

Interim technical report

Extra Costs Commission research

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March 2015

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Acknowledgements

A huge thank you to all of the people who took part in this research. Thank you to everyone in the External Affairs team who helped with recruitment and dissemination. Special thanks to Minesh Patel, David Owen, Anna Bird, George Selvanera, Rose Grayston, Caitlin Boswell Jones and Rachael Loveridge for help with research design and analysis.

Key findings

We conducted two new pieces of research – online focus groups and a survey – which reached over 2,500 disabled people and their families.

- Common areas of extra costs for disabled people were transport, fuel and energy and (unaffordable) insurance.
- People with different impairments or conditions can face different extra costs for specialist items, clothing, shoes and bedding, household goods and services and health and personal care.
- Extra costs are not just financial: disabled people and their families have to make sacrifices in some areas, such as recreation and holidays, and they often face social, emotional and job costs.
- Disabled people and their families and friends will leave a business if they show a lack of disability understanding and awareness – three quarters of our survey respondents said that they had done this.
- Interest in a range of smarter purchasing tools was high, and a membership discount card for disabled people was the most popular idea for a smarter purchasing tool.
- More could be done to ensure that they have the same opportunities as everyone else to become “savvy” shoppers.

“The costing for special needs items is usually the normal price times 10, sometimes times more. Surely there is a way to make these things cheaper?”

1. Introduction

We know that disabled people and their families face extra costs and have to spend more to achieve the same standard of living as a non-disabled person (Smith et al., 2004). The Extra Costs Commission was set up with the aim of investigating these extra costs and thinking of ways that we could drive them down. This technical report describes two pieces of research that have been carried out for the Commission: a project aimed at enhancing our understanding of the range of extra costs faced by different groups of disabled people and their families through a literature review and online focus groups ([Extra Costs framework, page 6](#)), and a survey looking at a wide range of consumer issues for disabled people and their families ([Extra Costs survey, page 18](#)). Together, these projects reached over 2,500 disabled people and their families. By hearing about their experiences, we hope that we can help drive down extra costs.

2. Extra Costs framework

We know that disabled people and their families face extra costs, but we still only have limited information on the scale and extent of these costs. The current piece of research aimed to develop a framework of extra costs – a way in which we can quantify and appreciate the different costs different disabled people face. This research takes a look at pre-existing data on extra costs, as well as conducting new research using online focus groups to establish extra costs for people with different impairments.

2.1. Previous research on extra costs

Previous research has attempted to put a figure on disabled people's extra costs. In many ways this is a difficult task. We need to think about what is an *additional* cost above what a non-disabled person would pay. Previous studies have used a number of different approaches, which makes it difficult to compare results. For example, some studies think about categories of extra costs from a non-disabled person's perspective. This approach might miss the specialised items disabled people have to buy. Some studies consider actual spend while others look at what people would need to spend in order to achieve a certain standard of living. Other studies take into account the costs that are not met by extra costs payments (i.e. DLA or PIP) while others don't take into account these payments; others talk to disabled people while others use statistical modelling techniques to estimate extra costs. We also need to think about whether the disabled person is a child, adult or older person.

Overall costs

Several studies have attempted to quantify the extra costs faced by disabled people and their families. Table 1 below shows some of the weekly overall extra costs estimated by a range of different sources.

Table 1. Overall weekly extra costs (£) according to previous research, all in 2014 prices.

		Group		
		Disabled adult	Disabled older person	Parent of disabled child
Study into extra costs of disability	Martin and White (1988)	17 – 50		
	Disablement income group (1988)	121		
	McKay (1990)	109		
	Berthoud (1991)	25		
	Philips (1993)	458		
	Smith et al. (2004)	537 – 2,087		
	Zaidi and Burchardt (2005)*	33 – 191	42 – 234	
	Wood and Grant (2010)	229 – 449	214 – 380	254 – 483
	Morciano et al. (2012)*		105	
	Hancock et al. (2013)*		49 – 63	
	Smyth and Robus (1989)			15 – 29
	Dobson and Middleton (1998)			157
	Dobson et al. (2001)			88 – 96
	Counting the costs (2014)			75

**These studies use estimates of extra costs based on statistical modelling of data.*

Table 1 shows that there is a wide range of estimated extra costs. For disabled adults, estimates range from £17 to £2,087. For a disabled older person, the range is from £42 to £380. Finally, for a parent of a disabled child this ranges from £15 to

£483. Reasons for these wide ranges include differences in how the figures have been estimated, exactly who has been asked about their extra costs and the areas of extra costs people have been asked about.

Areas of extra costs

There has been less research breaking down extra costs into different areas of costs. Within the categories of special costs, additional costs and recurrent costs (Tibble, 2005), there are a number of specific areas of extra costs. For example, Wood and Grant (2010) considered 19 areas of extra costs including specialised clothing, non-prescription medicine or products, private hire transport and help with house tasks. Wilkinson-Meyer et al. (2010) thought about “domains of life” such as health and well-being, participation in society and information and technology. Based on previous research, we will think about the categories of extra costs in terms of:

- Food and drink
- Clothing, shoes and bedding
- Housing, fuel and power
- Household goods and services
- Health and personal care
- Transport
- Communication
- Recreation, culture and holidays

Table 2 below shows the extra costs disabled people have reported to have in these categories. Two other categories which have been less examined are specialised equipment and insurance, although we know that these could be two areas for which disabled people have to pay more¹.

Table 2. Weekly extra costs (£) for disabled people (including data by high to low need) across cost categories.

¹ From the submissions received to our Call for Evidence – see main interim report for further details.

		Extra cost area							
		Food and drink	Clothing and footwear	Housing, fuel and power	Household goods and services	Health and personal care	Transport	Communication	Recreation, culture and holidays
Group	Med-high need ⁱ	31	8	23	61	28	15	19	45
	Intermittent need ⁱ	13	2	10	-1	28	22	2	14
	Low to medium need ⁱ	15	0	10	-2	28	2	3	14
	Visual impairment ⁱ	21	5	20	3	-2	12	8	34
	Hearing impairment ⁱ	-4	2	5	-8	33	2	26	47
	Disabled adult ⁱⁱ	12	17	-	12	36	28	-	-
	Disabled adult ⁱⁱⁱ	42	10	5	17	9	16	-	14

i. Smith et al. (2004) – for this study, extra costs were calculated by subtracting the costs that non-disabled people reported from the costs that disabled people reported. ii. Wood and Grant (2010). iii. Living Costs and Food Survey (2012).

Table 2 shows that there is no consensus over the extra costs people face in different areas. Particular areas of costs appear to be food and drink, housing, fuel and power, health and personal care and recreation, culture and holidays. Smith et al. (2004) consider level of need and show that costs rise as the level of need increases.

Other studies note that disabled people have to pay around 45% more for transport (Jones and O'Donnell, 1995) and that fuel was a common and expensive additional cost (Martin & White, 1988). If someone needs a personal assistant, this can also drive up extra costs (Smith et al., 2004). Parents of disabled children can also face a

wide range of different extra costs. Research by Contact a Family (2014) found that because of these extra costs, 83% of families with disabled children said that they were going without essentials, such as food and heating.

Costs by impairment type

There are few data on extra costs for different impairment types. Table 2 above includes some of the extra costs faced by people with a visual or hearing impairment (Smith et al., 2004). Recent research by Hill et al. (2015) showed that for a partially-sighted working adult to achieve the same minimum living standard as an equivalent person without any impairment, they would have to spend £50.49 a week more than this person. A severely hearing-impaired person would need to spend £163.03 a week more to achieve the same standard of living as an equivalent non-disabled person. Hill et al.'s (2015) method involves working out what people need in order to have a minimum acceptable standard of living and provides us with a good means of understanding extra costs. It would be valuable to expand this method of research to other groups of disabled people. Other research (Järbink et al., 2003) has looked at areas of extra costs for parents of children with autism. Extra costs included things such as paying for repairs following damage to the home, additional costs for therapy or education and costs for special activities.

2.2. Online focus groups

Given the lack of research in this area, online focus groups were conducted to investigate the extra costs people with different impairments or conditions have in the different categories specified above. The impairment types that we will consider are:

- Learning disability
- Mental health condition
- Physical impairment
- Sensory impairment (e.g. visual or hearing impairment)

- Autism spectrum condition
- Chronic condition (e.g. chronic pain condition)
- Neurological condition (e.g. Multiple Sclerosis)

2.3. Method

51 people (14 men and 37 women) took part in seven online focus groups of five to ten participants. We decided to use online groups as this would enable us to reach many different people with different experiences. The groups were largely organised around impairment type, with people with physical, chronic and sensory impairments mixed together, and people with mental health conditions, learning disabilities or autism mixed together. The groups consisted of people who were disabled themselves, parents of disabled children or individuals speaking on behalf of a disabled family member.

After joining the online group, participants were presented with each category of cost (e.g. food and drink, clothing, shoes and bedding, etc.) and were asked to (a) estimate their extra costs in the category (b) identify whether it was a high or low cost and (c) identify how the cost compared to other categories. In this way, we can attempt to understand the relative scale of different categories of costs. Participants could see the answers that others had given and were free to comment on these.

2.4. Results

Table 3 below shows the relative extra costs for people with different impairments or conditions. The colour coding of the table indicates the relative impact of the reported extra costs, that is, whether the cost was felt to be low, moderate or high. This coding is therefore subjective and based upon people's perceptions of extra costs. By asking people to think about high to low extra costs, we can attempt to think about different costs relative to one another and other aspects of life. For

example, someone might have to spend £50 extra every month on transport and £50 extra every month on clothing – but it might be the transport cost that they feel has the bigger impact on their life.

The lightest pink shows areas of low costs or where people said they did not feel that they had any extra costs, with the gradient increasing to indicate higher extra costs. The darkest pink areas are where people said that they could not afford items in that category. The numbers (median spend every month) reported for the extra costs can be seen in the [Appendix](#). Given the small sample size for each individual group, the numbers may not be representative of the whole population.

Table 3 shows that people with different impairments or conditions can have different experiences of extra costs, but there are also some areas of shared experiences.

Key similarities between groups

- **Transport** was a high extra cost for almost all groups. One factor that affected many was the fact that public transport is not accessible, so they had to use taxis.

“Many buses where I live are inaccessible to my powered wheelchair, meaning I have to pay for expensive taxis. I estimate I spend at least £50 a month on wheelchair taxis. This is a high cost to me.”

- **Insurance**, and most often travel insurance, was not affordable for most people.

“Insurance costs have become too expensive to travel on holiday. Last year my brother invited us to stay with him. A weeks travel insurance for my wife was £15 and for me £198. My flight would have only been £140. Needless to say I was unable to go.”

