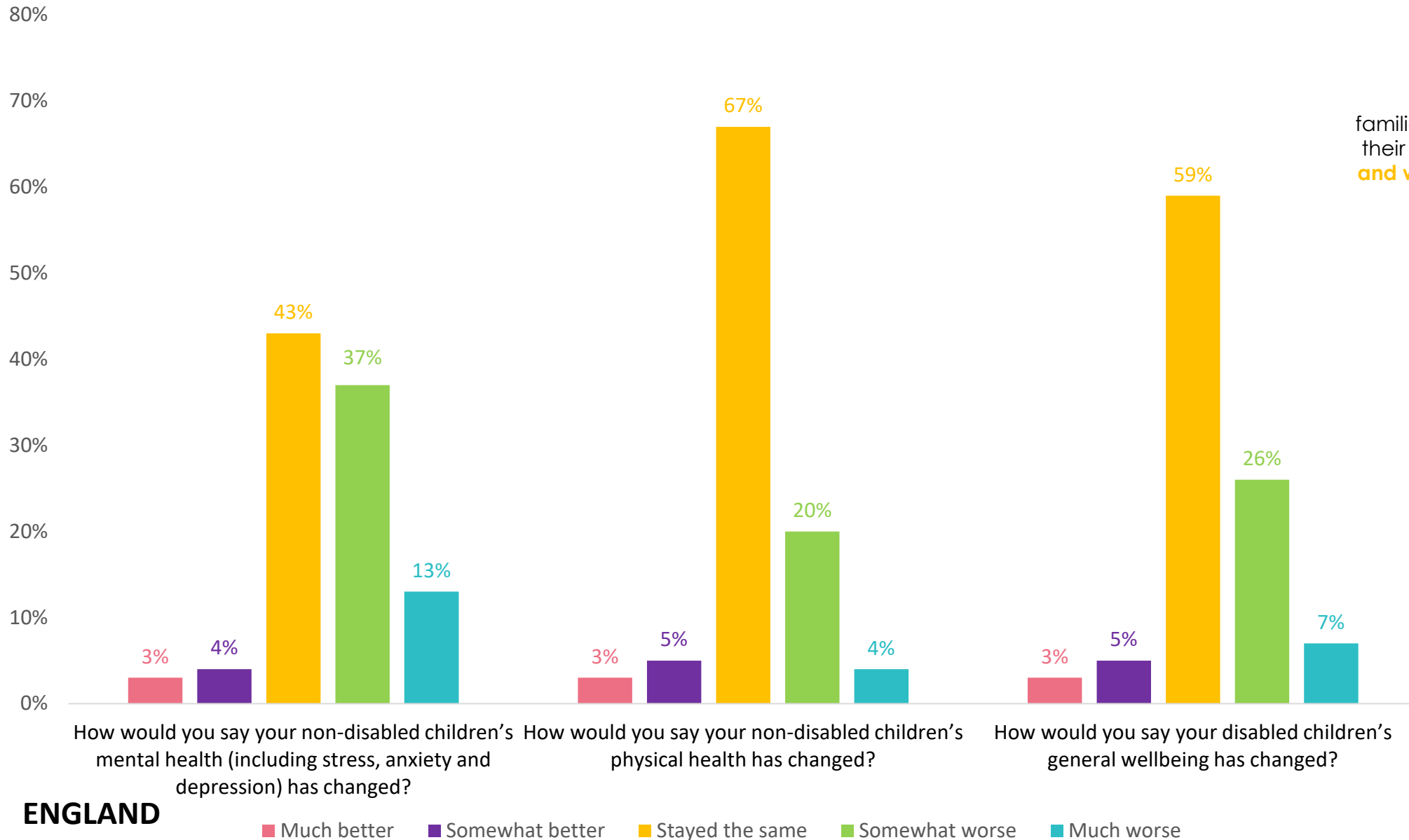
ENGLAND

The health and wellbeing of many non-disabled children has also been negatively affected.



Impact on non-disabled children

“Over the past 12 months...” (n=477)



53%

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

ENGLAND



11. Parents and carers

The health and wellbeing of many carers has also been negatively affected.



Impact on parents and carers

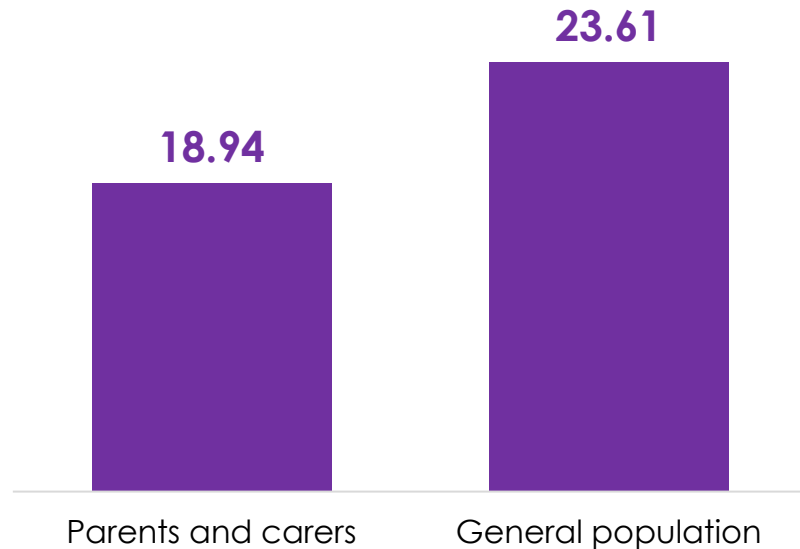
Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale) (n=778)

High wellbeing 35

66%

Low wellbeing (adjusted score of less than 19.5)

Low wellbeing 7



ENGLAND

6.76

Mean UCLA Loneliness Score

27%

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

44%

Probable depression (adjusted score of less than 18)



Parent's experiences of the impact of caring

"It's been very hard physically and mentally to keep doing what I'm doing for my children but I keep going because they mean everything to me."

"It's very hard when your the only one and having to do everything including school runs to two different schools everyday twice a day and keep on top of daily cleaning etc in the home"

"It's the hardest thing I have ever had to do all on my own and still on my own because I'm not getting the help my children need just hope in the future other people get the help they need"

"I do my best that's all I can do. Cost of living, covid etc the last couple of years had been very difficult and intensified the isolation"



Parent's experiences of the impact of caring

"A parent will go all the way for their child but is never thought about and thanked. It's hard on your mental health wellbeing"

"Lots of things are tough and difficult when someone has had special need child. More support for parents for their well-being and mental health."

"My children are amazing and I feel honoured to be their mum, but life gets hard and lonely and sometimes the future is scary."

"It can be very isolating as no one understand fully how stressful and isolating being a carer really is"



Parent's experiences of the impact of caring

"It can be very lonely and people need to be more open to disabilities. More schools need to share understanding of why some children behave the way they do"

"Family and friends find it hard to understand unless you've had a disabled child then I don't think you can fully understand how bad it can get. I just want people to try understand instead of just not inviting us or avoiding us because of my child. Having a disabled child isn't the end of the world even though some days it really does feel like it."

"People's opinions of neuro divergent children need to change drastically. To be accepted and understood"

"I have learnt a lot about myself through my son. Learning about patience, not to put myself under unnecessary pressures, to take time out for myself if I can and able to afford it."



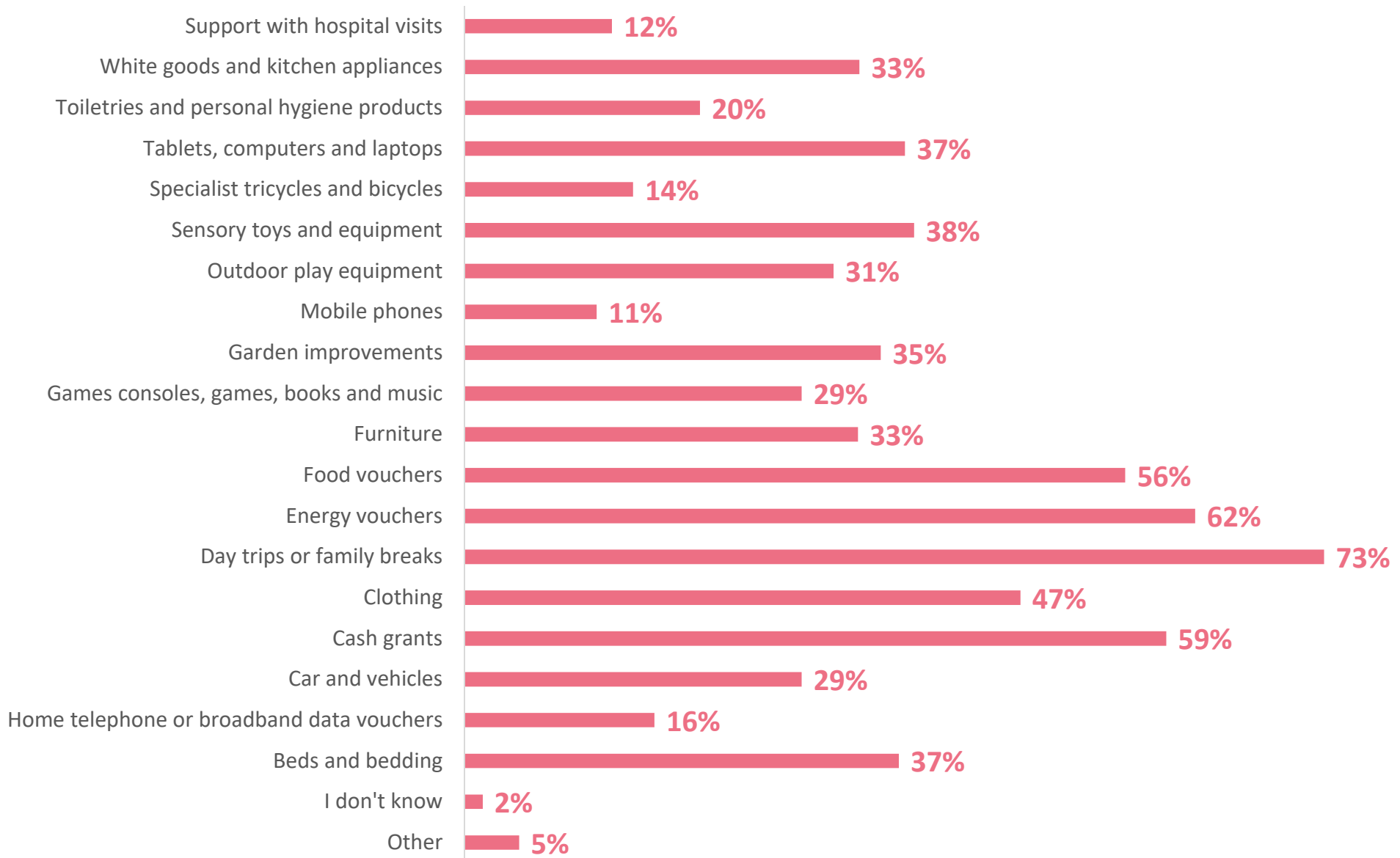
12. Other needs

We are also interested in understanding what other support Family Fund could offer and what other unmet needs families have.



Your needs

“Which grants could we potentially provide that would be most helpful to your family right now?” (n=778)

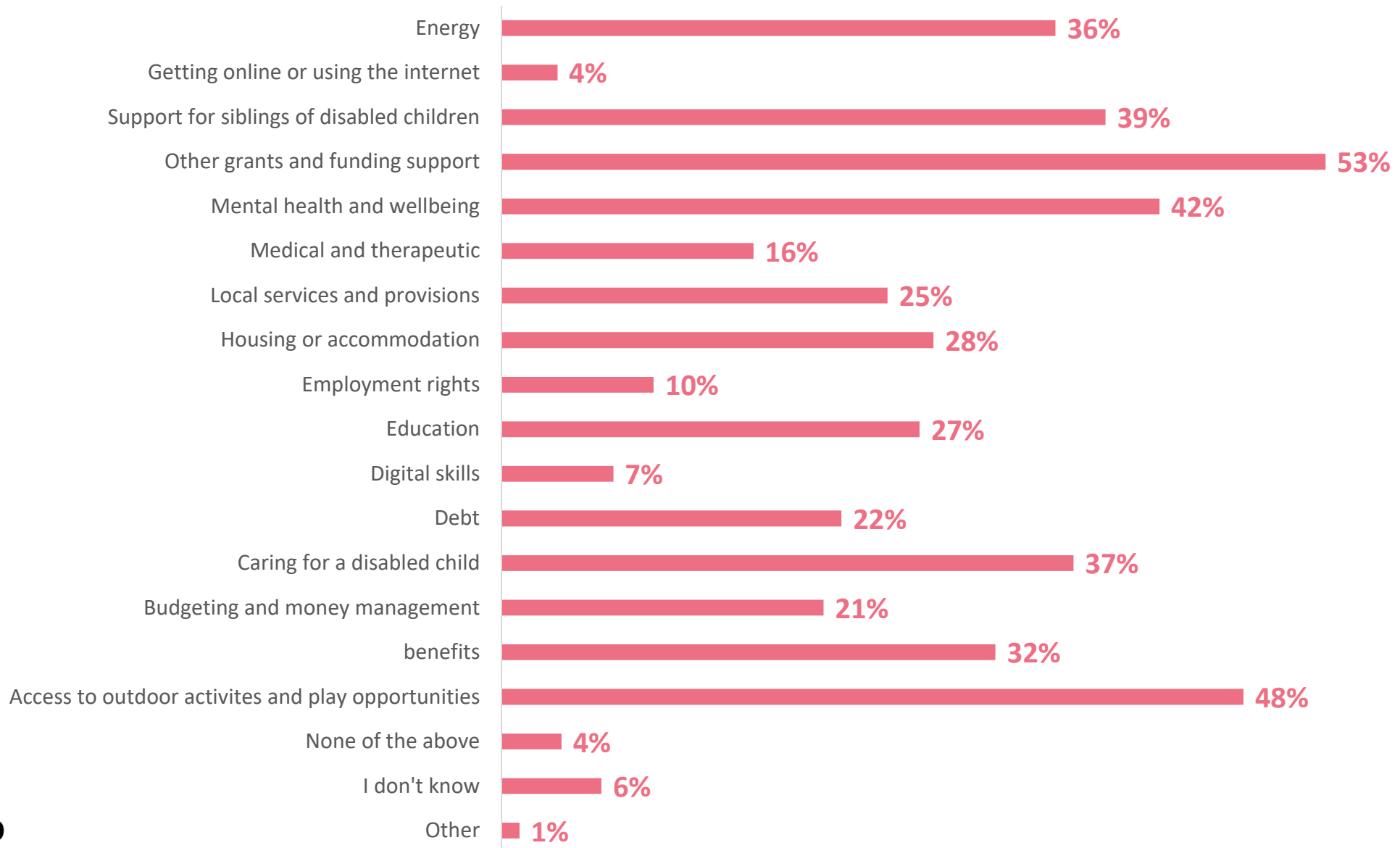


ENGLAND



Your needs

“Which topics could we potentially provide information and support on that would be most helpful to your family right now?” (n=778)



ENGLAND



Other family needs – access to services

“Having one child is very difficult for any family but to have two with very different needs and spending prolong time in hospital really splits up the family and has made it difficult for me and my husband to cope. Having support and help in these circumstances would be very useful especially when I've repeatedly asked for support for the disability Childrens team but was told because there's no safeguarding issue we can't get any help.”

“Access to healthcare such as paediatrics was challenging, a very long wait before being allocated a paediatrician. Child has been eligible for nappies on the NHS for 2 years now and still these are not in place. Second child, GP advised only option was private psychiatrist therefore have been funding this myself whilst waiting for NHS to take over.”

“The past 12 months my children have suffered mentally and physically from having appointments cancelled over and over again. My child is at serious risk of needing serious surgery's due to unfit wheelchair. [And] Knee surgery due to not receiving regular appointments or appointments being cancelled. My autistic children have been let down with the length of waiting lists”



Other family needs - education

I've been fighting for 4 years to get my son a school placement. The fight has just been won.

Just wished the education was much more accessible for our children to succeed and not punished for things they can't control.

My son hasn't be to school properly since covid. The one time he did go he was restrained, held by four teachers for four hours, police called. After that he didn't leave his room for two years he's slowly starting to come out retreating back in again when anxiety is to high. [service] won't help because he developed an unusual burst of confidence for two weeks we quickly got them to go to see him in school where he conducted himself well explained he didn't want medication but that given he's now back in his room not attending school again although he only attended a day two a week at most I don't know what the future holds

I requested a SEN school for my daughter she was then put in mainstream she lasted one day as the nothing in place she traumatised when come home and still does not have a school yet massive let down.



Other family needs – transitions to adulthood

“In my experience with my child, it’s been uphill battle to get him the right support and still no[w] [he’s] just turned 18. We have been left and he’s now classed as an adult. I just wish I had of known about things sooner and help out there and maybe things would’ve been different for him.”

“Not enough for young adults”

“I just wish the government could just support the families more. I have had to give up work to be a main carer for my 10 year old with autism and my 25 year old with autism. The help I need for the 25 year old is very difficult and I’m struggling to find the support.”



SCOTLAND



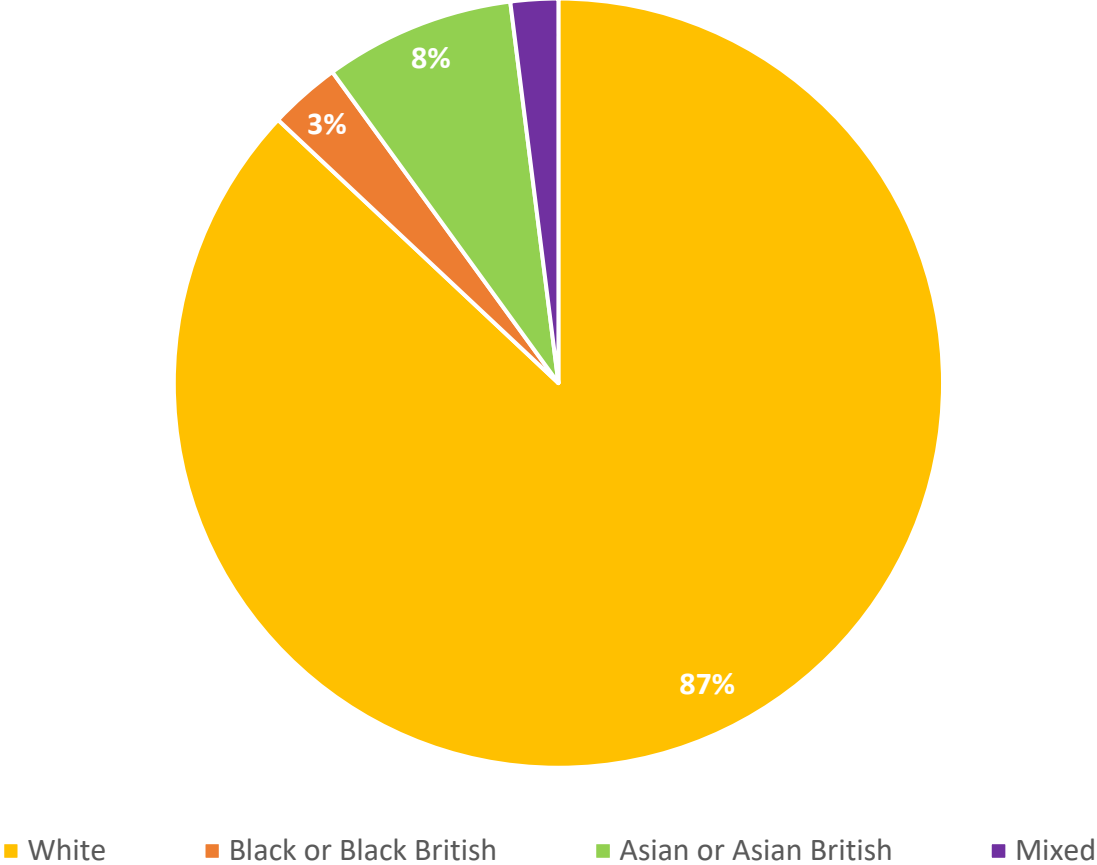
1. Profile of families

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

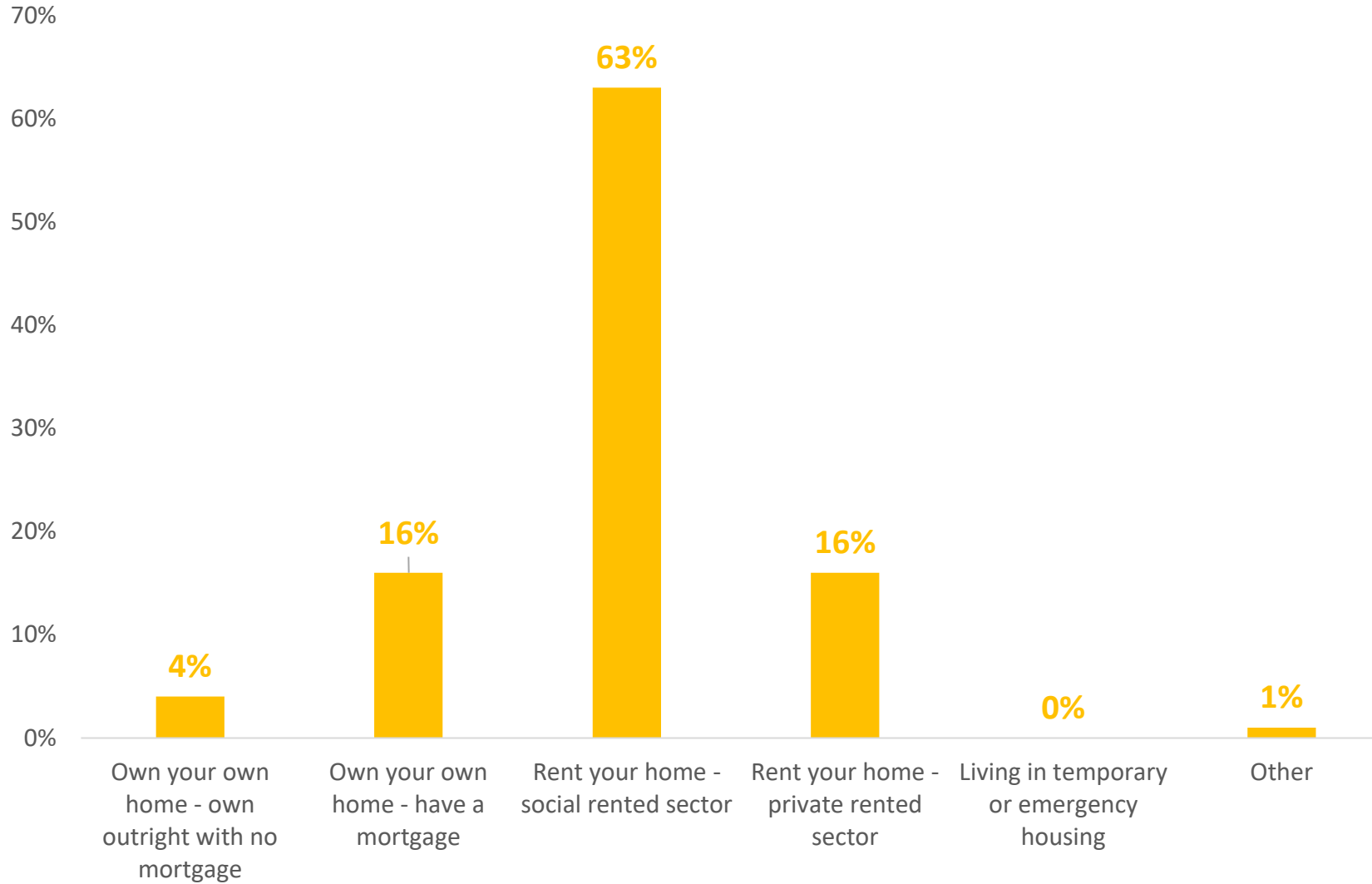


Who are the families who took part in Family Poll?

What is your ethnic group? [grouped]
(n=111)



Who are the families who took part in Family Poll? (N=110)



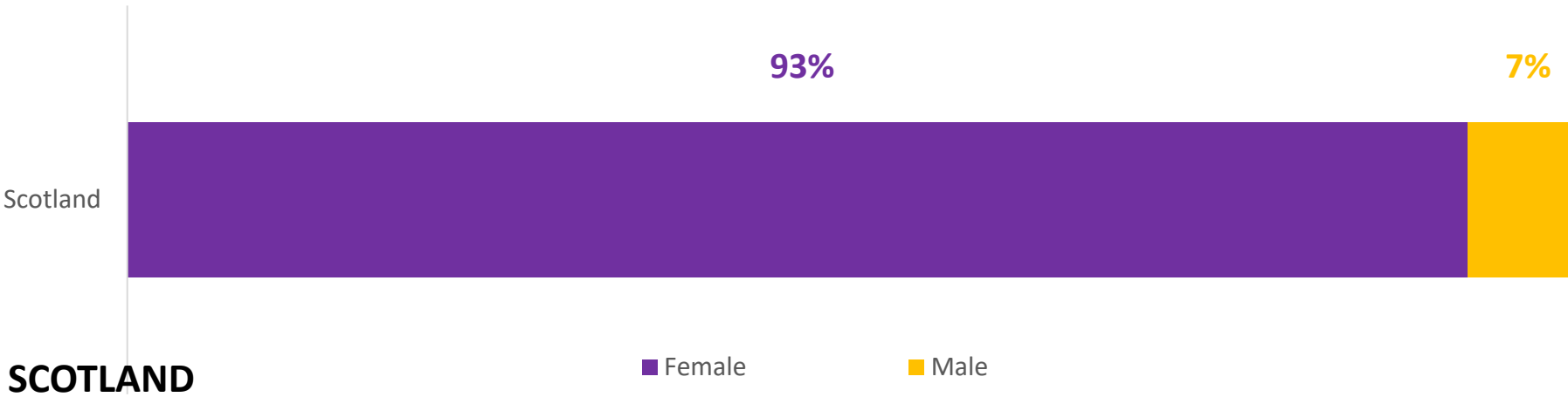
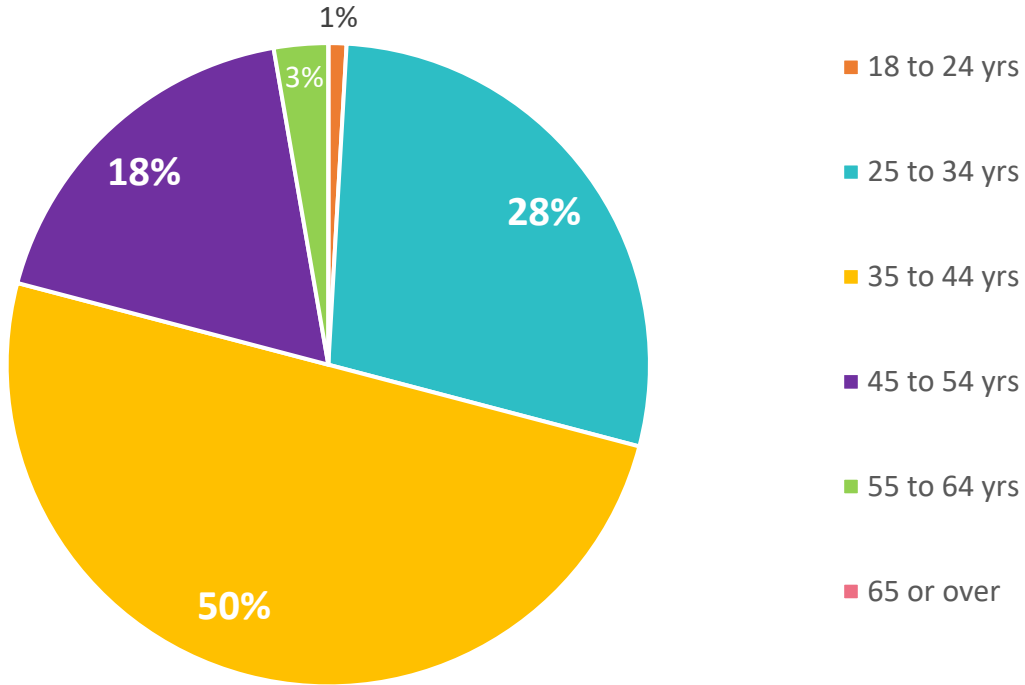
110
Responses from families

41 %
Of families that responded were **single adult households**

SCOTLAND



Parents and Carers (N=110)



65%

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

54%

Of respondents **have a long-term physical or mental health conditions or illness**

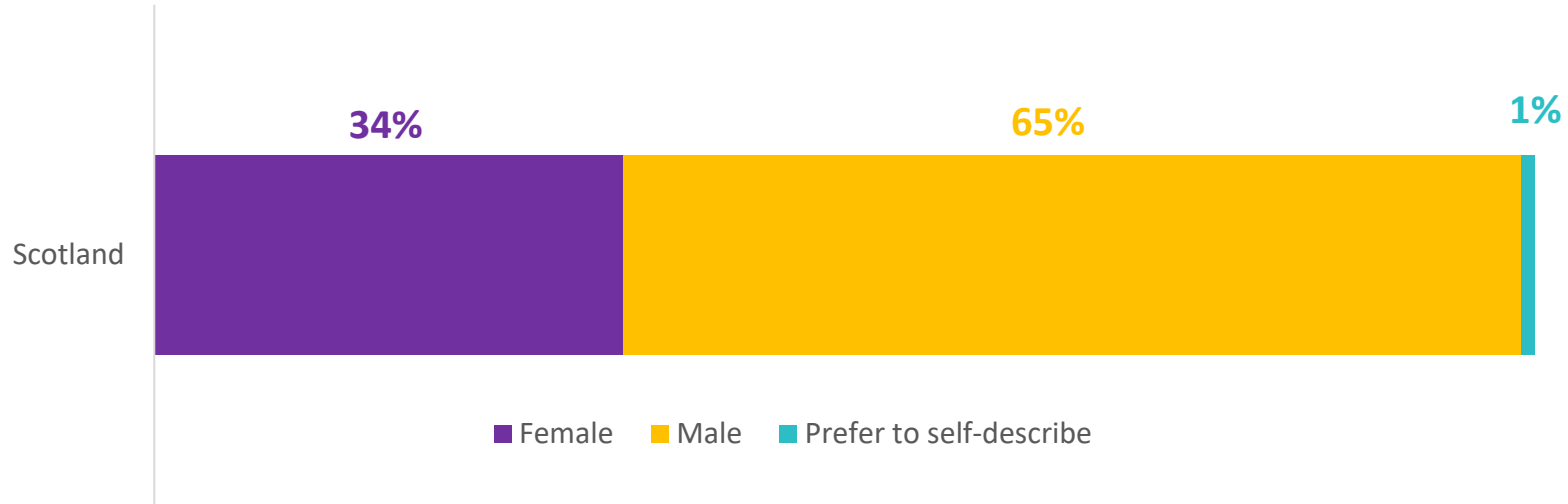
43%

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

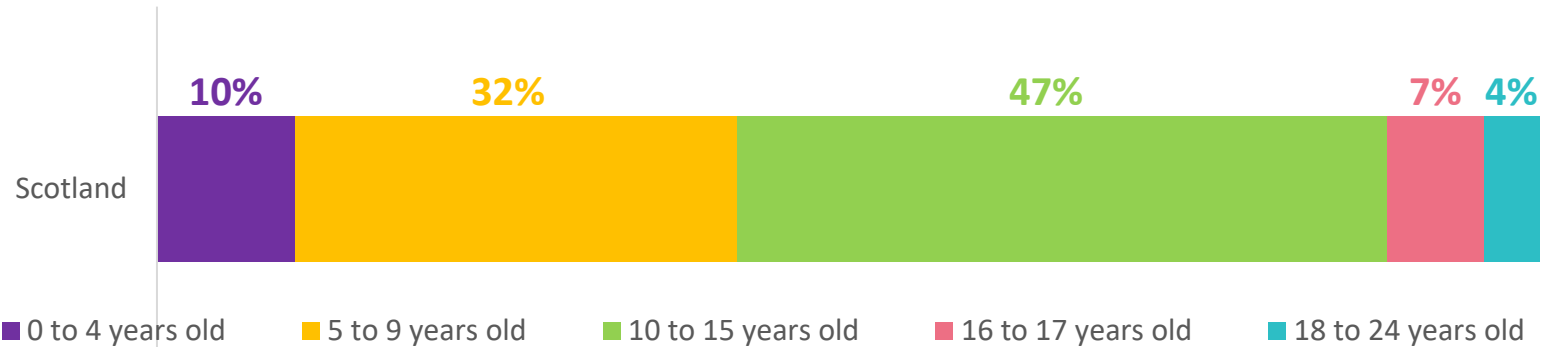
SCOTLAND



Disabled Children and Young People (N=110)



160+
Children with disabilities or serious illnesses



200+
Children without disabilities or serious illnesses

SCOTLAND



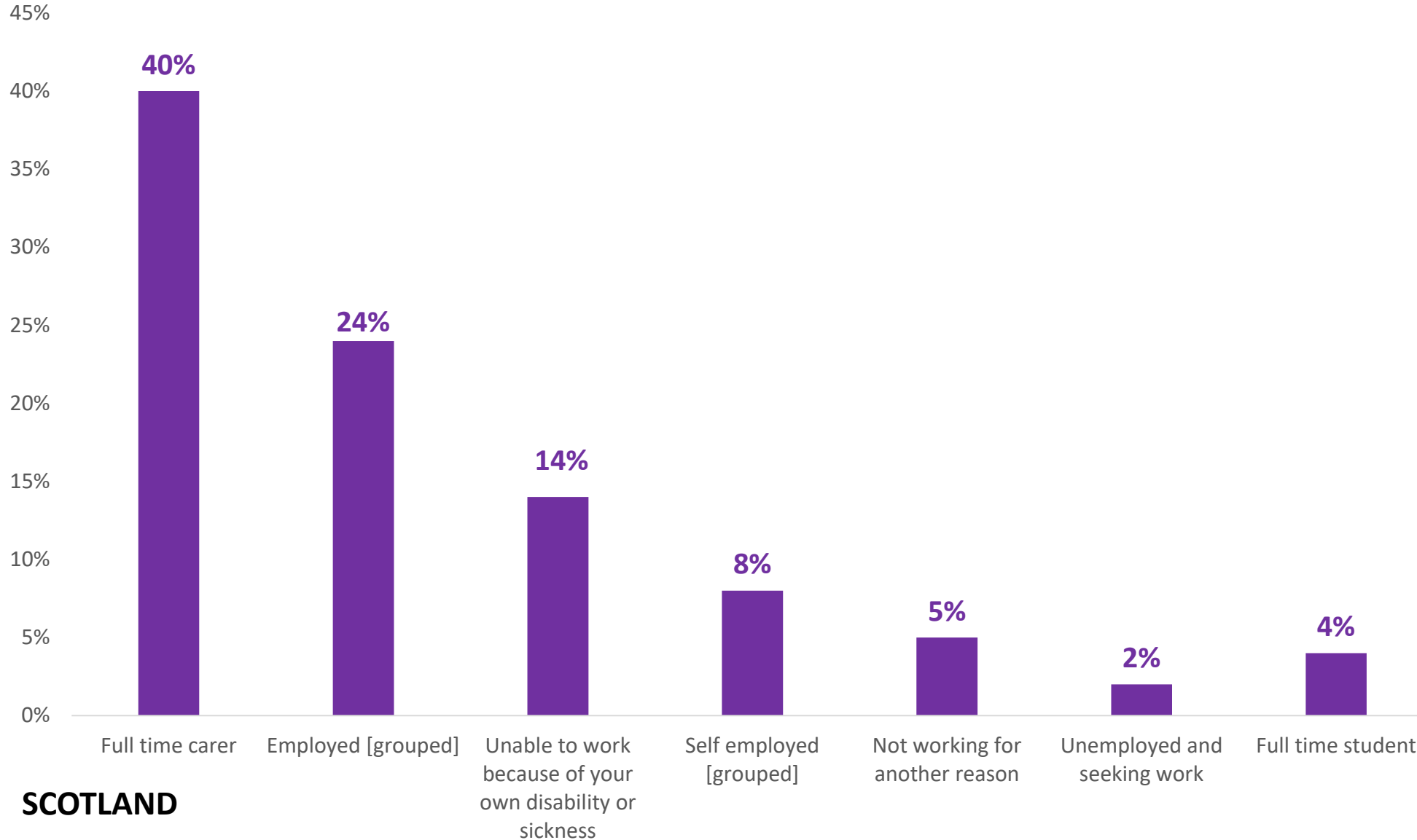
2. Reduced incomes

For many families raising disabled children, parents and carers' ability to earn an income is significantly limited by their commitment to caring for their child.



Working and caring

“Are you employed?” (n=111)



SCOTLAND

£18,344

The mean **annual household income** reported by families (n=96)

£1529

The mean **monthly household income** reported by families (n=96)

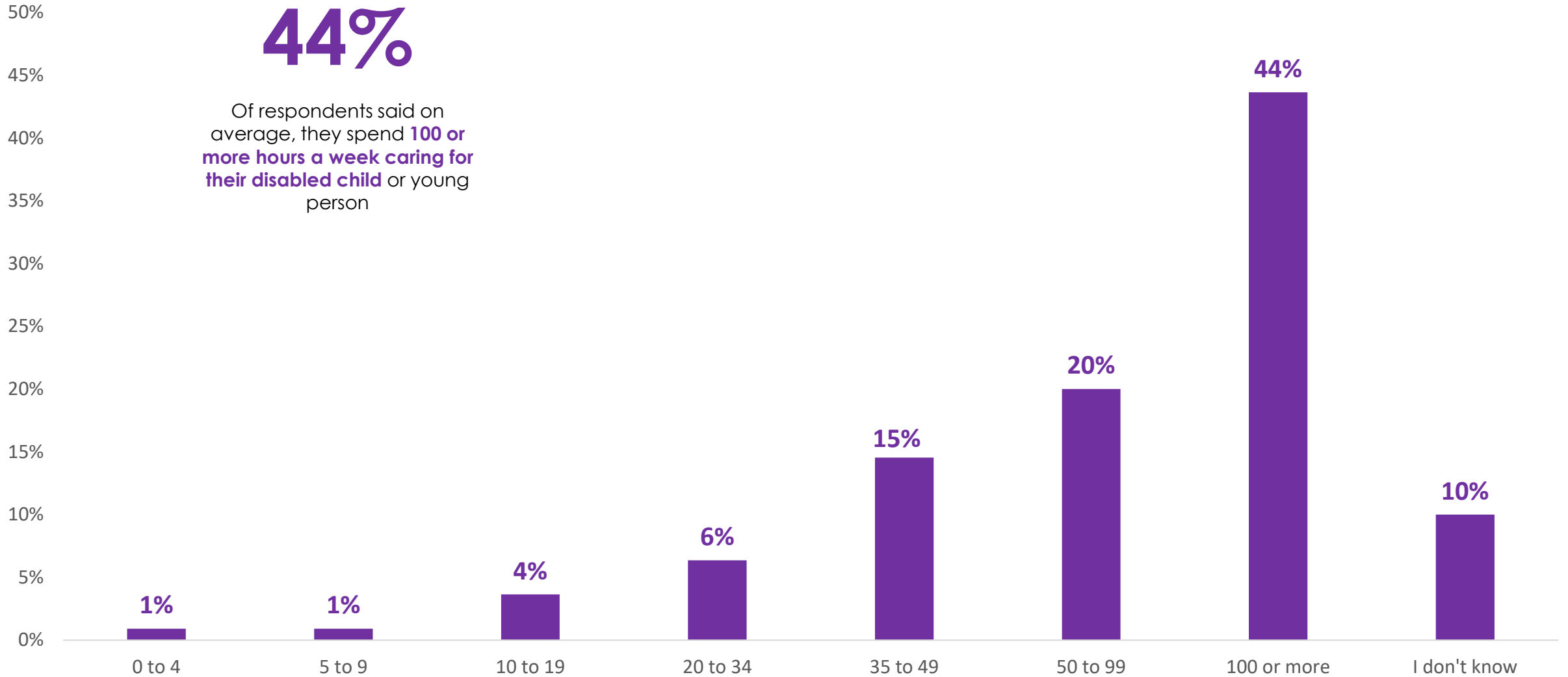


“About how many hours a week, on average, do you spend providing help for or looking after your disabled child or young person?” (n=111)



44%

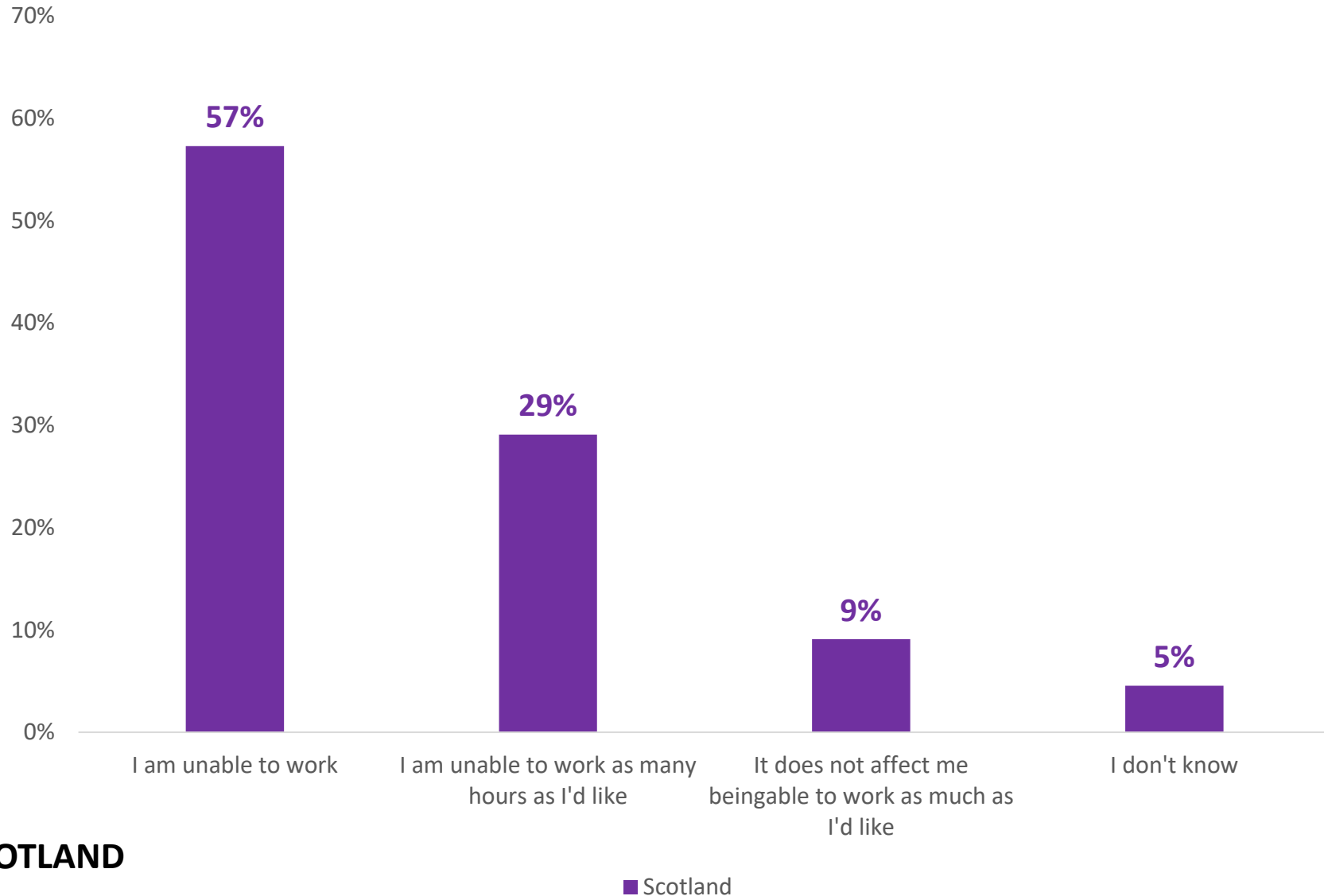
Of respondents said on average, they spend **100 or more hours a week caring for their disabled child** or young person



SCOTLAND

Caring

“Do your caring responsibilities for your disabled child or young person mean you cannot work as much as you would like?” (n=111)



44%

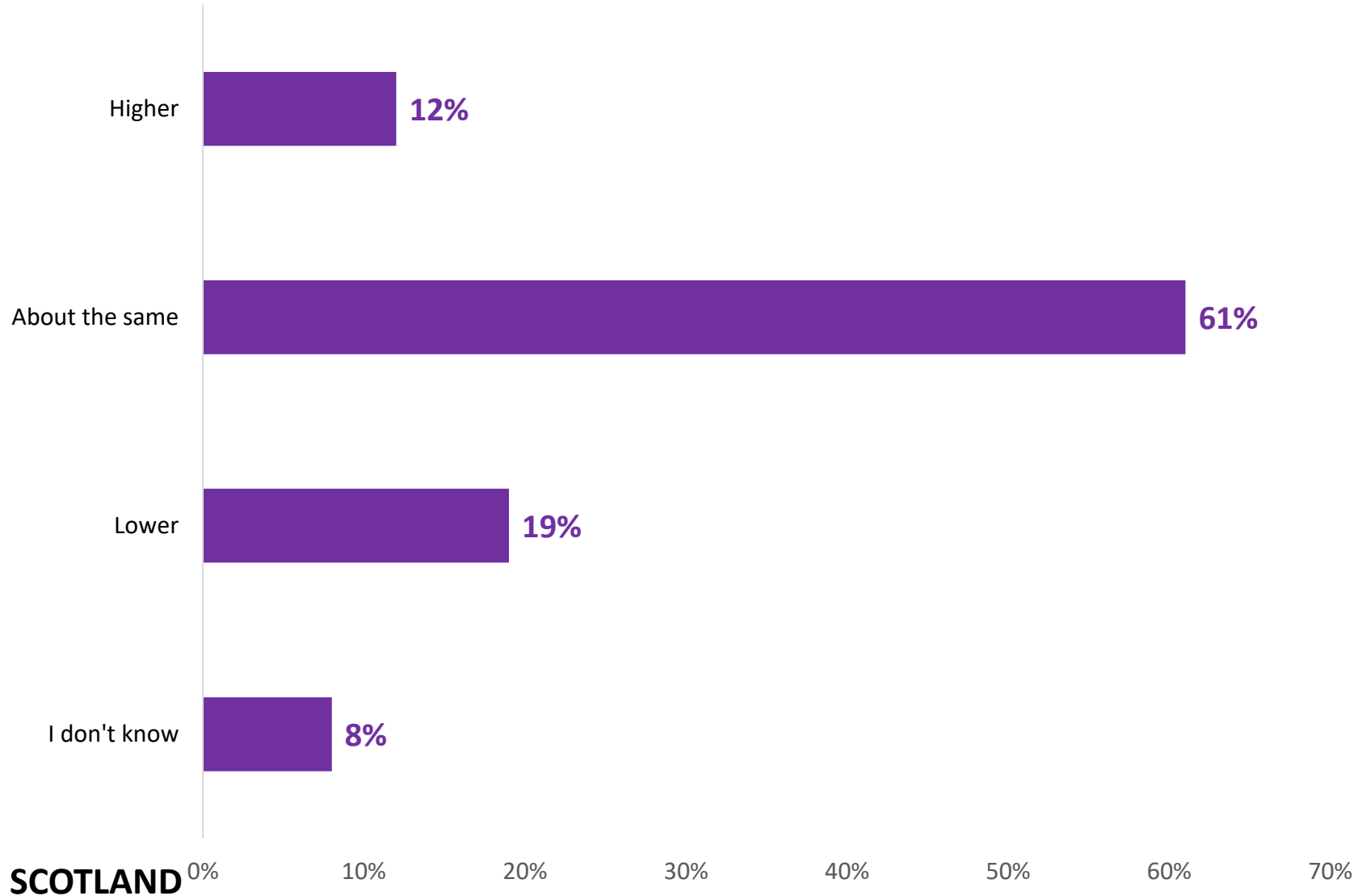
Of respondents said on average, they spend **100 or more hours a week caring for their disabled child** or young person

SCOTLAND



Income

“Thinking about your current regular household income, would you say it is higher, lower, or about the same as the income you had 12 months ago?” (n=110)



37%

Of respondents in **Scotland** who had a lower income this year said their household income is lower because their **benefits had been reduced** (n=19)

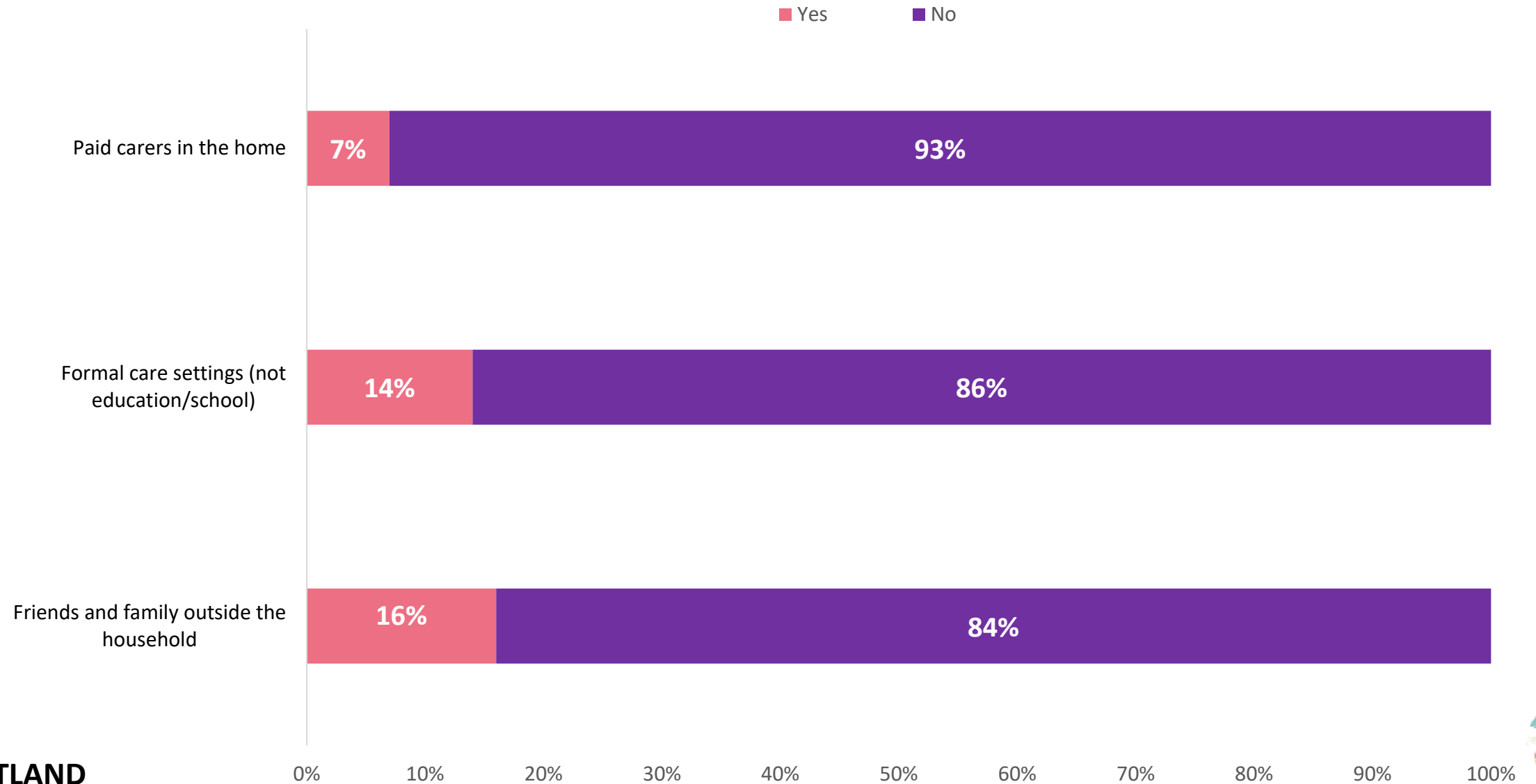
3. Access to other care

Even when families would like their child to be cared for by someone outside the household this isn't always available. This further limits their ability to earn additional income.