- For **housing, fuel and energy**, many people experienced moderate to high costs, driven up by a number of factors such as sensory sensitivities to temperature:

“My son has to be kept warm... Due to clothes spillages extra washing and drying in the washing machine. Lights have to stay on too, energy saving or not! For where we are this is a massive extra cost all in.”

- Many people had to make sacrifices in **recreation and culture**, where they could not afford to go out to do the things they enjoyed.

“I don't actually get out much and, due to that, probably expose myself to a reduction in costs through circumstances not choice”.

- **Communication**, in particular the internet, was not an extra cost but was seen as essential.

“I depend on having the internet at home as I am not really able to get to the shops and need to do most shopping online... I also depend on support forums for advice with things like DLA forms, sharing coping tips, and also social contact. This is part necessity and part pleasure.”

- Many people reported that they had **non-financial extra costs** – these were social, emotional and time costs, as well as the costs of lost employment.

“Sometimes extra costs are not always monetary but they come in emotional cost, physical cost and a cost to relationships. These are at times the hardest extra costs to bear and ones you cannot replace.”

Key differences between groups

- **Specialised items** caused high one-off costs for some groups (those with a chronic or neurological condition, physical or sensory impairment), with a range of expensive items needed, from wheelchairs to eye-gaze responsive computers.

“Extra costs incurred are: - Specialised amplified screen phone - £200 when a normal phone is approx. £20 - high cost. Hearing Aid equipment, i.e. dehumidifier box to dry them out £60 - high cost. Radio Aid equipment £1500 - very high cost.”

- There was a wide range of extra costs for **food and drink**, which depended on whether people had special diets (e.g. gluten free diet) or whether they were physically able to make fresh meals (e.g. difficulties with motor skills meaning they could not peel vegetables).

“Depends on how my hands are. If they are inflamed then I will buy ready prepared or frozen vegetables. Obviously the extra cost would vary but I estimate that it would be between £20 to £30 a month at these times.”

- There were moderate extra costs for **clothing, shoes and bedding**, depending on the group, in particular for people with autism, chronic

conditions, children with a learning disability and those with physical impairments. Extra costs depended on whether the person needed specialised clothing (e.g. due to sensory sensitivities) and the rate of wear-and-tear.

“Highest cost compared to others. Footwear is the bane of my life! Shoes for 'normal' wear last 3 days max (son drags his feet, scissoring). Estimate £100 per month.”

- Some groups (those with autism, a chronic or neurological condition, or physical or sensory impairment) felt that they had relatively high costs for **household goods and services**, where they needed help around the home or had one-off costs for home adaptations.

“I am unable to physically do any repairs / DIY to my home directly as a result of disability and my husband has enough to do with having to work full time to support us... So we feel we have little choice but to employ professionals for all those little odd jobs most people would attempt themselves.”

- Extra costs for **health and personal care** differed between groups, with extra costs triggered by therapy (e.g. for mental health) or personal assistants (e.g. for those with a physical or sensory impairment).

“Due to mental illness and lack of NHS provision I am currently paying for psychotherapy... and acupuncture for pain relief! This costs £40 a time.”

2.5. Summary

Extra costs are wide-ranging and can differ depending on the type of impairment or condition that people have. There are some common experiences though, such as in the areas of transport, heating and (unaffordable) insurance. As a framework or guide, we could think about extra costs as a “mosaic” dependent on impairments or

conditions and area of cost (Table 3). It is important to note that extra costs are not purely financial, but there are costs too in terms of social, emotional or job costs. These can be the costs that have the greatest impact on people's lives.

Future research could go down a number of different avenues. We think it is worth looking at the picture for disabled people as whole: we have shown that there are common experiences. However, disabled people do not form one homogenous group, and we acknowledge that splitting people into groups by impairment type is only one way of describing experiences of extra costs. It is important that individual disabled people are able to recognise their own experiences in research looking at a wider group. The Commission is interested in research that can help future analysis of what can be done to drive down extra costs. The Commission's interim report outlines possible actions that could be taken – research that helps evaluate the impact of these actions would be particularly valuable.

3. Extra Costs survey

The Commission wanted to know more about disabled people and their families as consumers: how do they buy things, do they feel that they are getting the best deal, and what do they think about different initiatives that might help drive down extra costs. If we know more about disabled people's consumer experiences, we can understand more about what businesses can do to make sure they are giving disabled people and their families a fair deal. There are 12.2 million disabled people in the UK² – a sizeable market who should have the same consumer opportunities as others.

The aim of this survey was (a) to find out what would be most useful to empower disabled people as consumers and (b) to identify ways in which disabled people could be supported to buy goods and services more effectively, to ultimately find ways of driving down extra costs.

3.1. Method

Survey development

During the early stages of survey development we worked with a small group of people. Four disabled people and one parent of a disabled child were interviewed about their experiences of shopping, things that helped or stopped them getting good deals, and their relationships with businesses, notably shops. Their answers helped to inform the design of the survey questions, and they also reviewed and offered feedback on the survey before it was finalised.

² Family Resources Survey, 2012/13:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/325491/family-resources-survey-statistics-2012-2013.pdf

Survey design

The survey looked at a number of different areas under the following categories:

- Buying habits
- Shopping around and getting deals
- Smarter purchasing tools
- Relationships with businesses
- Energy
- Demographics

Who did the survey?

2,580 people completed the survey in its entirety. Of this, 64% were disabled themselves, 27% were parents of a disabled child and 9% were carers of a disabled person. Further information on the people who completed the survey can be found in the [demographics](#) section. Where differences exist, this report shows comparisons between disabled people and parents or carers. Since many more women completed the survey, data have been weighted³.

Caveat: The majority of respondents completed the survey online – only 10 completed it offline. This means that this survey is not representative of all disabled people, who we know are less likely than non-disabled people to have internet access⁴. The results from the people who completed the survey offline are presented as a [case study](#) at the end of the results section.

³ Weighting is a frequently used statistical method of ensuring that data are more representative of the population (gender distribution of disabled people and of parents/carers in this case)

⁴ ONS Internet Access Quarterly update 2014: <http://www.ons.gov.uk/ons/rel/rdit2/internet-access-quarterly-update/q1-2014/stb-ia-q1-2014.html#tab-Disability>

3.2. Results

Buying habits

Over four in ten (45%) disabled people and their families said that they shopped online monthly, while a third (34%) said that they shopped online weekly. For non-disabled people, 27% are thought to shop online weekly⁵. When it came to shopping in store, over four in ten disabled people and their families (44%) said that they shopped in store weekly and a third (34%) said that they shopped in store monthly.

There were some significant differences in buying habits in store between disabled people and parents or carers (Figure 1). Disabled people were more likely to have shopped in store a few times a year or monthly. Parents and carers were more likely to have shopped in store on a weekly basis. There were no significant differences between disabled people and parents or carers when it came to shopping online.

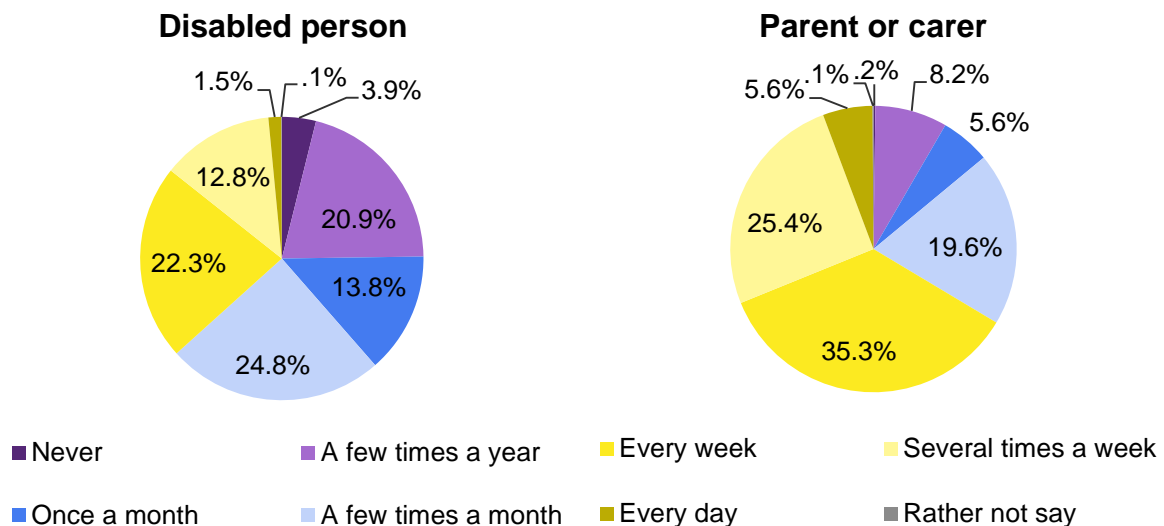


Figure 1. Frequency of shopping in store by disabled people and parents or carers.

When shopping online, over half (51%) said that they either had only some of the information they needed or wished they had more information when making choices

⁵ PWC UK Total Retail survey: <http://www.pwc.co.uk/retail-consumer/total-retail/uk-total-retail-survey-findings-2013-overview.jhtml>

buying things online. Three in ten (28%) said they had the right information. When shopping in store, under half (46%) said that they only had some of the information they needed or wished they had more information. Four in ten (39%) felt like they had the right information⁶.

We also asked people to explain why they felt like they did or did not have enough information when they were shopping. When shopping online, many felt that they needed clearer and better product descriptions:

“I am visually impaired, and sometimes when there is just a picture of the product I am buying I feel I can't judge if it's the right product. More detailed product descriptions would really help me.”

When shopping in store, many found it hard to shop around efficiently:

“It is not easy to shop around (visit different stores to compare products, prices, availability etc.) and usually feels like settling for what is available rather than having a genuine choice.”

People were asked about their experiences of shopping online and in store, as shown in Figure 2 below. There are some key differences and similarities:

- Online shopping has certain benefits over shopping in store: online shopping was more accessible, had more choice, more savings, more items in stock and took less effort or energy.
- Shopping in store was better for getting advice or support, being able to haggle and getting refunds or returns.

⁶ This question was based on a Department for Business, Innovation and Skills (BIS) survey, which was conducted with non-disabled and disabled people. Comparative data, however, was not available when this report was published.

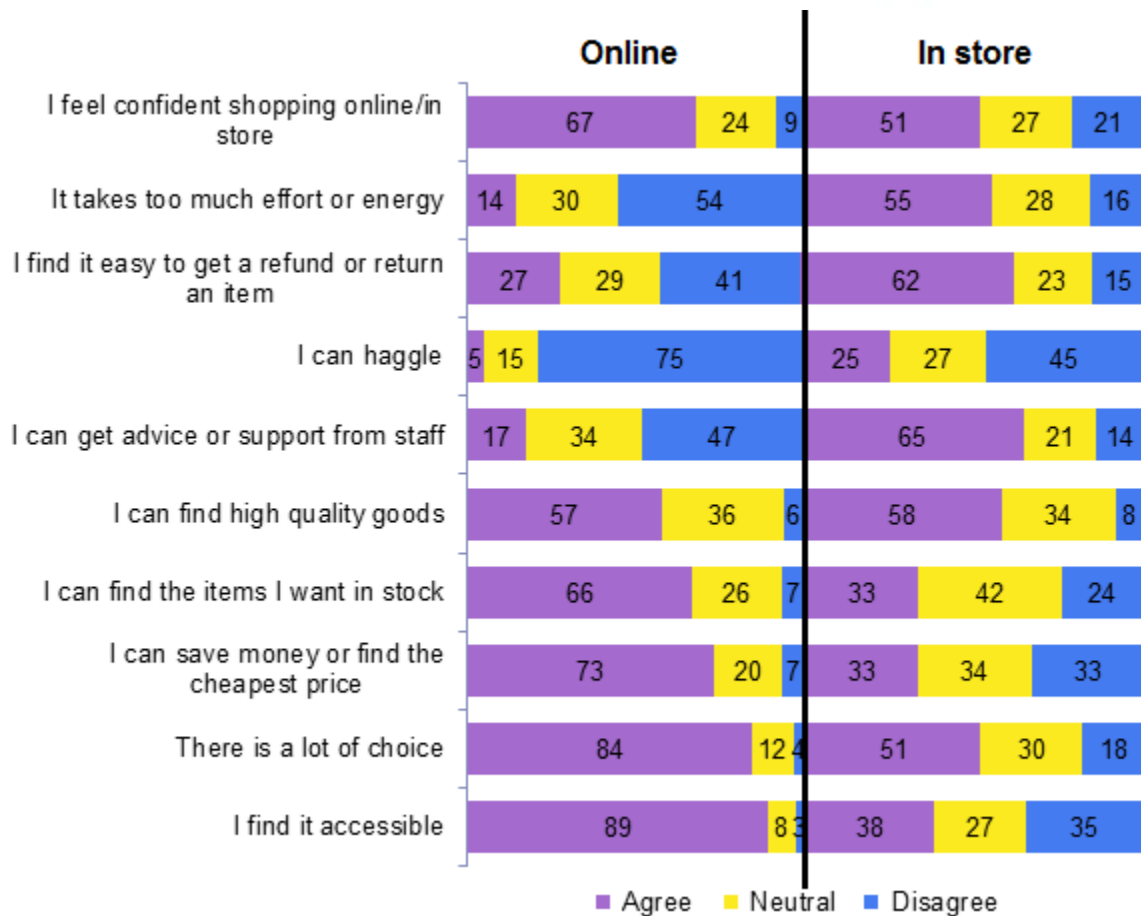


Figure 2. Experiences of shopping online and in store.

There were some key differences between disabled people and parents or carers when it came to shopping experiences in store. Disabled people were more likely to say they found shopping in store inaccessible (43%) compared to parents and carers (21%). Disabled people were also more likely to say it took too much effort or energy (64% versus 40%) and feel less confident shopping in store (27% versus 11%). These differences could contribute to the above finding that disabled people shop less in store than parents or carers.

People had the opportunity to share their experiences qualitatively. Most often, people said that they found online shopping accessible and convenient:

“I have confidence shopping online as everyone is treated equally; you are not seen as “a disabled shopper” who needs help.”

However, there were also some negative aspects to online shopping. This included some websites being inaccessible:

“Websites are usually poorly designed for alternative fonts, so for example if you're dyslexic and use a custom font then input boxes are hard to find or text flows incorrectly.”

Many people also reported difficulties with returns and refunds:

“Having to pay postal returns doesn't seem fair when this is the only way I can shop. Most returns are because fabric/feel wasn't as expected or has fastenings I cannot use.”

With shopping in store, the most frequent concern was that shops were inaccessible and stressful:

“Often stores have cluttered aisles or are too narrow. I find it hard to manoeuvre myself around (especially in clothing stores) because although I am not a wheelchair user, I need walking aids and often can't safely get in between racks.”

Many also felt that shop staff were not helpful:

“A lot of store staff don't seem able or are unwilling to help. When some of them see you are disabled they tend to assume your brain is also disabled and shy away.”

Shopping around and getting deals

We asked people about how they made decisions when it came to making purchases⁷. Figure 3 shows that eight out of ten (81%) tried to find the best deal before buying something they wanted and eight in ten (83%) tried to find a couple of good options before choosing between them.

⁷ BIS survey question, data for non-disabled people not available when this report was published.

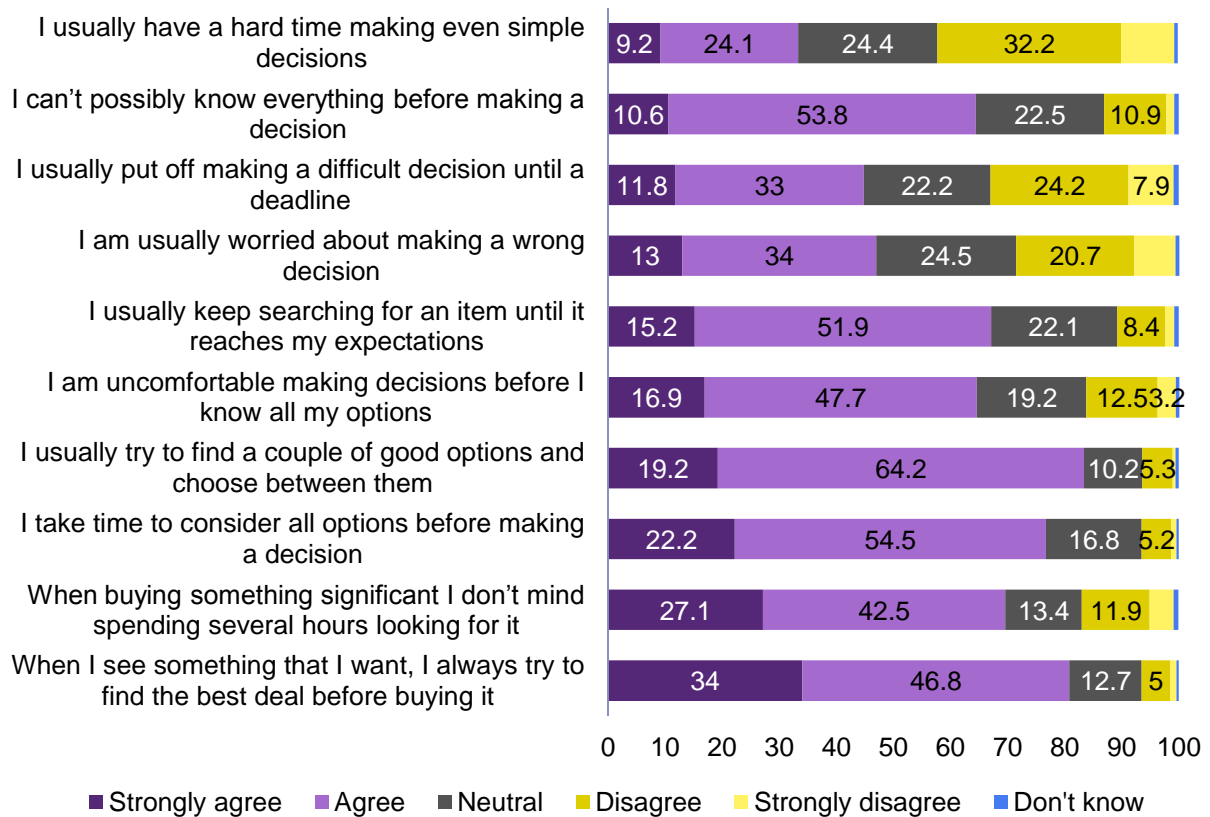
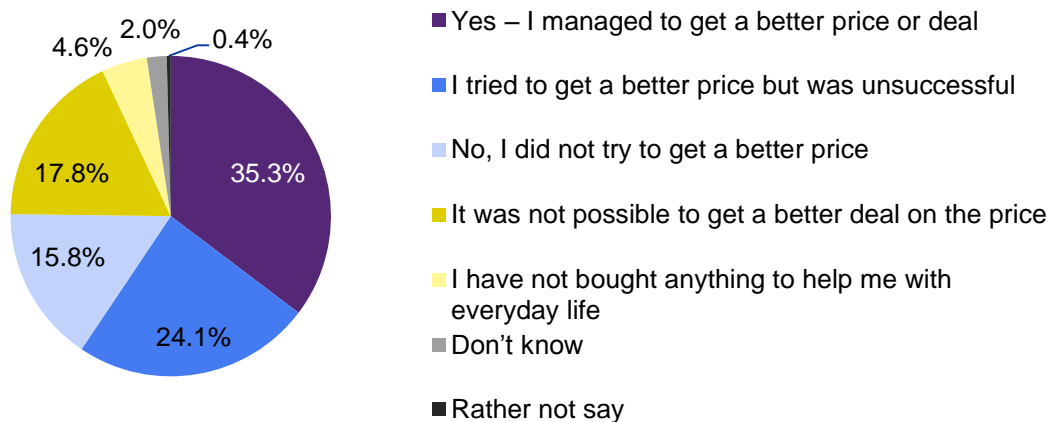


Figure 3. Decision making when making purchases.

We asked people about their experiences of getting a better deal for specialised items (Figure 4)⁸. Over a third (35%) said they had managed to get a better price or deal, while a quarter (24%) said they had tried to get a better price but hadn't been successful. Around one in six (16%) had not tried to get a better price. Around 18% said it was not possible to get a better deal on the price. 4.6% said they had not bought anything to help me with everyday life, 2.0% said they didn't know, and 0.4% said they rather not say.



⁸ Based on BIS survey question, data for non-disabled people not available when this report was published.

Figure 4. Responses to the question “Thinking about the last time you bought something to help you with everyday life, such as a wheelchair, hearing aid or iPad, did you try to get a better price or deal?”

We asked the people who said they hadn’t tried to get a better deal why they hadn’t tried (Figure 5)⁹. Most often, people did not feel comfortable asking for a better price (31%), followed by those that thought it wouldn’t make a difference or that they wouldn’t be successful (27%).