Access to care outside the household

“Are your disabled children cared for by the following?” (n=110)

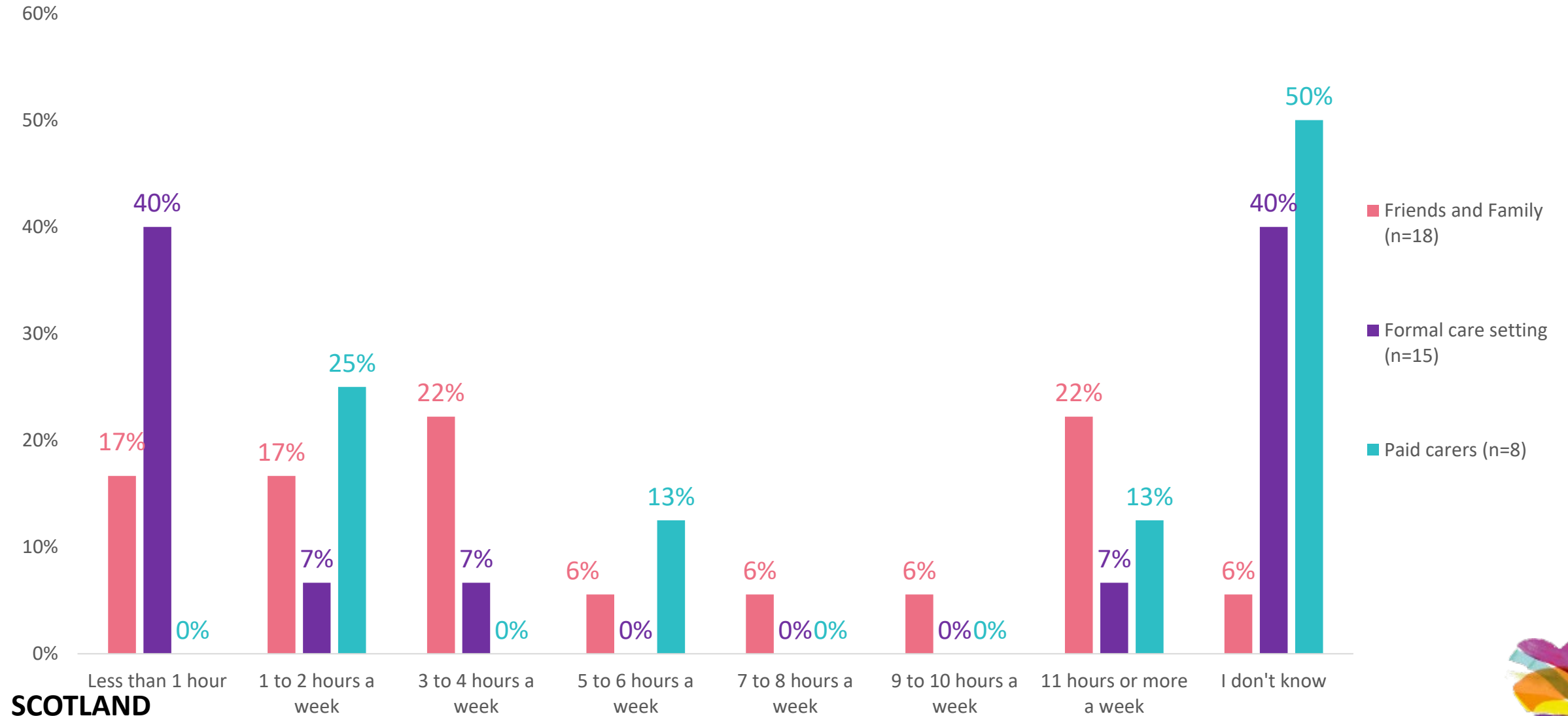


SCOTLAND



Access to care outside the household

“On average, how many hours a week are your children cared for by the following?”

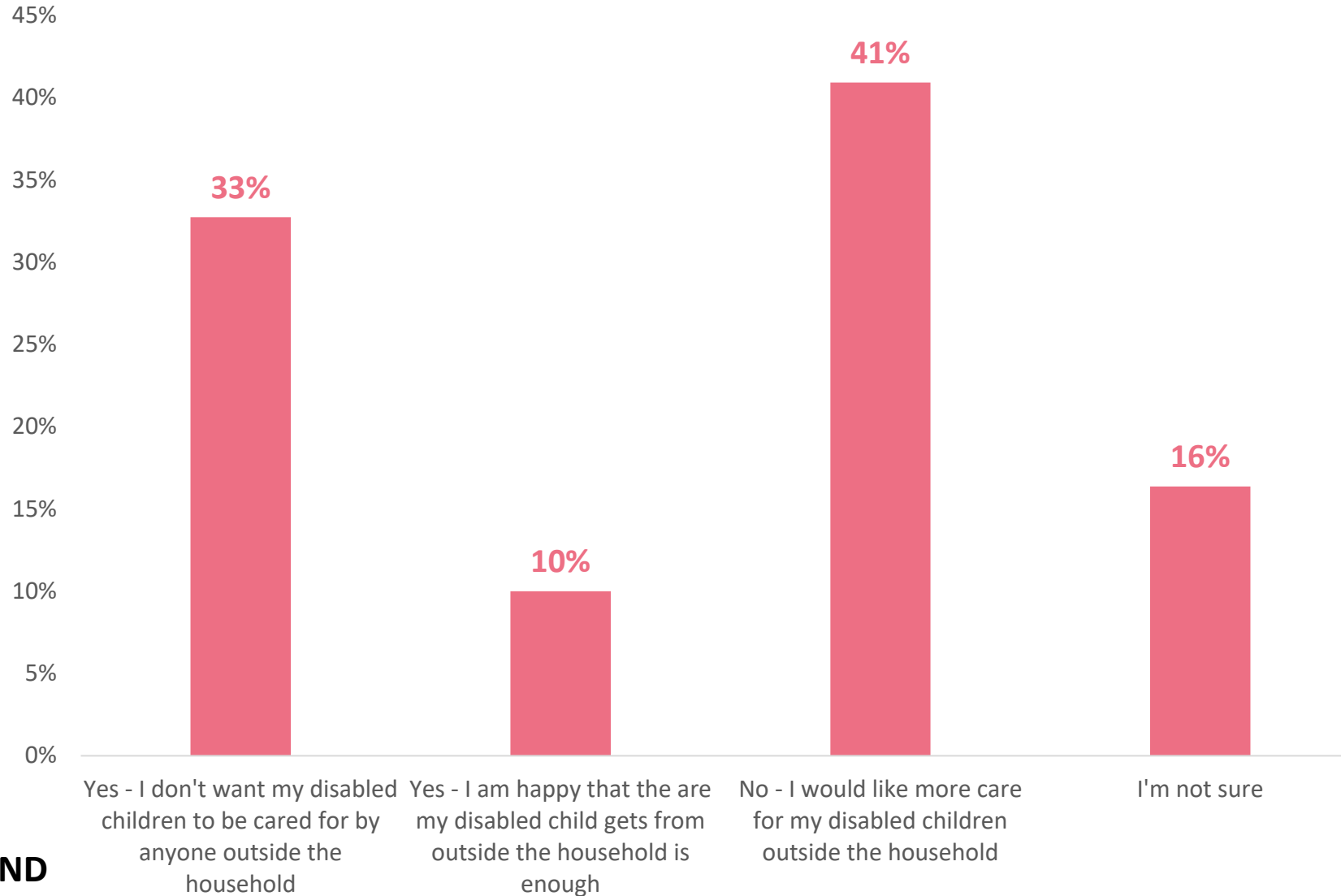


SCOTLAND



Unmet need for care

“Do you have access to as much care (outside of school/education settings) from people outside the household as you would like for your disabled child?” (n=110)

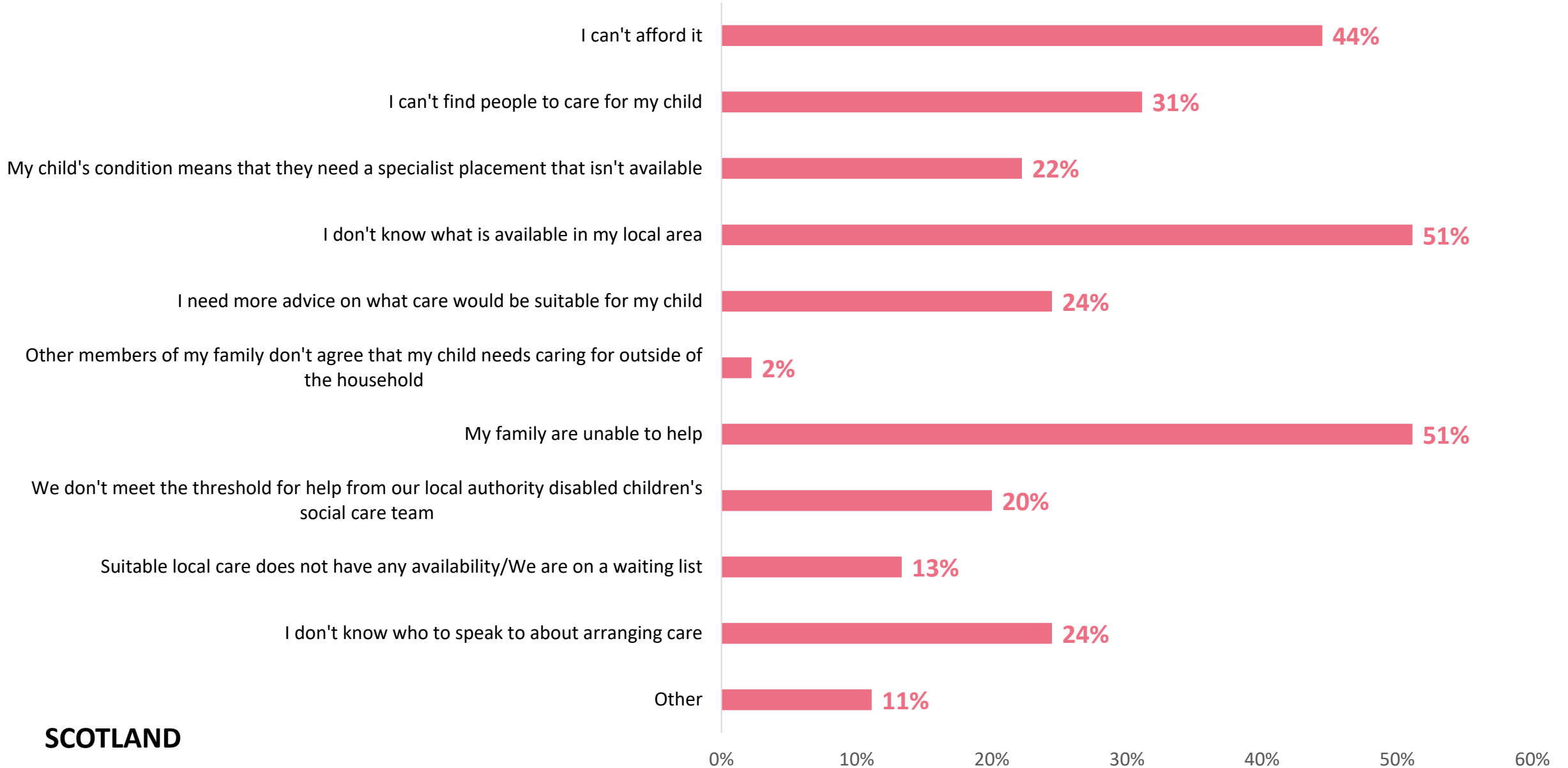


SCOTLAND



Unmet need for care

Why are you unable to access as much care from outside the household for your disabled child as you would like? (n=45)



SCOTLAND

Family's experiences of care outside the household

"I never know who to call and ask. It's getting passed around talking to someone to the next person. I don't have time to sit on the phone explaining it all"

"To be more help and support not throwing money at people actually helping them in the right direction they want help to go in"



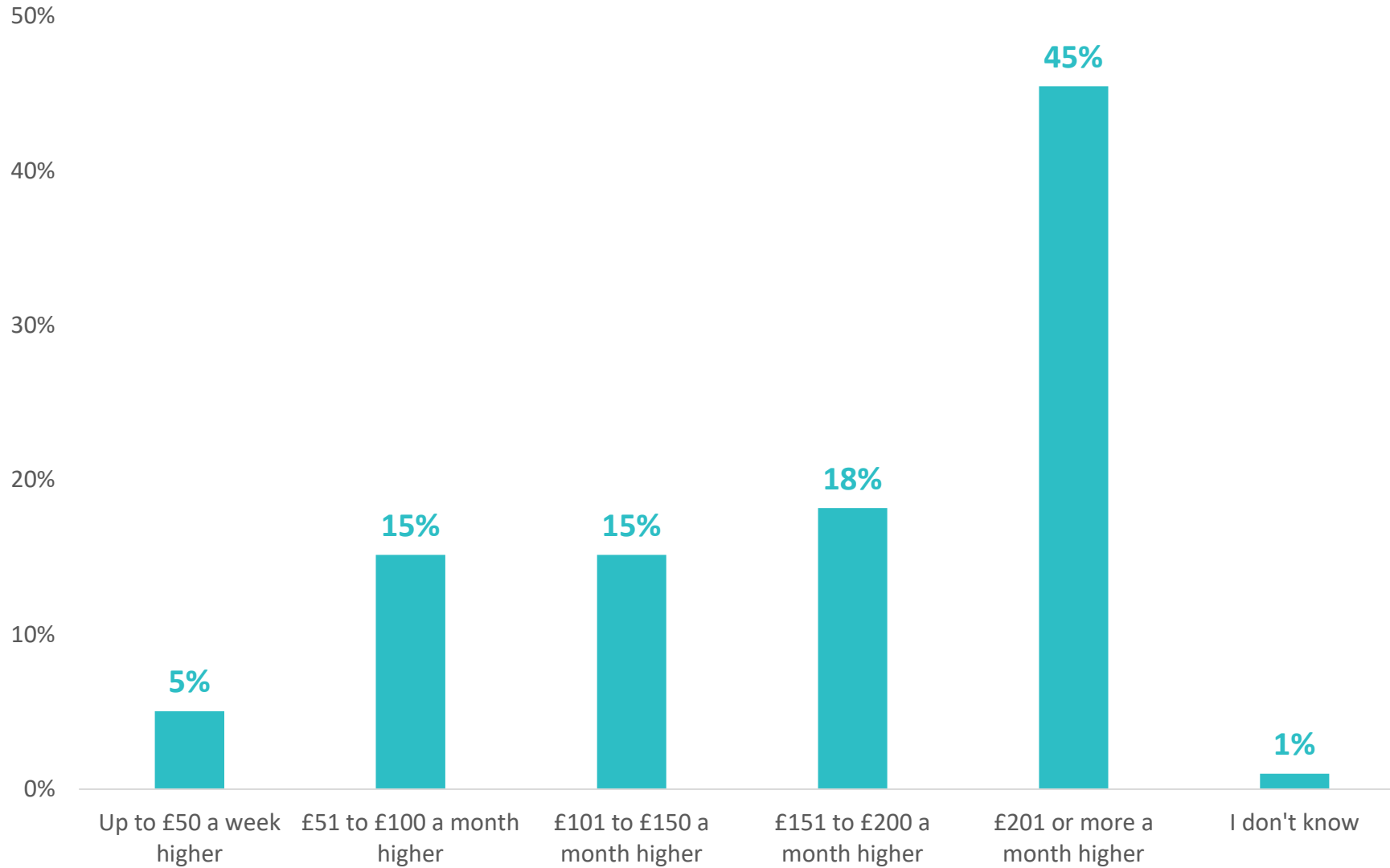
4. Increased and additional costs

Families raising disabled children face higher costs as a result of their children's disability which make them even more sensitive to the increasing cost of living. These increased costs include both additional items and increased cost of everyday items



Household Bills

“ Thinking about how much higher your current regular household bills are compared to 12 months ago, which of the following describes the change?”(n=99)



90%

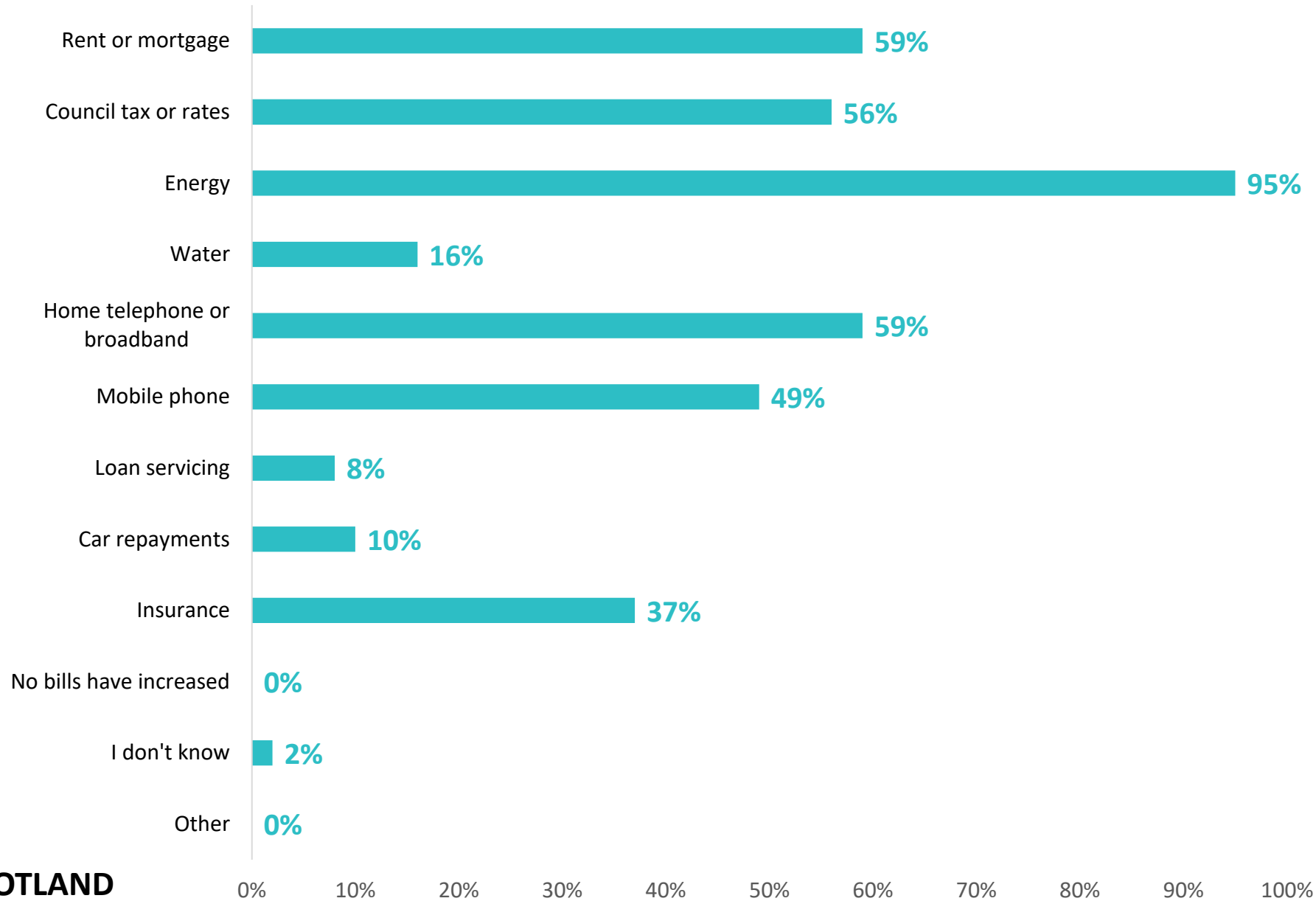
Of respondents report their current household bills are higher than 12 months ago (n=90)

SCOTLAND



Household Bills

“Which, if any, regular household bills have increased compared to 12 months ago?” (n=99)



43%

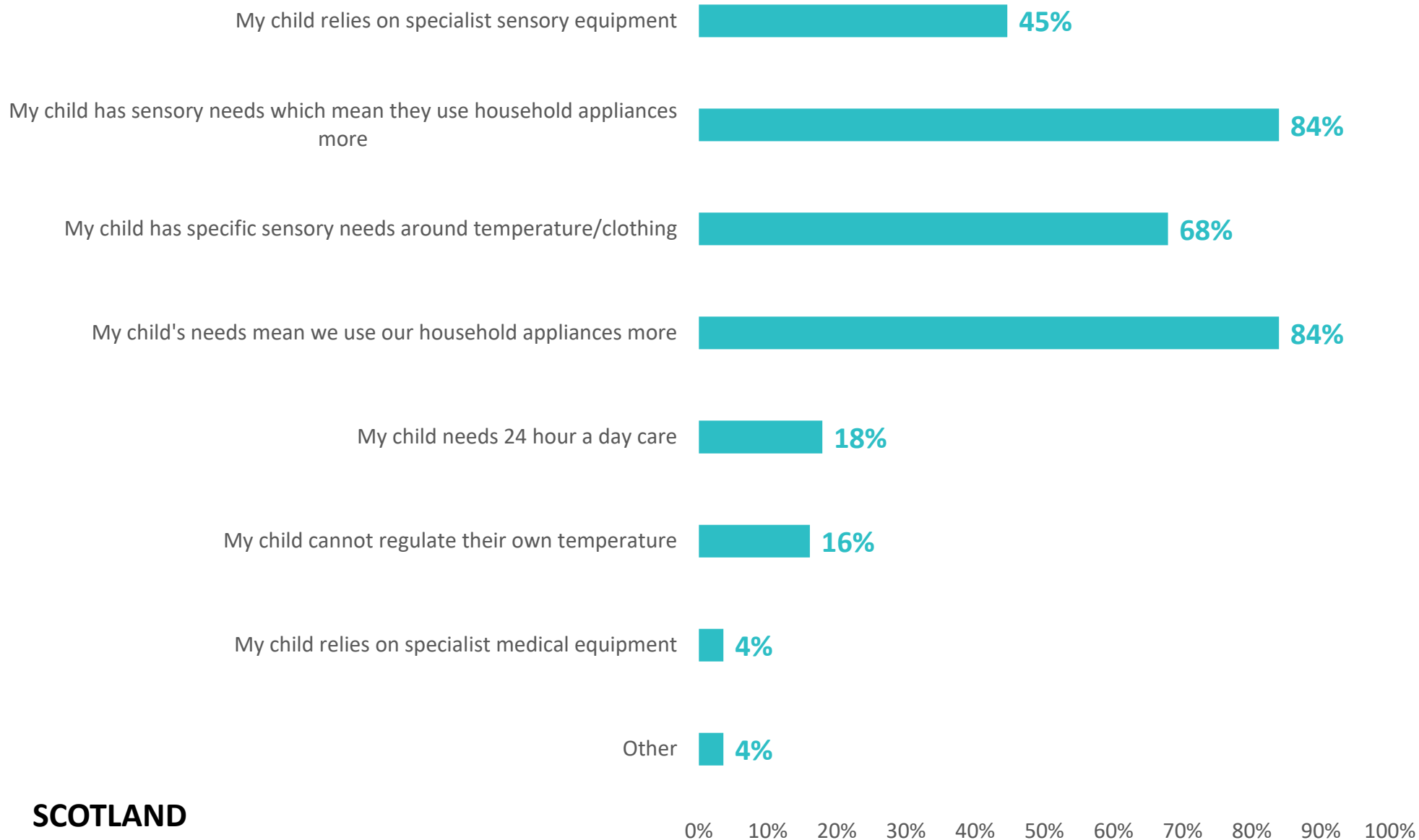
Of respondents report they have **fallen behind on their rent or mortgage** (n=110)

SCOTLAND



Additional Costs

“What are the reasons that mean you have to use more energy than families raising non-disabled children?” (n=56)

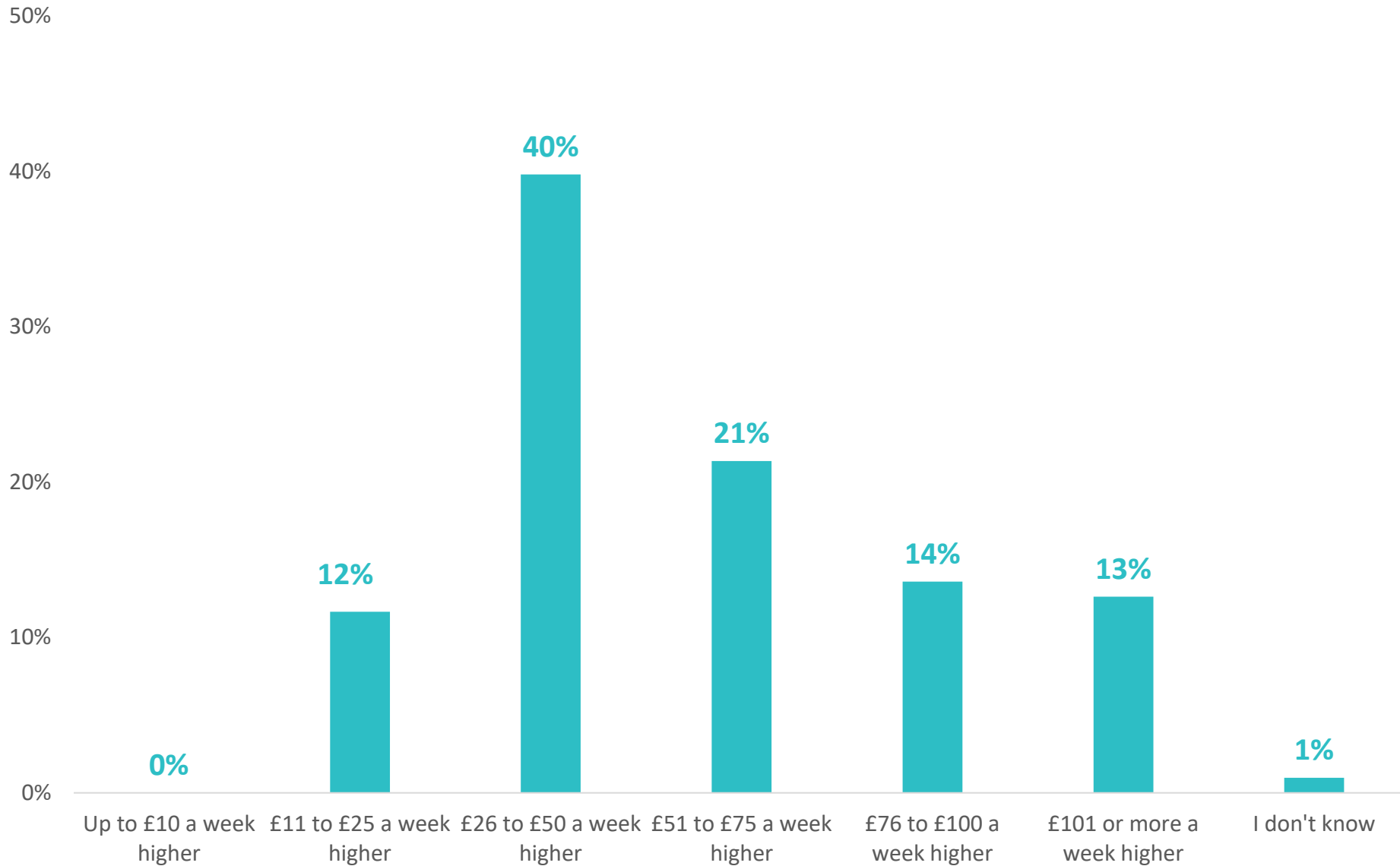


51%

Of respondents said they have to **pay more for energy** as a result of their disabled children's conditions or illnesses (n=110)

SCOTLAND

“Thinking about how much higher your current weekly food shop is compared to 12 months ago, which of the following describes the change?” (n=103)



94%

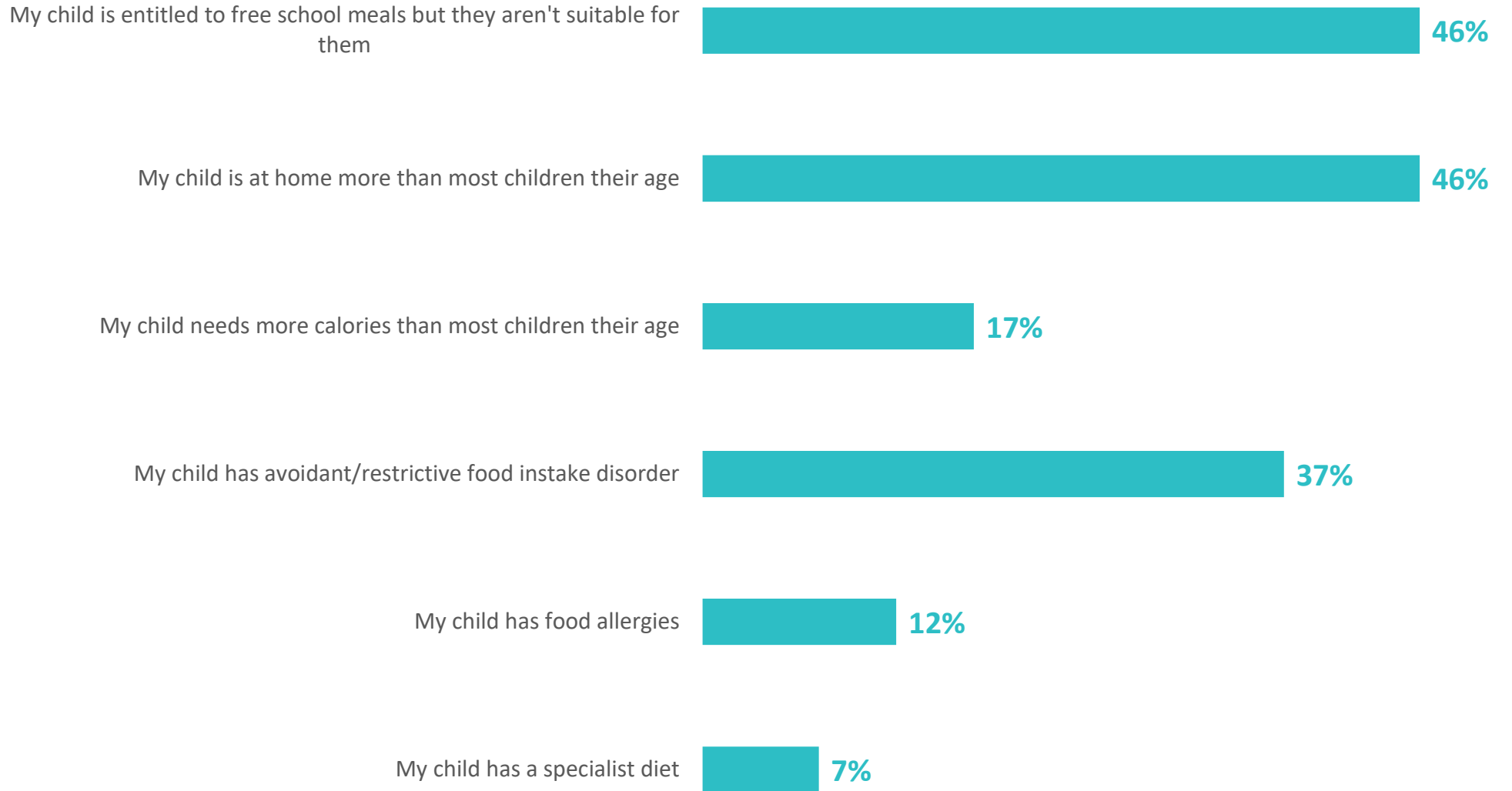
Of respondents said their weekly food shop is higher than 12 months ago (n=110)

SCOTLAND



Additional Costs

“What are the reasons that mean you have to spend more on food and groceries than families raising non-disabled children?” (n=81)



75%

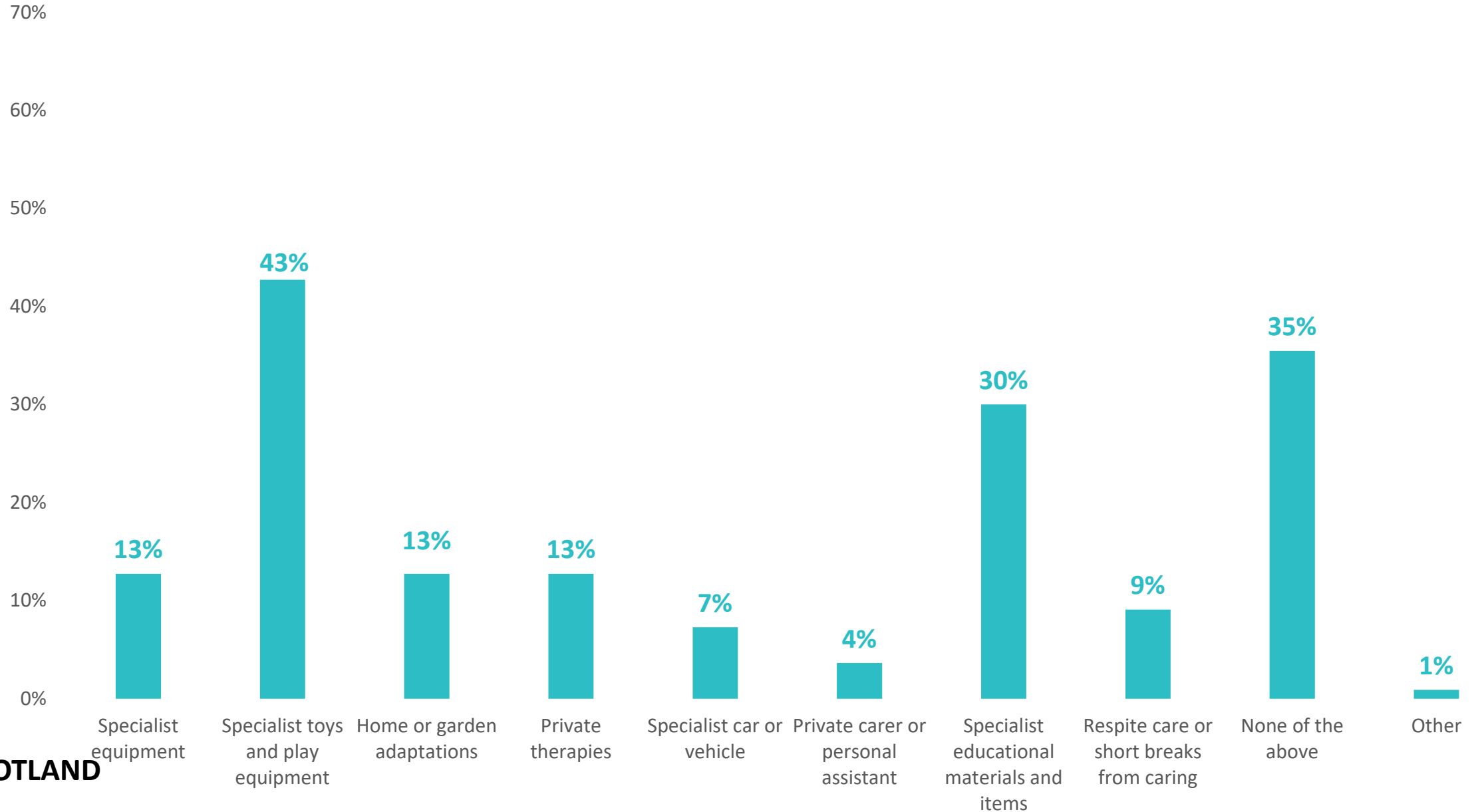
Of respondents said they have **to spend more on food and groceries** than families raising non-disabled children (n=110)

SCOTLAND

0% 10% 20% 30% 40% 50%

Additional Costs

“As a result of your disabled children’s conditions or illnesses, have you had to buy any of the following specialist items and services using your own money?” (n=110)



SCOTLAND

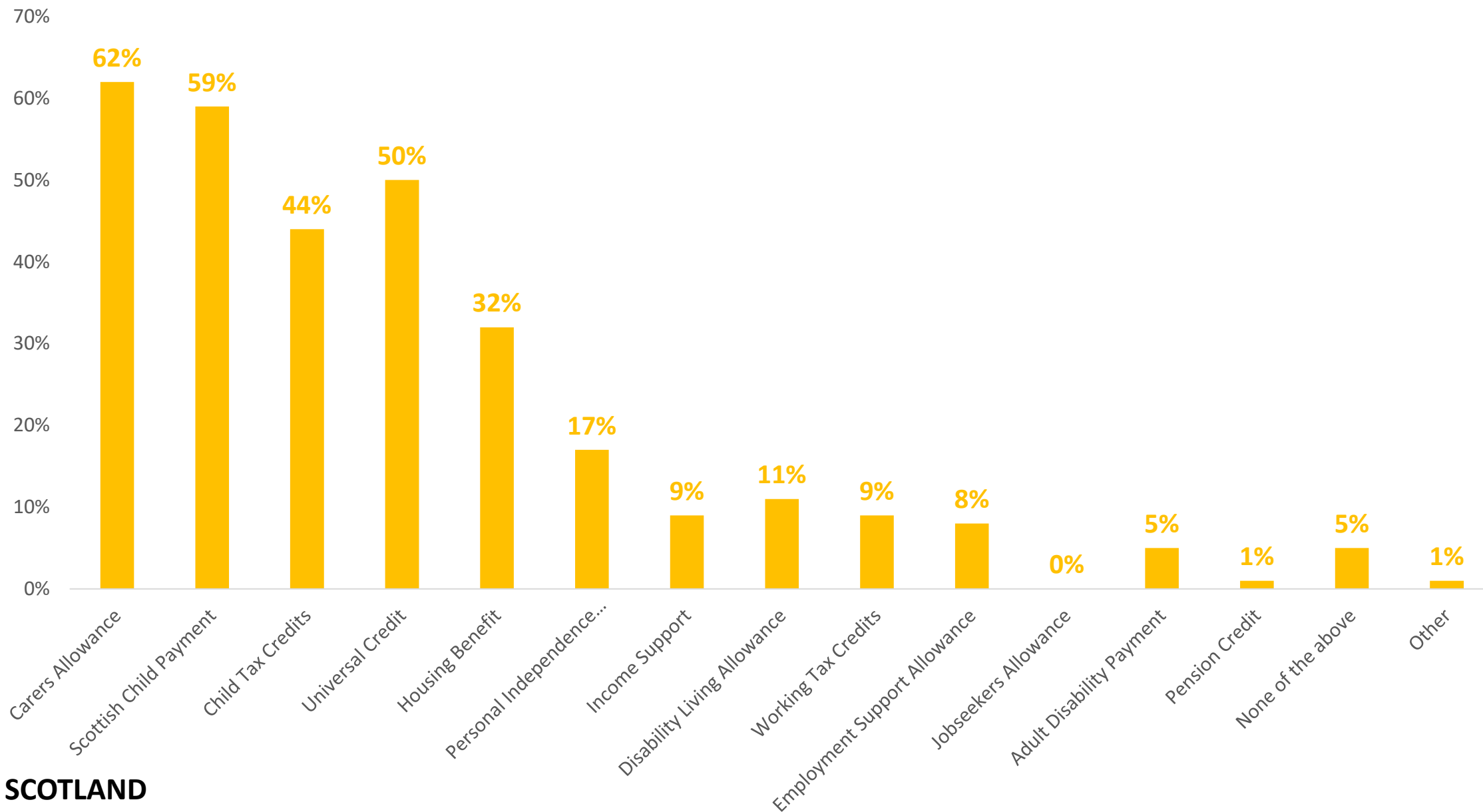
5. Relying on benefits

The vast majority of families have to rely on state benefits for at least some of their income.



Benefits families receive

Which benefits do one, or more, adults in your household currently receive? (n=110)



SCOTLAND



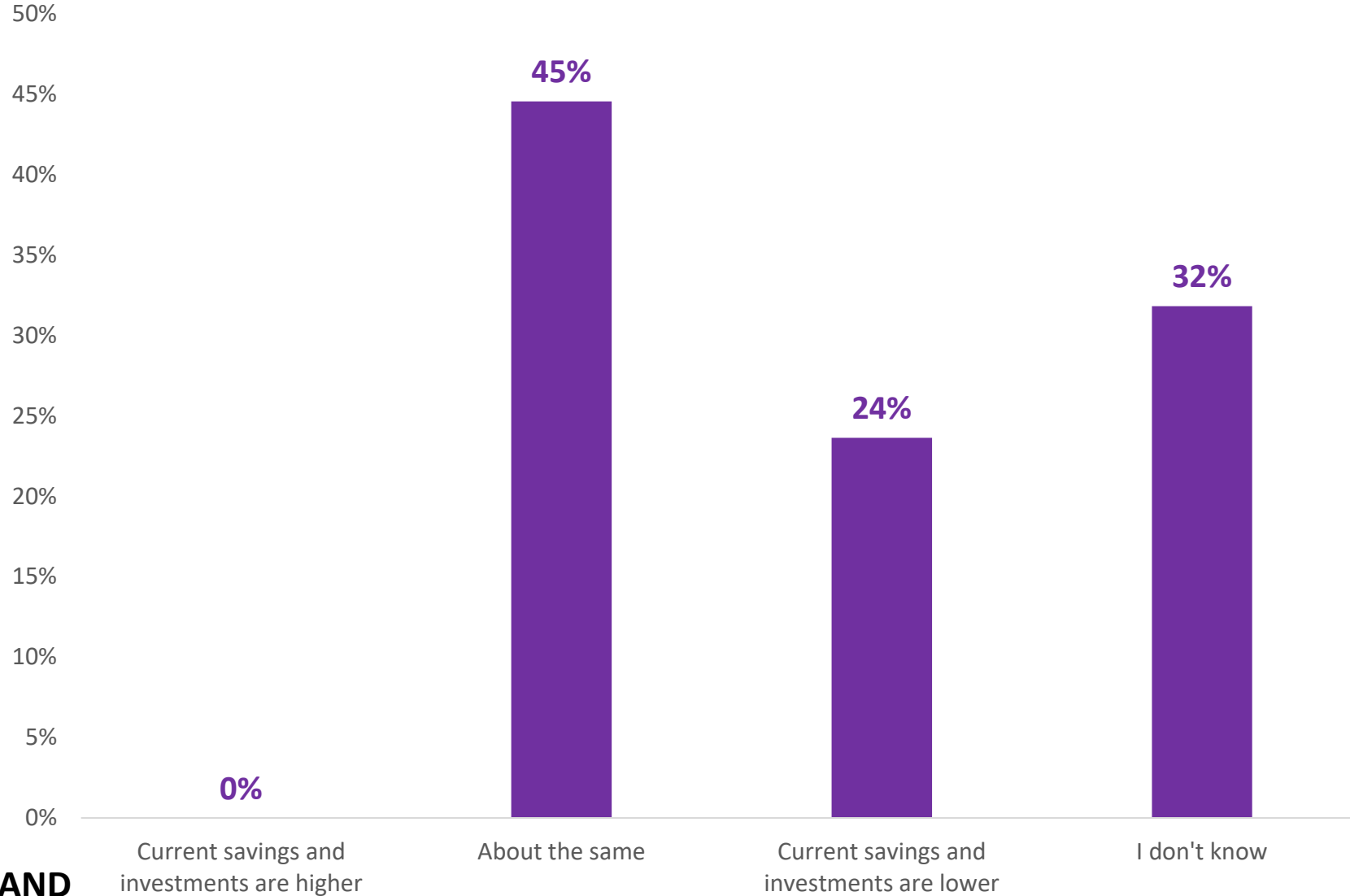
6. Savings

Families are in a financially precarious position with many having very limited access to savings and relatively small unforeseen costs being enough to cause significant financial distress



Family savings

“Thinking about your current household savings and investments, would you say they are higher, lower, or about the same as your household savings and investments 12 months ago?” (n=110)



SCOTLAND

79%

families report that they have **no savings** or investments



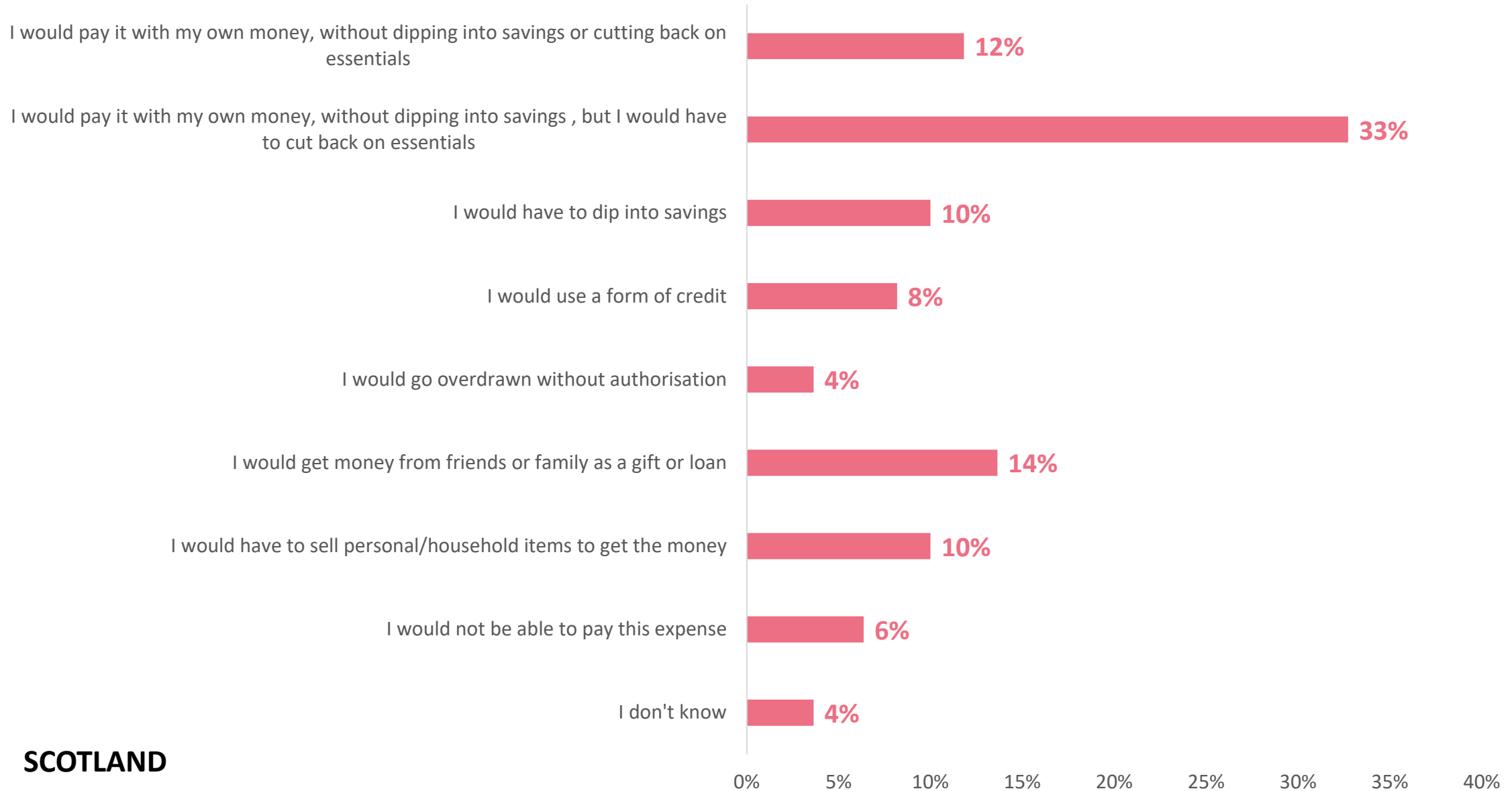
7. Going into debt

Where families cannot make any further cut backs, they are often forced to go into debt to pay for essential items and bills.



Trying to financially cope

“Would your household be able to pay an unexpected expense of £200?” (n=110)

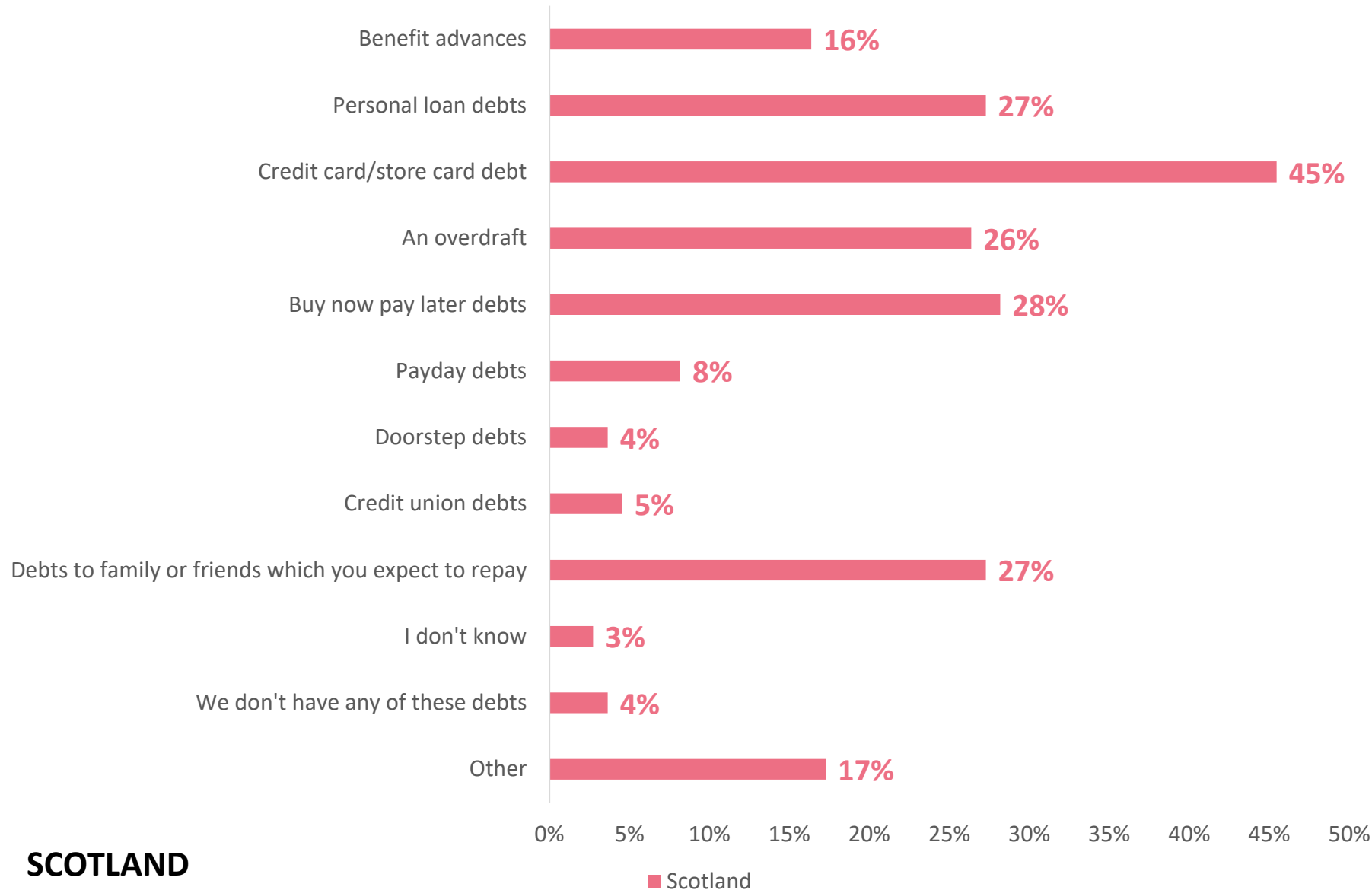


SCOTLAND



Going into debt

“Do you have any of these debts?” (n=110)



SCOTLAND

84%

families report that **keeping up with the repayment** of their debts is a difficulty or burden.

43%

families report that it's fairly or very likely they will need to borrow more money or **go further into debt in the next six months**

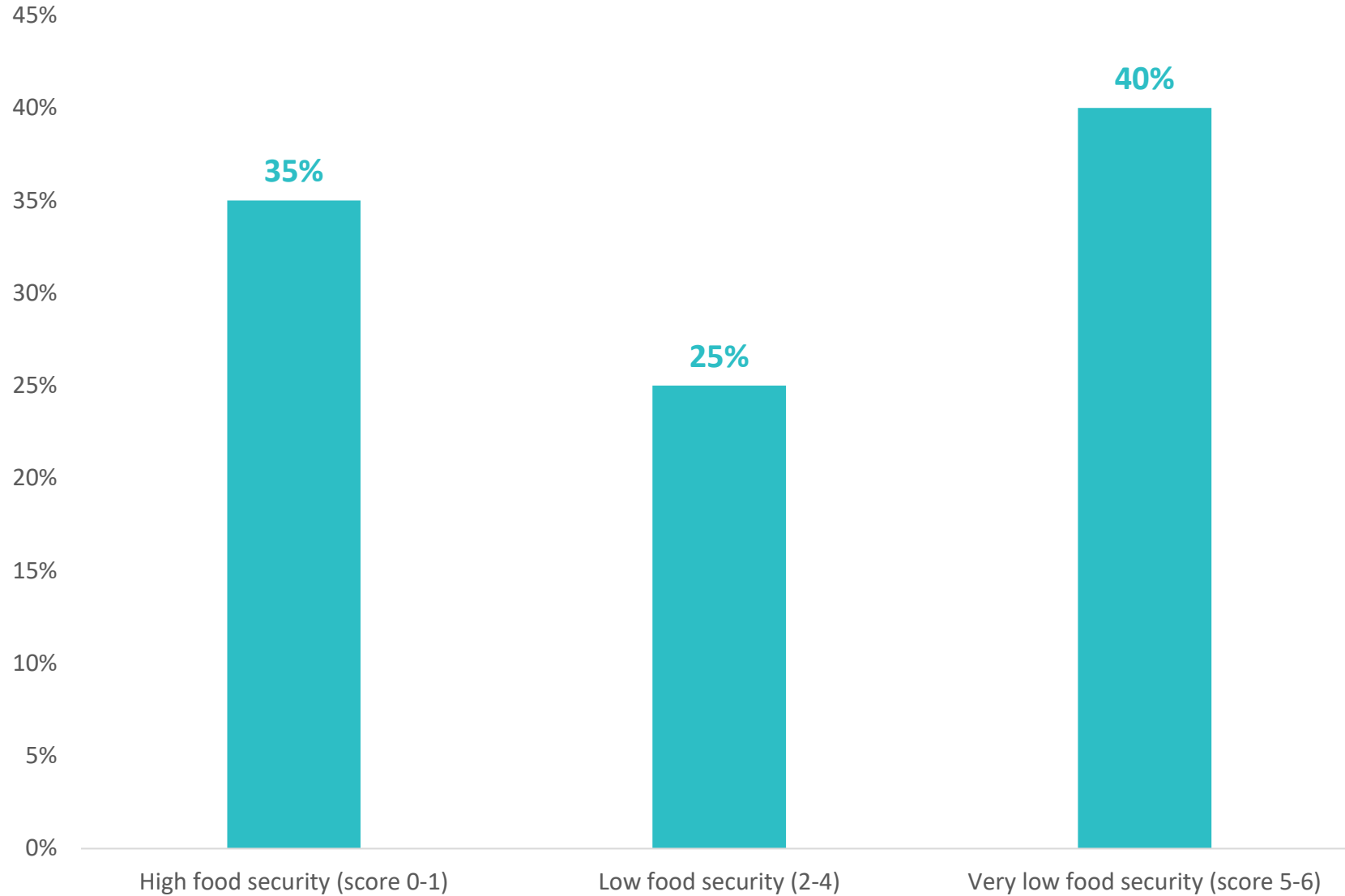


8. Going Without

Many families raising disabled children not only face an income penalty, they also face extra costs as a direct result of their children's conditions and illnesses.



U.S. Household Food Security Survey Module: Six-Item Short Form Food Security Scale (n= 110)



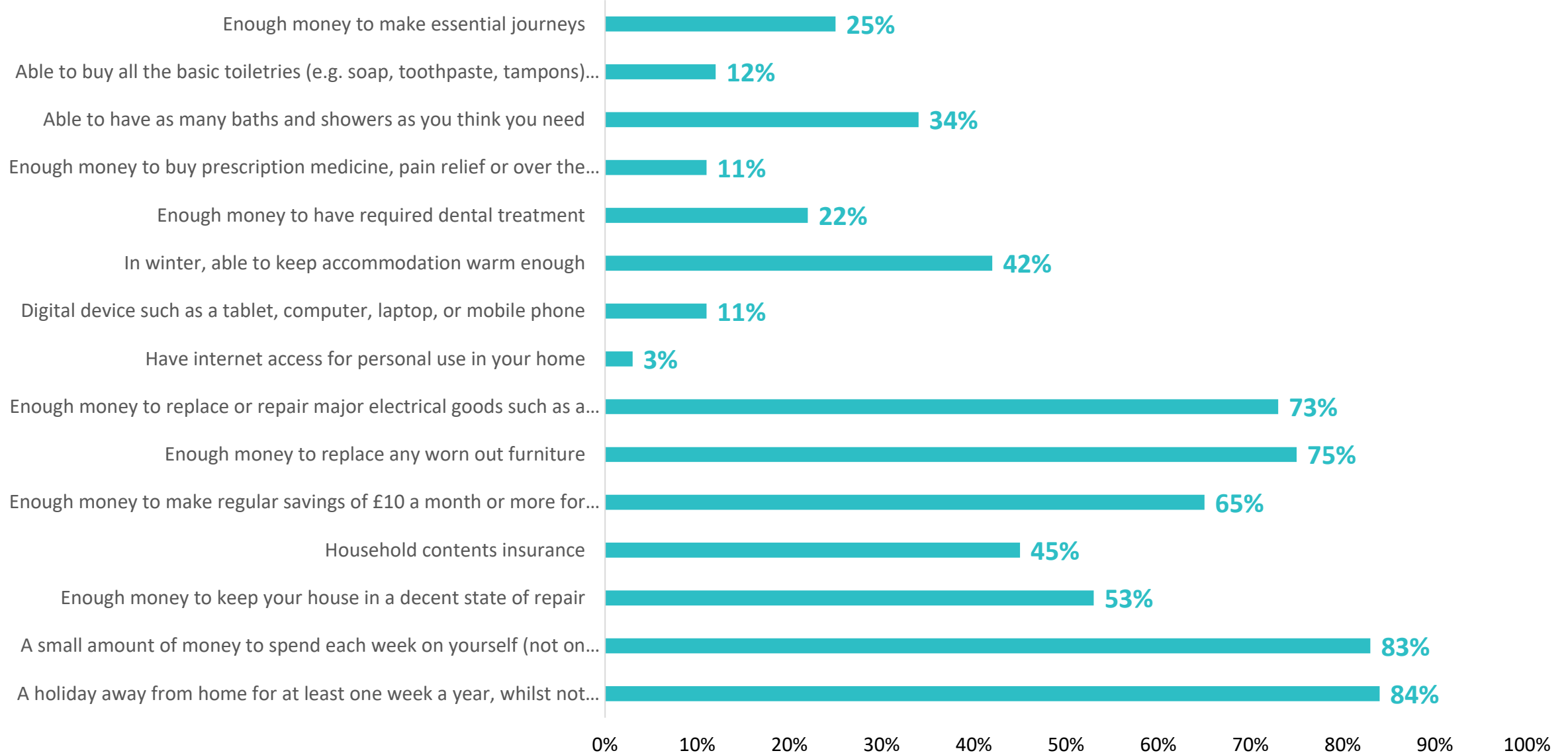
30%

families report that they have had to use a food bank because there wasn't enough money for food



Going Without – Parent/Carer

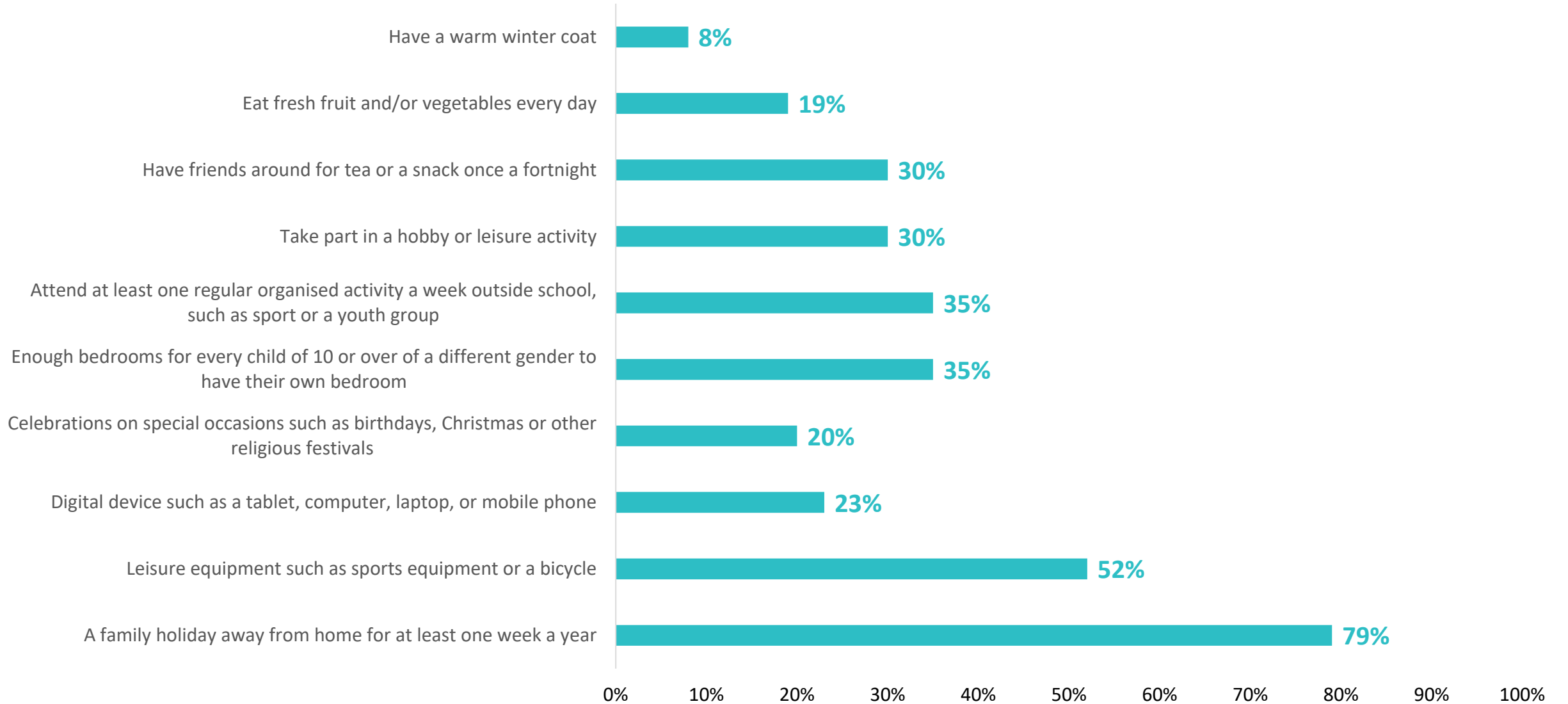
“We can’t afford this” (n=110)



SCOTLAND

Going Without – Disabled Children and Young People

“We can’t afford this” (n=110)



SCOTLAND

The resulting wellbeing impacts

9. Disabled children

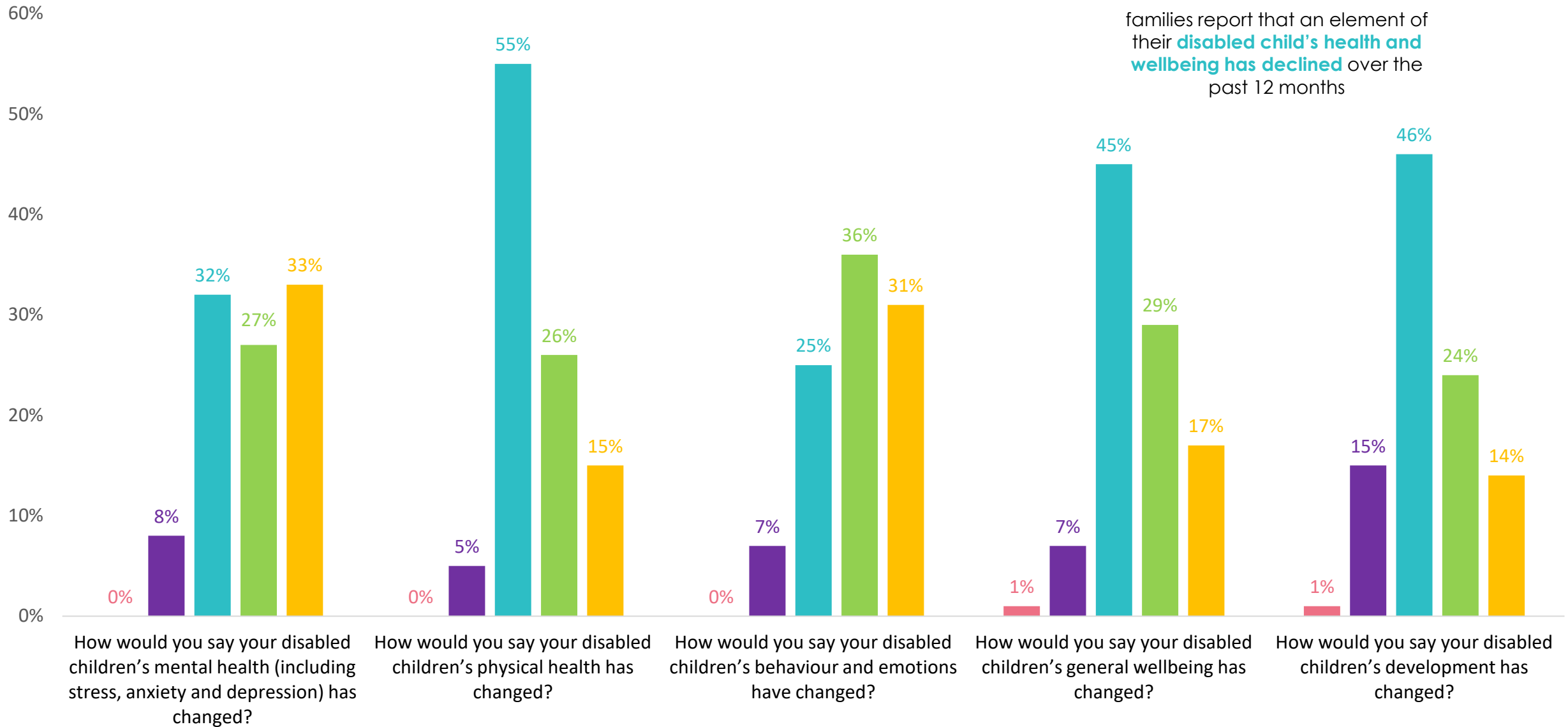
The situation families find themselves in has a negative impact on the health, wellbeing and quality of life of disabled children.



78%



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



SCOTLAND

■ Much better ■ Somewhat better ■ Stayed the same ■ Somewhat worse ■ Much worse

Disabled children's wellbeing

"We support everything he does and let him try anything he wishes to try with socialising. As this is a big thing for him. He is the best and we love him very much. He has ok days and terrible days. He struggles to make friends and he is more than often socially isolated as he has not got any friends. He loves climbing and running about he has so much energy and is most of the time a happy boy."

"Covid really hit our home hard, My wee boy used to be so bubbly now he's so anxious, shy and worried all the time"

"My daughter's mental health would be a lot worse if she didn't have the home computer to use provided by family fund. I wouldn't have been able to buy it myself."



The resulting wellbeing impacts

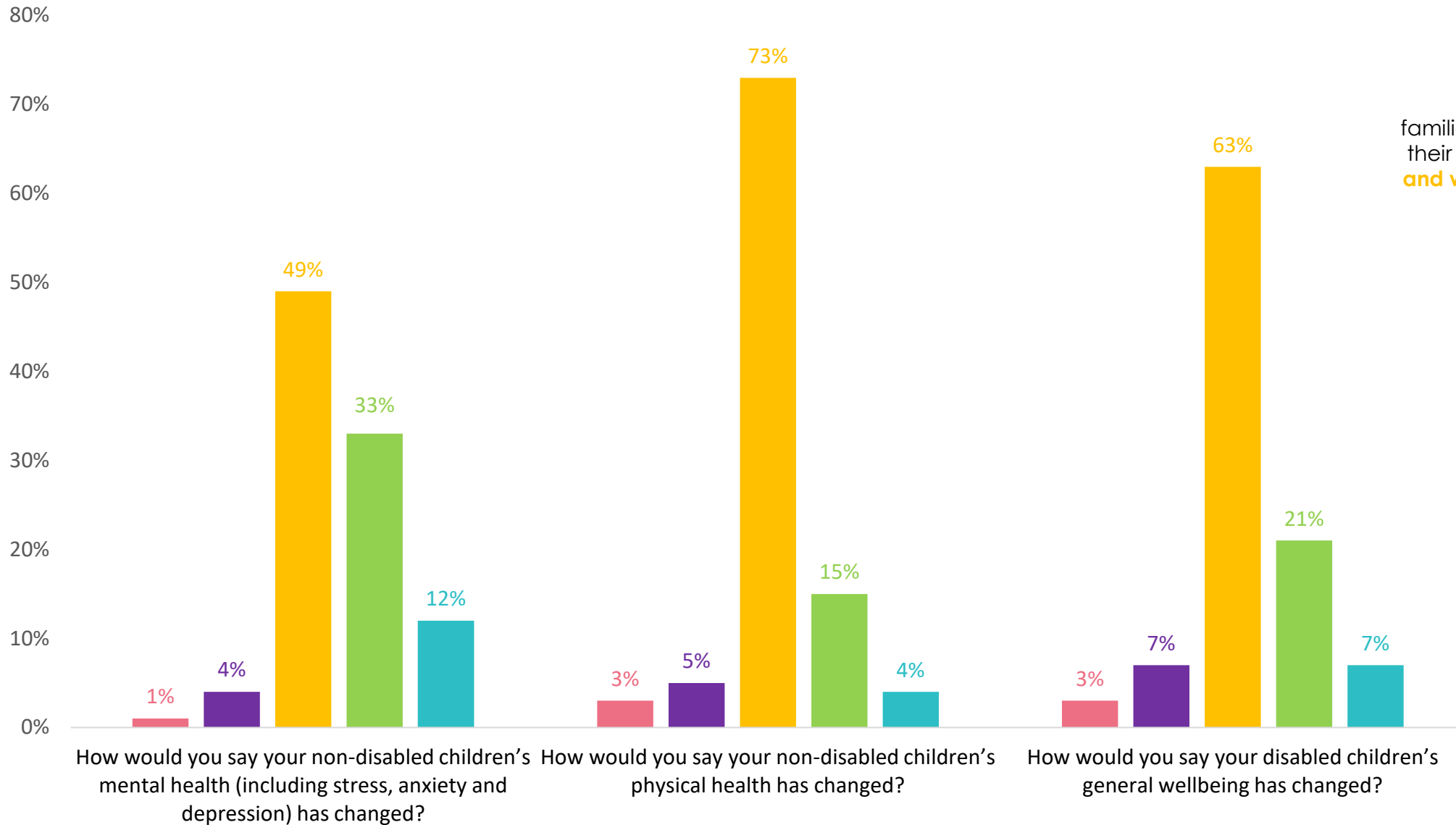
10. Non-Disabled children

The health and wellbeing of many non-disabled children has also been negatively affected.



Impact on non-disabled children

“Over the past 12 months...” (n=73)



49%

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

SCOTLAND

■ Much better ■ Somewhat better ■ Stayed the same ■ Somewhat worse ■ Much worse



The resulting wellbeing impacts

11. Parents and carers

The health and wellbeing of many carers has also been negatively affected.



Impact on parents and carers

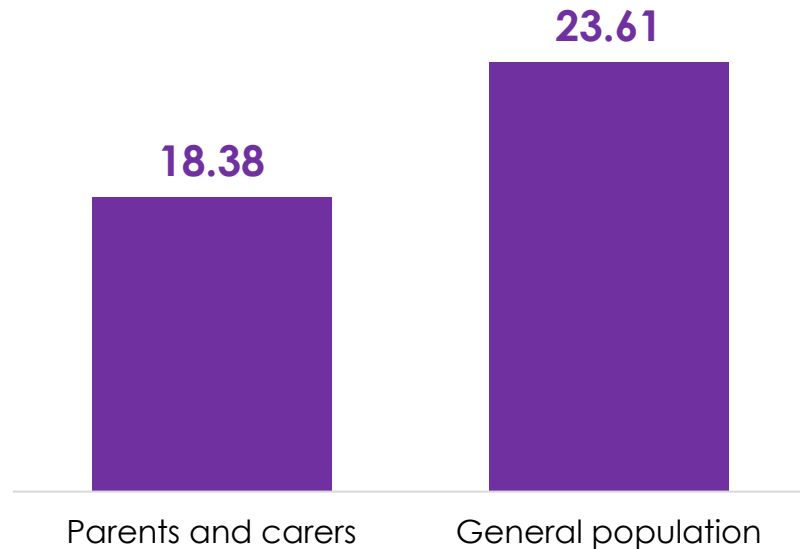
Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale) (n=110)

High wellbeing 35

70%

Low wellbeing (adjusted score of less than 19.5)

Low wellbeing 7



SCOTLAND

6.69

Mean UCLA Loneliness Score

27%

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

45%

Probable depression (adjusted score of less than 18)



Parent's experiences of the impact of caring

"When I have given it all my all and am at the edge of mental meltdown, I really do not have people to talk to which is really challenging and frustrating for me.... all by myself, all at myself"

"It's challenging when you're doing it all for yourselfThere is not enough support groups and also when he got diagnosed with autism that was it nothing more so no support which I had to fight for which we have and now he has ADHD as well. I do think community lacks groups etc for us and it's hard when u work as it makes time hard as it is usually when I at work they have groups"

"Taking care of my son is extremely mentally and physically hard work, especially since I am a single parent. Sometimes I don't have the strength and I need help myself and I pray not to give up."



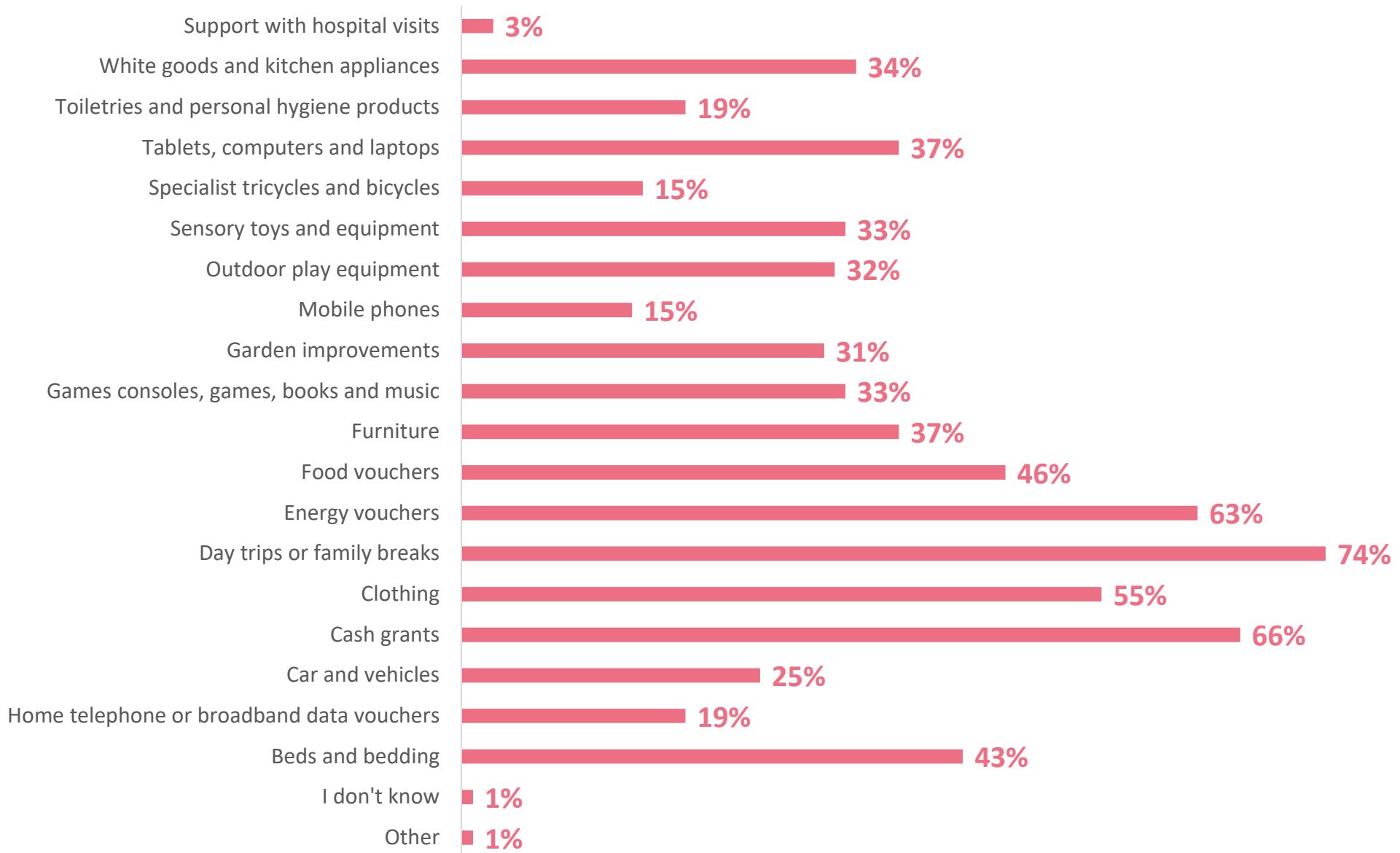
12. Other Needs

We are also interested in understanding what other support Family Fund could offer and what other unmet needs families have.



Your needs

“Which grants could we potentially provide that would be most helpful to your family right now?” (n=110)

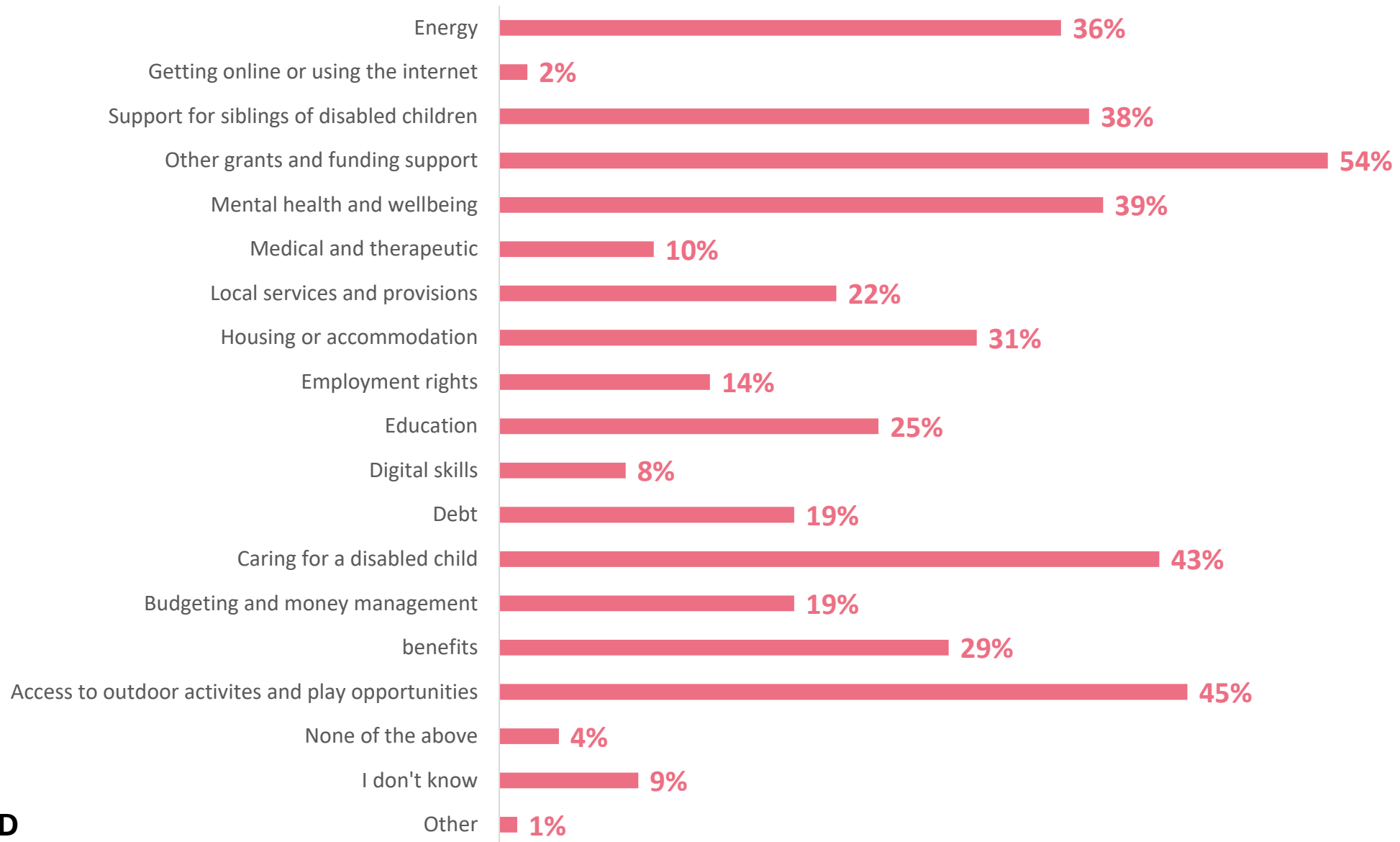


SCOTLAND



Your needs

“Which topics could we potentially provide information and support on that would be most helpful to your family right now?” (n=110)



SCOTLAND



Other family needs

“Unable to get suitable education for Archie, due to lockdown he hasn't attended school”*

“It has been really hard. My child's condition is so rare that we won't know what will happen in the near future and it is very frustrating as I feel like there is NO help or support for the family as a whole”

“no support for disabled carers.”

“Schools could be more understanding and lose the misconceptions about ADHD just being bad behaviour.”



WALES



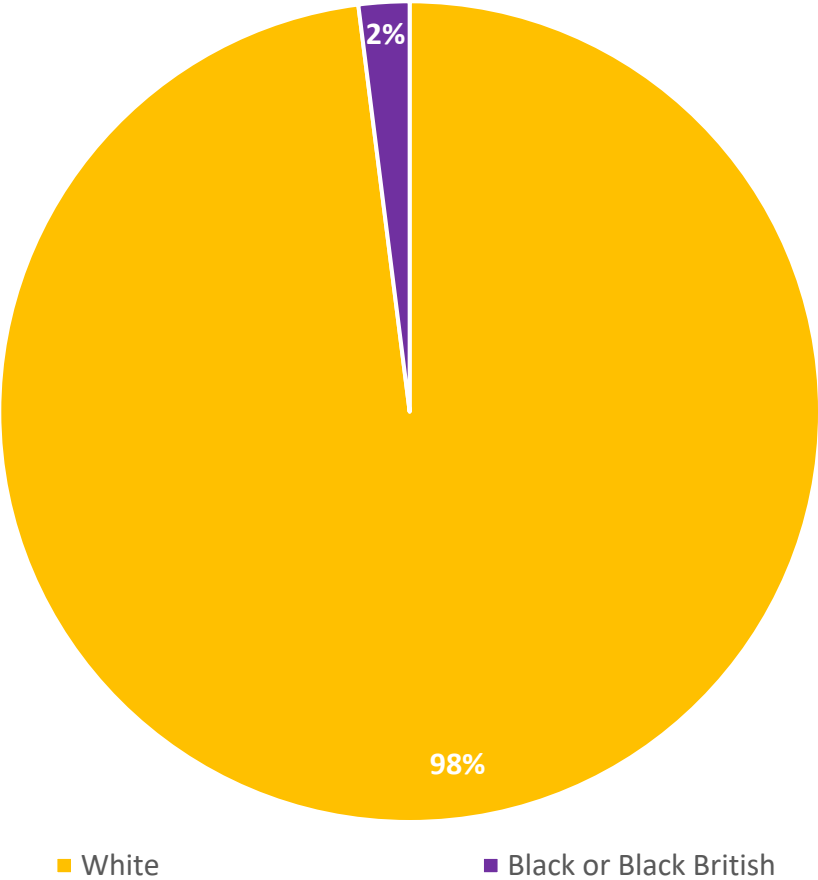
1. Profile of families

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

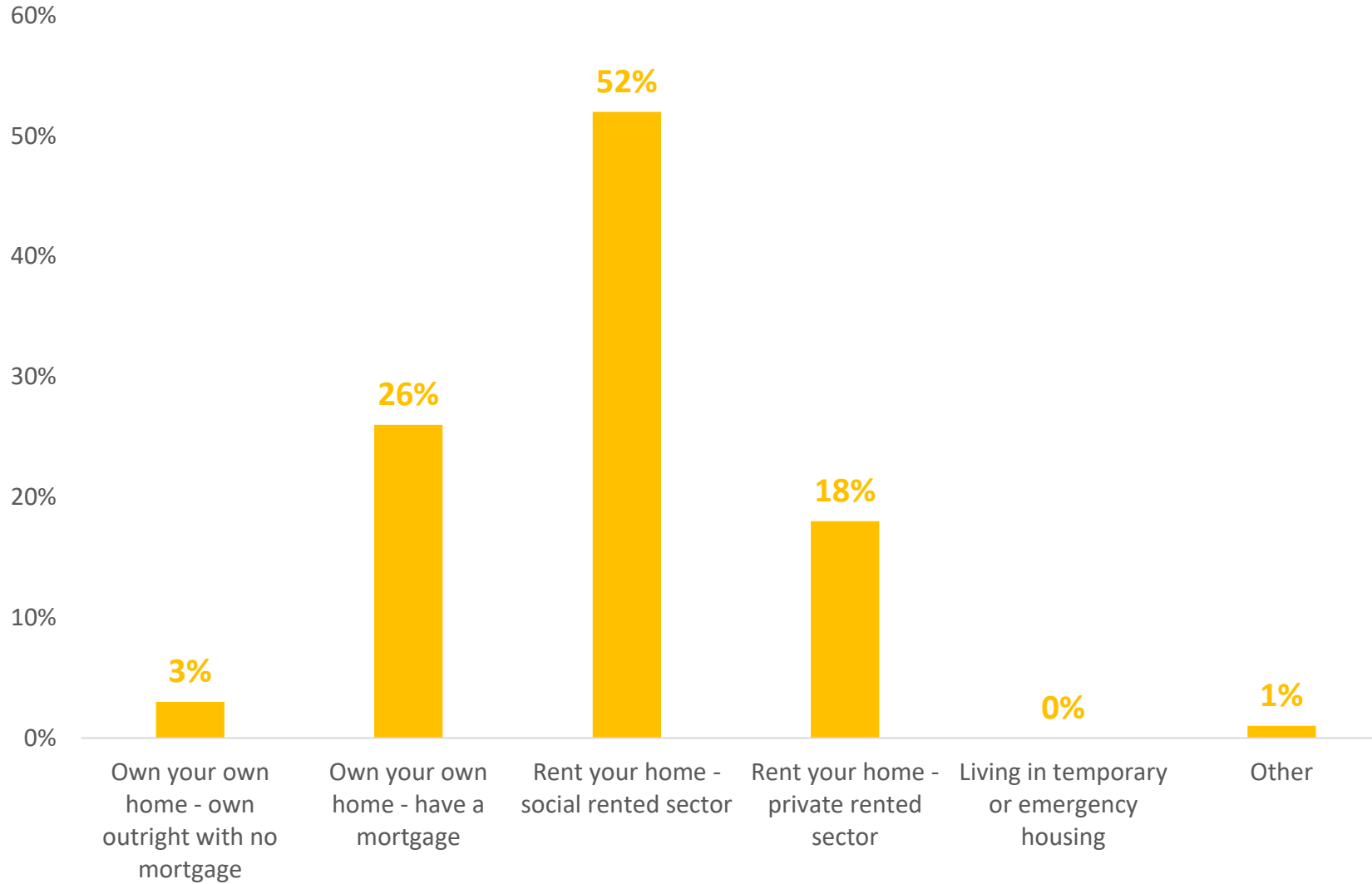


Who are the families who took part in Family Poll?