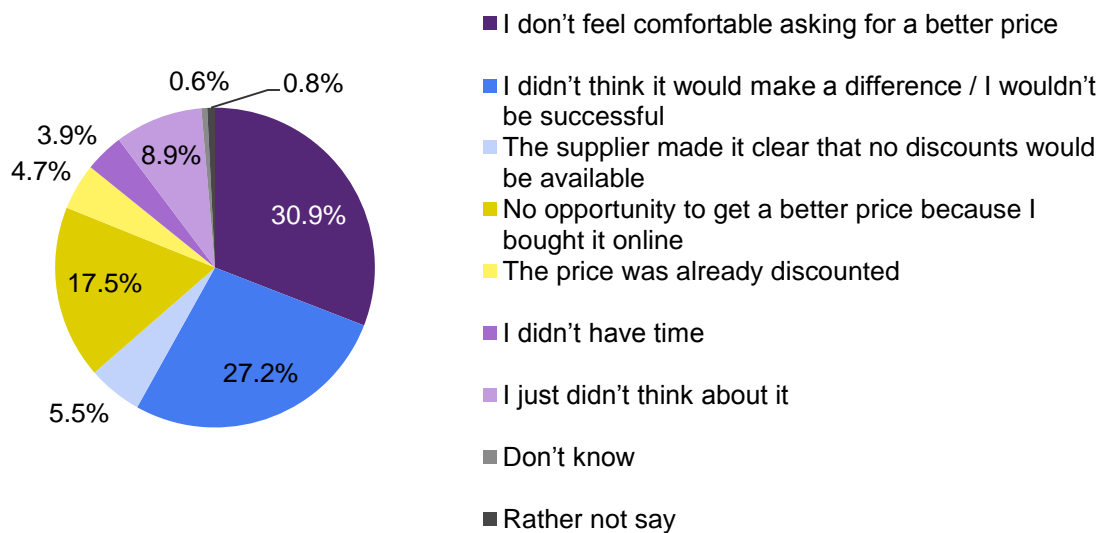


Figure 5. Responses from those who had not asked for a better price or deal when asked why they had not tried to get a better price.

We asked if people knew that if they were disabled that they could get tax relief on products designed or adapted for personal or domestic use¹⁰. Half (48%) had heard of this, and of those who had heard of it, seven in ten (70%) said that they had used this scheme. Disabled people were more likely to have heard of this scheme (54%) than parents or carers (36%).

People were asked about the things that they had used to get good deals (Figure 6). Nine in ten (91%) had used one-stop-shops such as Amazon. The next most frequently used methods were in store deals (73%), membership discount schemes

⁹ BIS survey question, data for non-disabled people not available when this report was published.

¹⁰ Tax relief for disabled people: <https://www.gov.uk/financial-help-disabled/vat-relief>

(66%) and vouchers or coupons (63%). Interestingly, parents were more likely to use social media than disabled people (50% versus 38%), and disabled people were more likely to use information sharing sites such as Money Saving Expert (64% versus 53%). A 2014 survey by the BIS¹¹ noted that half of non-disabled people reported using price comparison sites and 36% consulted friends and family – a lower number than reported here by disabled people and their families.

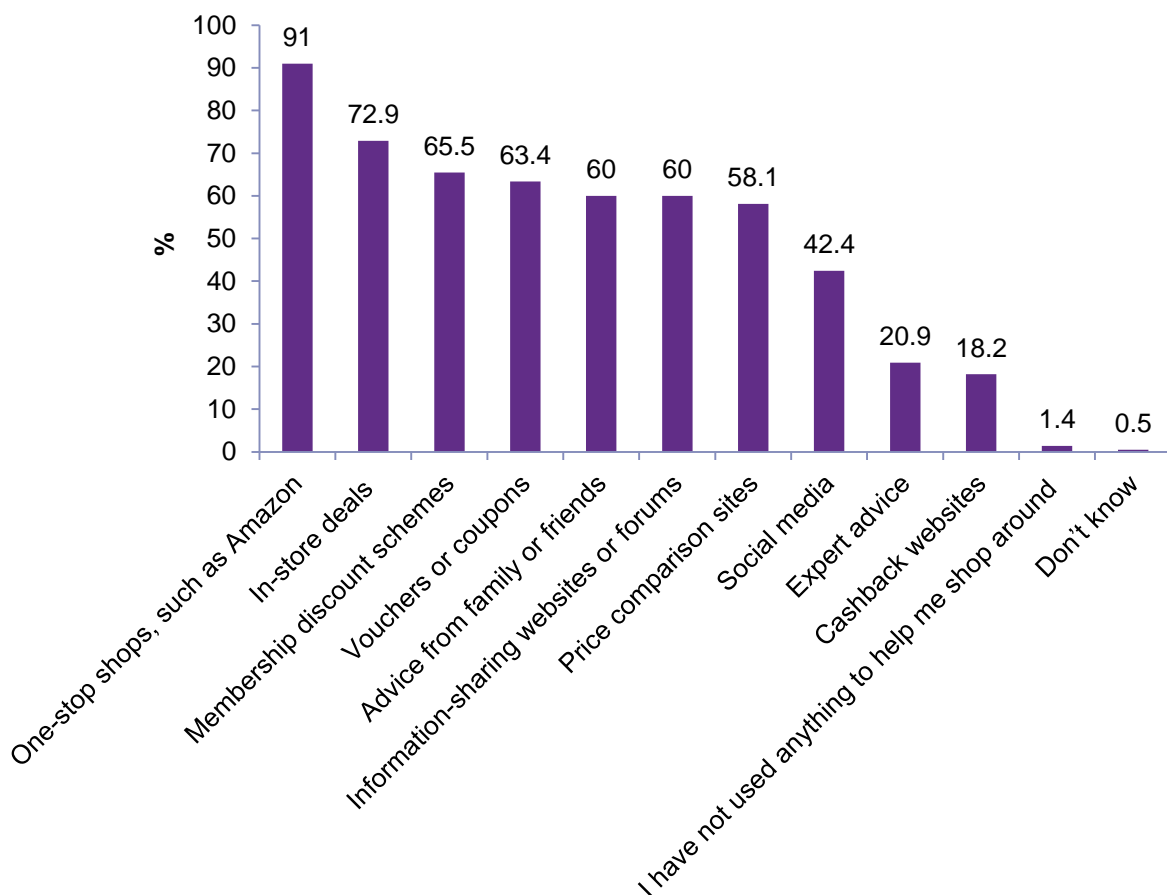


Figure 6. Things people have used to get deals.

We asked people about what things had stopped them getting a good deal (Figure 7). Half (49%) said that they had no opportunity to negotiate and four in ten (44%) said they had not been able to take advantage of last minute deals and discounts.

Disabled people were more likely than parents or carers to say that lack of

¹¹ Department for Business, Innovation and Skills Consumer Detriment survey 2014
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/319043/bis-14-881-bis-consumer-detriment-survey.pdf

understanding of their needs (39% versus 29%) and not being able to take advantage of last minute deals (48% versus 36%) had stopped them getting a good deal.

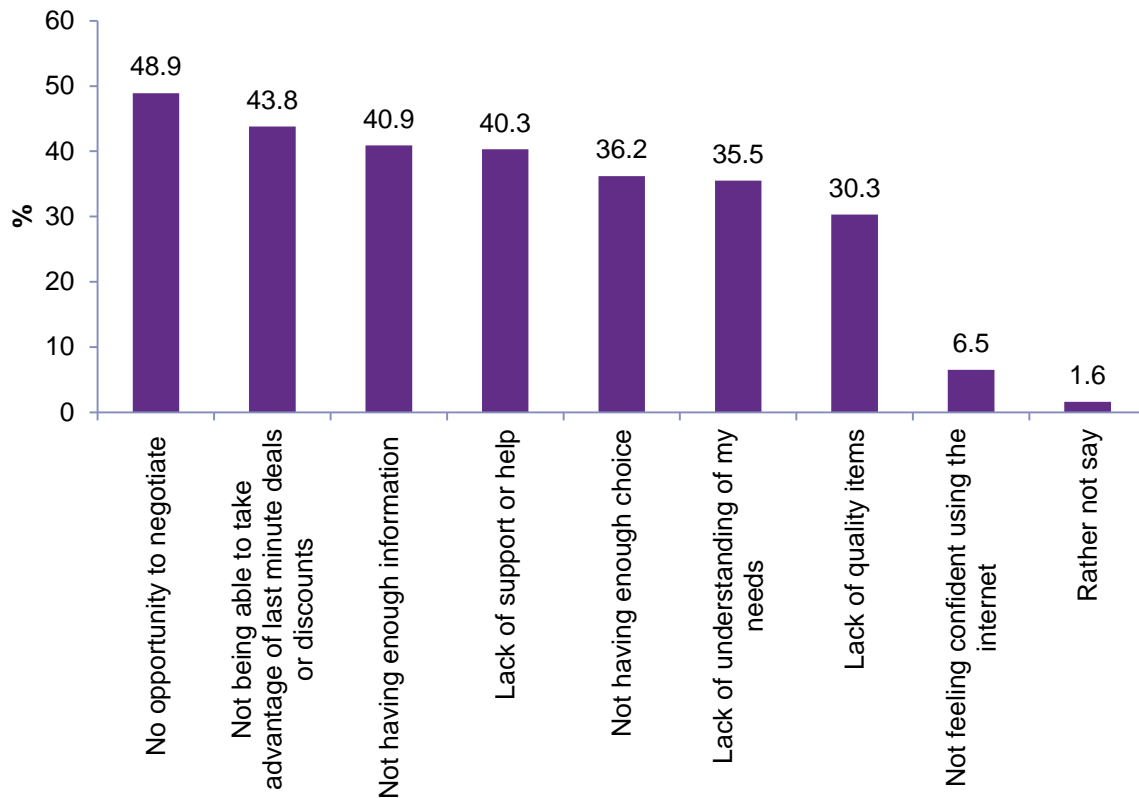


Figure 7. Things that had stopped people getting a good deal.

We asked people which sources of information they had used about different products, services or entitlements related to disability (Figure 8). Half (46%) had used GOV.UK, three in ten (31%) had used Citizens Advice and a quarter (24%) hadn't looked for information or advice. More disabled people had used Disability Rights UK than parents or carers (21% versus 12%).