What is your ethnic group? [grouped]
(n=90)



Who are the families who took part in Family Poll?



WALES

90

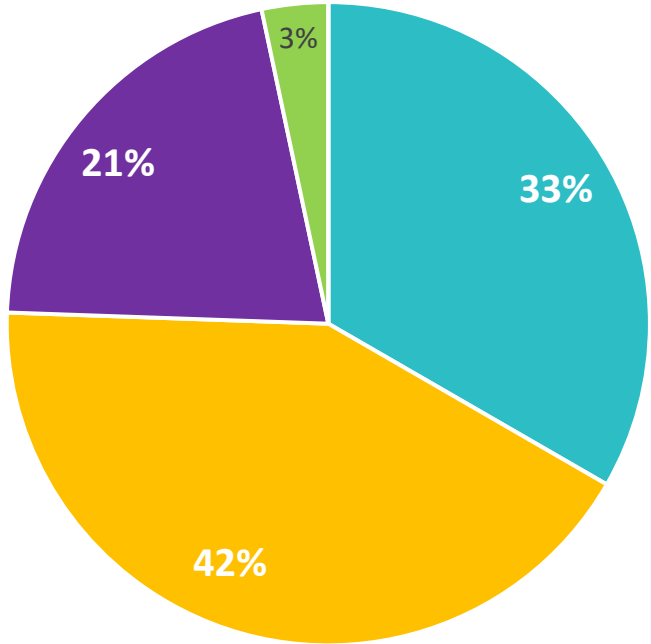
Responses from families

47 %

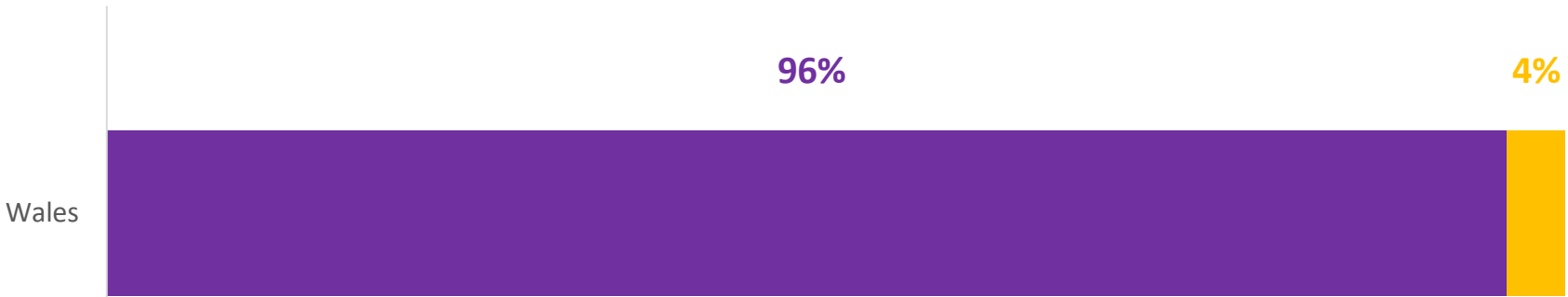
Of families that responded were **single adult households**



Parents and Carers (N=90)



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



WALES

■ Female ■ Male

63 %

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

58 %

Of respondents **have a long-term physical or mental health conditions or illness**

47 %

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



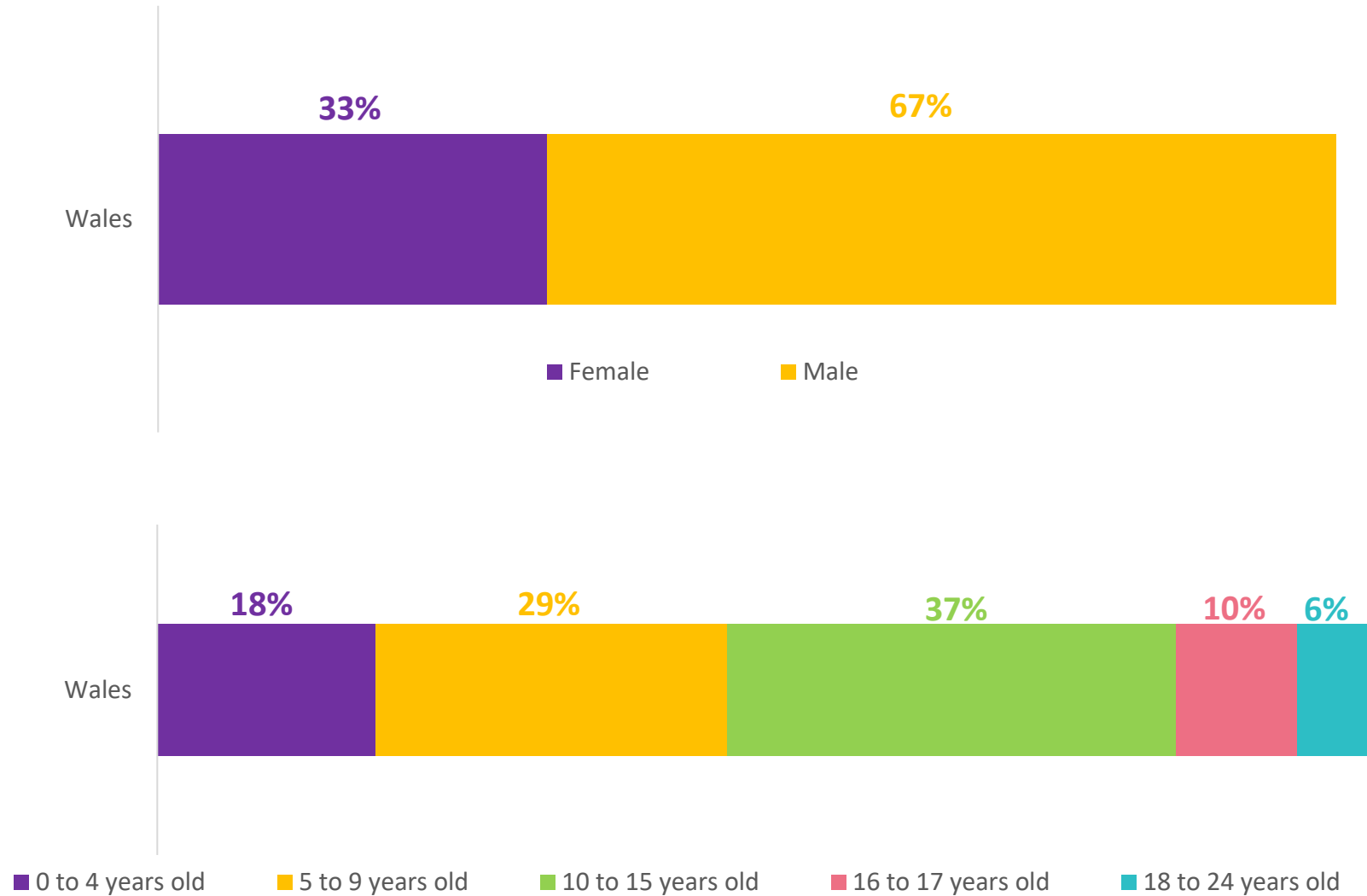
Disabled Children and Young People (N=90)

120+

Children with disabilities or serious illnesses

80+

Children without disabilities or serious illnesses



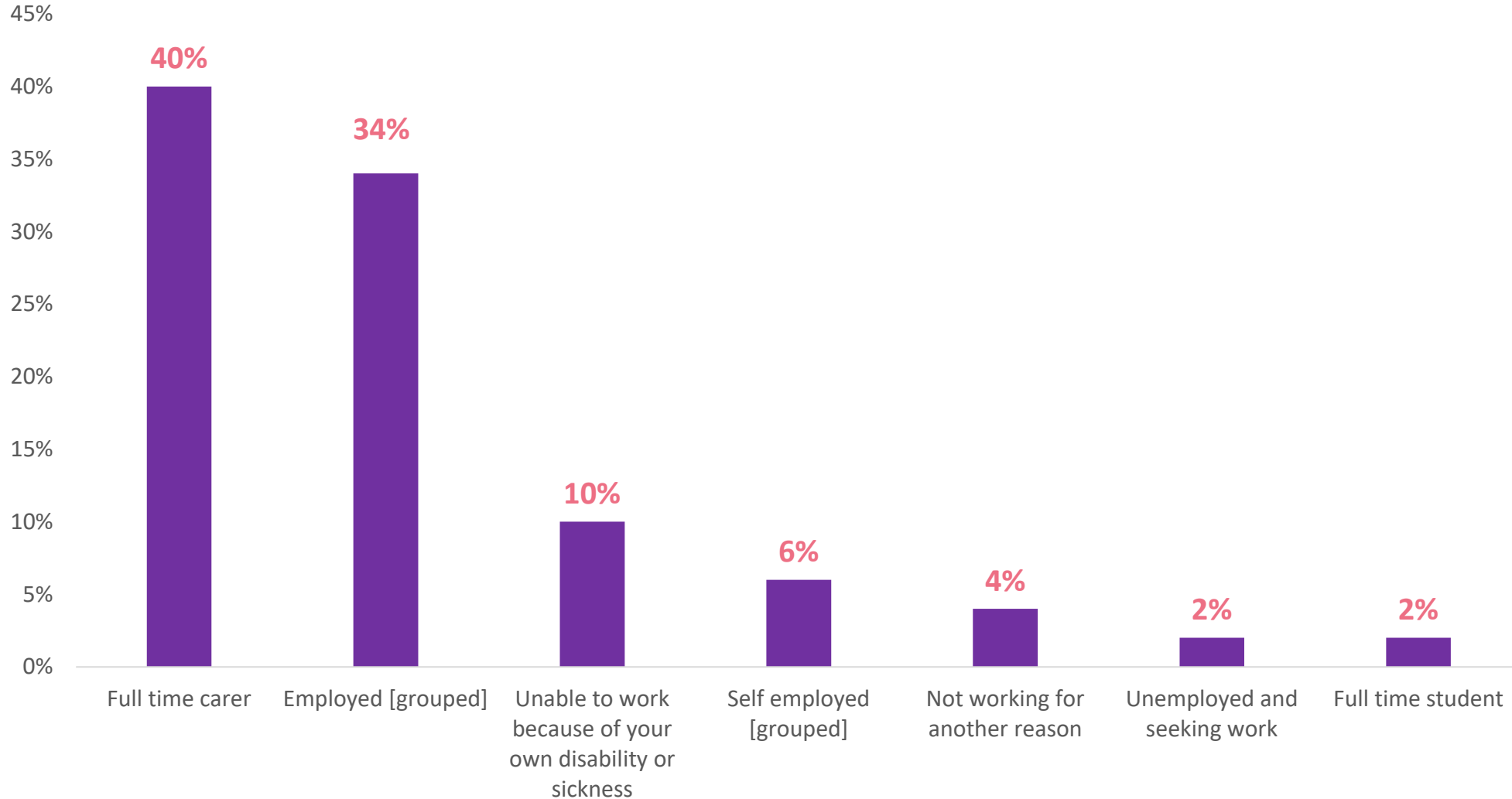
2. Reduced incomes

For many families raising disabled children, parents and carers' ability to earn an income is significantly limited by their commitment to caring for their child.



Working and caring

“Are you employed?” (n=90)



£19,054

The mean **annual household income** reported by families (n=82)

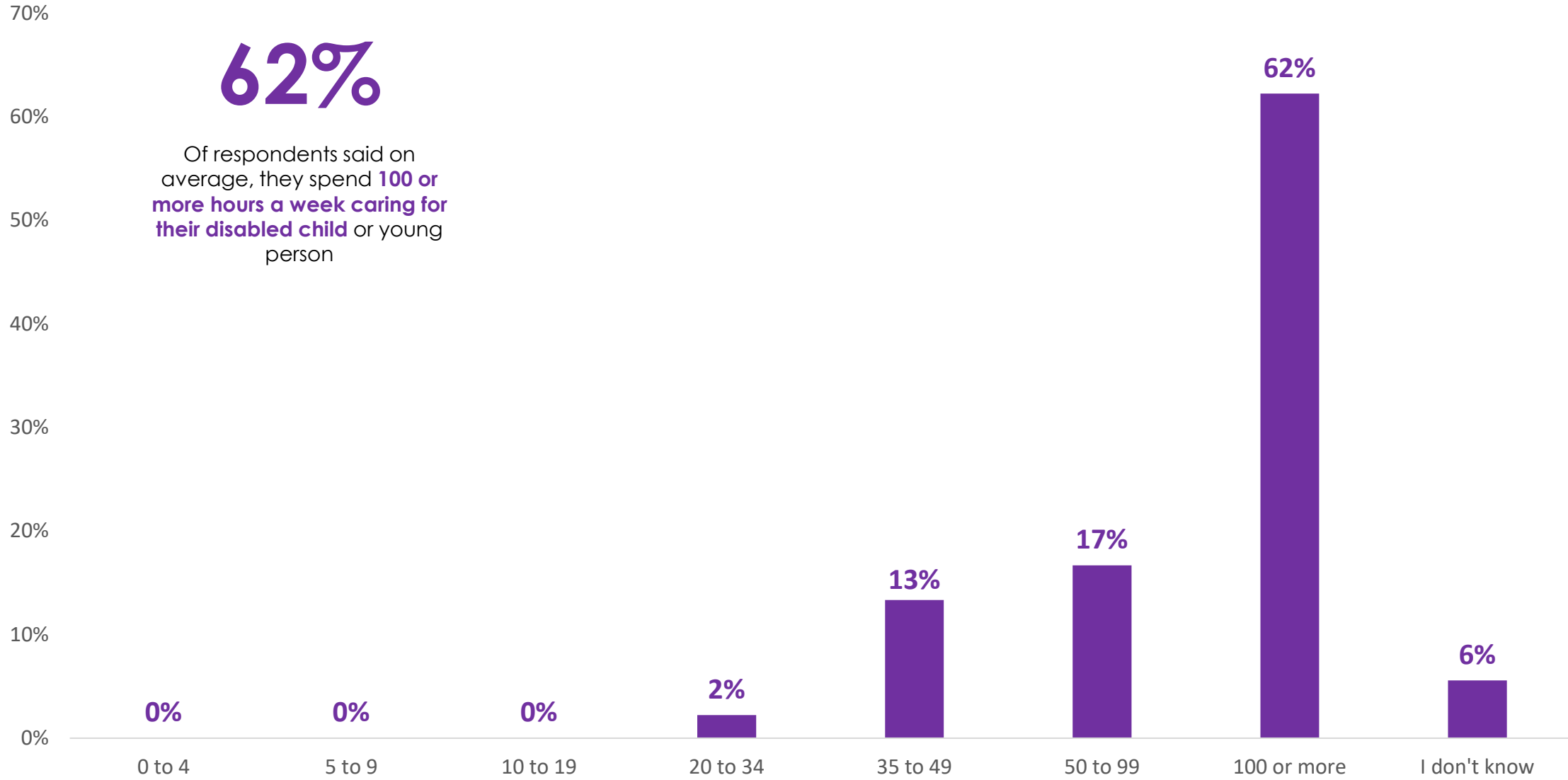
£1588

The mean **monthly household income** reported by families

WALES



“About how many hours a week, on average, do you spend providing help for or looking after your disabled child or young person?” (n=90)

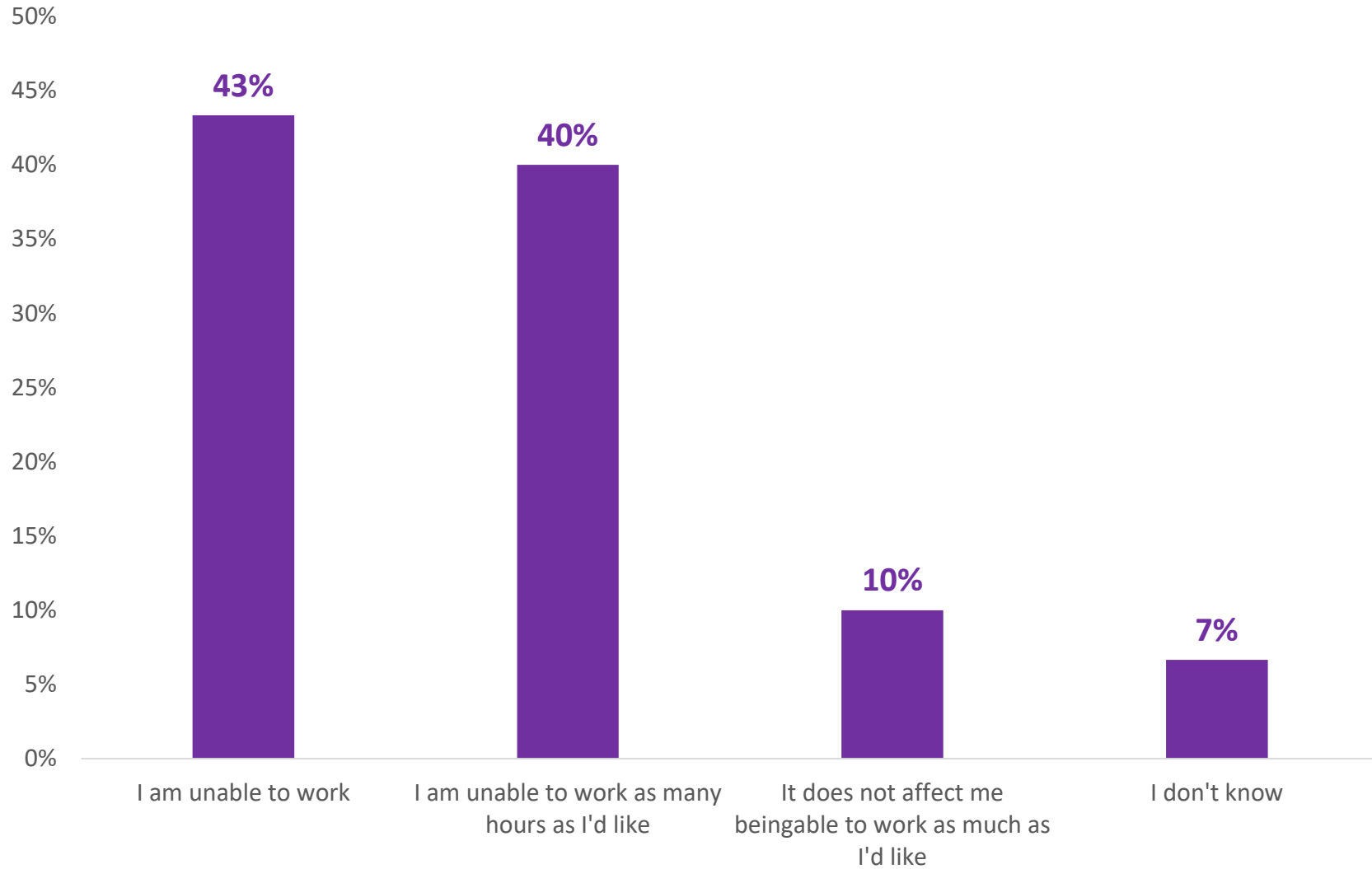


62%

Of respondents said on average, they spend **100 or more hours a week caring for their disabled child** or young person

Caring

“Do your caring responsibilities for your disabled child or young person mean you cannot work as much as you would like?” (n=90)

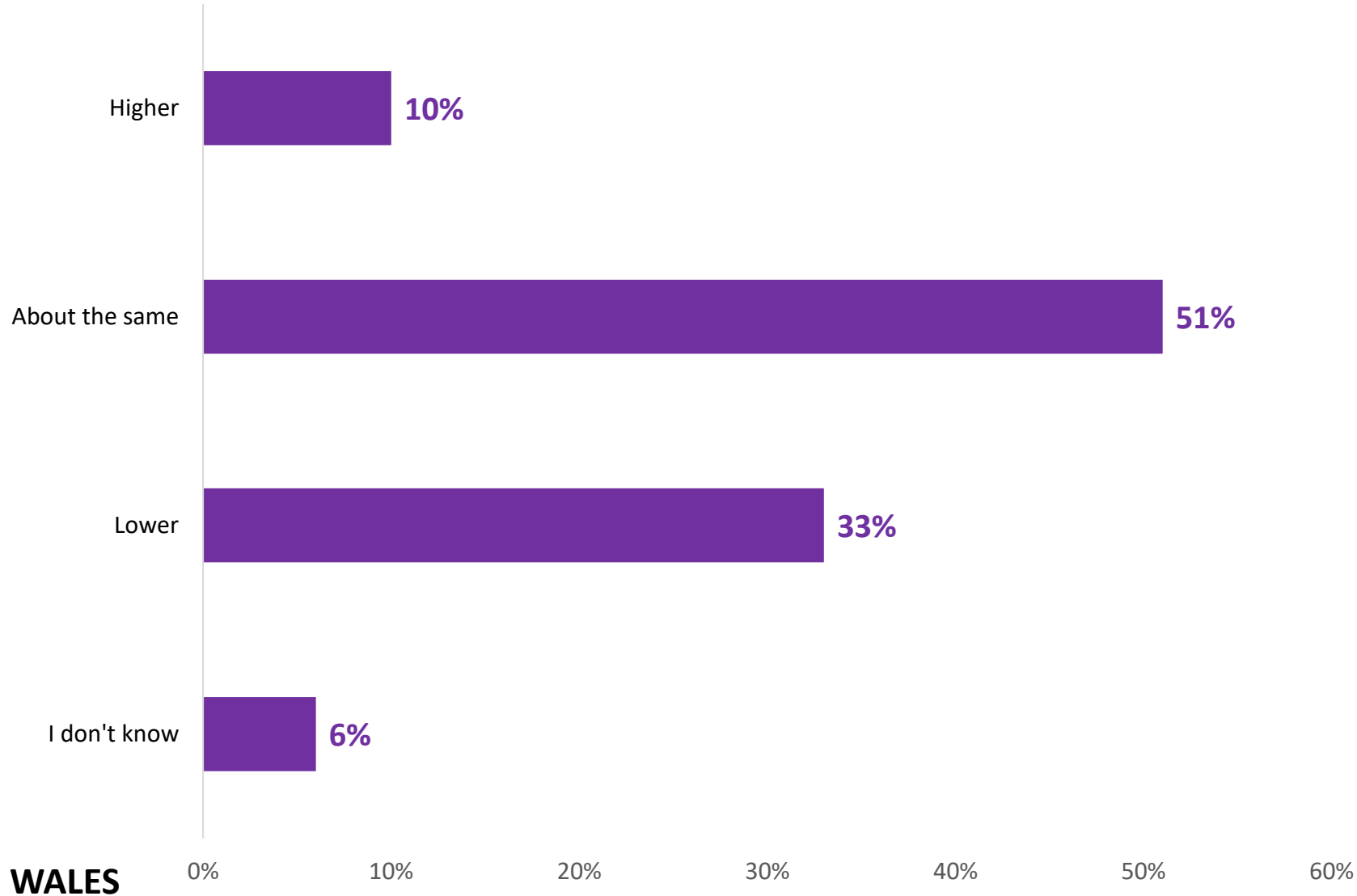


WALES



Income

“Thinking about your current regular household income, would you say it is higher, lower, or about the same as he income you had 12 months ago?” (n=90)



55%

Of respondents who said their household income is lower because **they had reduce their hours/stop working** to meet the care needs of their disabled child or young person

The financial cost of caring

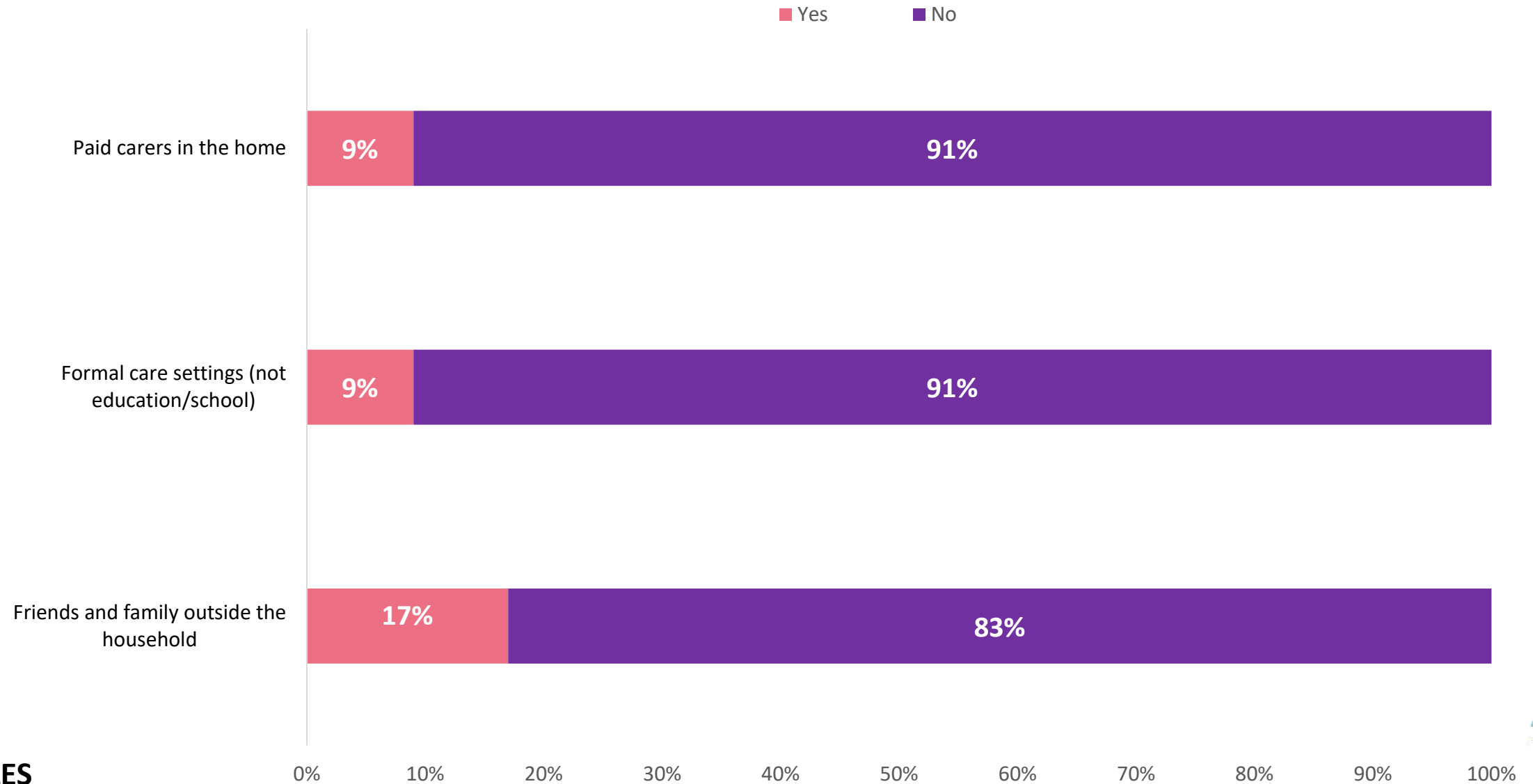
3. Access to other care

Even when families would like their child to be cared for by someone outside the household this isn't always available. This further limits their ability to earn additional income.



Access to care outside the household

“Are your disabled children cared for by the following?” (n=90)

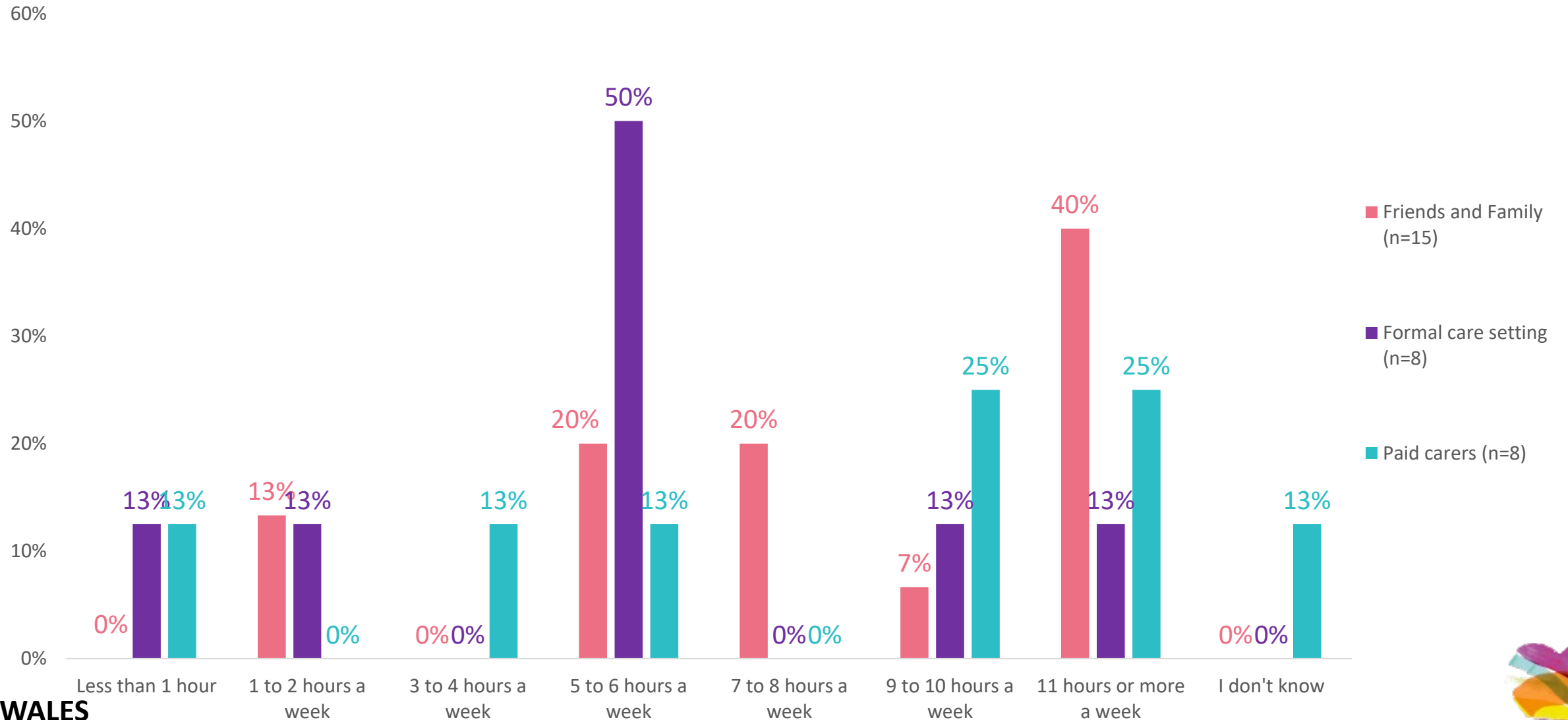


WALES



Access to care outside the household

“On average, how many hours a week are your children cared for by the following?”

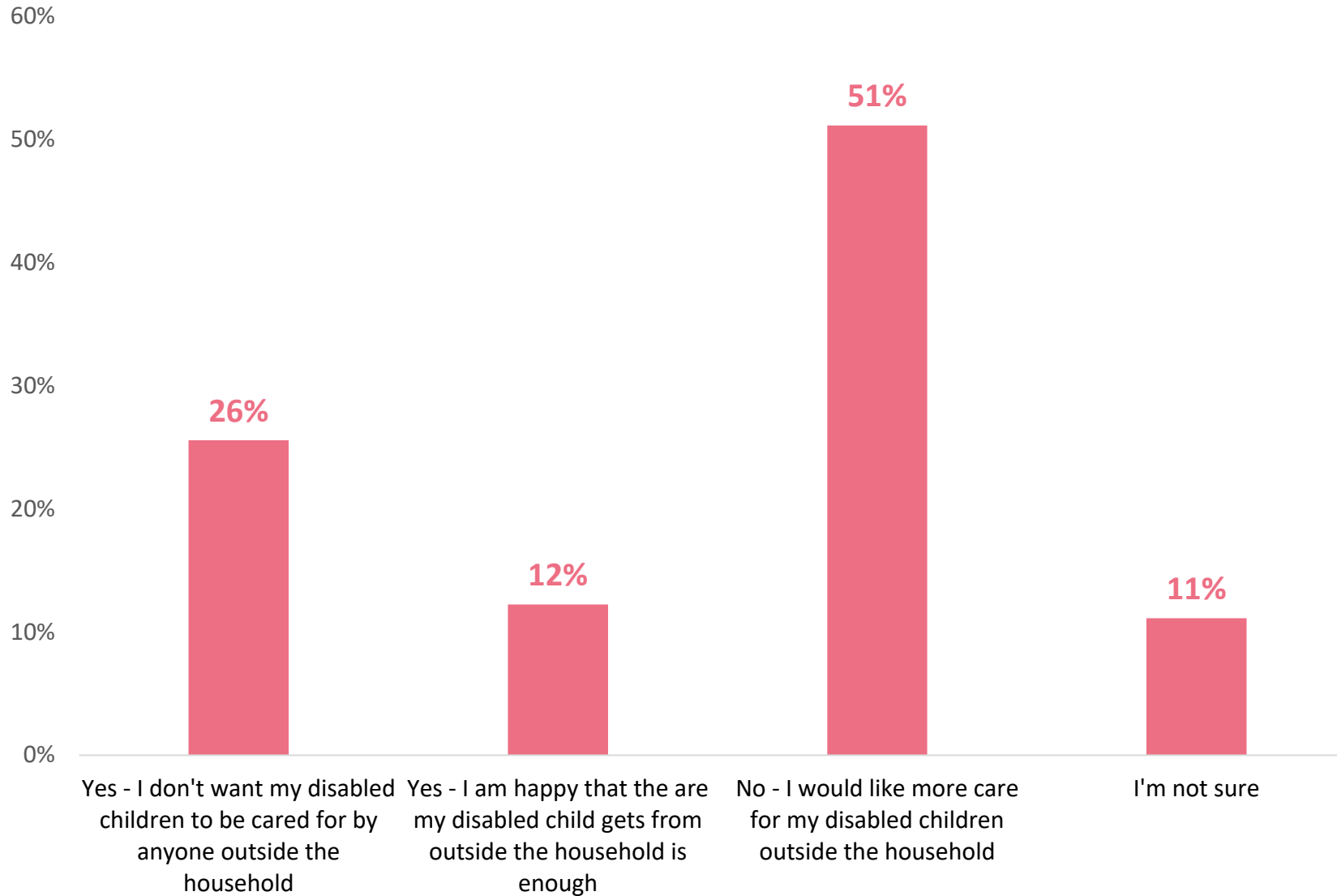


WALES



Unmet need for care

“Do you have access to as much care (outside of school/education settings) from people outside the household as you would like for your disabled child?” (n=90)

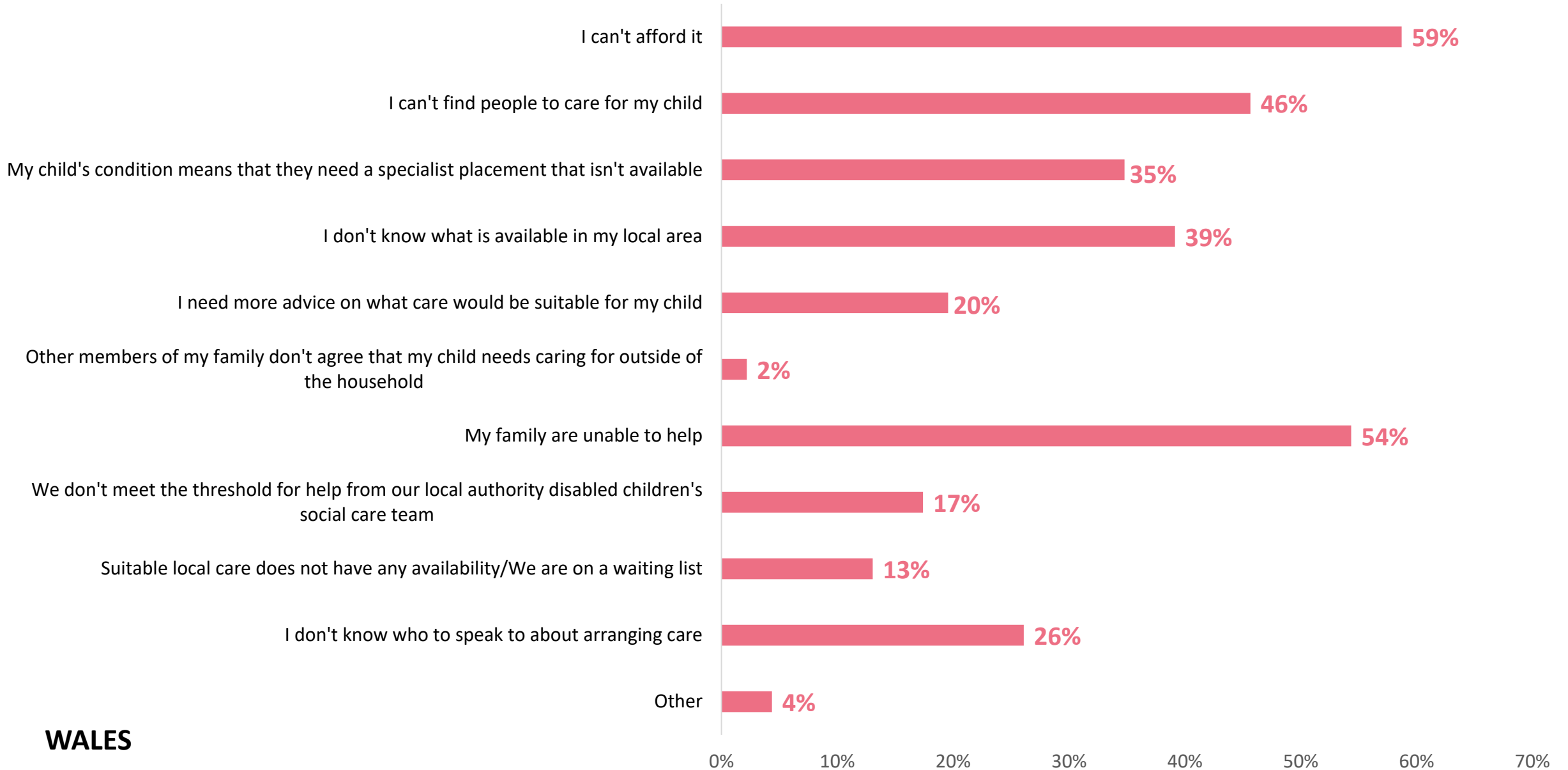


WALES



Unmet need for care

Why are you unable to access as much care from outside the household for your disabled child as you would like? (n=46)



WALES

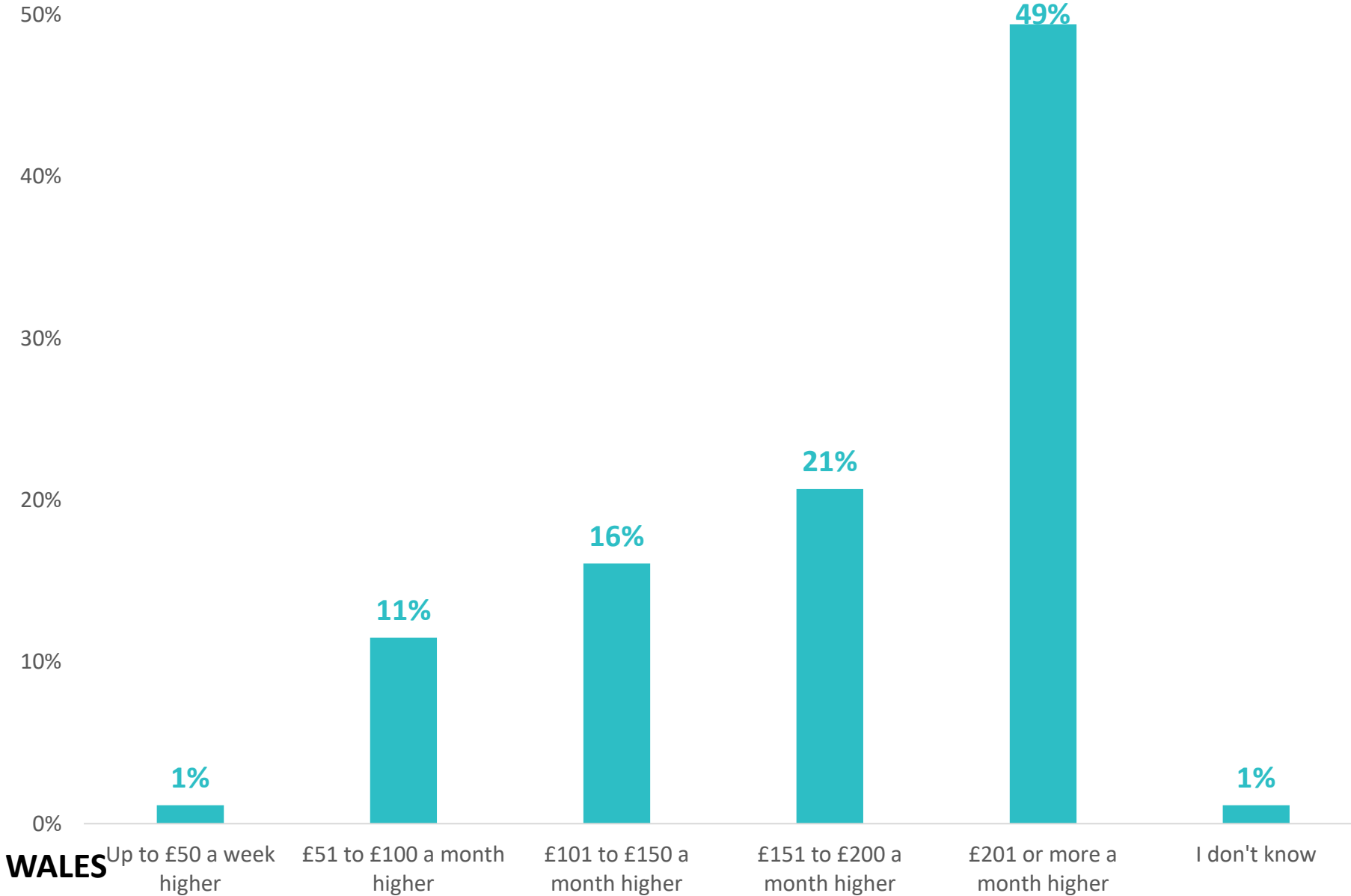
4. Increased and additional costs

Families raising disabled children face higher costs as a result of their children's disability which make them even more sensitive to the increasing cost of living. These increased costs include both additional items and increased costs of everyday items



Household Bills

“Thinking about how much higher your current regular household bills are compared to 12 months ago, which of the following describes the change?” (n=87)



97%

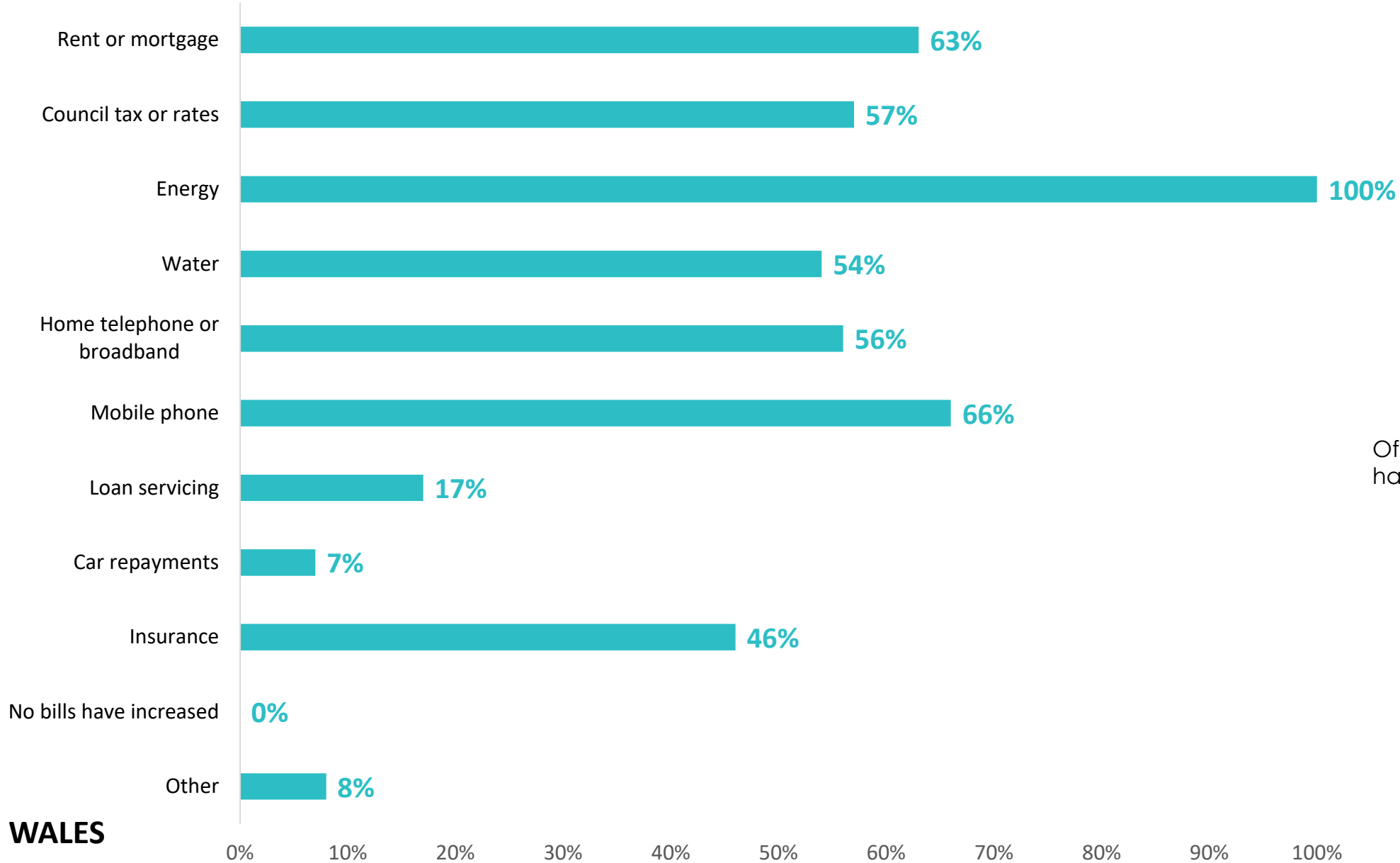
Of respondents report their current household bills are higher than 12 months ago (n=90)