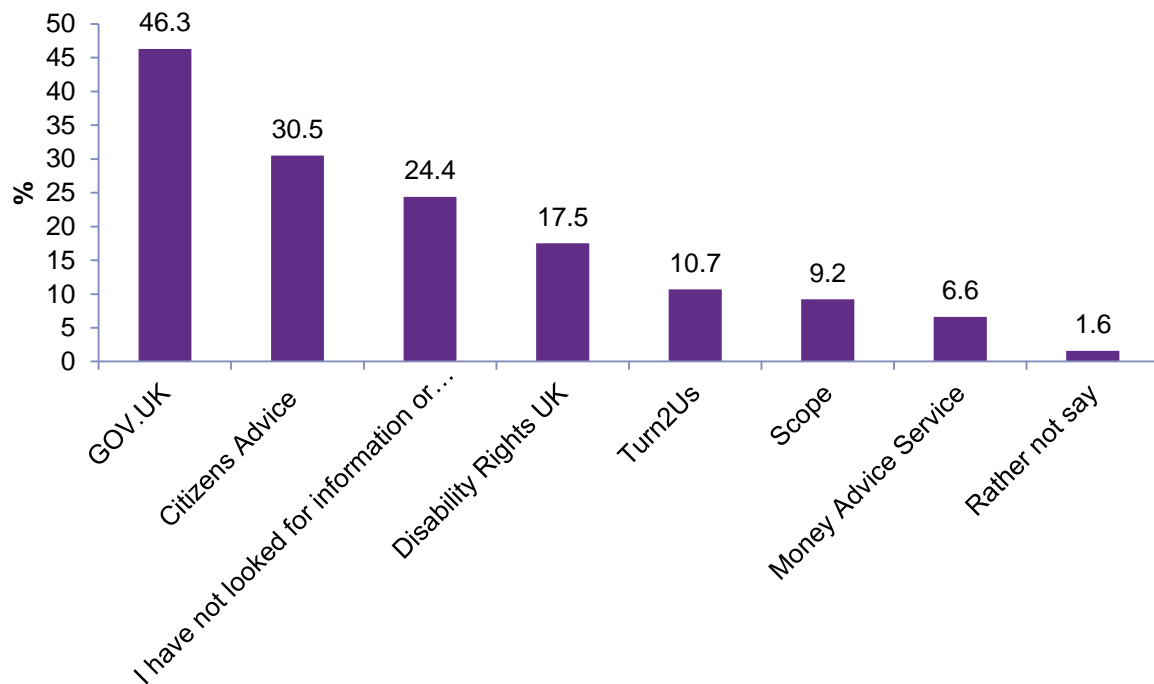


Figure 9. Sources of information and advice about products, services or entitlements related to disability people had used.

It is worth noting that although many people had used these services, many questioned the quality of help they had received:

“Ever tried getting through to these services? They're too busy and apparently badly underfunded and the advice is only as good as the person you get on the end of the phone.”

Smarter purchasing tools

We wanted to know what disabled people and their families thought about various ideas for smarter purchasing tools (tools that are used to help people shop around and get better deals). Six ideas were proposed (Figure 10). The idea that was rated as most useful was a membership discount card for disabled people, with 91% rating this as very useful or useful. In general, all of the ideas we suggested were very highly rated.

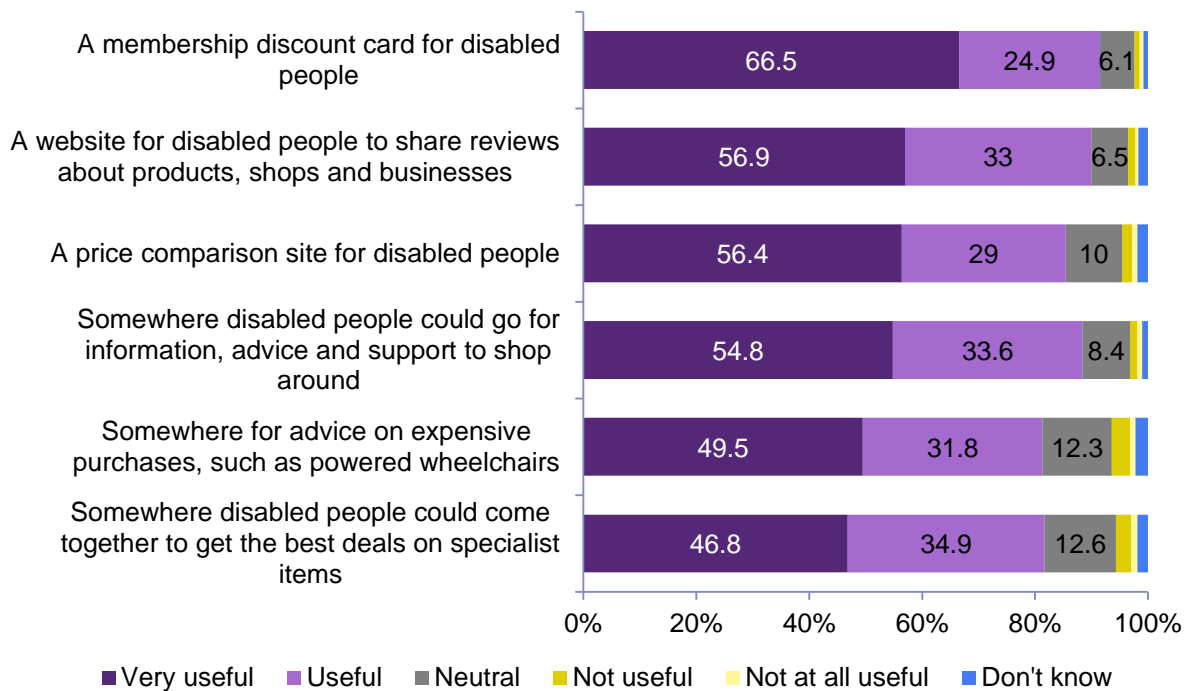


Figure 10. Ratings of proposed smarter purchasing tools.

When asked to pick just one of the ideas they would find most useful (Figure 11), the most popular idea was the membership discount card, followed by a website for disabled people to share reviews. The least popular idea was somewhere for advice on big expensive purchases such as powered wheelchairs.

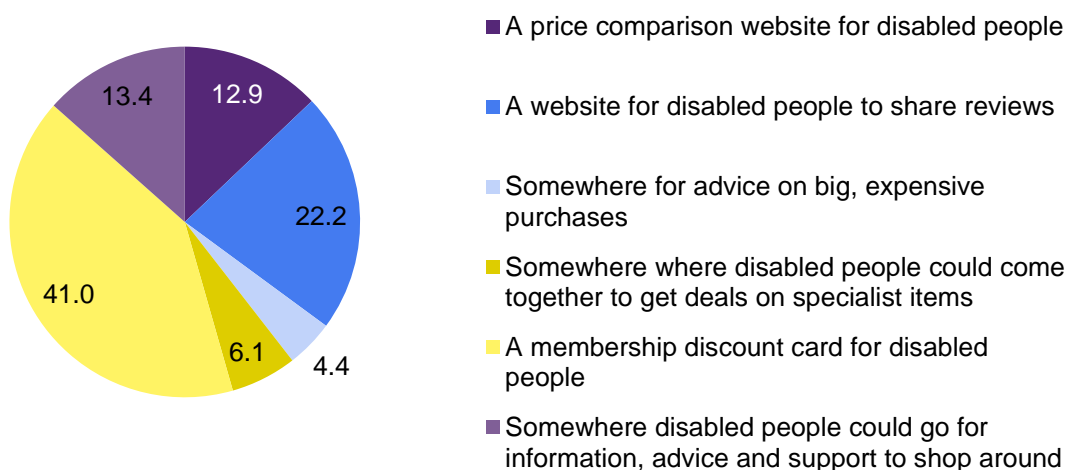


Figure 11. Most popular ideas for smarter purchasing tools.

When asked to share any other thoughts on these ideas, many people said that they would need to be applicable to all disabled people:

“It [should apply] to all disabilities as much as possible. My disabilities are invisible.... Most of the time a discount scheme only applies to things such as wheelchairs and hearing aids etc. which is great but doesn't help people with other disabilities”.

Some people did not want something that singled them out as disabled:

“Generally we don't need separate services, just better support on existing sites.”

We wanted to know what factors would be important to people if they used the proposed smarter purchasing tools. All of the factors were rated as important (Figure 12), but the most important factor was that they could trust it, followed by being easy to use. The least important factor was that it was branded in a way they liked.

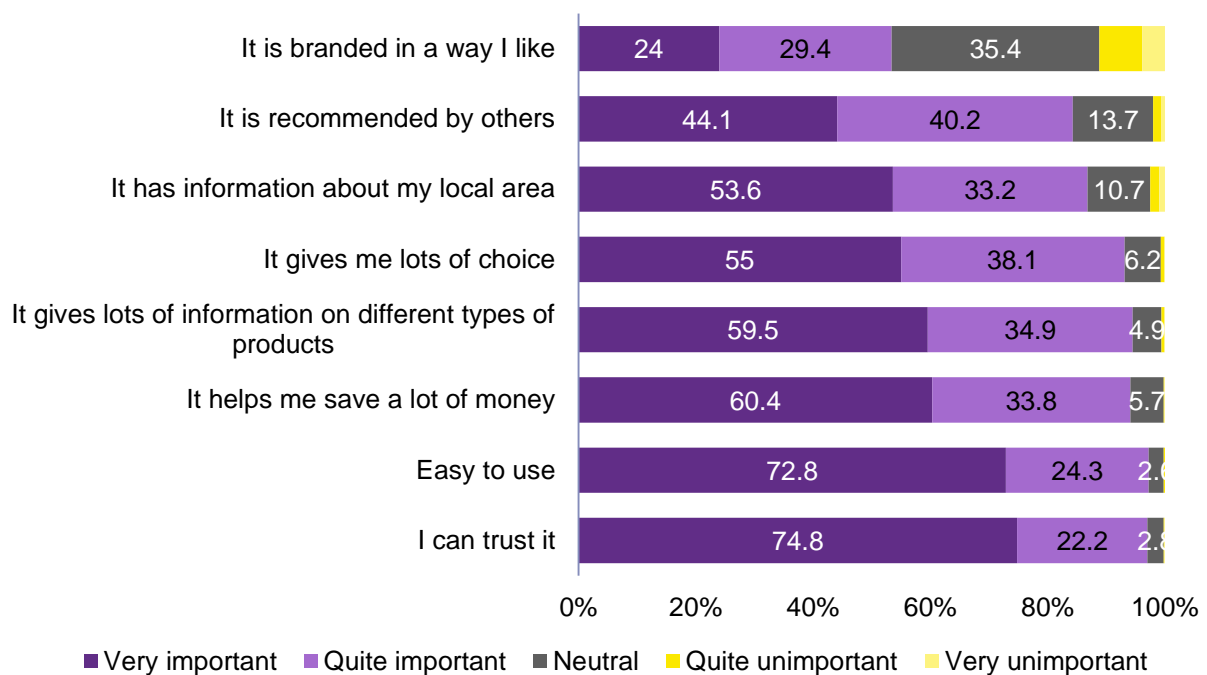


Figure 12. Importance of different factors when using smarter purchasing tools.

We asked what factors were important when looking for advice or information when buying things (Figure 13). The most important factor was that the advice or information came from someone who had similar experiences, followed by

independent advice or information. The least important factor was that the advice or information was interactive.

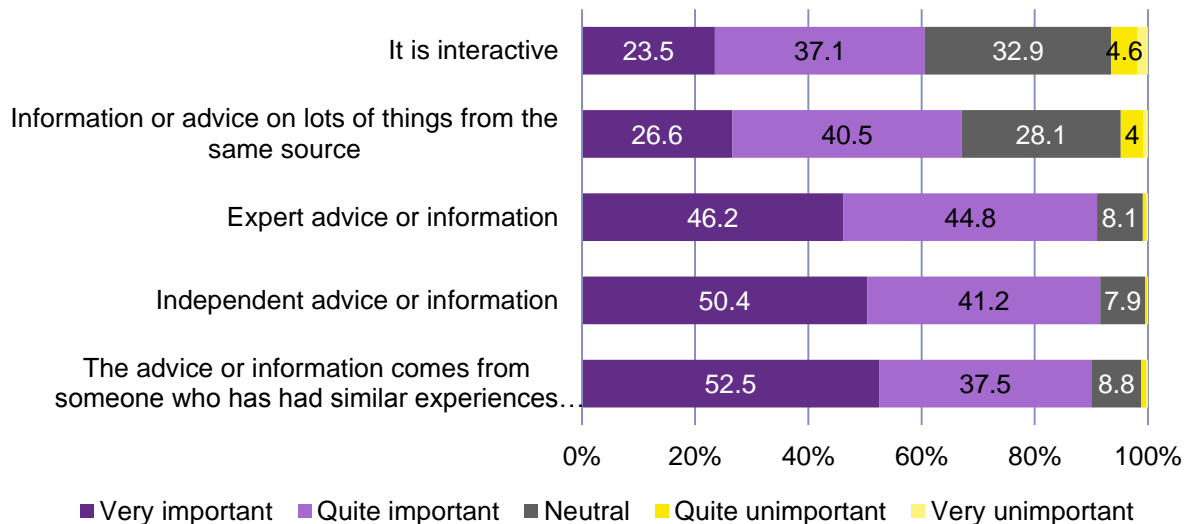


Figure 13. Importance of different factors when looking for advice or information when buying things.

Relationships with businesses

We asked people to select the three factors that would make them return to a business. The three most popular factors (Figure 14) were friendly and helpful staff, good accessibility and that they knew they could get value for money.

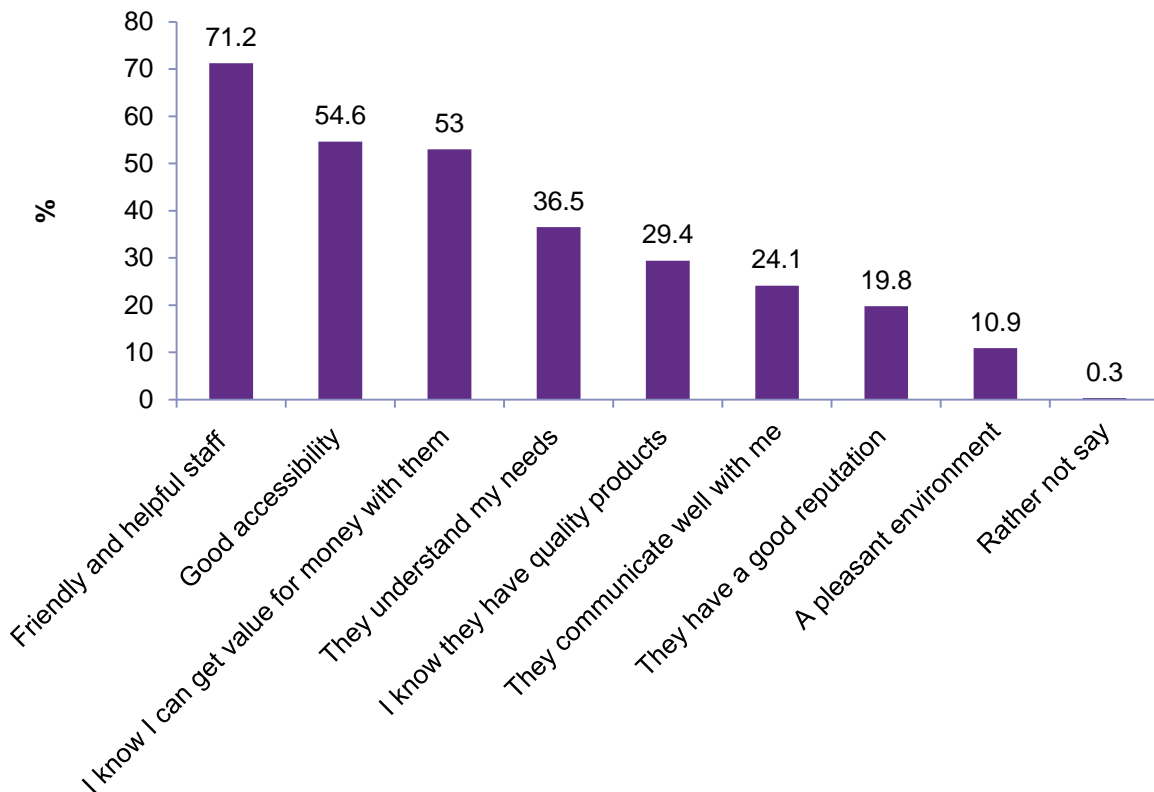


Figure 14. Factors which would make people return to a business.

We asked people whether they had left a shop or business because of poor disability awareness or understanding: three quarters (75%) of disabled people and their families said that they had done this. Seven out of ten (70%) had left a high street shop, half (50%) had left a restaurant, pub or club, and a quarter (27%) had left a supermarket (Figure 15). Twice as many disabled people (13%) as parents or carers (6.3%) said they had left a phone or internet provider and twice as many had left a bank or building society (17% versus 8%).

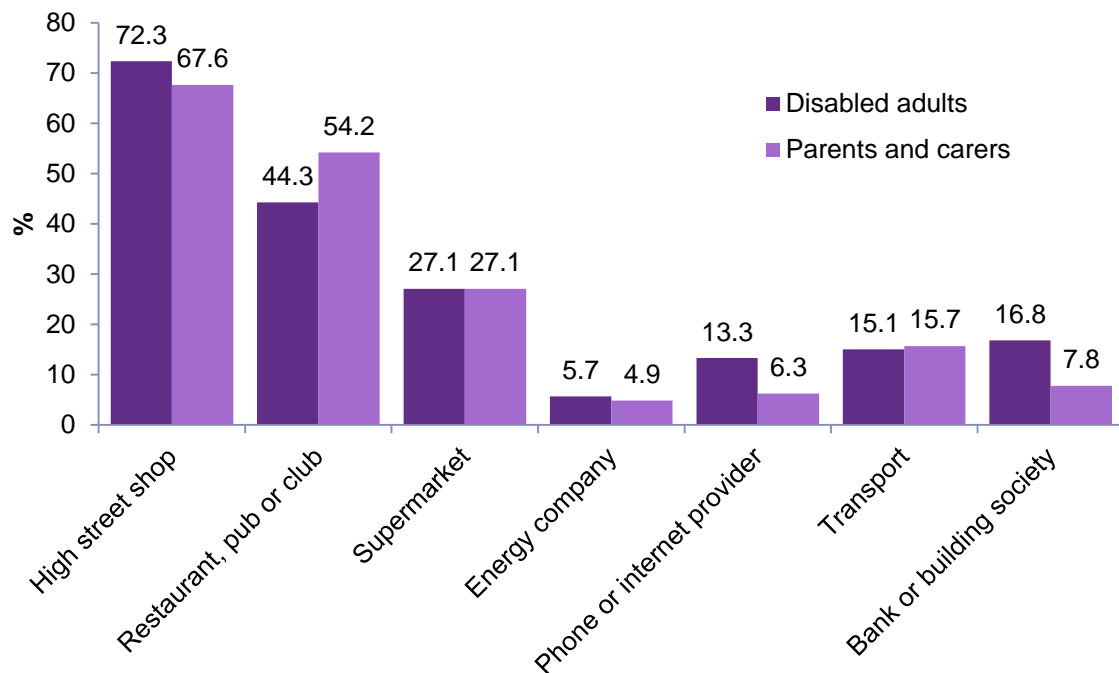


Figure 15. Types of businesses that disabled people and parents and carers had left because of poor disability awareness or understanding.

We asked those who had left a business how much they used to spend, every month, at the place they had left. They were asked to think about the most recent time they had left a business if they had left more than one place. Table 4 shows the median spend as the median provides a more reliable indicator by taking into account high numbers which may have skewed results. Parents and carers appear to have spent more in most areas, but this may be because they are reporting the amount spent on behalf of the whole family.

Table 4. Median spend at the business that people had left because of poor disability awareness or understanding.

Type of business	Median spend: Disabled adults	Median spend: Parents and carers
High street shop	£40	£50
Restaurant, pub or club	£40	£50
Supermarket	£200	£250
Energy company	£84	£100
Phone or internet provider	£40	£50
Transport provider	£30	£40
Bank or building society*	£600	£50

**People were asked to give the amount that they used to deposit at the bank every month.*

If we were to extrapolate these figures to the whole population of disabled people¹², we could estimate that 8.4 million people may have walked away from business because of poor disability awareness. This, in turn, could equate to £1.8 billion lost to businesses in a month (Table 5).

Table 5. Estimates of population and loss of money to businesses if disabled customers left that business.

Type of business	Number of disabled people in the population who could have left this business	Potential loss of money for business
High street shop	6,048,000	£241,920,000
Restaurant, pub or club	3,696,000	£147,840,000
Supermarket	2,268,000	£453,600,000
Energy company	504,000	£42,336,000
Phone or internet provider	1,092,000	£43,680,000
Transport provider	1,260,000	£37,800,000
Bank or building society*	1,428,000	£856,800,000
	TOTAL	£1,823,976,000

We were also interested to know whether disabled people and their families had influenced other people they knew to leave a business because of their experience. Four in ten (43%) said that their friends or family left a business too and a third (36%) said they did not know if this had happened. We gathered further detail on the types of friends or family who had left the business (Figure 16).