WALES



Household Bills

“Which, if any, regular household bills have increased compared to 12 months ago?” (n=87)



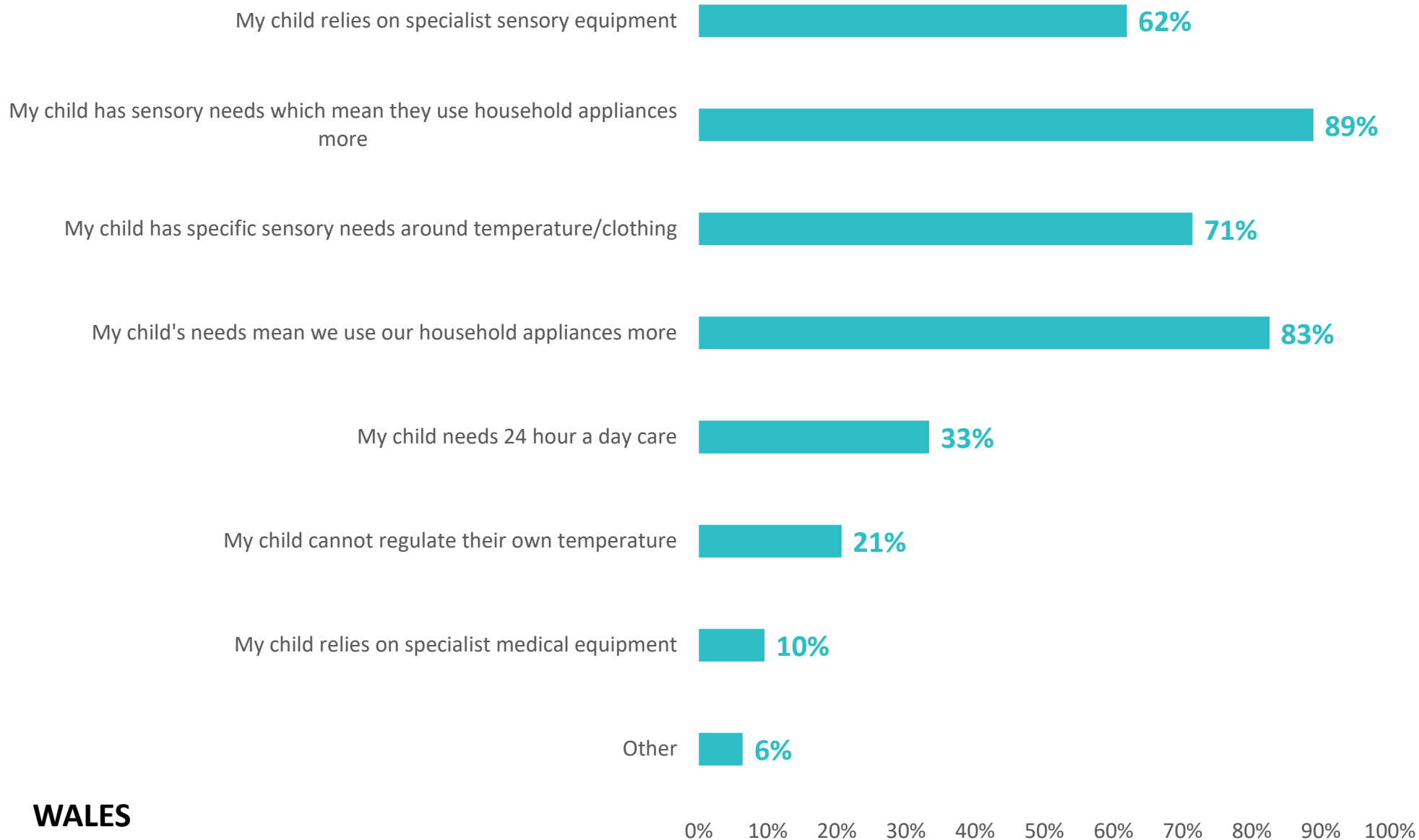
43%

Of respondents report they have **fallen behind on their energy bills** (n=90)

WALES

Additional Costs

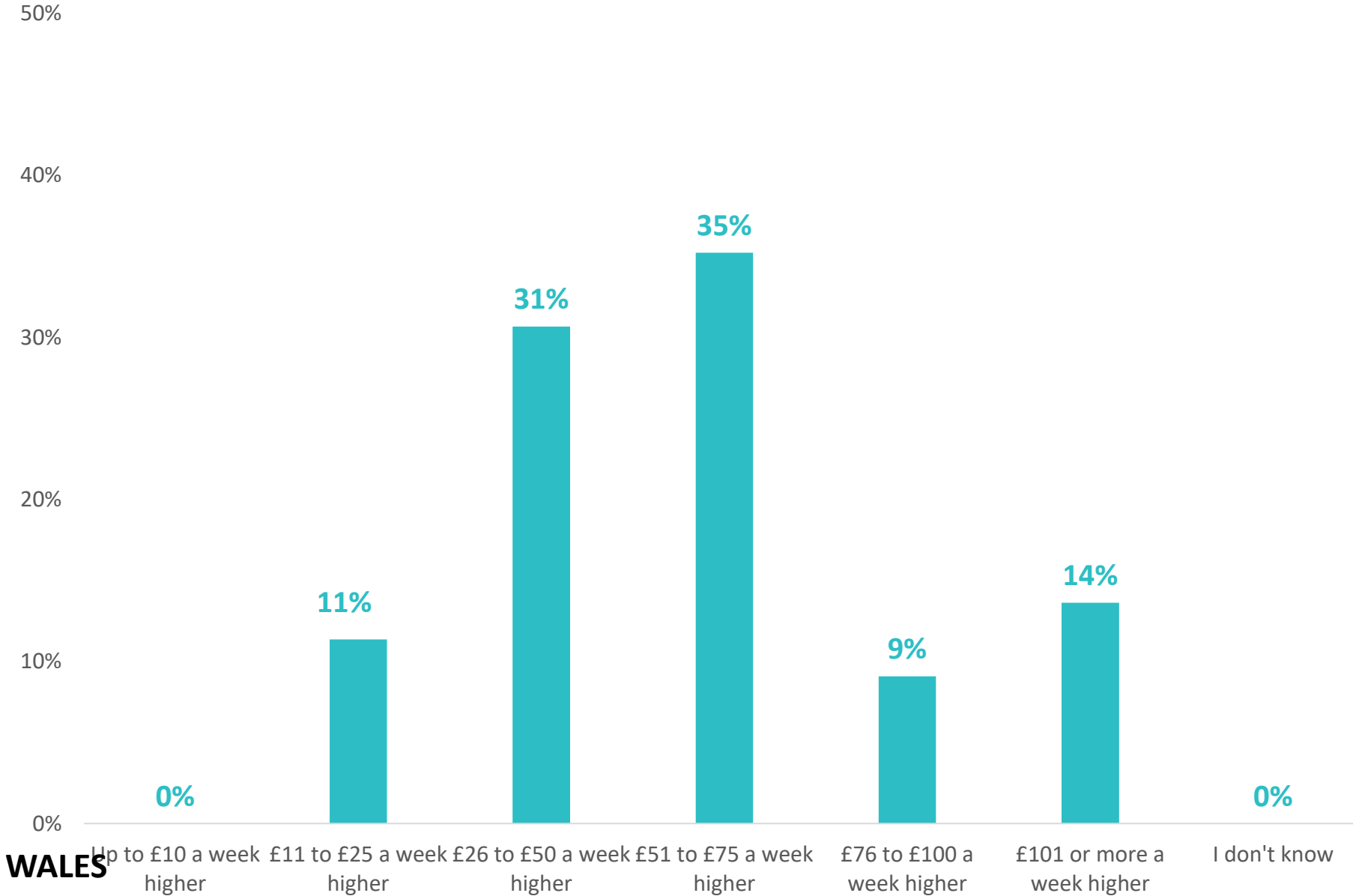
“What are the reasons that mean you have to use more energy than families raising non-disabled children?” (n=63)



70%

Of respondents said they have to **pay more for energy** as a result of their disabled children's conditions or illnesses (n=90)

“Thinking about how much higher your current weekly food shop is compared to 12 months ago, which of the following describes the change?” (n=88)



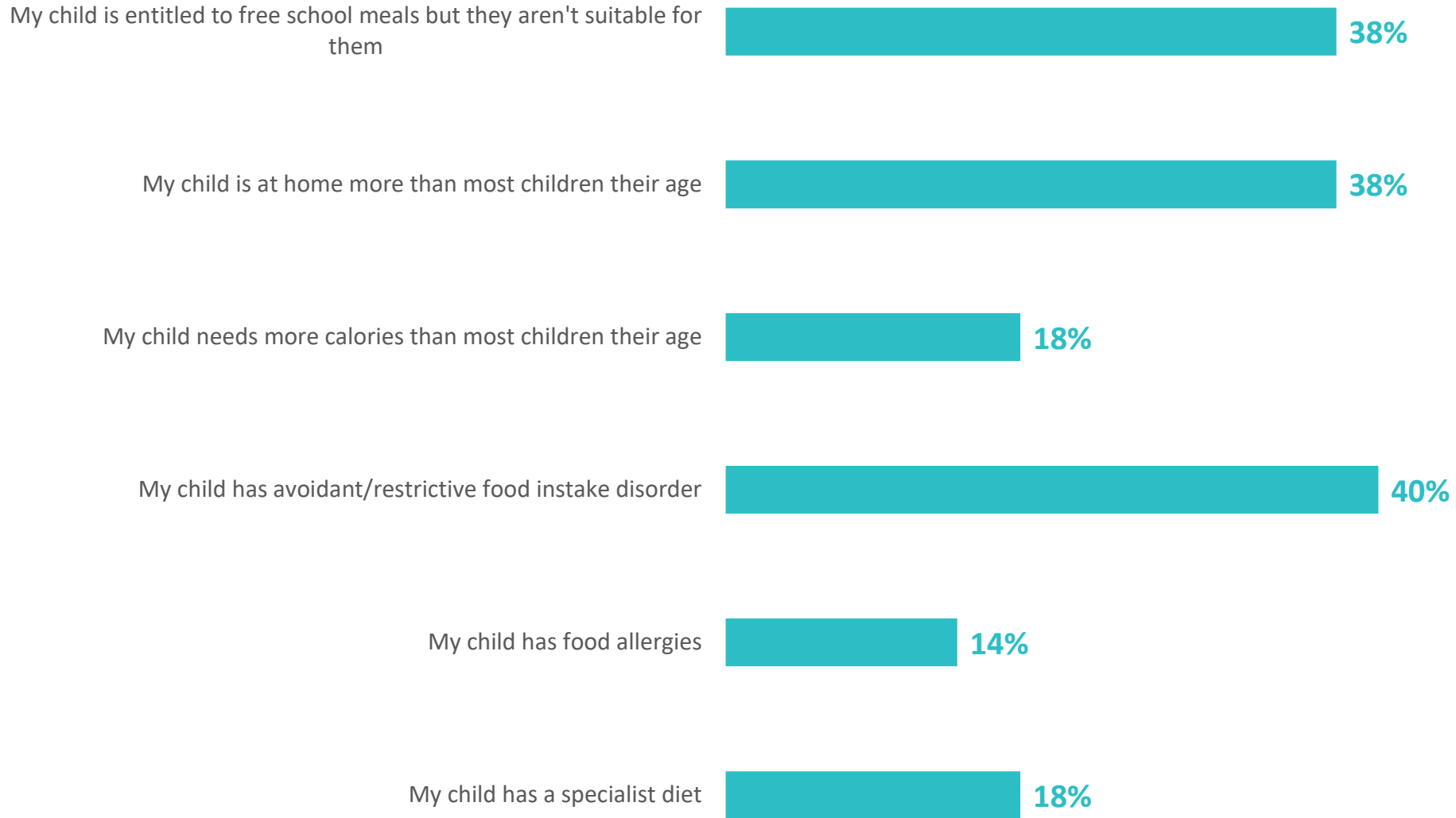
98%

Of respondents said their weekly food shop is higher than 12 months ago (n=90)



Additional Costs

“What are the reasons that mean you have to spend more on food and groceries than families raising non-disabled children?” (n=77)



86%

Of respondents said they have to spend more on food and groceries than families raising non-disabled children (n=90)

Family's experiences of needing to spend more

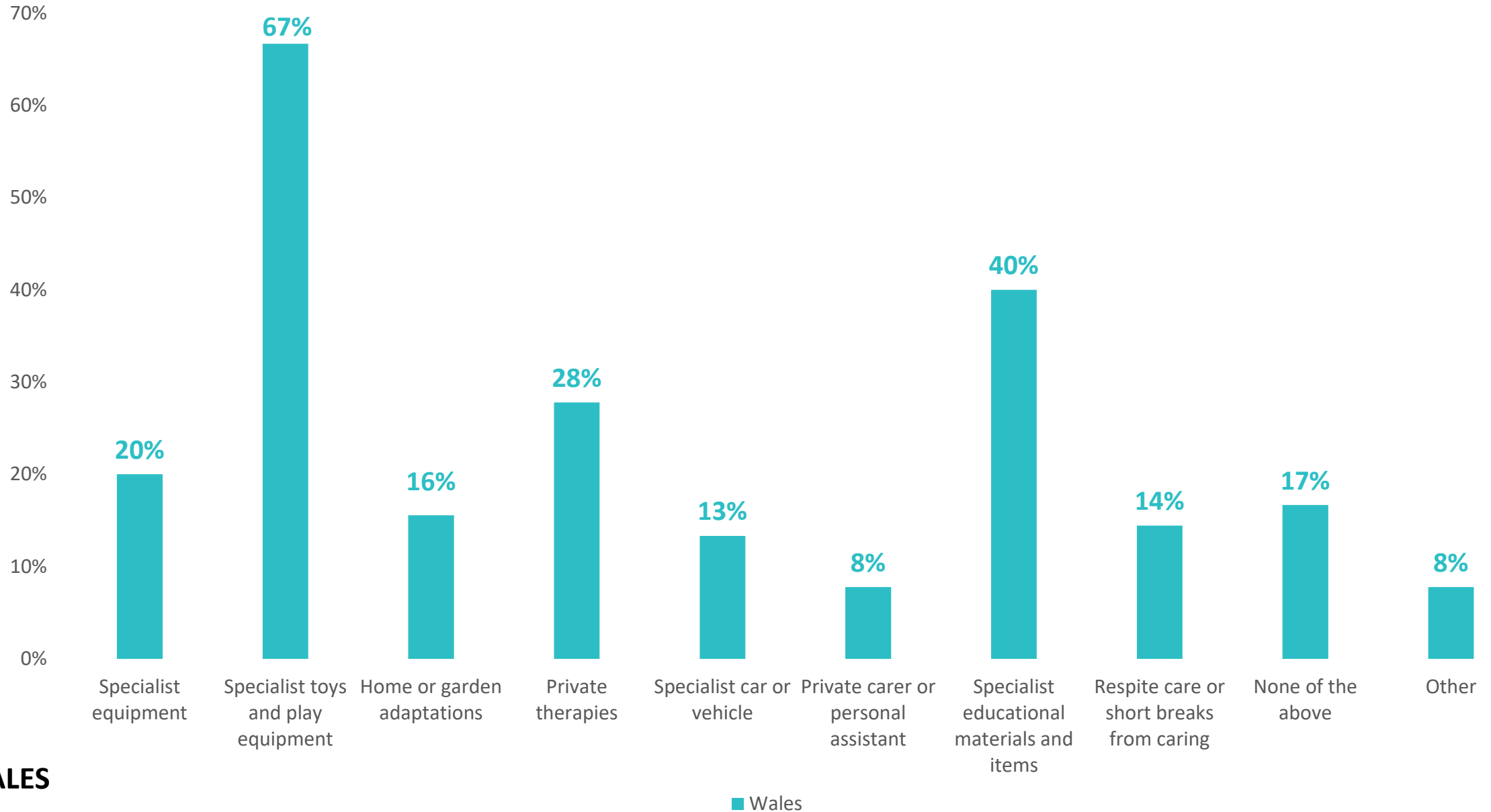
"It's hard, it really is. Trying to smile through the mental pain and worry if we can make it to our next pay day, fear of my children missing out because we can't afford to do nice things. Right now it feels one big negative but seeing my children smile and tell me they love me makes life one big positive even if that feeling only lasts a minute"

"Things are harder with the increased cost of living."



Additional Costs

“As a result of your disabled children’s conditions or illnesses, have you had to buy any of the following specialist items and services using your own money?” (n=1,116)



WALES

The financial cost of caring

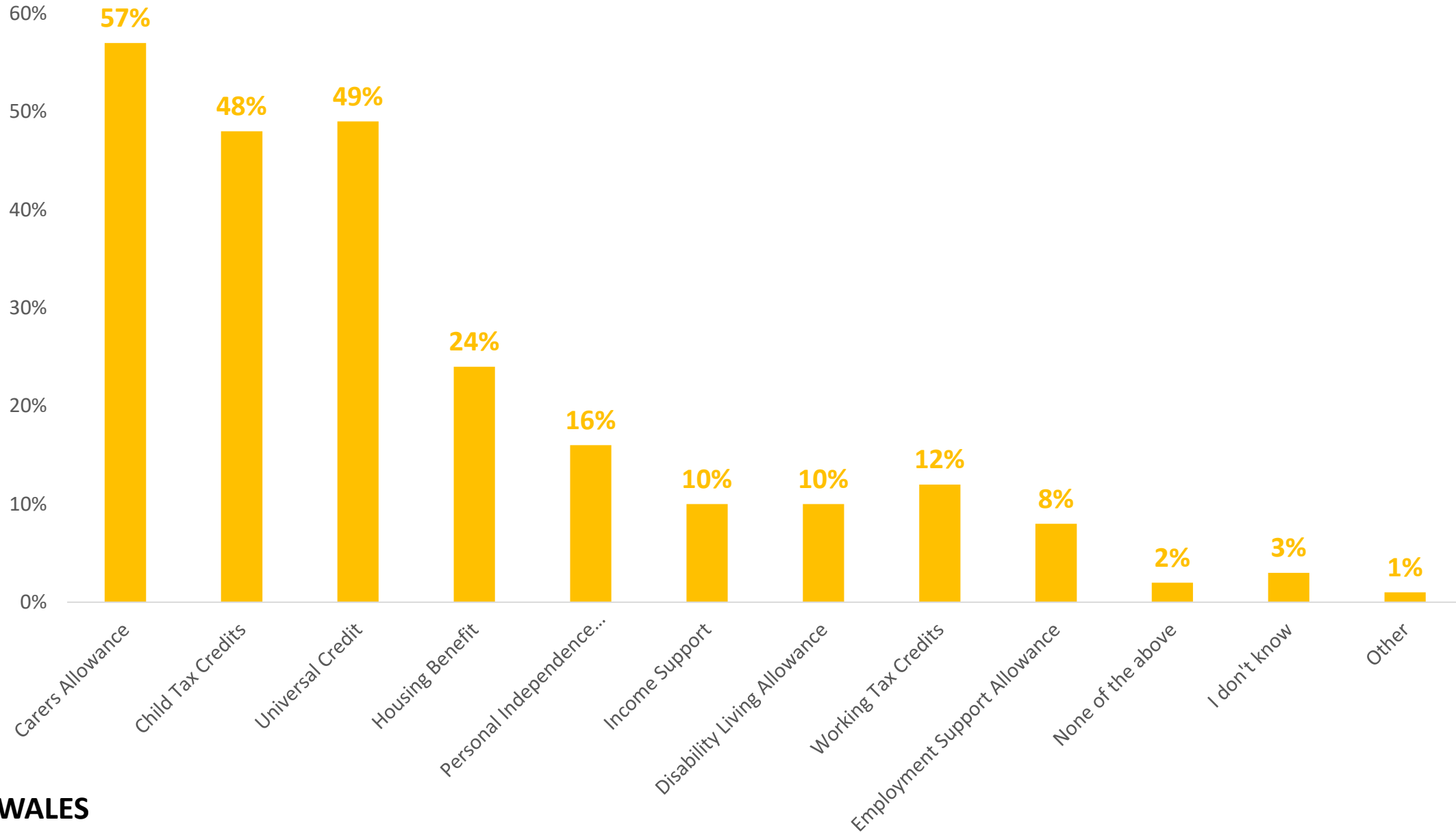
5. Relying on benefits

The vast majority of families have to rely on state benefits for at least some of their income.



Benefits families receive

Which benefits do one, or more, adults in your household currently receive? (n=90)



WALES



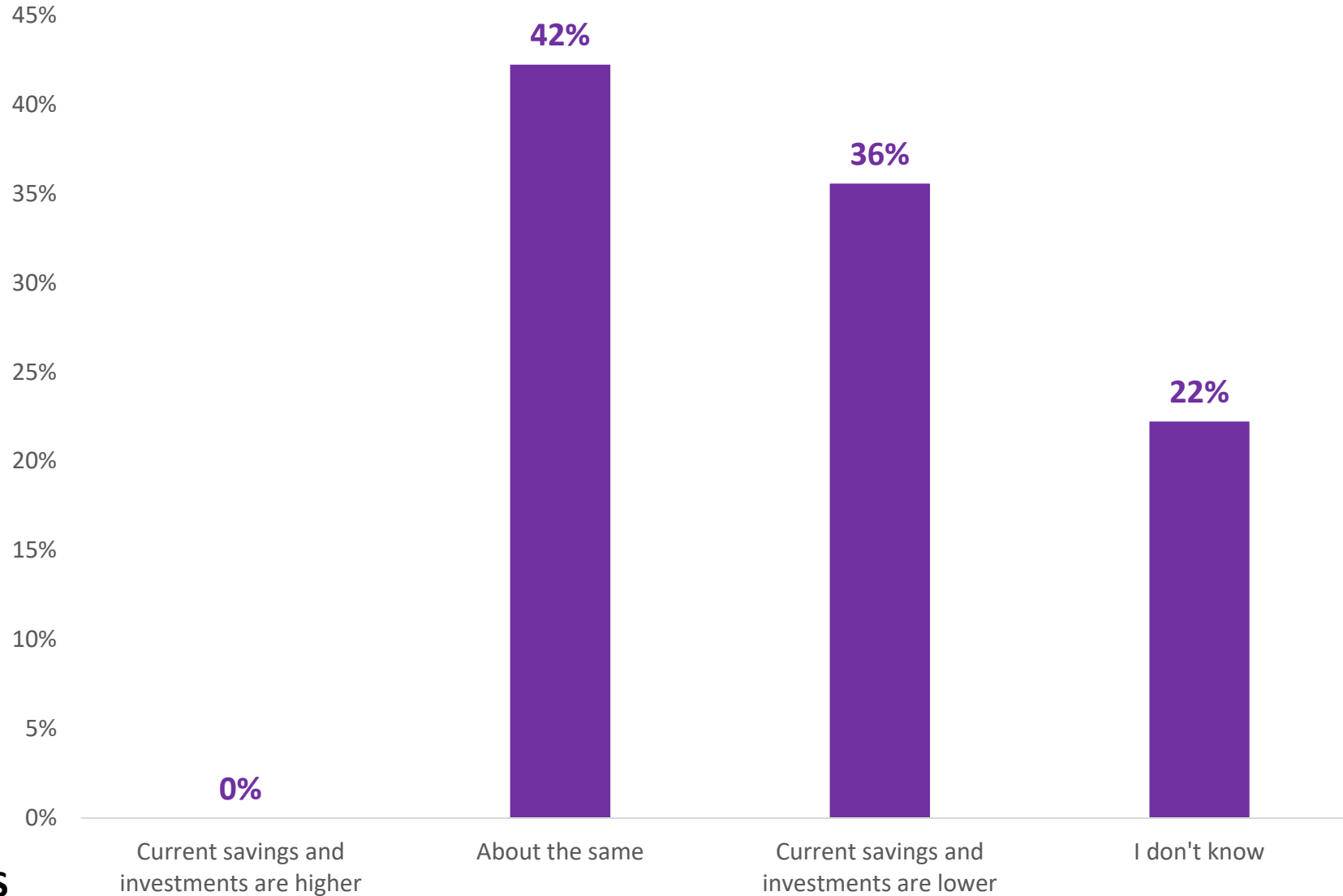
6. Savings

Families are in a financially precarious position with many having very limited access to savings and relatively small unforeseen costs being enough to cause significant financial distress



Family savings

“Thinking about your current household savings and investments, would you say they are higher, lower, or about the same as your household savings and investments 12 months ago?” (n=90)



83%

families report that they have **no savings** or investments

WALES



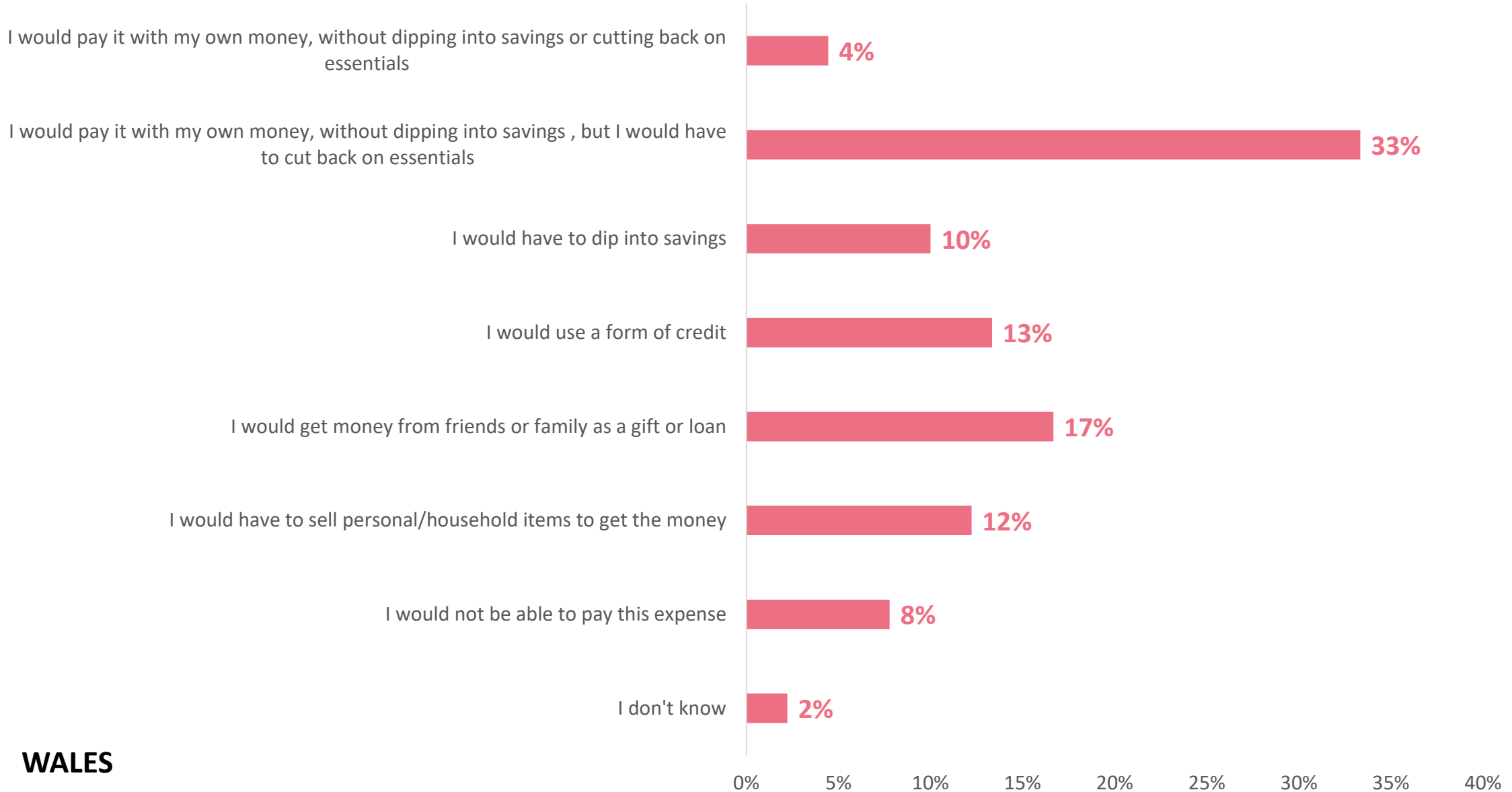
7. Going into debt

Where families cannot make any further cut backs, they are often forced to go into debt to pay for essential items and bills.



Trying to financially cope

“Would your household be able to pay an unexpected expense of £200?” (n=90)

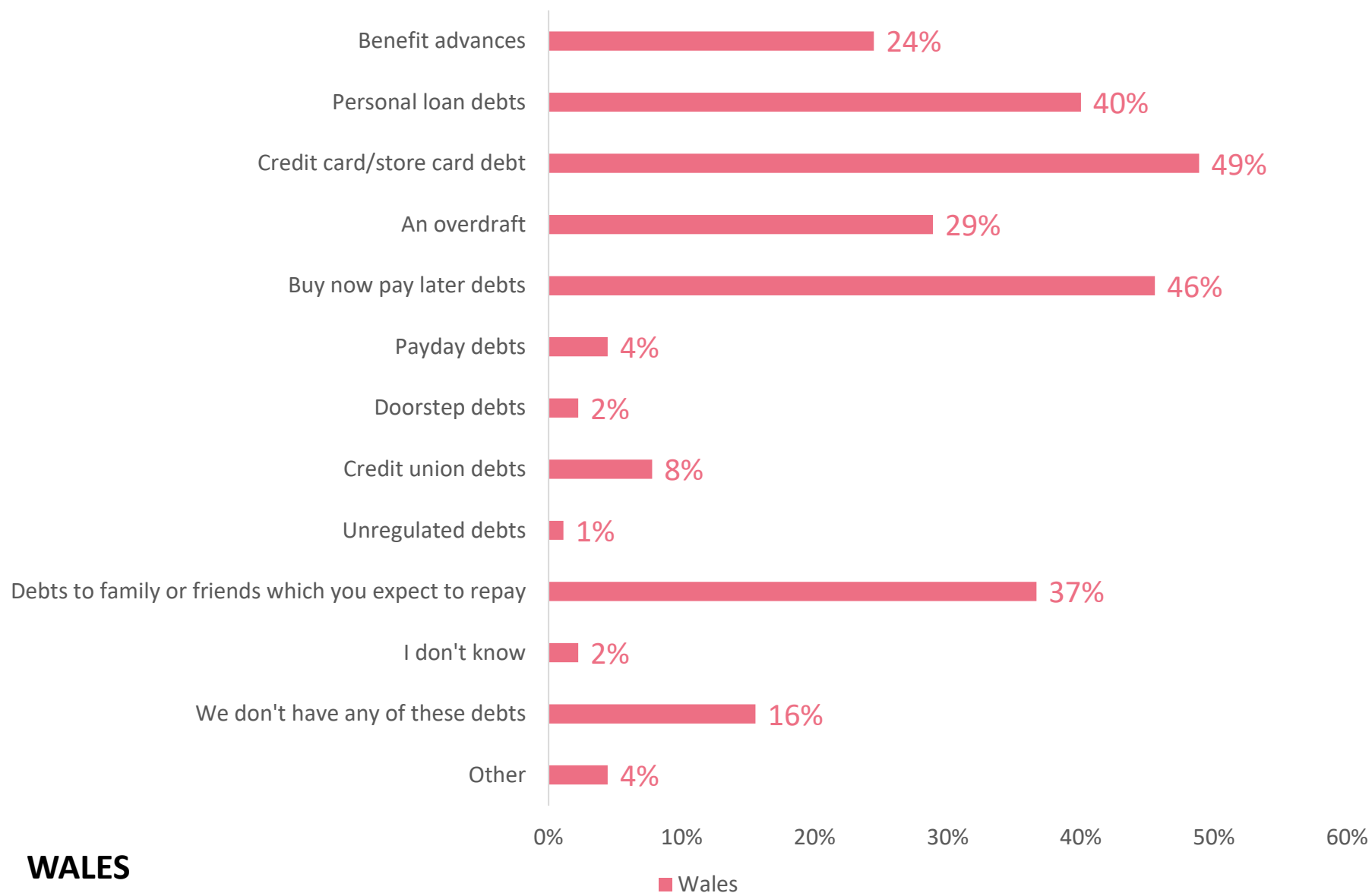


WALES



Going into debt

“Do you have any of these debts?” (n=90)



86%

families report that **keeping up with the repayment** of their debts is a difficulty or burden. (n=74)

52%

families report that it's fairly or very likely they will need to borrow more money or **go further into debt in the next six months**

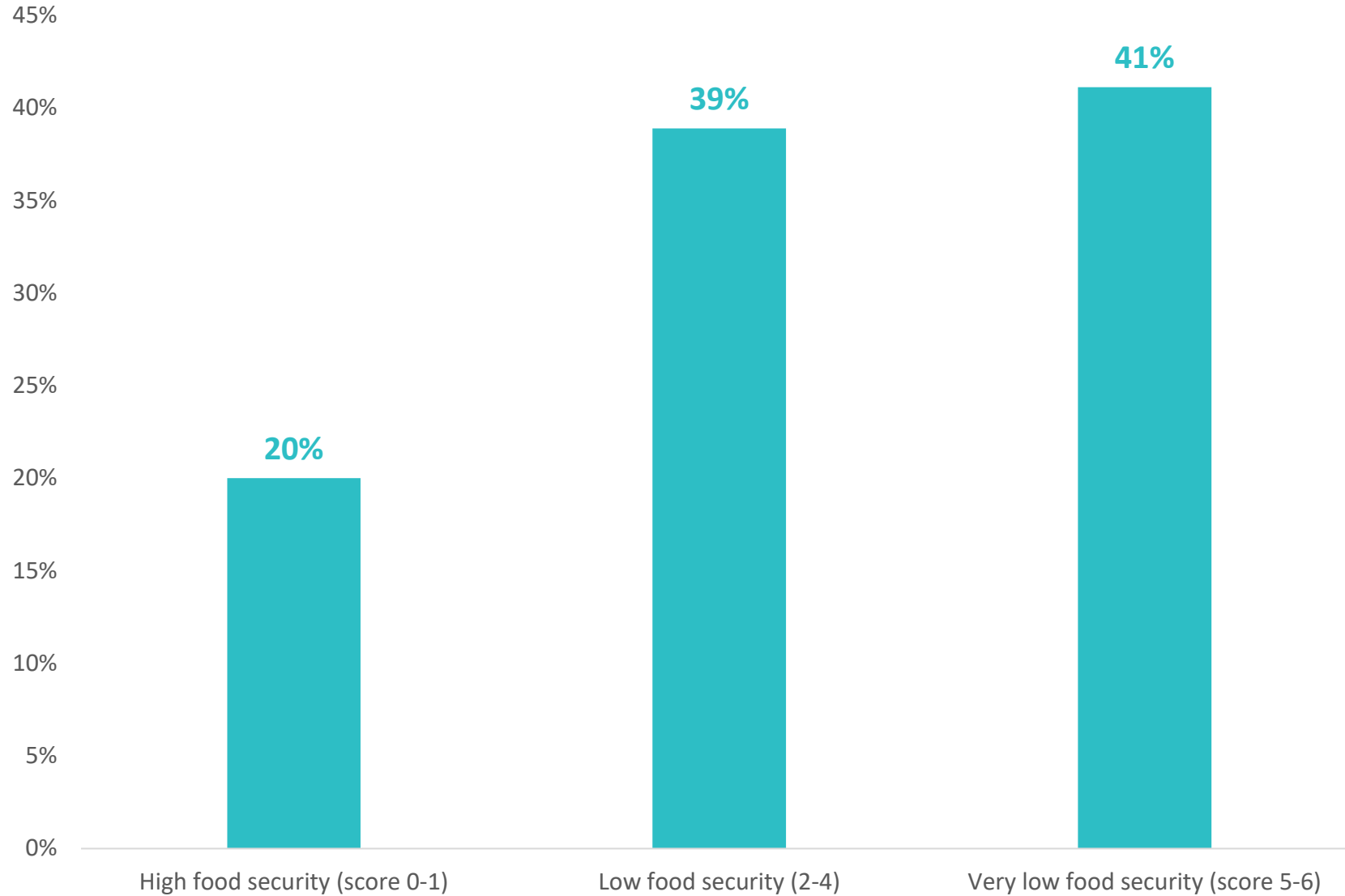


8. Going Without

Many families raising disabled children not only face an income penalty, they also face extra costs as a direct result of their children's conditions and illnesses.



U.S. Household Food Security Survey Module: Six-Item Short Form Food Security Scale (n= 90)



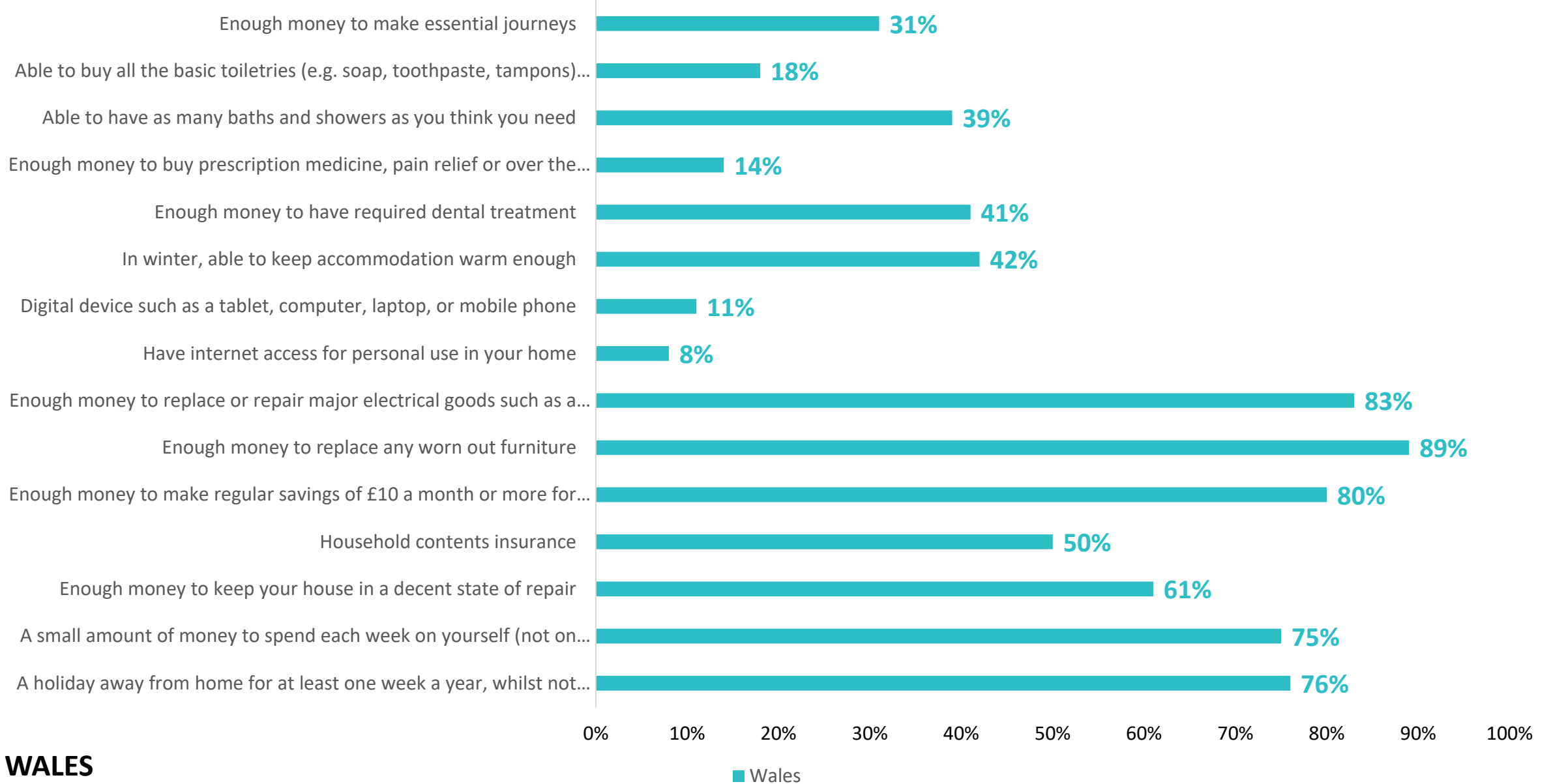
40%

families report that they have had to use a food bank because there wasn't enough money for food



Going Without – Parent/Carer

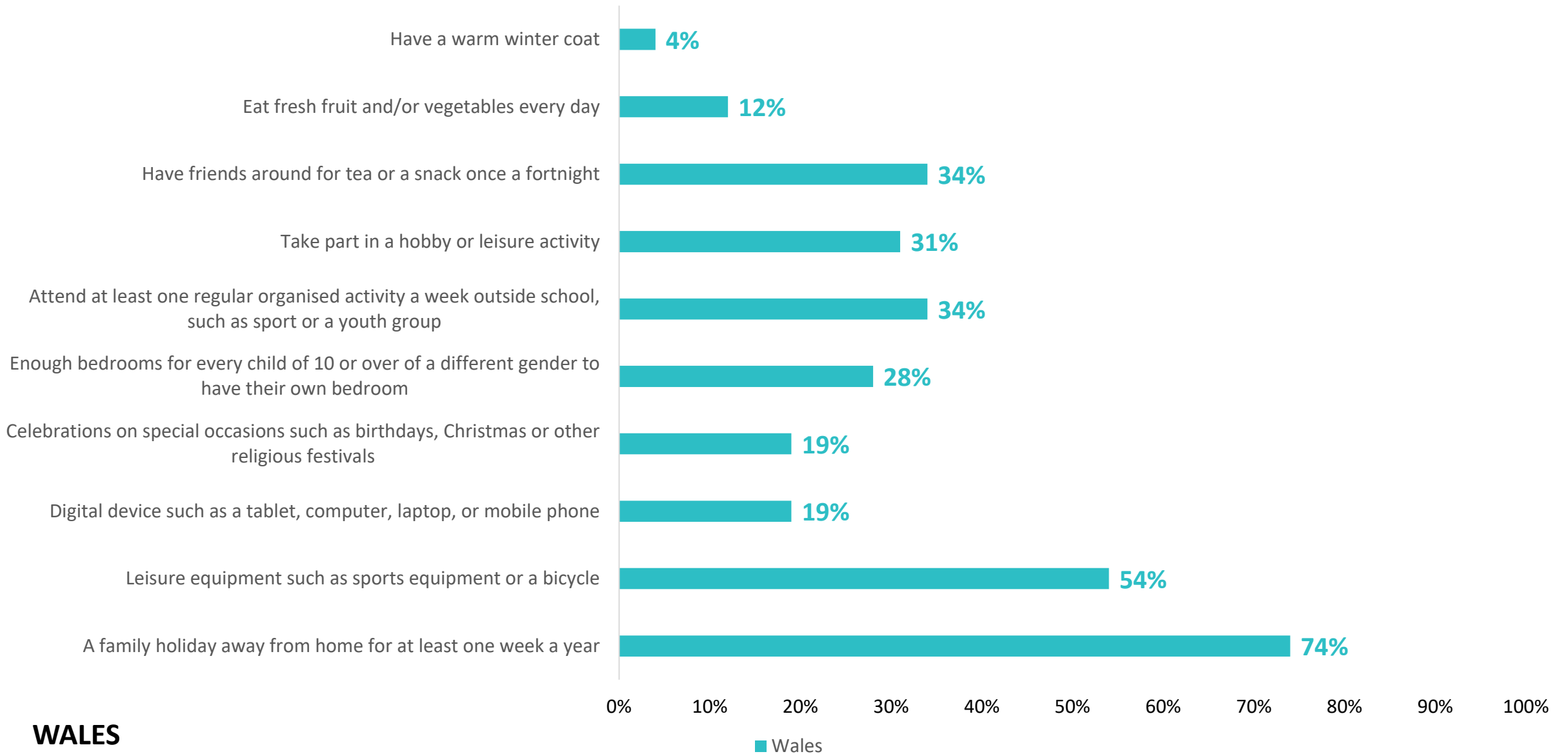
“We can’t afford this” (n=90)



WALES

Going Without – Disabled Children and Young People

“We can’t afford this” (n=90)



The resulting wellbeing impacts

9. Disabled children

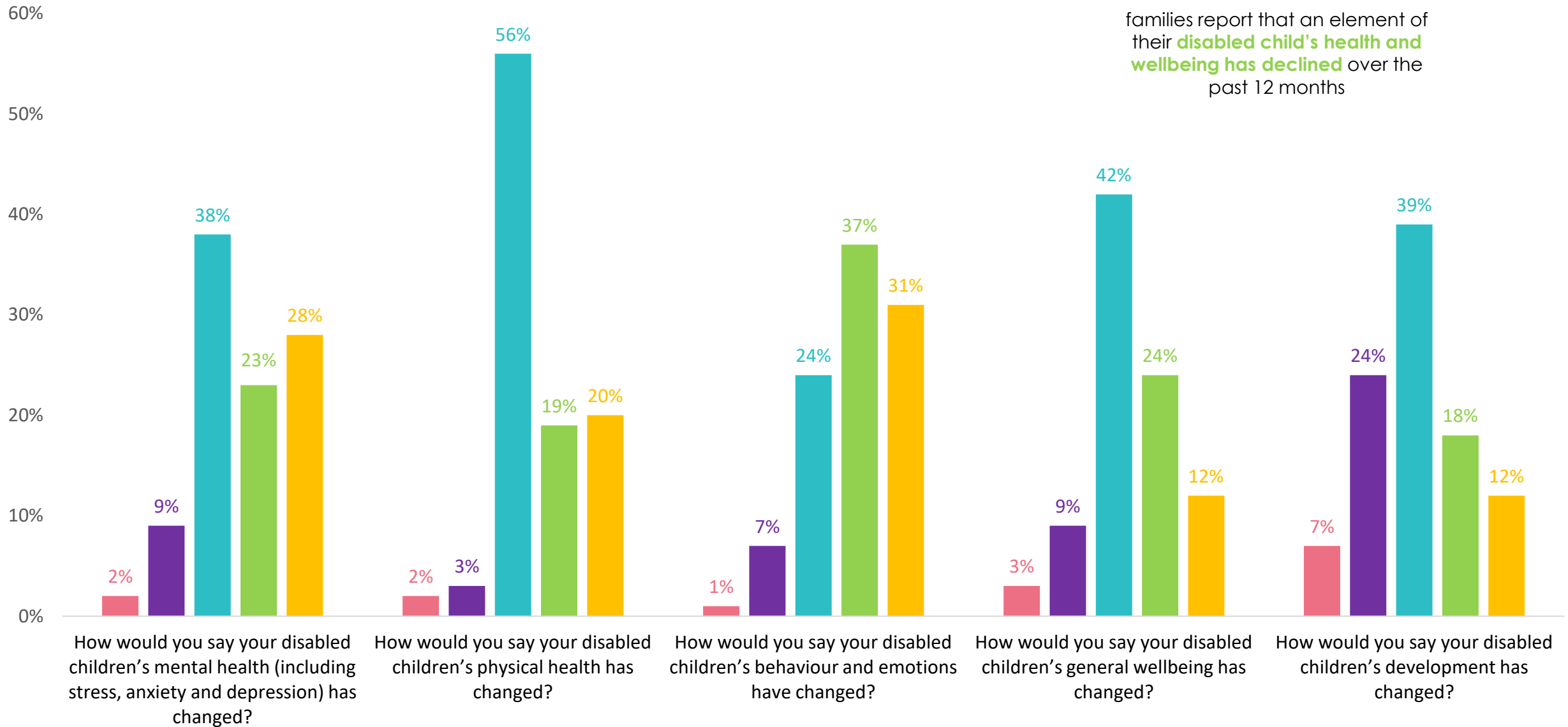
The situation families find themselves in has a negative impact on the health, wellbeing and quality of life of disabled children.