¹² Data used from the Family Resources Survey (2012-13)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/325491/family-resources-survey-statistics-2012-2013.pdf

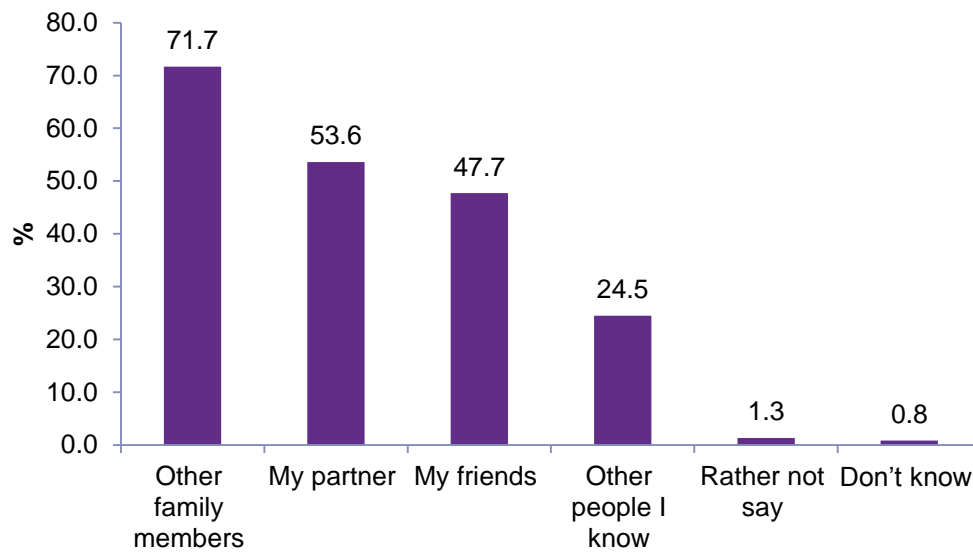


Figure 16. Types of friends or family who left a business because of the respondent's experience.

Energy

Since energy had been identified as an important area of extra costs ([see Extra Costs framework](#)), we wanted to know more about disabled people's experiences with energy suppliers. When asked if they had changed their energy supplier in the last two years¹³ (Figure 17), over half (54%) had switched deals, either to a new supplier or to a better deal with their current supplier. One in six (16%) said that they hadn't checked whether they were on the best deal. Interestingly, in a 2014 BIS survey¹⁴, only 13% of non-disabled people reported switching energy supplier and 27% had considered it in the last year¹⁵.

¹³ BIS survey question, data for non-disabled people not available when this report was published.

¹⁴ Department for Business, Innovation and Skills Consumer Detriment survey 2014
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/319043/bis-14-881-bis-consumer-detriment-survey.pdf

¹⁵ NB our survey asked people to think about the last two years. Comparative data from the latest BIS survey was not available at the time of publication.

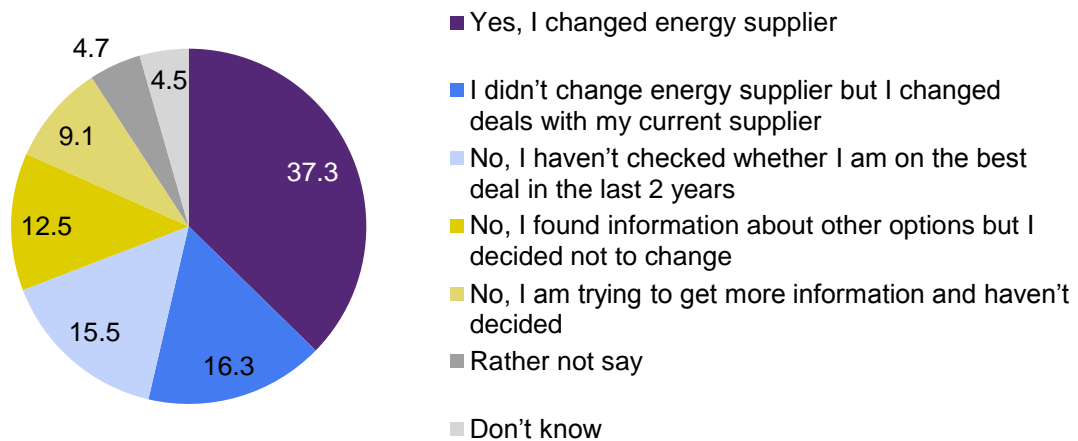


Figure 17. Energy supplier switching habits.

Of those who said they hadn't checked if they were on the best deal, four in ten (41%) said they hadn't checked because it takes too much time or it is too complex to change. Three in ten (28%) said that they were satisfied with their current supplier (Figure 18).

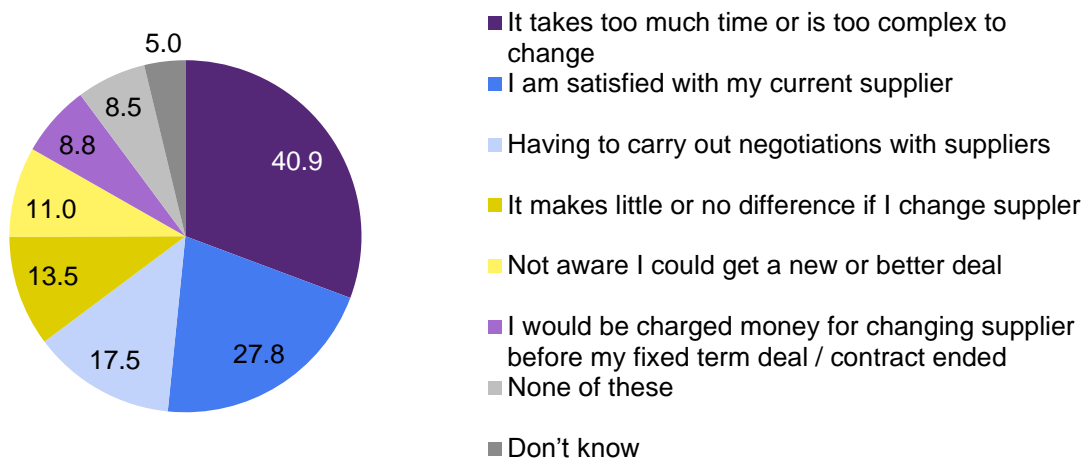


Figure 18. Reasons why people hadn't checked if they were on the best energy deal.

We wanted to know which energy-related schemes people had heard of:

- Eight in ten (83%) had not heard of the Priority Services Register
- Two in ten (19%) had not heard of or weren't sure if they had heard of the Winter Fuel Payment. Six in ten (60%) had heard of it, and two in ten (22%) had used this scheme.

- Four in ten (40%) had not heard of or weren't sure if they had heard of the Warm Home Discount Scheme. Four in ten (36%) had heard of it, and two in ten (23%) had used this scheme.
- A quarter (24%) had not heard of or weren't sure if they had heard of Cold Weather Payments. Half (49%) had heard of it, and a quarter (27%) had used this scheme.
- Over eight in ten (85%) had not heard of or weren't sure if they had heard of the Energy Company Obligation. One in ten (13%) had heard of it, and only 3% had used this scheme.

We wanted to know whether people would be interested in a collective switching scheme for their energy supplier. A collective switching scheme is where a group of people come together to try and get a better deal from an energy supplier. Four in ten (38%) said that they would be interested in this, a third (33%) said they would not be interested, and three in ten (30%) didn't know if they would be interested. Significantly more disabled people (40%) than parents or carers (33%) said they would be interested in this idea.

Demographics

Gender

The majority of our sample (82%) were female, 17% were male, 0.5% were transgender and 1% preferred not to say. To account for this bias, weighting was applied to all the data.

Age

The average age of our survey respondents was 46, although this ranged from 18 to 89. The average age at which the disabled people in this survey had become disabled was 30, and this ranged from people who were born with their impairment or condition to age 86. For parents, the average age that their child had become disabled was 3, and this ranged from those born with their impairment to age 26. For carers, the average age that the person they cared for had become disabled was 28, ranging from those born with their impairment to age 85.

Impairments and conditions

A wide range of impairments and conditions were reported (Figure 19), and there were key differences here between disabled people and parents or carers. For example, eight in ten (81%) disabled people said that they had a physical impairment, compared to only half (51%) of parents or carers who said their child or person they cared for had a physical impairment. Parents and carers were more likely to report a learning disability, behavioural impairment, or autism spectrum condition.

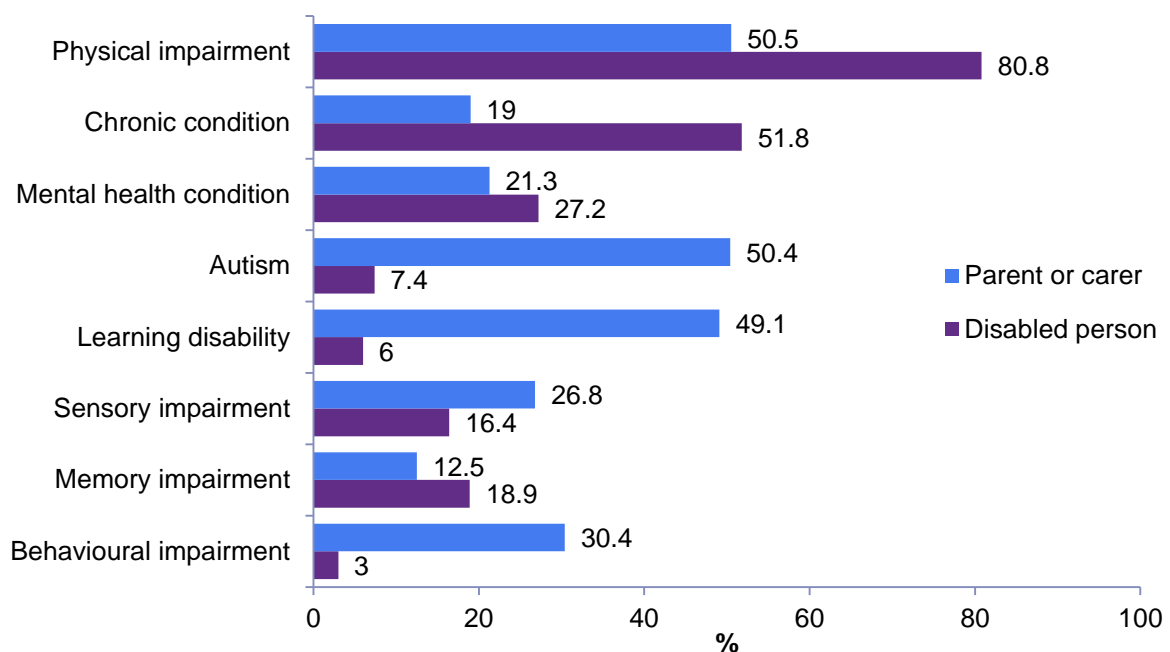


Figure 19. Types of impairments and conditions reported by disabled people and parents/carers.