74%



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



WALES

■ Much better ■ Somewhat better ■ Stayed the same ■ Somewhat worse ■ Much worse

Disabled children's wellbeing

Everything is a waiting game while you watch your child slowly get worse and your finances slowly deteriorating so you cannot have any respite or family days out because you're too scared of what might happen when outside."

"It's very rewarding when they progress or learn a new skill, cope in a new environment. Remembering you may not always feel good enough but your child thinks you are the best thing in the world."

"I feel more support should have been offered as my child was isolating for so long he struggled with getting back to the big outdoors"



The resulting wellbeing impacts

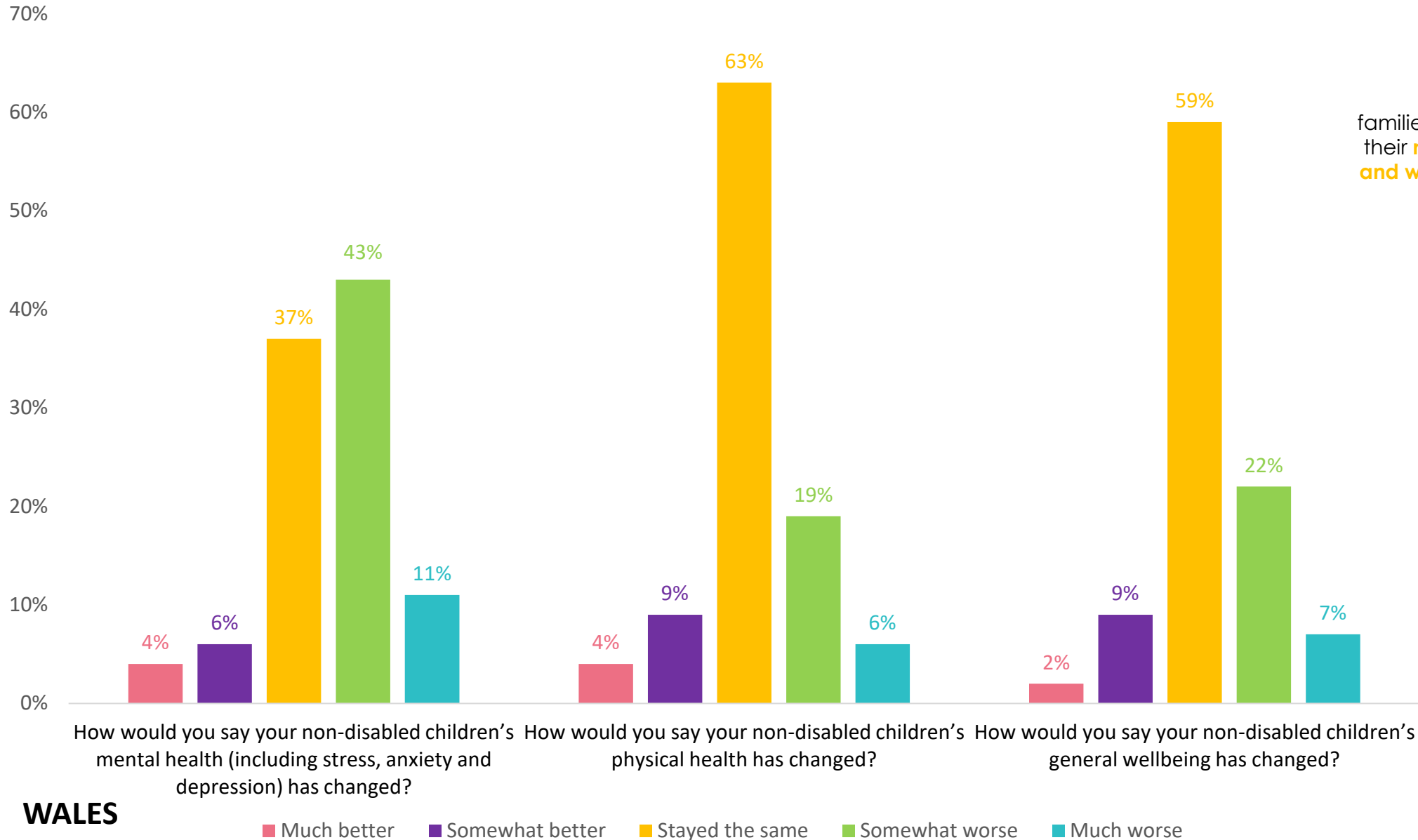
10. Non-Disabled children

The health and wellbeing of many non-disabled children has also been negatively affected.



Impact on non-disabled children

“Over the past 12 months...” (n=54)



57%

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

WALES



11. Parents and carers

The health and wellbeing of many carers has also been negatively affected.



Impact on parents and carers

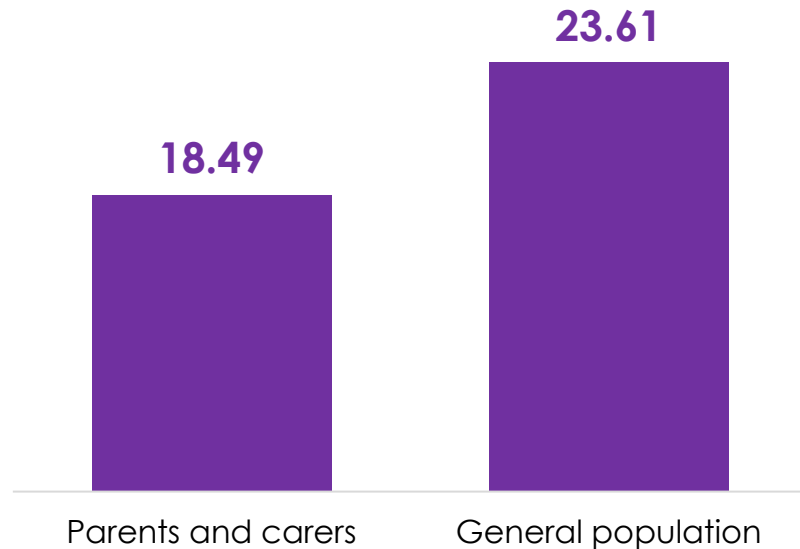
Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale) (n=90)

High wellbeing 35

79%

Low wellbeing (adjusted score of less than 19.5)

Low wellbeing 7



WALES

7.27

Mean UCLA Loneliness Score

33%

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

48%

Probable depression (adjusted score of less than 18)



Parent's experiences of the impact of caring

"It often feels lonely even with the best support from family. Other people's lack of understanding can be brutal."

"My kids are amazing - talented, intelligent, funny, joyful, but they're also shy and sensitive and fearful and I just wish there was another adult who cared about their successes and was there to help support them in their sadness. Anyone caring for a kid with additional needs, needs help and support. I don't have any."

"I wish our families would be a thought before hand rather than an after thought. I'm sick of having to change my son on a disabled toilet floor. I'm sick of having to avoid places because of the looks and stares. The tuts from families who don't understand ours."

"My experience of caring for my son has been very hard on my mental health with fighting schools, filling in relentless forms and not getting any personal or private support from GPs, paediatrics"



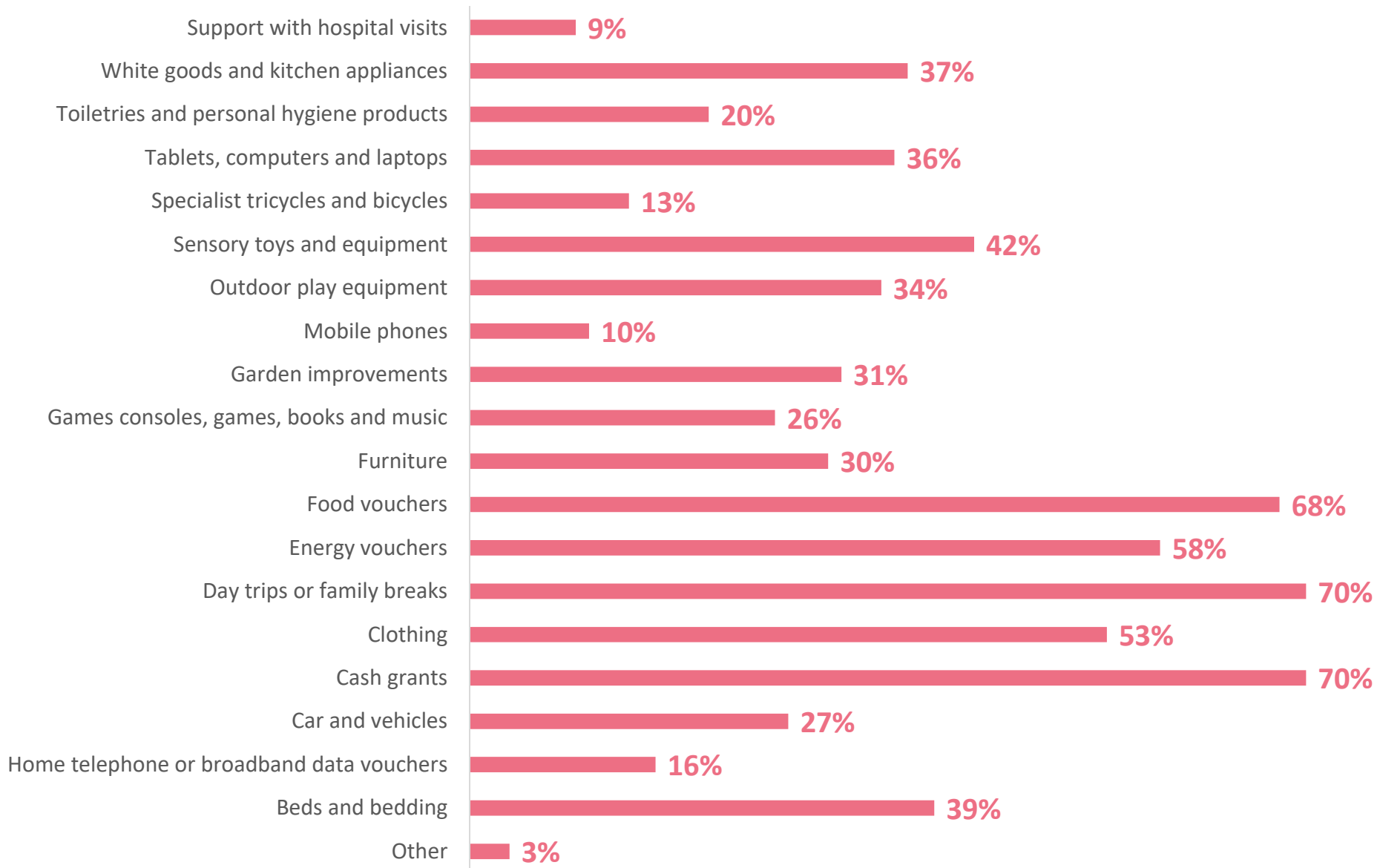
12. Other Needs

We are also interested in understanding what other support Family Fund could offer and what other unmet needs families have.



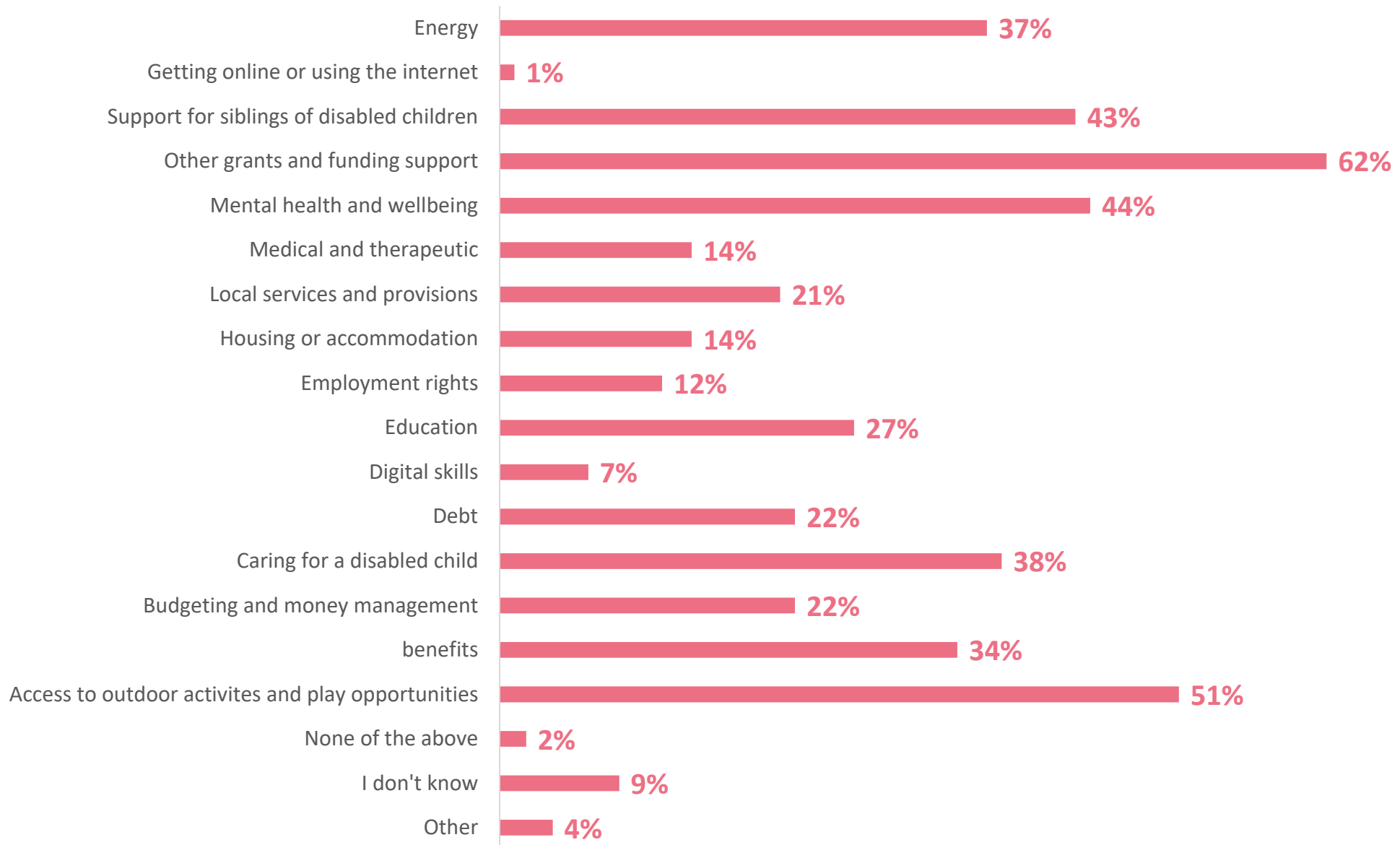
Your needs

“Which grants could we potentially provide that would be most helpful to your family right now?” (n=90)



Your needs

“Which topics could we potentially provide information and support on that would be most helpful to your family right now?” (n=90)



WALES



Other family needs

There isn't enough support for those children that fall in the middle eg who are able to cope with support in a mainstream school but who have additional needs around their social and emotional behaviour.

I am a member of a lot of charities and you still don't get proper advice and help when it is really needed

Everything is a battle, it shouldn't be that way. Help and support should be transparent and readily available.

Still waiting for services to help. Even though they know we are struggling with challenging behaviour



NORTHERN IRELAND



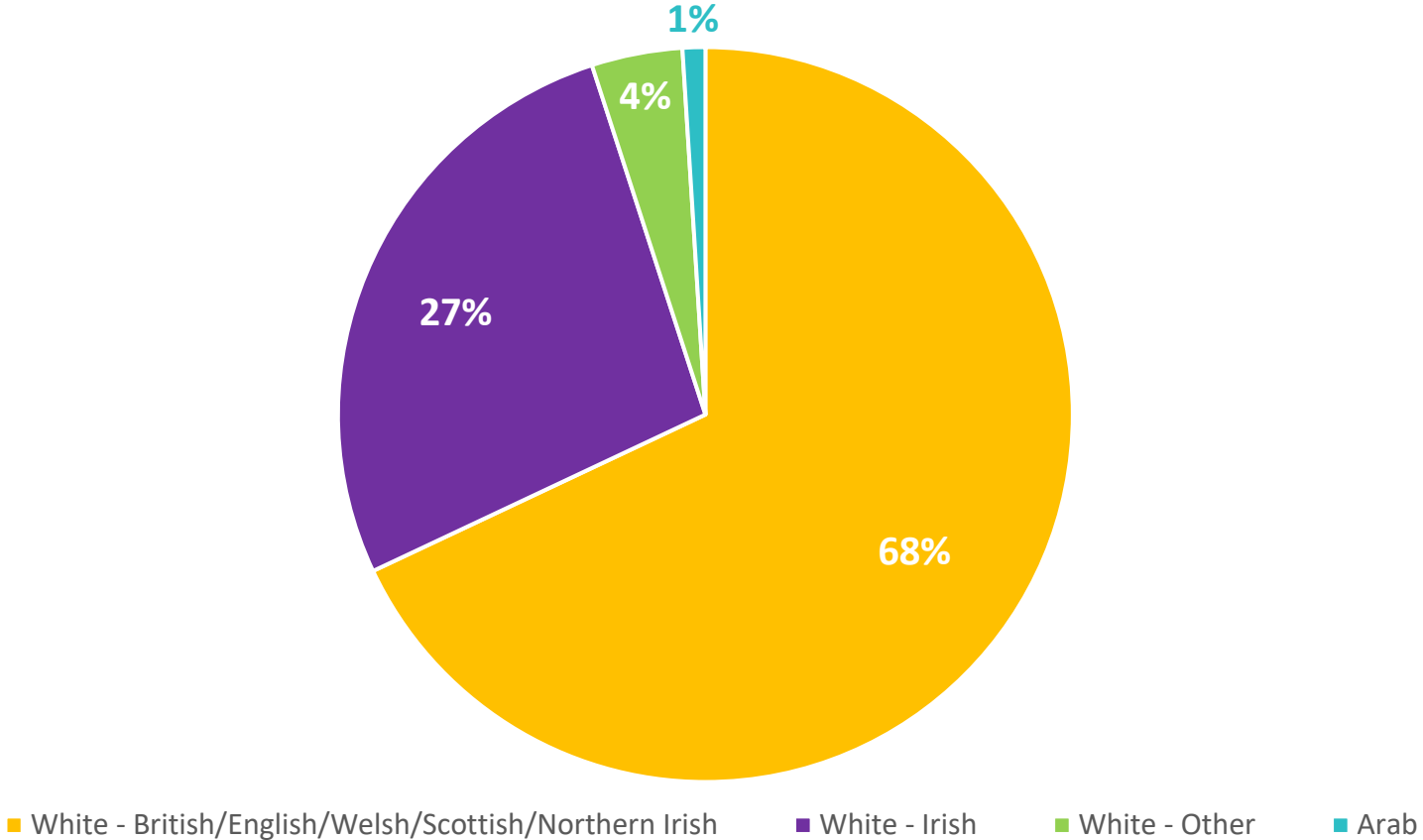
1. Profile of families

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

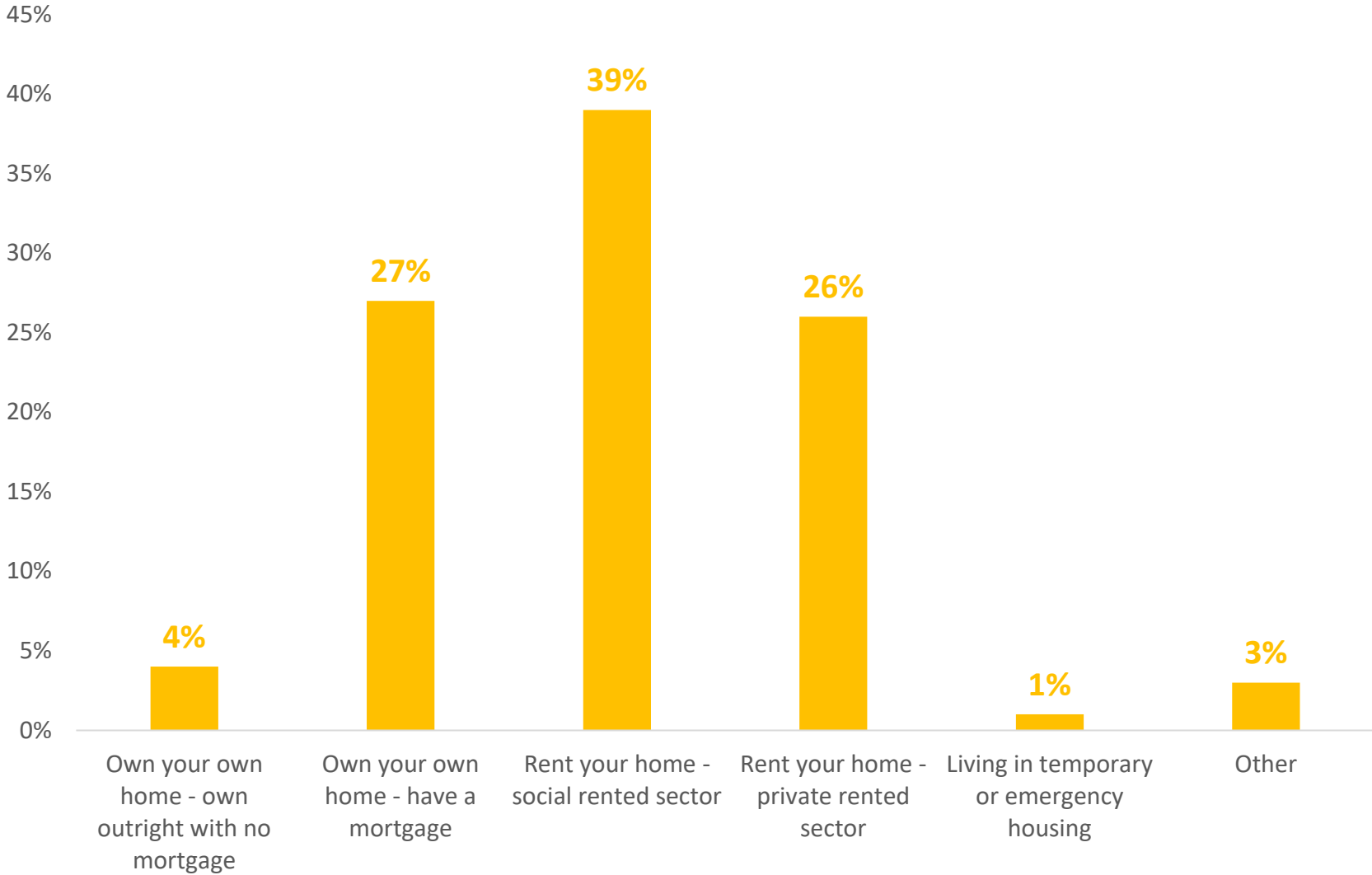


Who are the families who took part in Family Poll?

What is your ethnic group? (n=139)



Who are the families who took part in Family Poll?



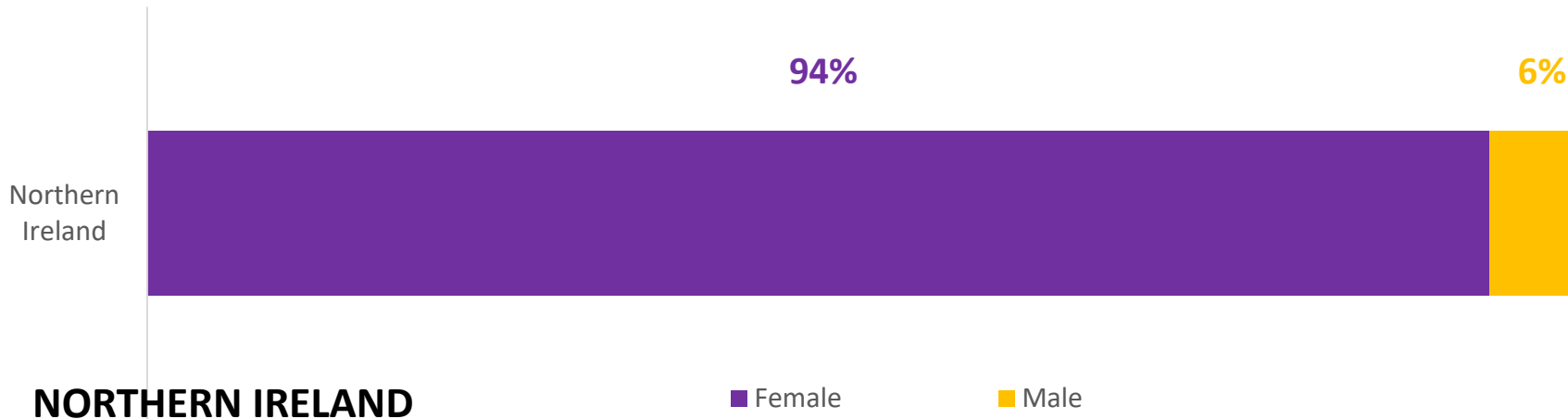
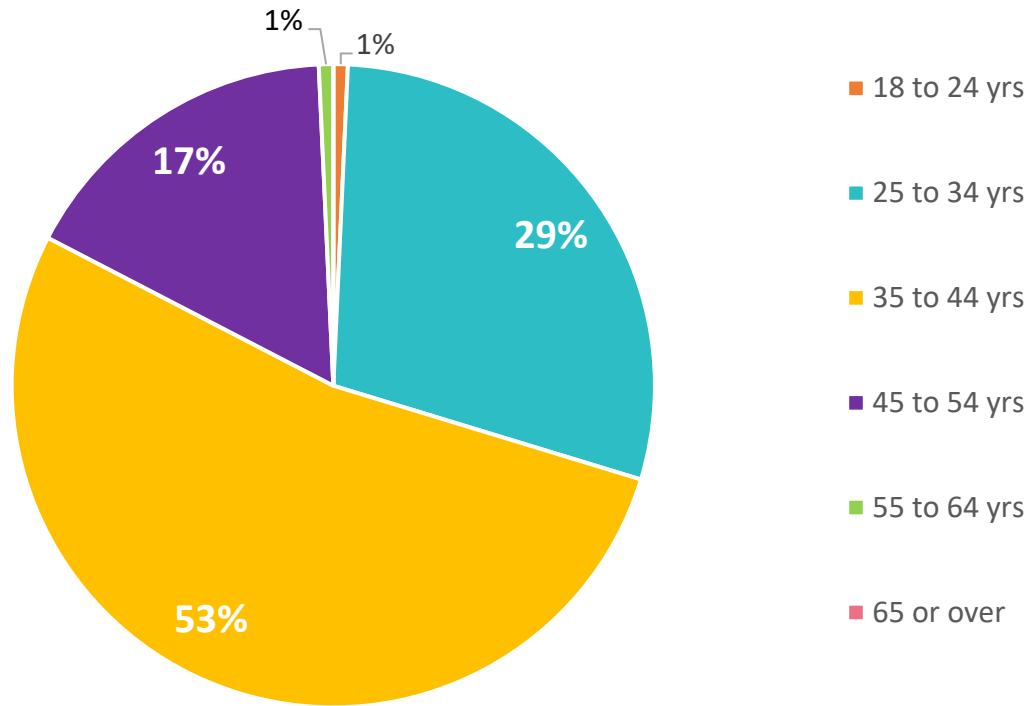
NORTHERN IRELAND

139
Responses from families

62 %
Of families that responded were **single adult households**



Parents and Carers (N=138)



70%

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

58%

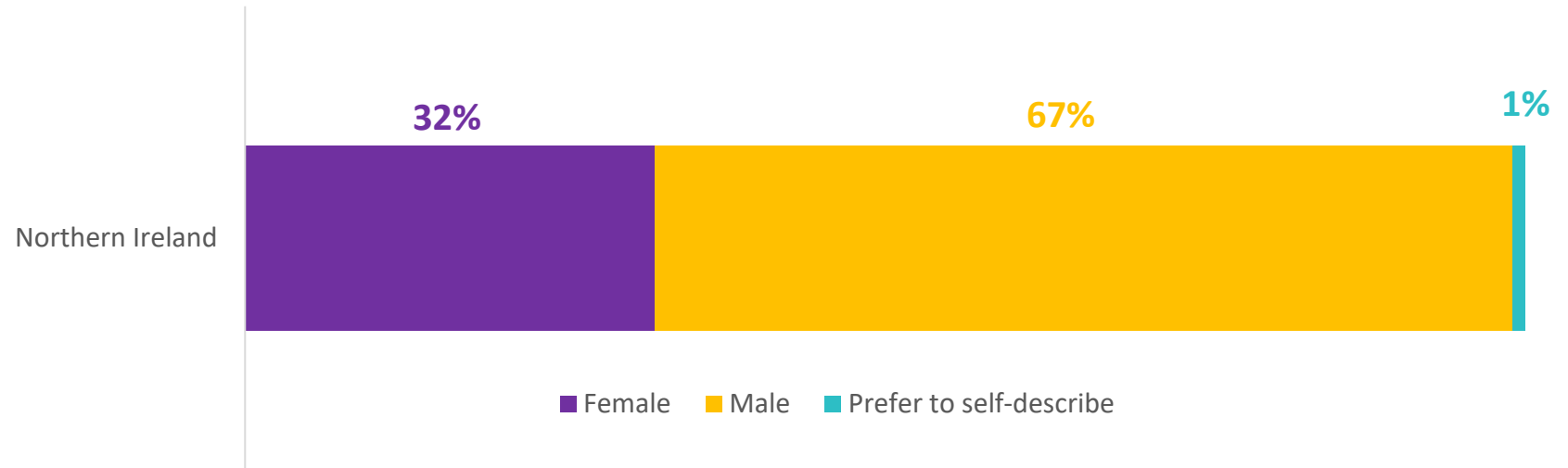
Of respondents **have a long-term physical or mental health conditions or illness**

50%

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

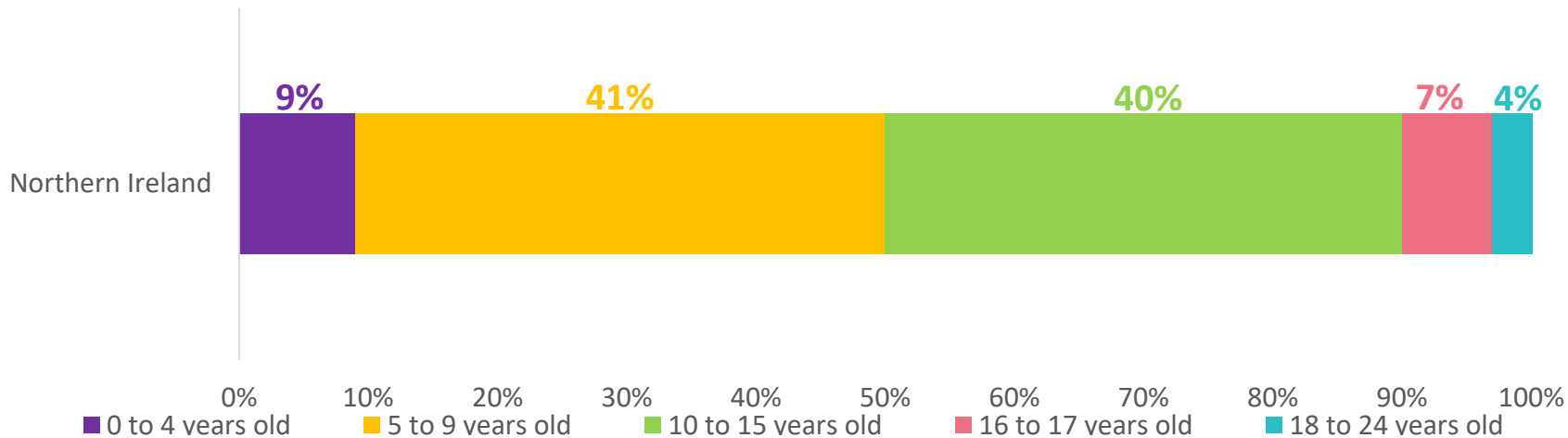


Disabled Children and Young People (N=138)



210

Children with disabilities or serious illnesses



143

Children without disabilities or serious illnesses



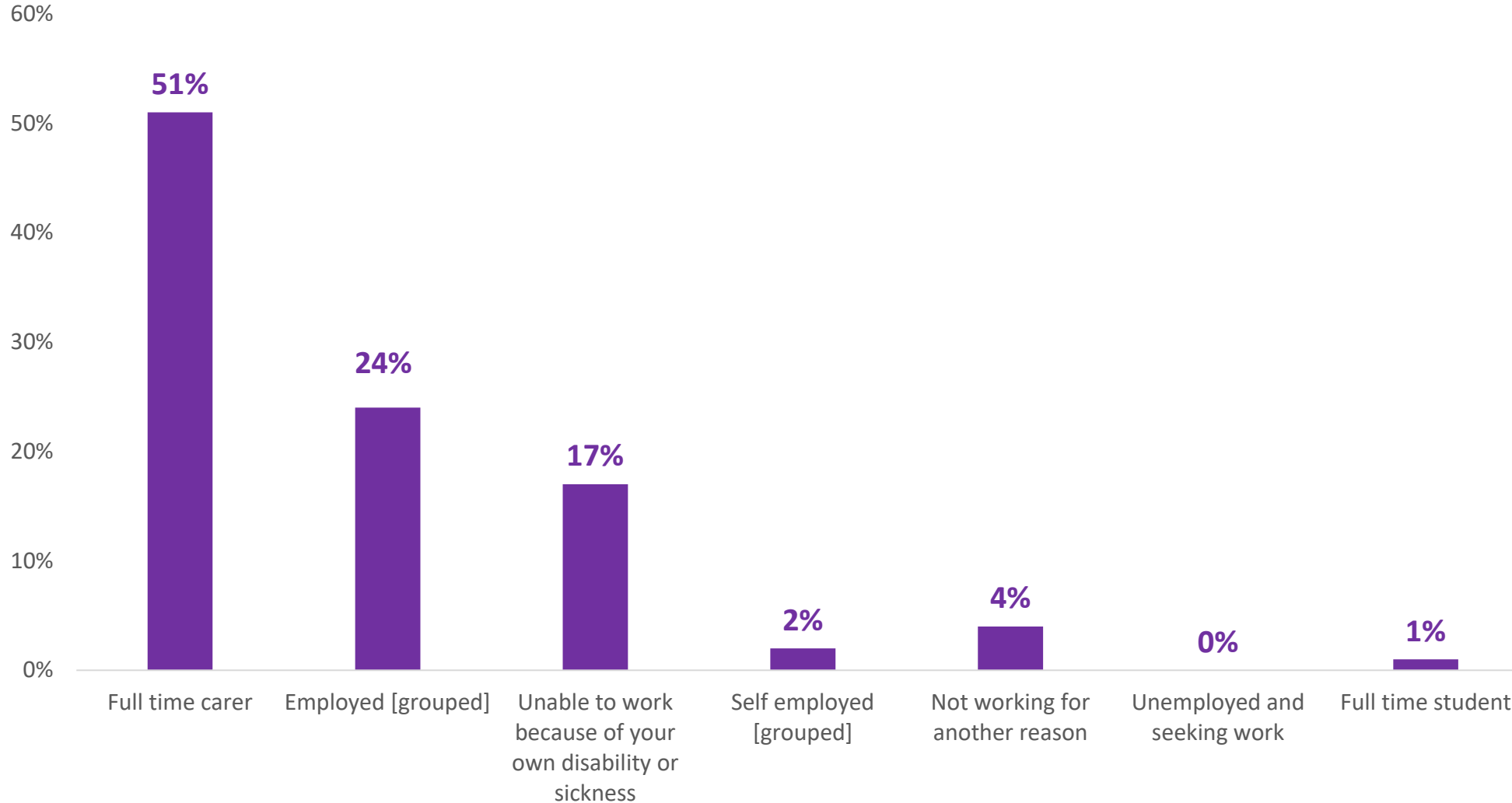
2. Reduced incomes

For many families raising disabled children, parents and carers' ability to earn an income is significantly limited by their commitment to caring for their child.



Working and caring

“Are you employed?” (n=138)



£17,744

The mean **annual household income** reported by families (n=122)

£1479

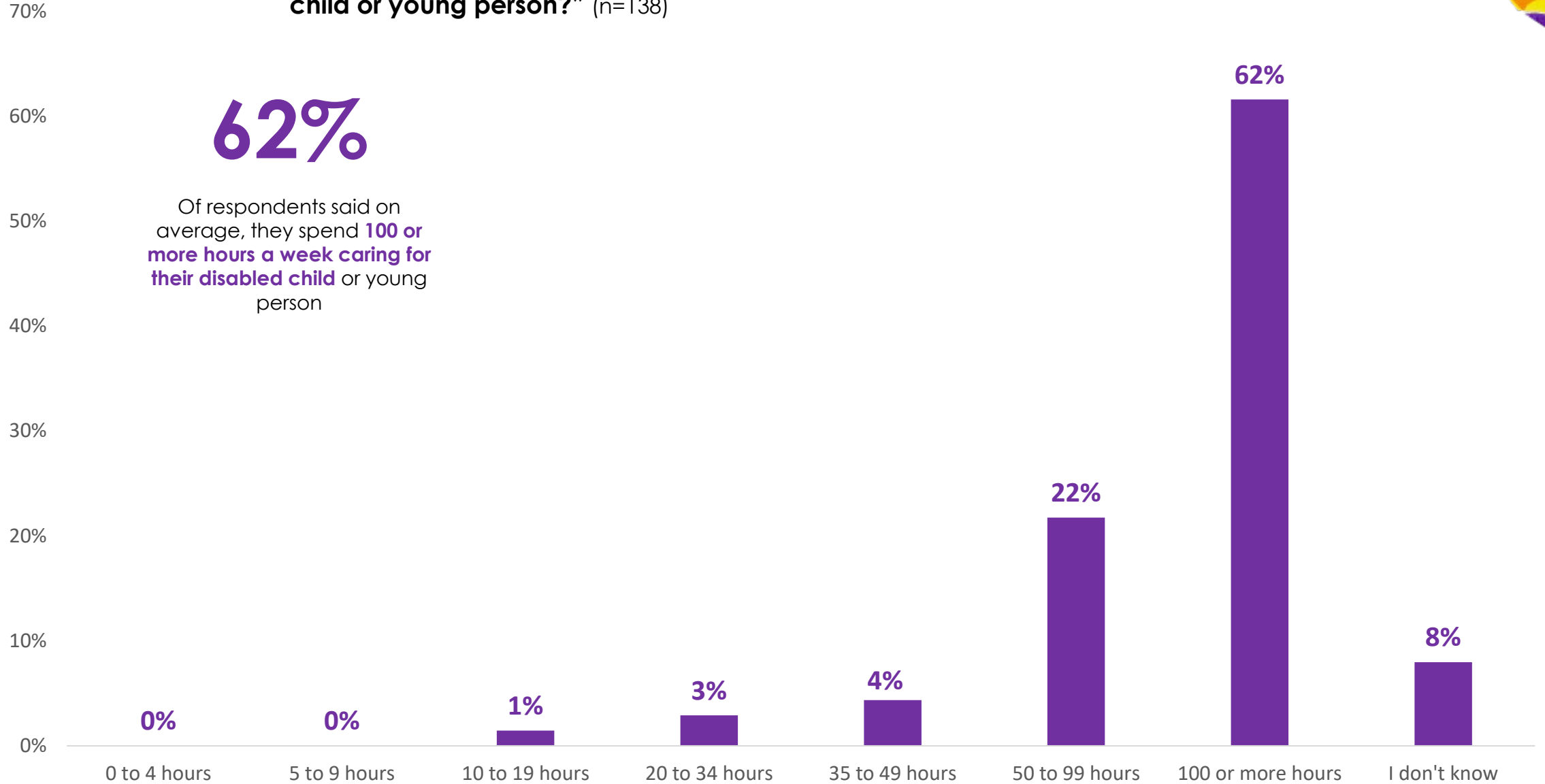
The mean **monthly household income** reported by families (n=122)

NORTHERN IRELAND



Caring

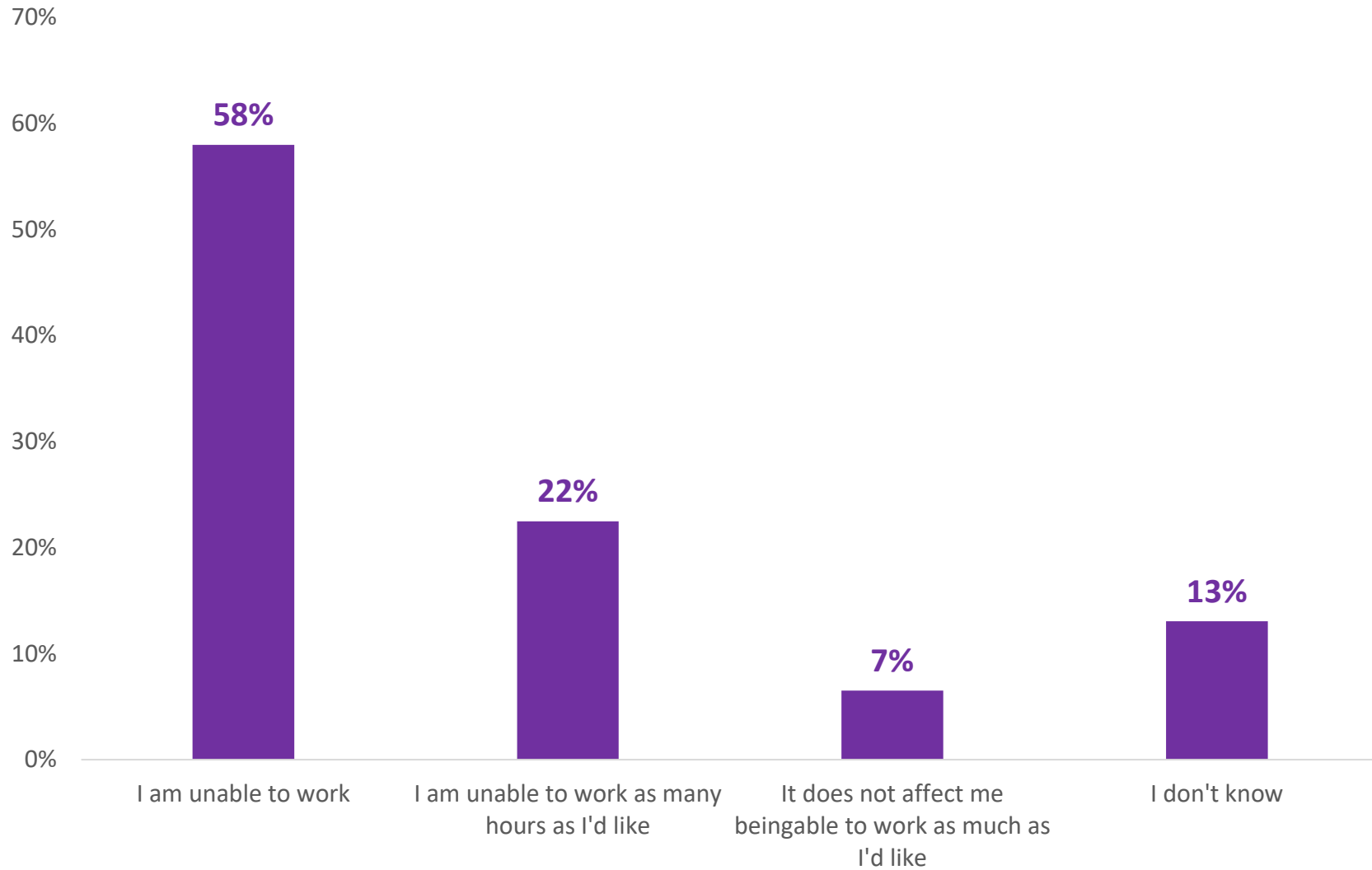
“About how many hours a week, on average, do you spend providing help for or looking after your disabled child or young person?” (n=138)



NORTHERN IRELAND

Caring

“Do your caring responsibilities for your disabled child or young person mean you cannot work as much as you would like?” (n=138)

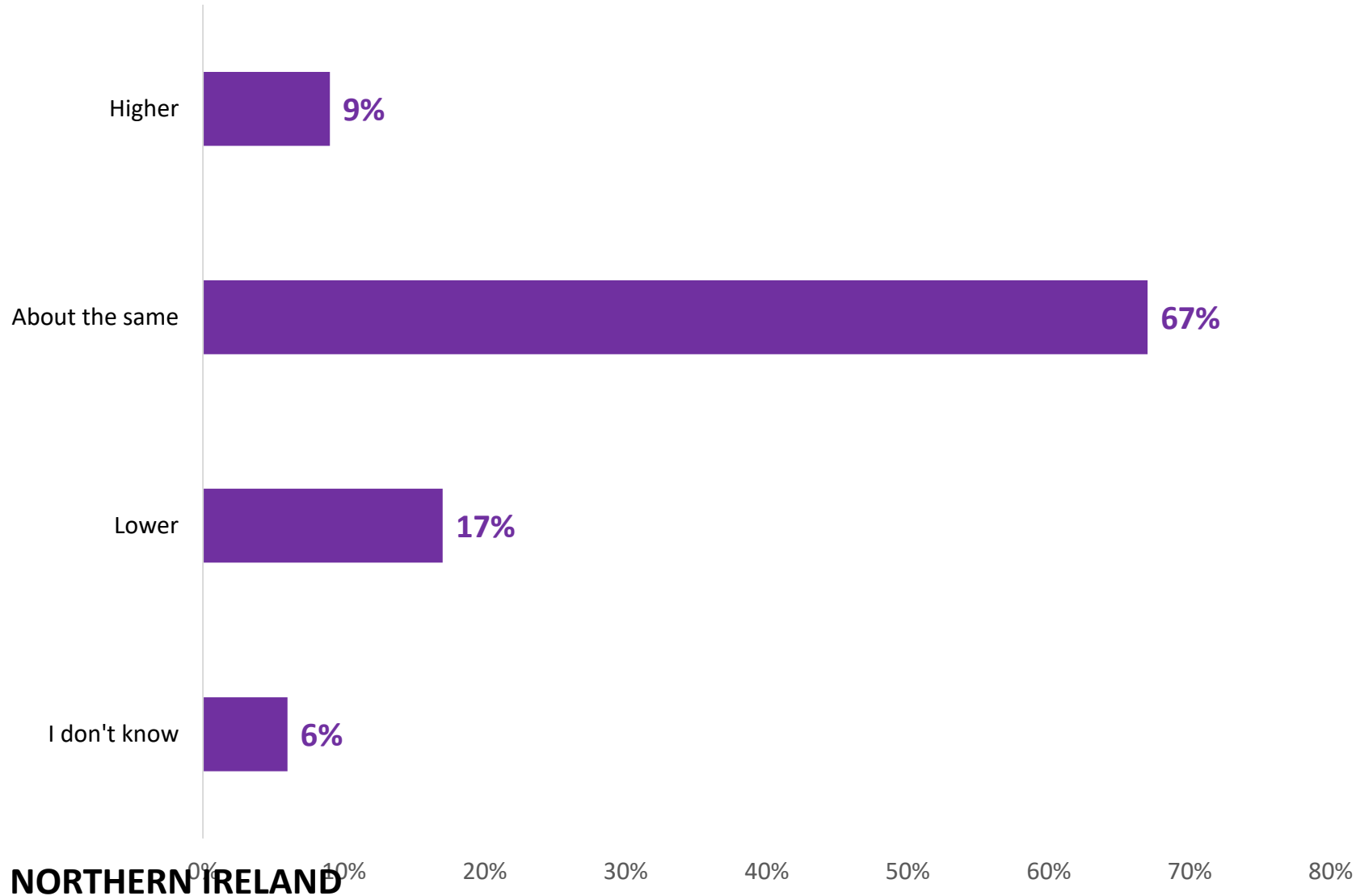


NORTHERN IRELAND



Income

“Thinking about your current regular household income, would you say it is higher, lower, or about the same as he income you had 12 months ago?” (n=138)



43%

Of respondents in **Northern Ireland** said their household income is lower because their **benefits had been reduced** (n=21)

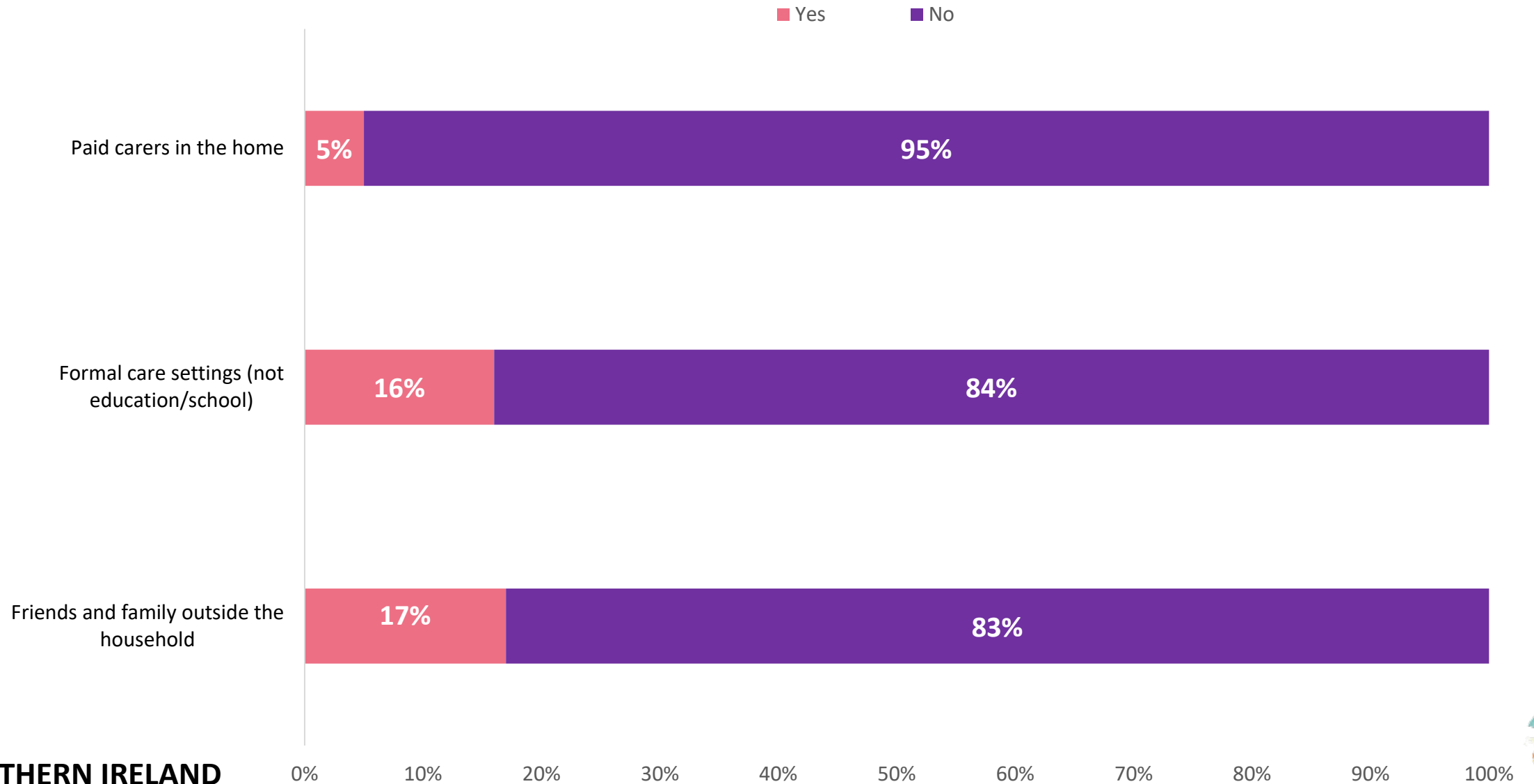
3. Access to other care

Even when families would like their child to be cared for by someone outside the household this isn't always available. This further limits their ability to earn additional income.



Access to care outside the household

“Are your disabled children cared for by the following?” (n=138)

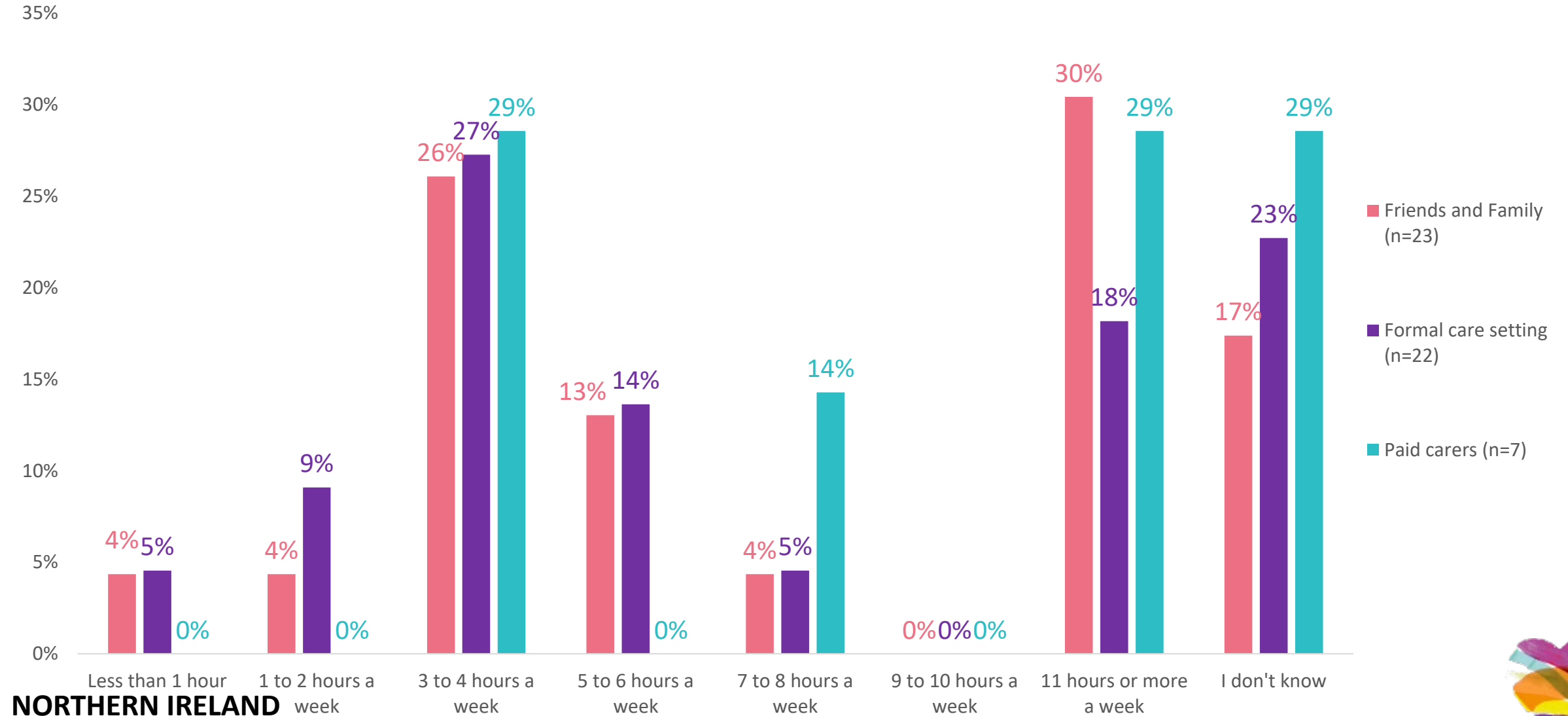


NORTHERN IRELAND



Access to care outside the household

“On average, how many hours a week are your children cared for by the following?”

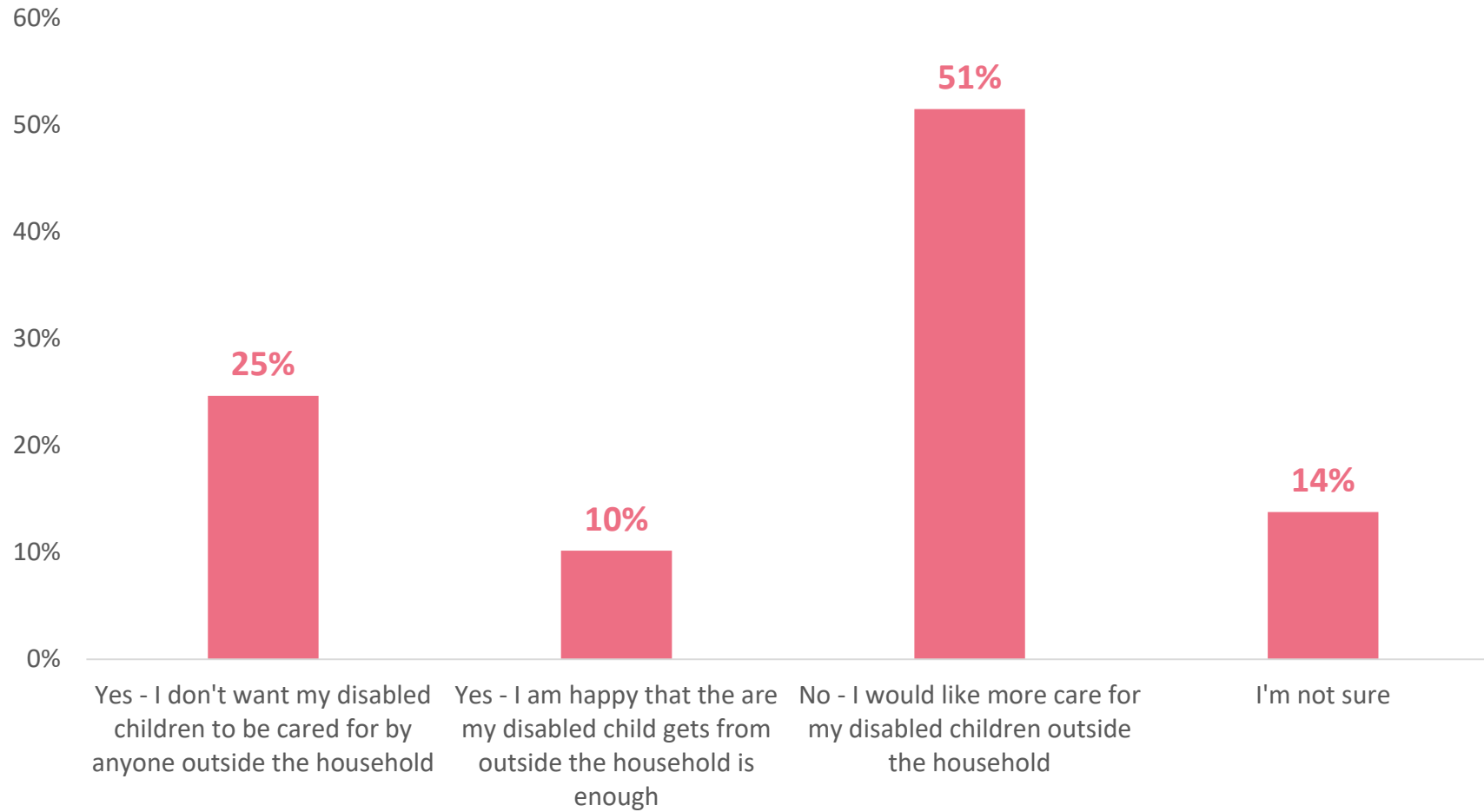


NORTHERN IRELAND



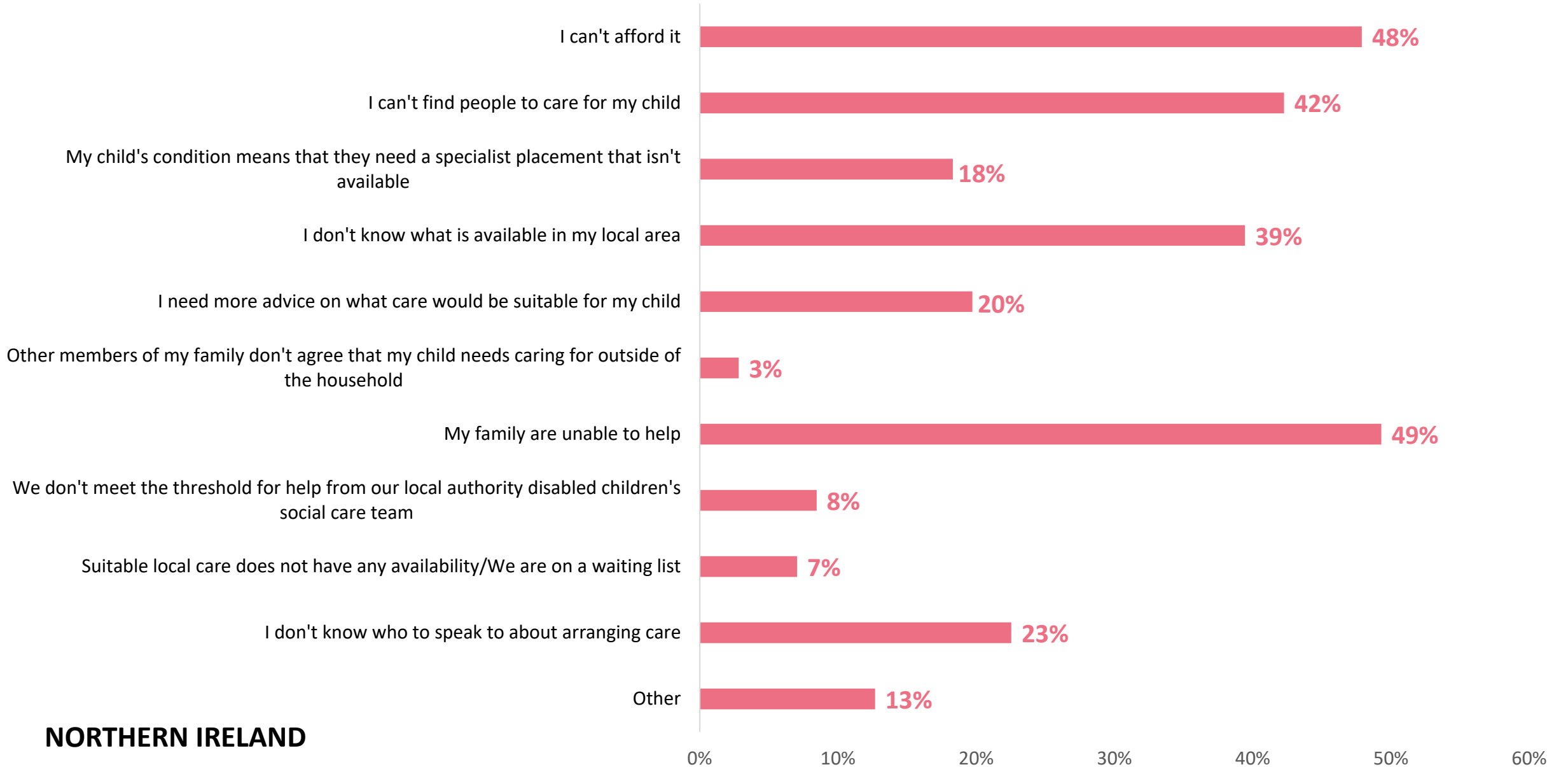
Unmet need for care

“Do you have access to as much care (outside of school/education settings) from people outside the household as you would like for your disabled child?” (n=138)



Unmet need for care

Why are you unable to access as much care from outside the household for your disabled child as you would like? (n=71)



NORTHERN IRELAND

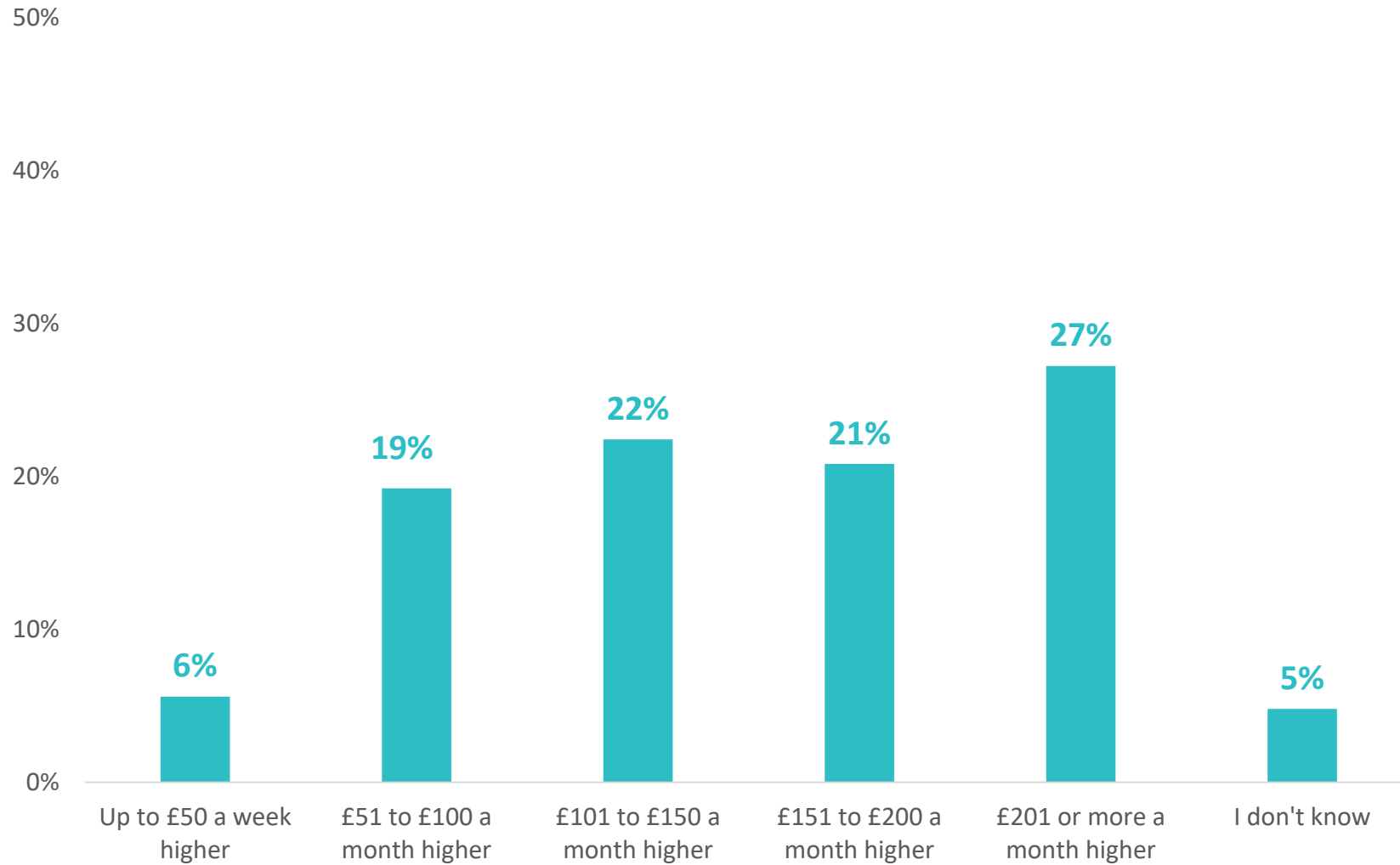
4. Increased and additional costs

Families raising disabled children face higher costs as a result of their children's disability which make them even more sensitive to the increasing cost of living. These increased costs include both additional items and increased costs of everyday items



Household Bills

“ Thinking about how much higher your current regular household bills are compared to 12 months ago, which of the following describes the change?”(n=125)



91%

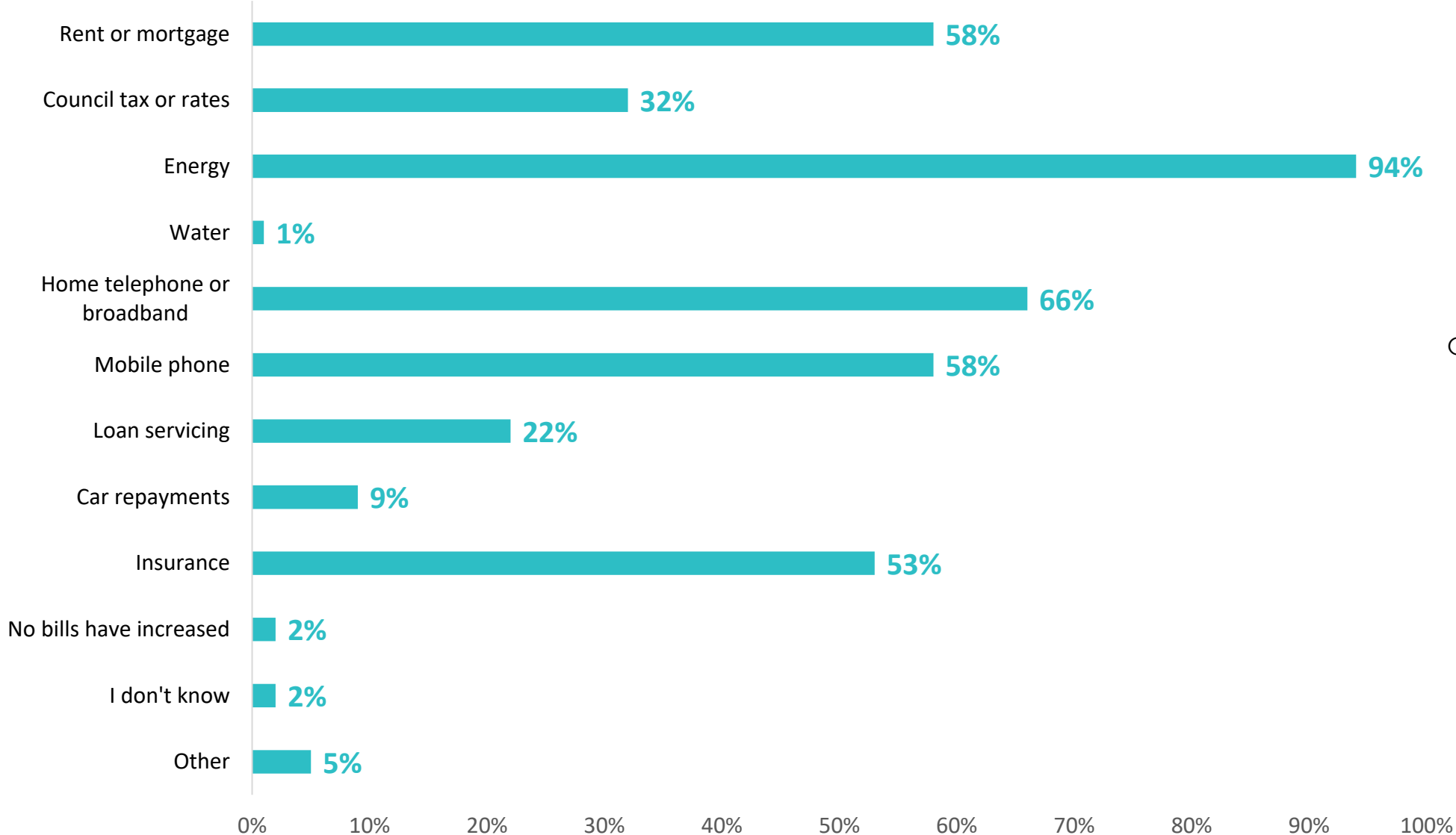
Of respondents report their current household bills are higher than 12 months ago (n=138)

NORTHERN IRELAND



Household Bills

“Which, if any, regular household bills have increased compared to 12 months ago?” (n=125)



47%

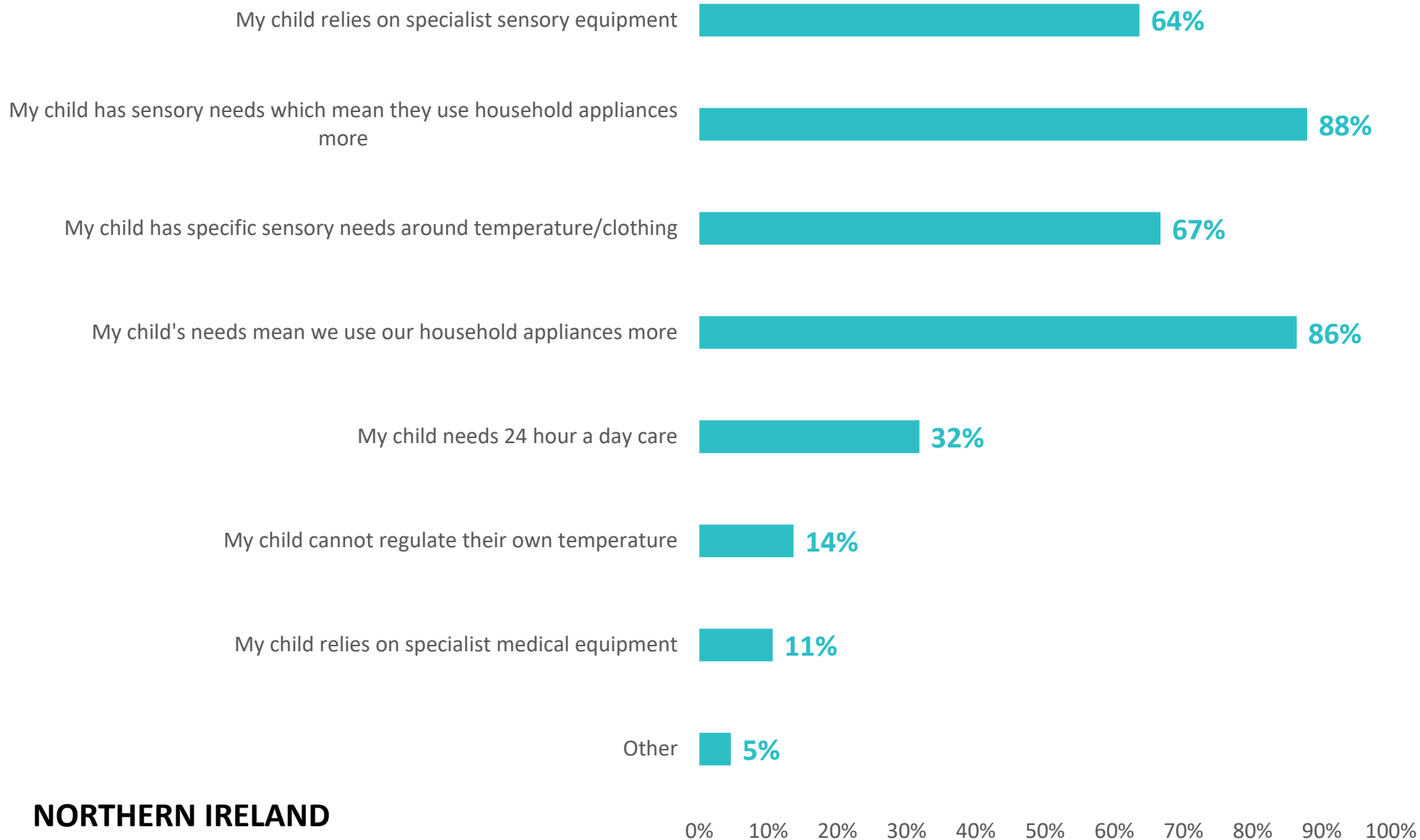
Of respondents report they have **used credit to pay essentials household bills** (n=138)

NORTHERN IRELAND



Additional Costs

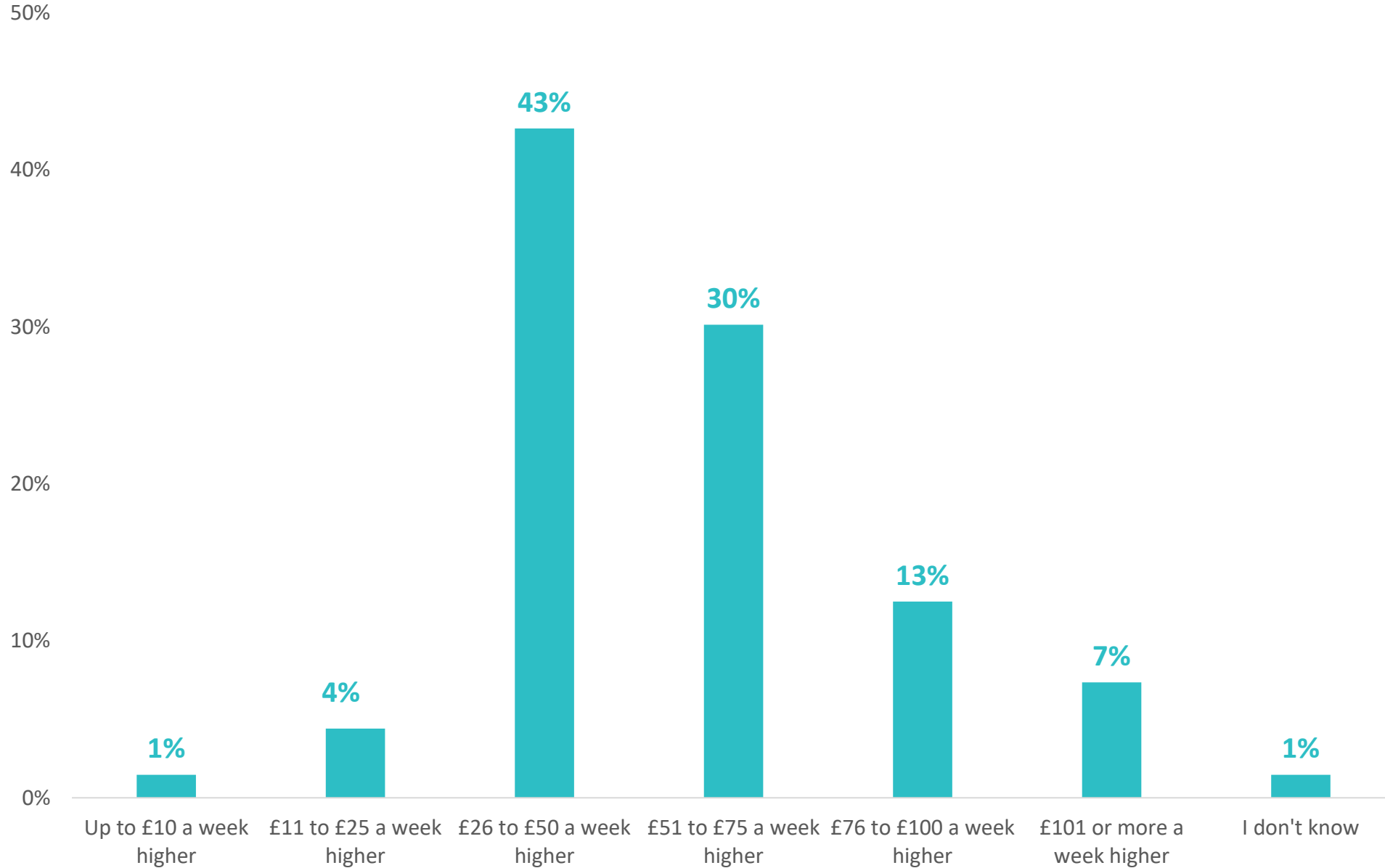
“What are the reasons that mean you have to use more energy than families raising non-disabled children?” (n=66)



48%

Of respondents said they have to **pay more for energy** as a result of their disabled children's conditions or illnesses (n=138)

“Thinking about how much higher your current weekly food shop is compared to 12 months ago, which of the following describes the change?” (n=88)



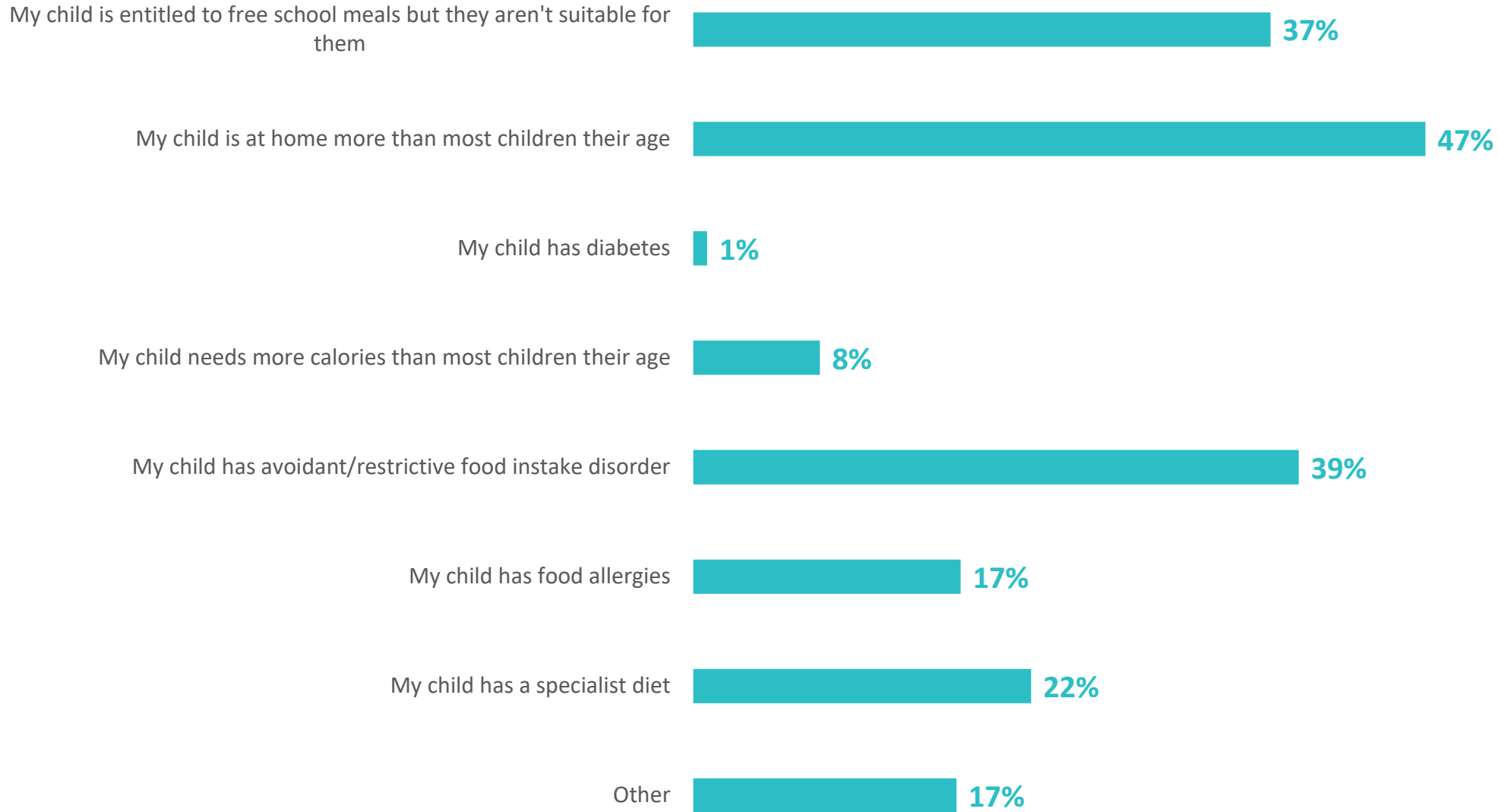
99%

Of respondents said their weekly food shop is higher than 12 months ago (n=138)



Additional Costs

“What are the reasons that mean you have to spend more on food and groceries than families raising non-disabled children?” (n=110)



80%

Of respondents said they have to spend more on food and groceries than families raising non-disabled children (n=138)

Family's experiences of needing to spend more

"My sons diet limitations because of food avoidance has been very expensive. Really struggling with price of food at the moment"

"I get DLA for myself and my 2 disabled children, every penny is used on heating, electric, fuel and food. I feel its unfair that the current cost of living means I have nothing left to save etc"

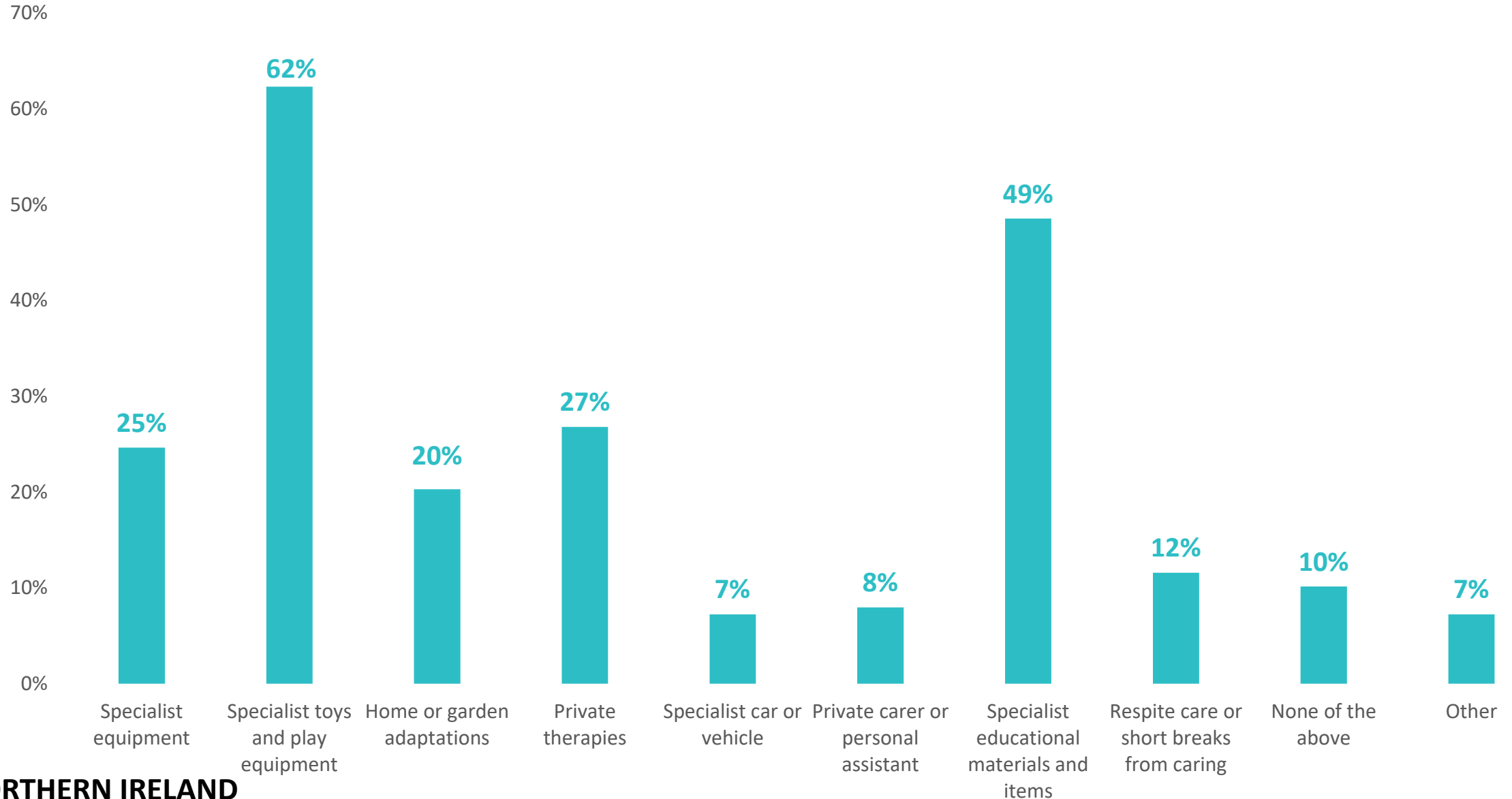
"With the cost of literally everything rising significantly over the past year, we've found it really hard having to cut out some of the fun things in life that we can no longer afford, and it's hard that the kids don't understand why we can't go to the cinema every week any more"

"Everything is getting more expensive but benefits have remained stagnant which has added additional pressure to my own situation because I can't just go out and work extra hours to make ends meet because of caring responsibilities."



Additional Costs

“As a result of your disabled children’s conditions or illnesses, have you had to buy any of the following specialist items and services using your own money?” (n=138)



NORTHERN IRELAND

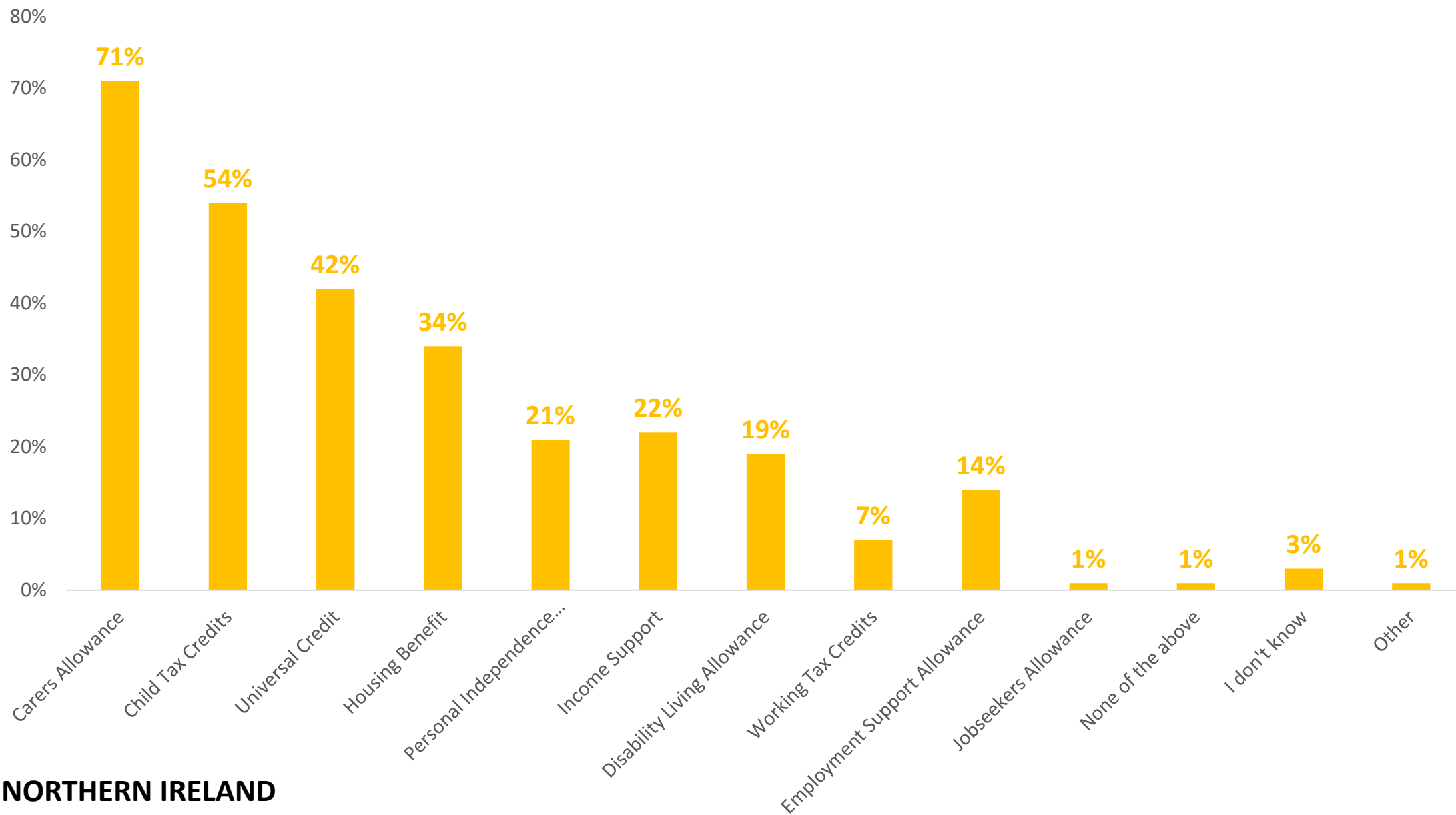
5. Relying on Benefits

The vast majority of families have to rely on state benefits for at least some of their income.



Benefits families receive

Which benefits do one, or more, adults in your household currently receive? (n=138)



NORTHERN IRELAND



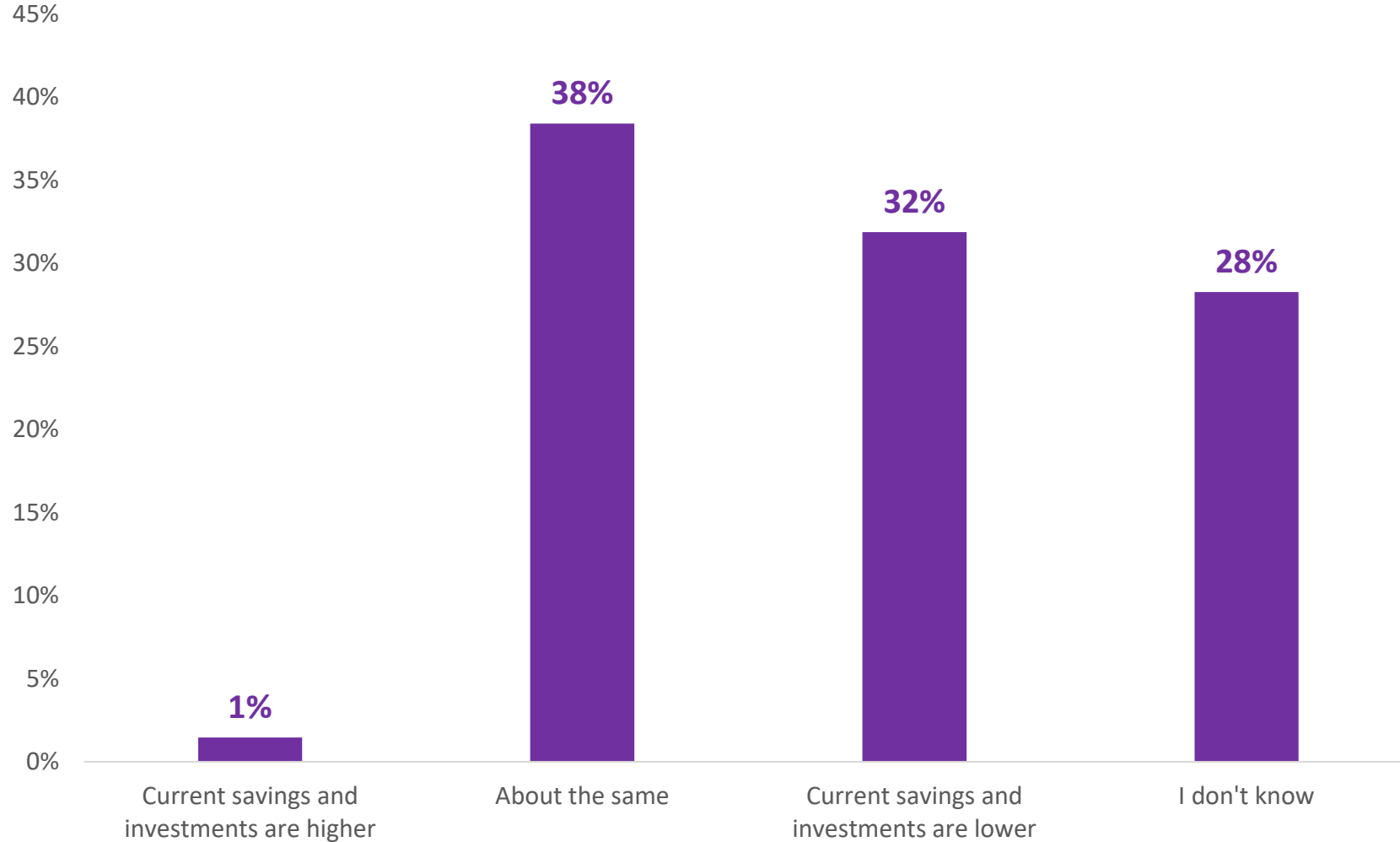
6. Savings

Families are in a financially precarious position with many having very limited access to savings and relatively small unforeseen costs being enough to cause significant financial distress



Family savings

“Thinking about your current household savings and investments, would you say they are higher, lower, or about the same as your household savings and investments 12 months ago?” (n=138)



81%

families report that they have **no savings** or investments



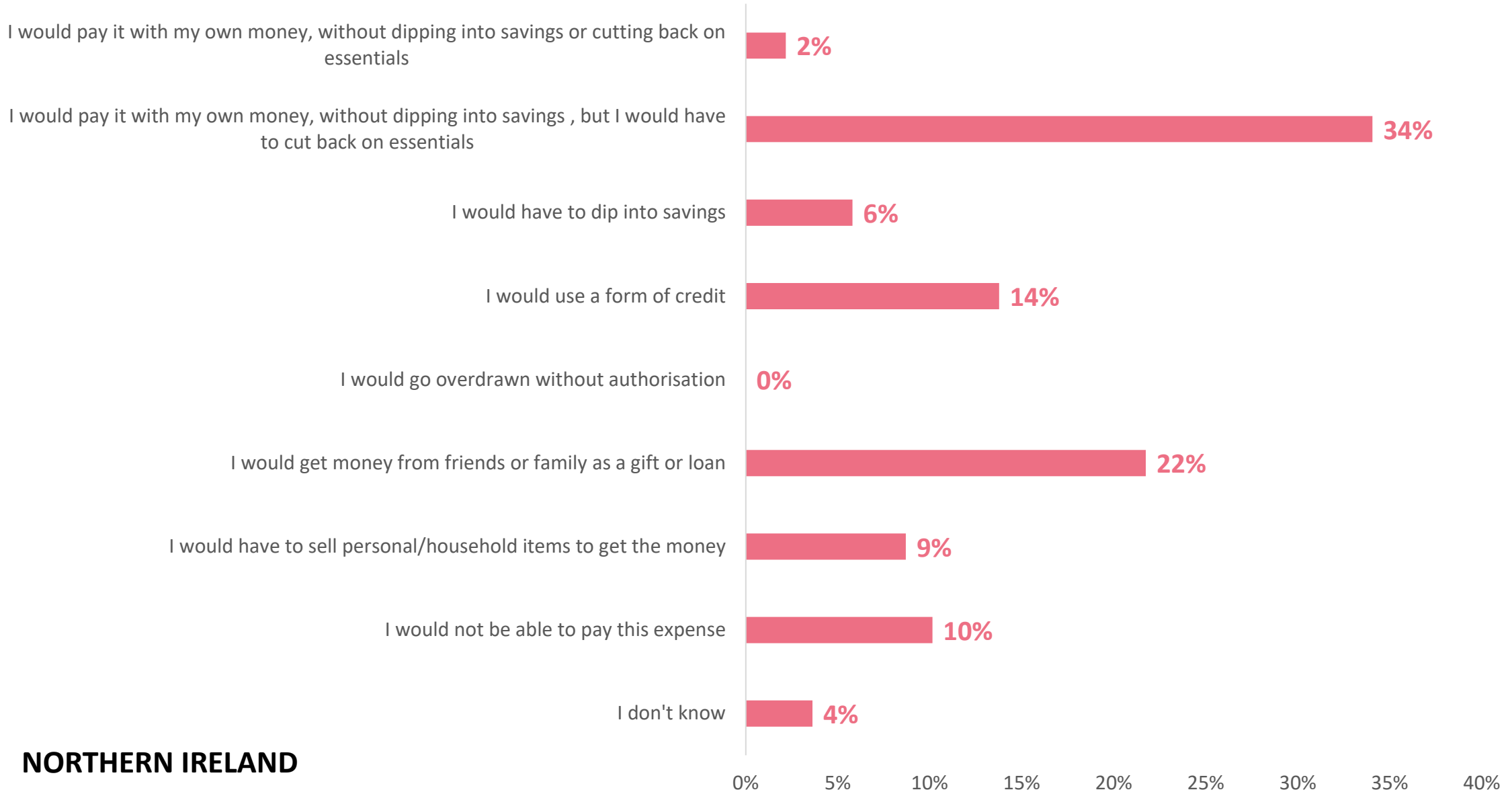
7. Going into debt

Where families cannot make any further cut backs, they are often forced to go into debt to pay for essential items and bills.



Trying to financially cope

“Would your household be able to pay an unexpected expense of £200?” (n=138)

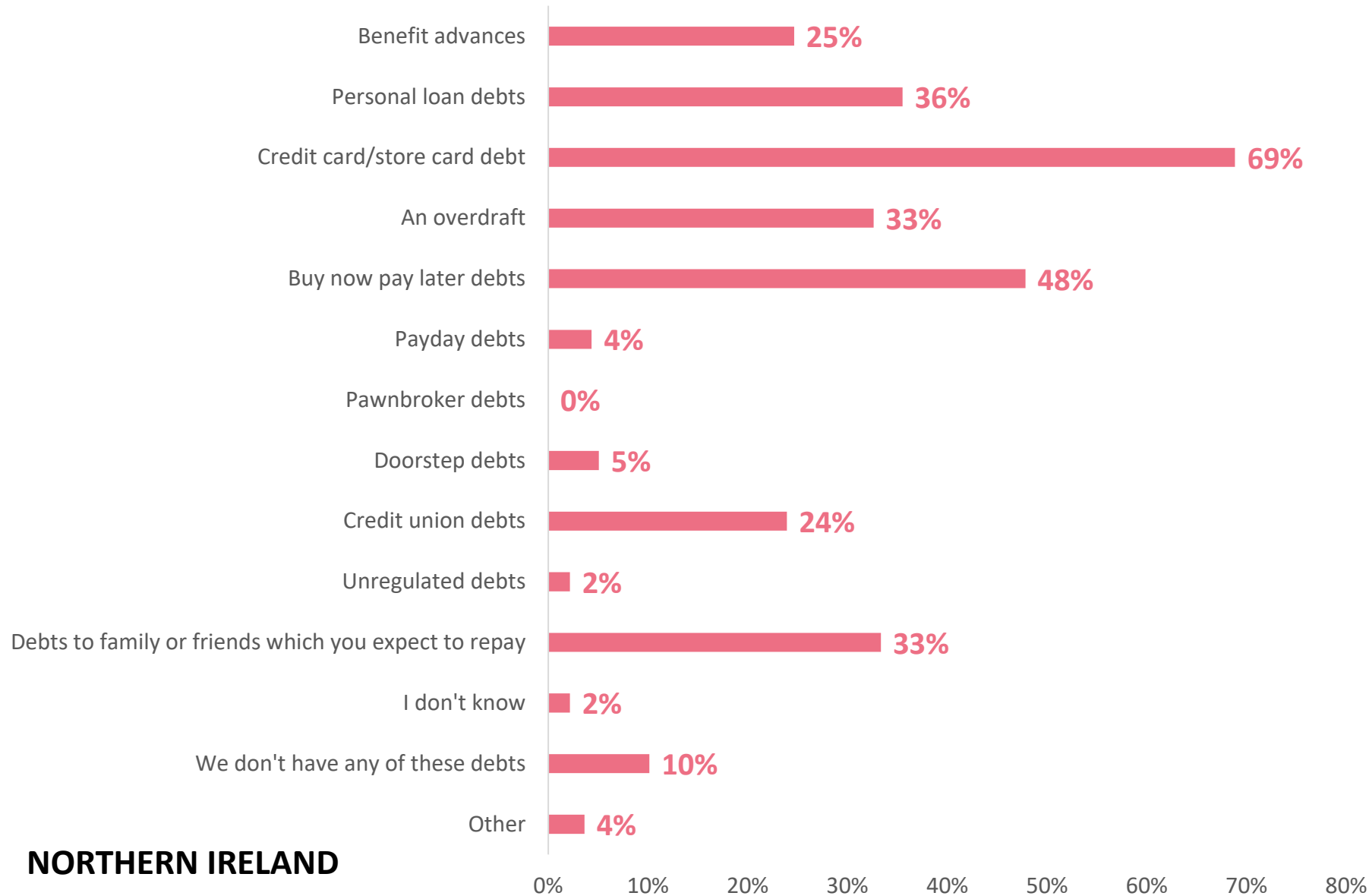


NORTHERN IRELAND



Going into debt

“Do you have any of these debts?” (n=138)



NORTHERN IRELAND

98%

families report that **keeping up with the repayment** of their debts is a difficulty or burden. (n=121)

66%

families report that it's fairly or very likely they will need to borrow more money or **go further into debt in the next six months**



Family's experiences of going into debt

"Very tough.. Just have nothing left each month and getting into debt because of the cost of living"

"We are trying to manage our debt so we have minimal interest and charges. Hopefully in time our finances will balance out when we can work more reliably"

"Debts, and worry how to keep food on the table and the house warm"

"Everything has gone up in price and I'm now in debt and I've never been in debt before"

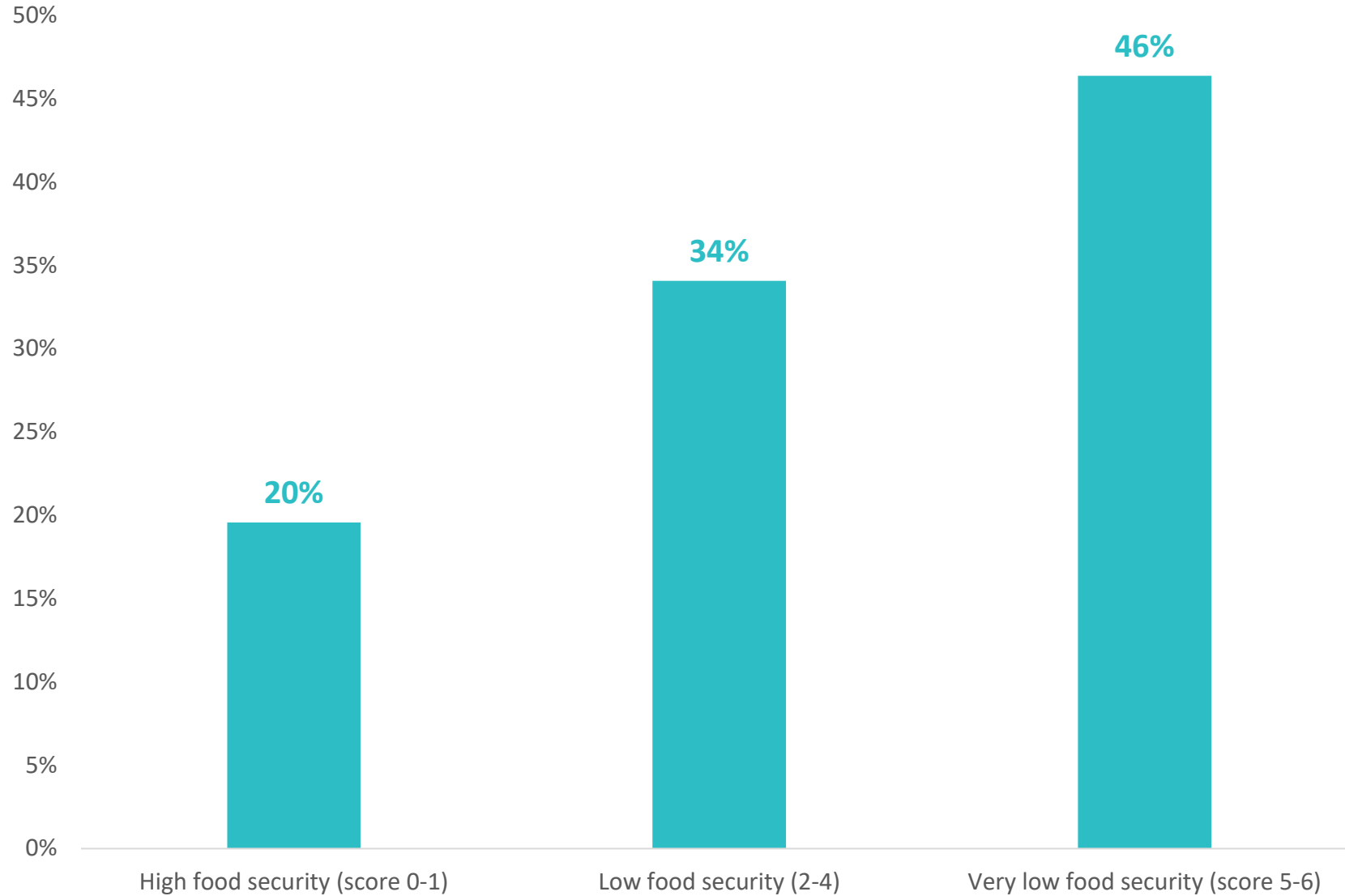


8. Going Without

As a result of the challenges families face working and the extra costs in bringing up a disabled child, families often find themselves having to go without necessities



U.S. Household Food Security Survey Module: Six-Item Short Form Food Security Scale (n= 138)



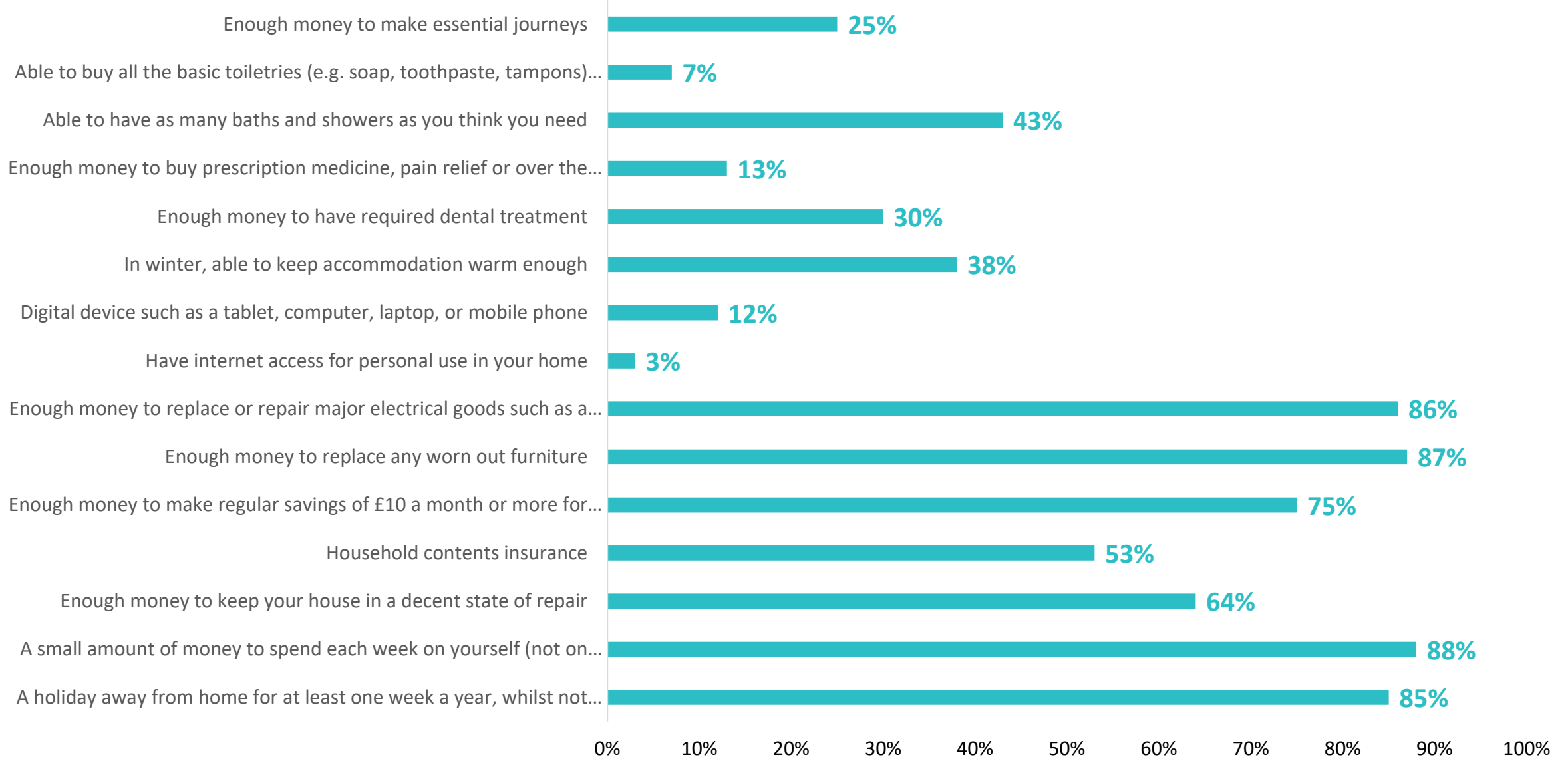
21%

families report that they have had to use a food bank in the last 12 months because there wasn't enough money for food



Going Without – Parent/Carer

“We can’t afford this” (n=138)

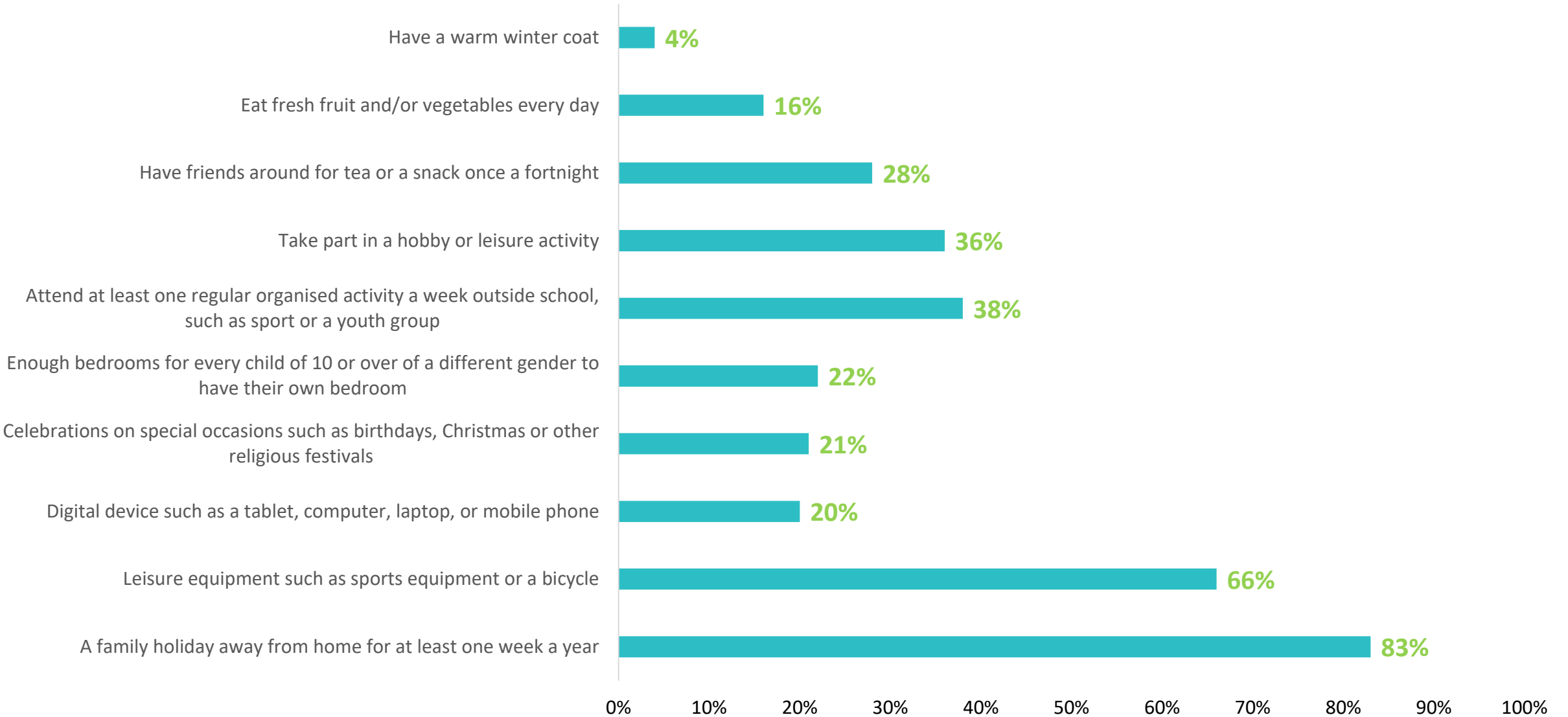


NORTHERN IRELAND

■ Northern Ireland

Going Without – Disabled Children and Young People

“We can’t afford this” (n=138)



NORTHERN IRELAND

9. Disabled children

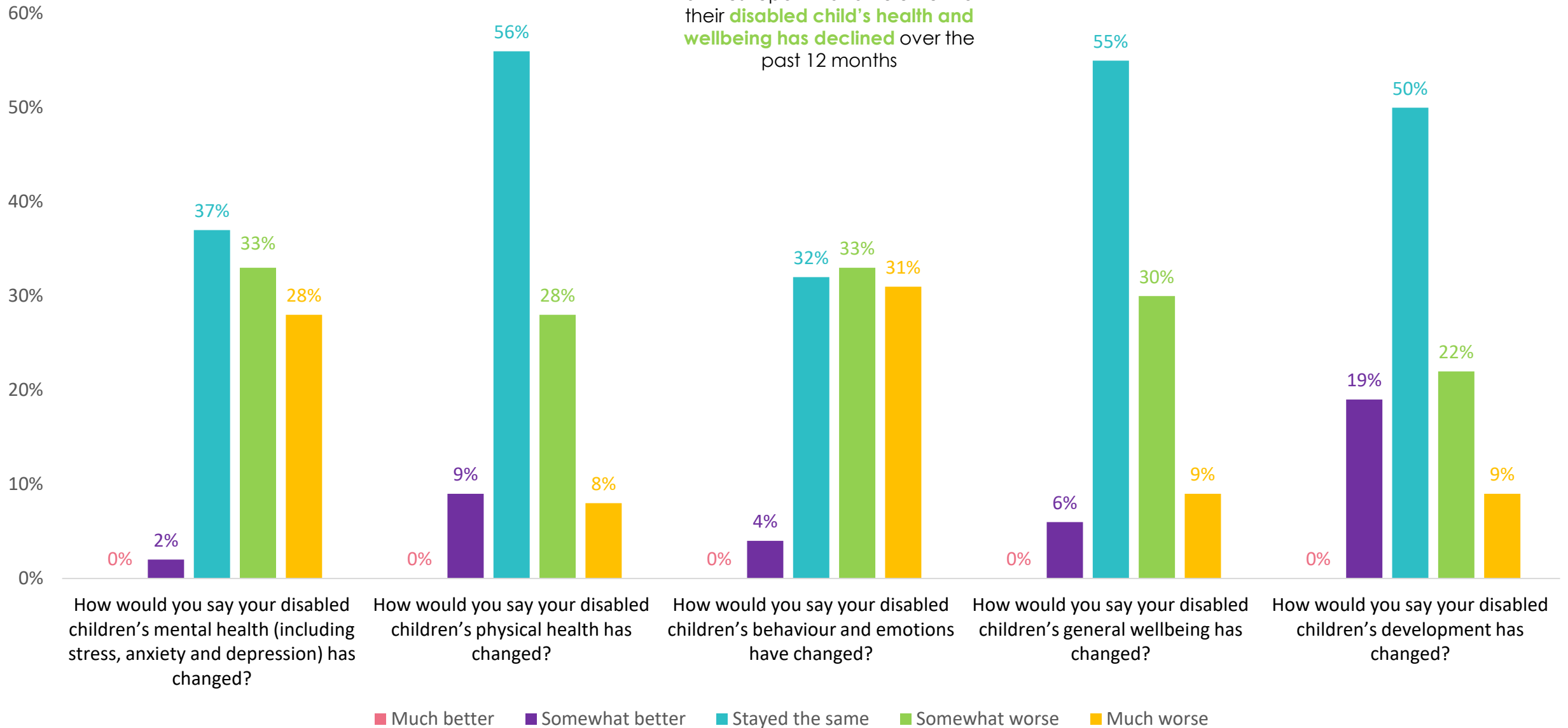
The situation families find themselves in has a negative impact on the health, wellbeing and quality of life of disabled children.



75%



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



Disabled children's wellbeing

No help with a child with asd, adhd, learning difficulties, dyslexia and torettes going through puberty and huge explosive emotions- no support with these issues.

Due to my child's leg issues we had been sorted at a and e on few occasions then left to fend for ourselves having to return to hospital as she was in so much pain was as if they didn't believe her as she was a child. Having to ring OT myself for help for things at home while she's recovering. Still waiting on things!

I've had little help with my child, no support for myself and no physiologist to address her fears and anxieties



The resulting wellbeing impacts

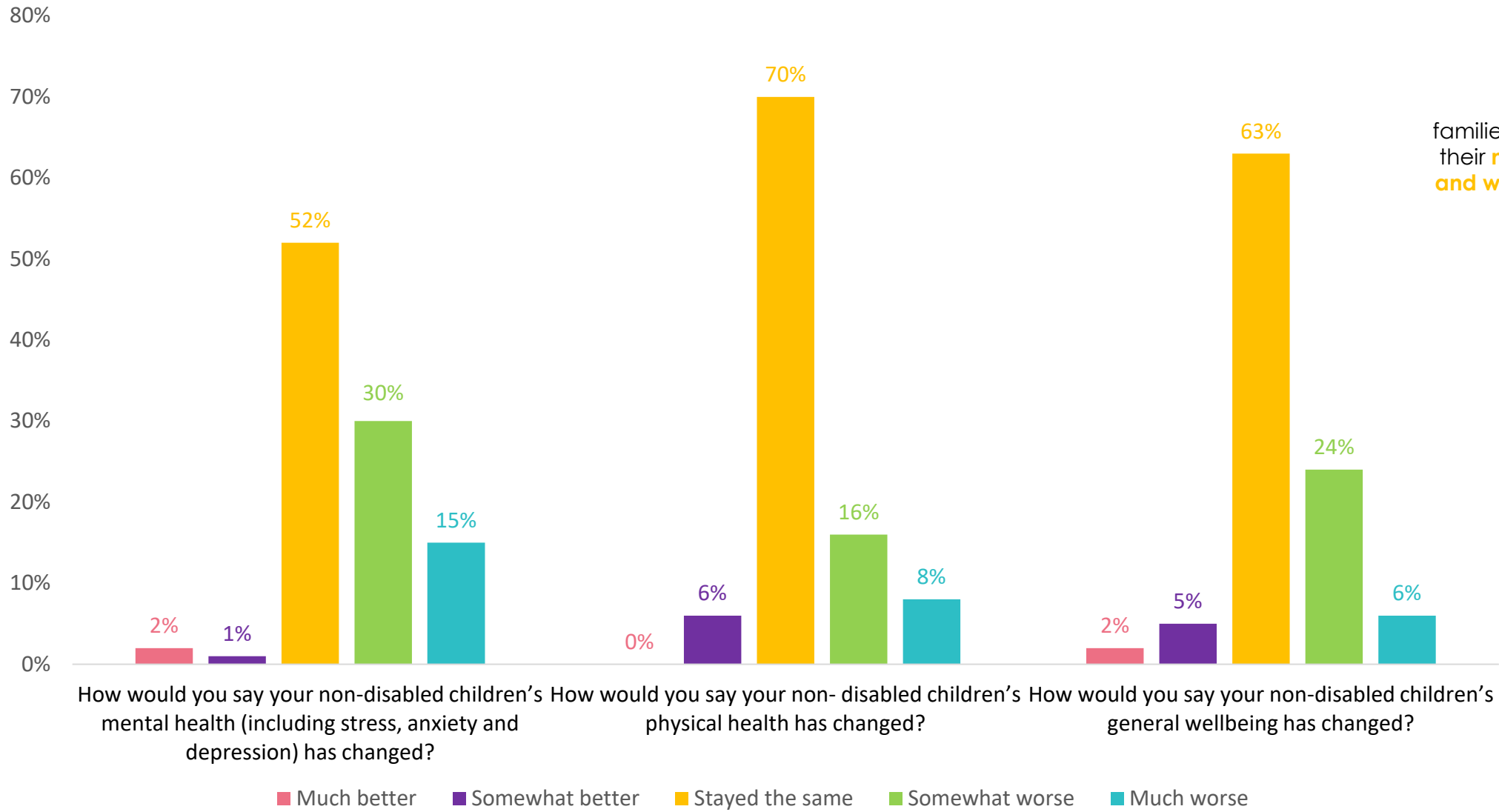
10. Non-Disabled children

The health and wellbeing of many non-disabled children has also been negatively affected.



Impact on non-disabled children

“Over the past 12 months...” (n=87)



47%

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



The resulting wellbeing impacts

11. Parents and carers

The health and wellbeing of many carers has also been negatively affected.



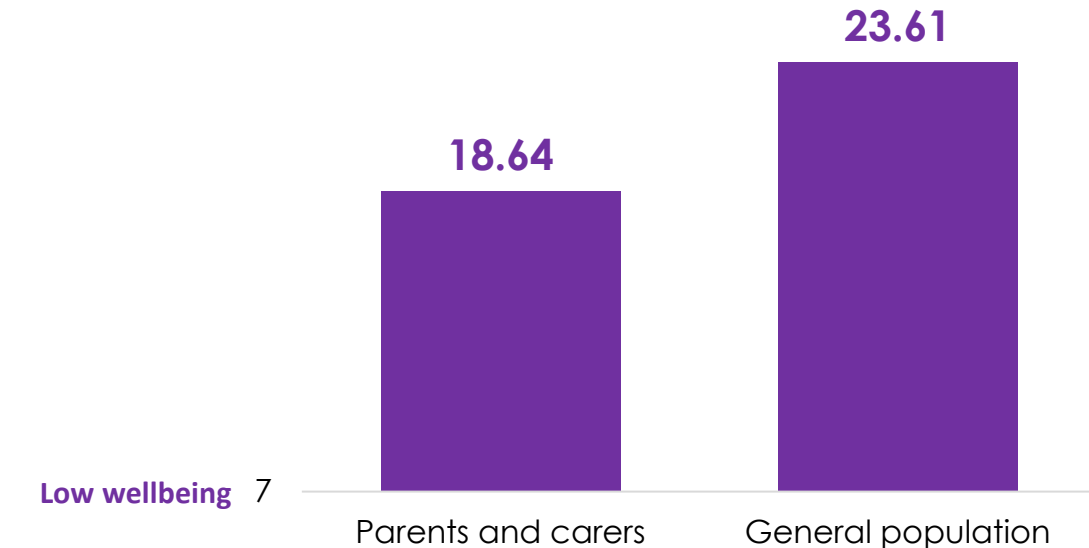
Impact on parents and carers

Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale) (n=138)

High wellbeing 35

70%

Low wellbeing (adjusted score of less than 19.5)



Low wellbeing 7

NORTHERN IRELAND

6.91

Mean UCLA Loneliness Score

30%

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

48%

Probable depression (adjusted score of less than 18)



Parent's experiences of the impact of caring

"Caring for a disabled child can be very lonely. You lose your identity as a person and just become the carer."

"I feel I have nothing in common with my friends who have kids who are not disabled. Our lives are so different and family or friends don't fully understand how little time we have and how all consuming it is."

"We have lost the friendship of all our extended family due to the disabilities in our household. No one truly understands how hard it is"

"Although sometimes it can be stressful, I am so grateful everyday for my child and wouldn't change her for the world she makes me smile everyday."



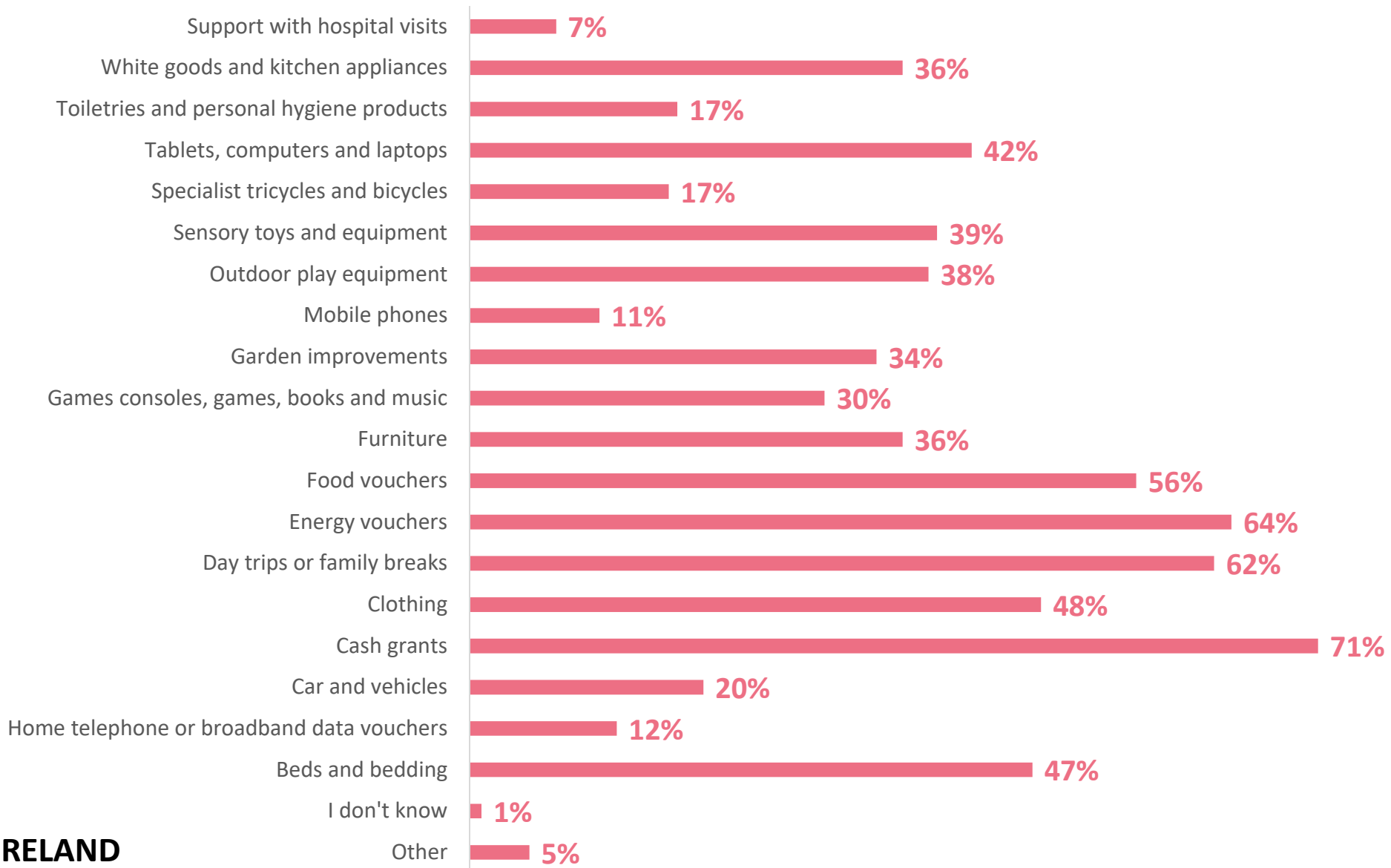
12. Other Needs

We are also interested in understanding what other support Family Fund could offer and what other unmet needs families have.



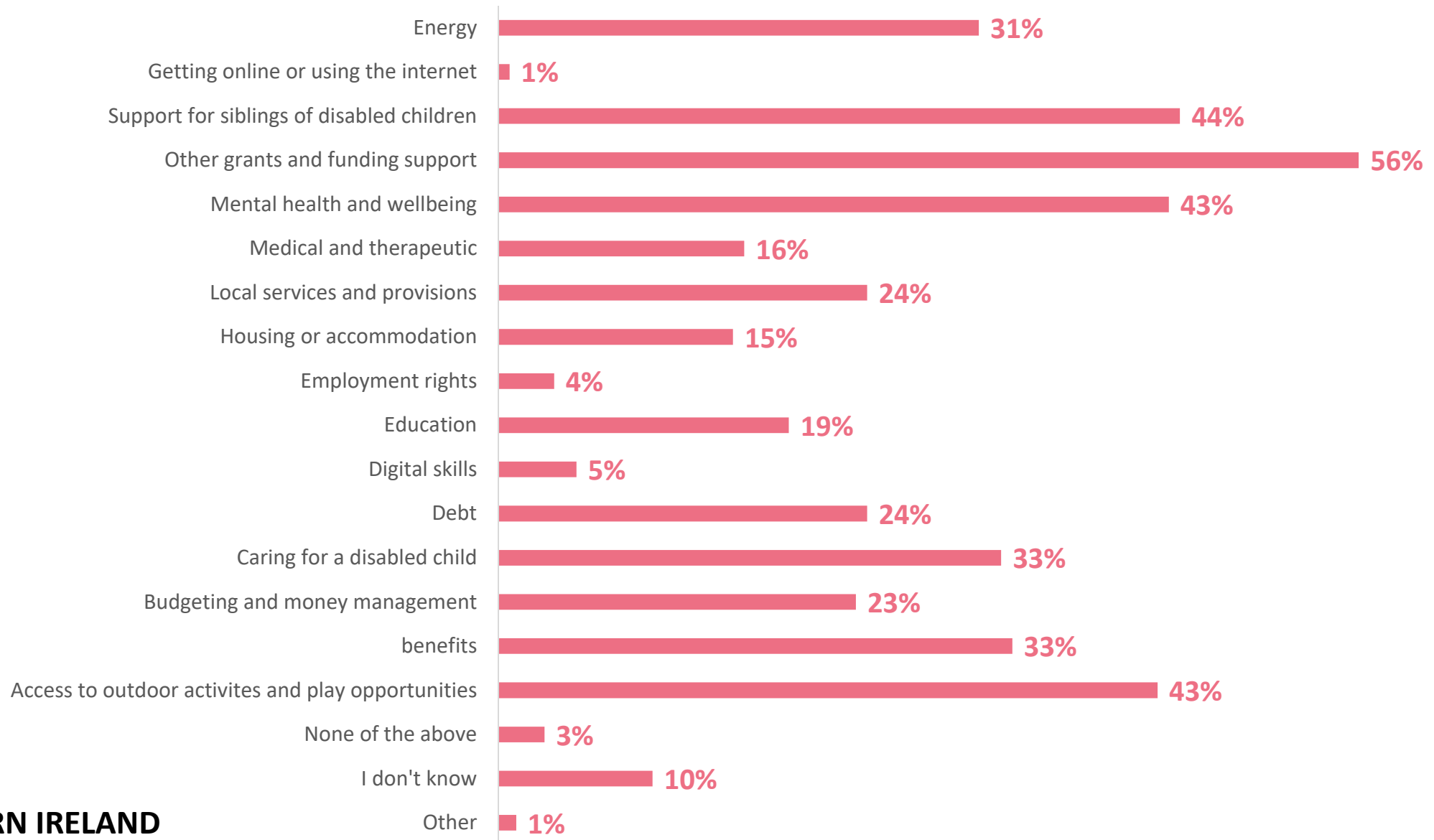
Your needs

“Which grants could we potentially provide that would be most helpful to your family right now?” (n=138)



Your needs

“Which topics could we potentially provide information and support on that would be most helpful to your family right now?” (n=138)



NORTHERN IRELAND



Other family needs

“We are so lucky that our child doesn’t understand how hard they have it. She is the most perfect child on the planet and deserves the world it’s just hard having to fight for everything including education and health services”

“It’s been all about ensuring services are in place for my child and making sure he has a voice through me”

“My children have opened my mind, eyes and heart more than ever before. Their disabilities have made me a stronger and better parent because I have to stand up for their rights to ensure they are able to be a part of society and receive a good education. That’s the most difficult part that I’m always needed 24/7 and I have had to put my career on hold so that I am always on call for my children and when the school phones. I live for my children and want the world for them but sometimes I feel that I cannot do it all on my own. It’s okay to need help and support.”





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:

research@familyfund.org.uk

partnerships@familyfund.org.uk





Family Fund

Helping disabled children

Family Fund Trust. Private company limited by guarantee. Incorporated in England and Wales. Registration no. 3166627. Registered charity no. 1053866. Scottish charity no. SC040810. Family Fund Trust is authorised and regulated by the Financial Conduct Authority (FCA) under reference number 912508. Registered office: Unit 4, Alpha Court, Monks Cross Drive, Huntington, York, YO32 9WN.