We also looked at the number of impairments that were reported (Figure 20). Over a third (35%) reported only one impairment or condition, one in three (28%) reported two impairments or conditions, and two in ten (20%) reported three impairments or conditions. Two in ten (18%) reported more than four impairments or conditions.

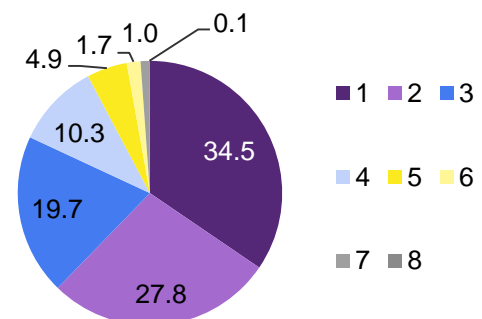


Figure 20. Number of impairments or conditions

Employment status

Over a third (37%) of our sample was not able to work. A third (33%) were employed or self-employed (full or part time; Figure 21). There were some differences between disabled people and parents or carers: while half (47%) of the parents and carers were employed or self-employed, half (49%) of the disabled people were not able to work.

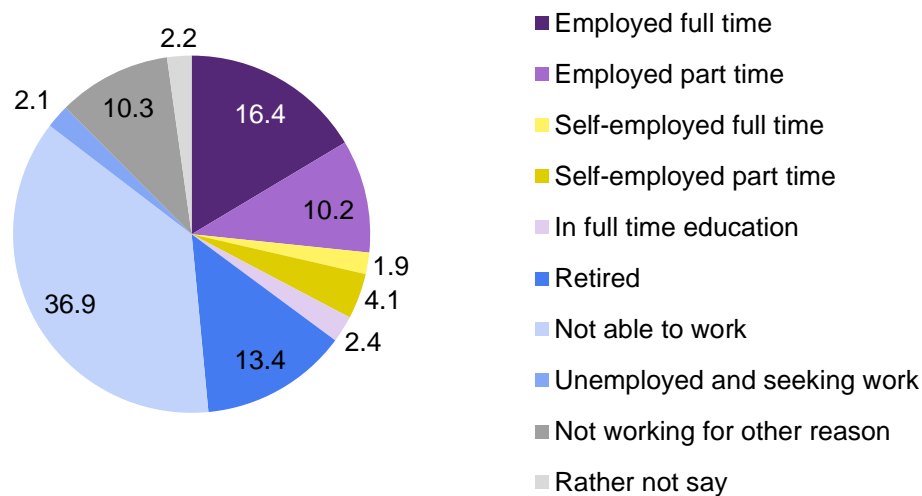


Figure 21. Employment status of survey respondents.

Financial situation

Half (54%) reported that they were sometimes or constantly struggling to keep up with bills and credit commitments. One in ten (12%) were falling behind with some or many bills and commitments, while a quarter (27%) were keeping up without problems (Figure 22).

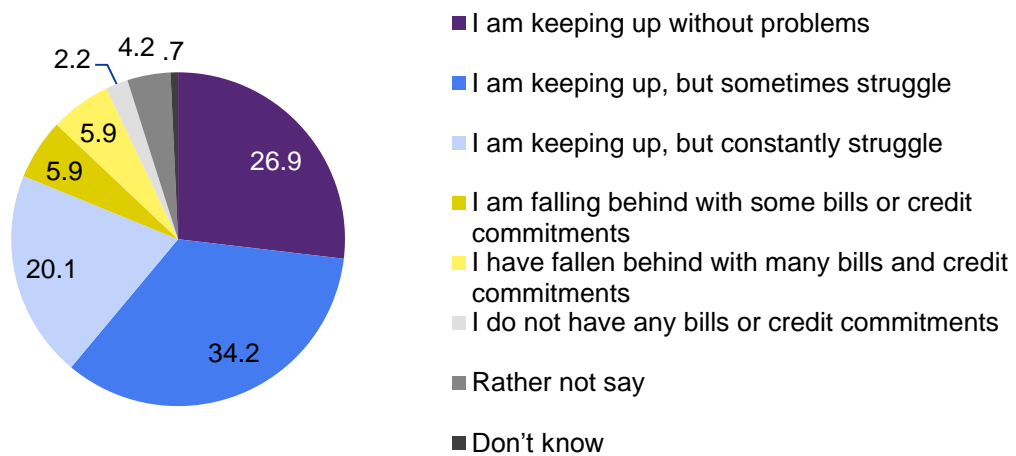


Figure 22. Financial situation of survey respondents.

Ethnicity

The majority of our sample was white British (91%), with a small range of other ethnicities (Figure 23).



Figure 23. Ethnicity of survey respondents.

Location

We collected data on where people lived, with almost four in ten (38%) living in a suburban area, three in ten (30%) in an urban area, and a quarter (24%) in a rural area (Figure 24).

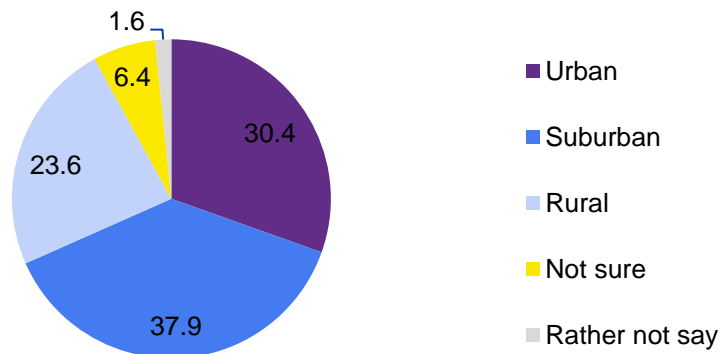


Figure 24. Areas where survey respondents lived.

Case study: Offline survey respondents

Nine disabled adults (7 male and 2 female) and one mother of a disabled adult completed our survey offline. They had a range of impairments including physical impairments, sensory impairments, memory impairments or a learning disability. Most had been born with their impairments, and were now on average 43 years old.

Nine said that they never shopped online, and one said that they shopped online a few times a year. When shopping in store, six shopped weekly, three shopped monthly and one shopped in store a few times a year. Most reported positive experiences of shopping in store, for example, feeling that they had the right information, finding it accessible, being able to find the items they wanted and get the support they wanted. Six had managed to get a better deal on a specialised item.

Seven out of ten did not know that they could get tax relief on some adapted or specialised items. All but one respondent had not used the online methods of getting deals, instead using advice from family and friends (five out of ten), membership discount schemes (four out of ten), in store deals (three out of ten), and vouchers and coupons (three out of ten). Four said that a lack of understanding of their needs had stopped them getting a good deal in the past. The most popular ideas for smarter purchasing tools were a membership discount card for disabled people and somewhere for advice on big, expensive purchases such as powered wheelchairs. The most important factor if using a smarter purchasing tool was that it should be easy to use, followed by being trustworthy.

The top three factors that would make them return to a business were: good accessibility, friendly and helpful staff, and understanding of their needs. Six out of ten had left a business or shop because of poor disability awareness or understanding. Most often, they had left a high street shop or a restaurant, pub or club.

Only two people had changed their energy supplier, two had changed deals with their current supplier, five did not know and one had not checked. Only one person had heard of the Priority Services Register and the Energy Company Obligation, two had heard of Cold Weather Payments and Warm Home Discount and three had heard of the Winter Fuel Payment. Four said that they wouldn't be interested in a collective switching scheme, and four did not know.

Key points: Almost all of the people who completed our survey offline did not shop online and therefore did not use online means of getting good deals. They therefore shopped around using offline means such as by using advice from family or friends. Aside from these key differences, many of the results are similar to the results from online survey respondents in terms of what they want from smarter purchasing tools and their experiences with shops and businesses.

3.3. Summary

Disabled people and their families form a sizeable consumer market that cannot be ignored. They *will* walk away from a business because of poor disability awareness or understanding, and they have an influencing power – their friends and other family will leave a business too because of their experience.

Although there was little comparative data available for non-disabled people¹⁶, disabled people and their families are savvy shoppers – for example, nine in ten use one-stop-shops such as Amazon to get better deals and a third had managed to get a better deal on a specialist item. If people were to use smarter purchasing tools that

¹⁶ Some of our questions are also used in a BIS survey, from which we do not currently have comparative data. These data should be available in the coming months.

were specifically designed for disabled people and their families, such as a membership discount scheme. We should think carefully about how to develop such a scheme – for example, some of our respondents suggested that this would need to be applicable to all disabled people but would also have to avoid causing any stigmatisation.

Over half had switched energy deals (either with their current supplier or to a new supplier). We know from the Extra Costs framework that energy is an area of high costs for many and therefore it is not surprising that they attempt to get the best deal. Many people were not aware of several of the energy schemes available– these must be better publicised.

We have to consider whether the market enables disabled people to get a better deal in the first place – if shops are inaccessible or staff are not helpful, then disabled people are not being given the same opportunities as non-disabled people. Future research should endeavour to reach more people who do not use the internet – especially since they will not use many of the methods (such as one-stop-shops and price comparison sites) that people who do use the internet use to get better deals.

4. Conclusion

Life does cost more if you are disabled – and this has to change. This research involved over 2,500 disabled people and their families and showed that extra costs can be wide ranging, and they impact on people’s lives in more than just financial ways. Disabled people and their families must not be ignored as consumers. We also need to ensure that we do not exclude those who cannot access the internet.

The Extra Costs Commission’s interim report makes a number of recommendations for driving down extra costs. This research has informed the development of many of these recommendations. For example, our research shows that disabled people and their families would find a membership discount scheme really useful – and the Commission recommends that disability organisations should attempt to pilot such a scheme through partnerships with key retailers.

If you have any questions, comments or suggestions regarding the research presented in this technical report, please contact us at

ExtraCostsCommission@scope.org.uk.

“The true costs are not always in money. The highest cost to us has been the loss of quality of life, of family life, and the loss of freedom of choice.”

Appendix

Median extra costs (£) reported in focus groups

		Extra cost area								
		Food and drink	Clothing, shoes and bedding	Housing fuel and power	Household goods and services	Health and personal care	Transport	Communication	Recreation and culture	Insurance
Disabled adults	Impairment									
	Autism	35	25	35	-	18	350	24	15	4
	Chronic condition	40	25	30	65	50	55	0	30	2
	Learning disability	0	0	25	0	0	50	20	40	0
	Mental health condition	40	0	40	0	120	50	0	20	10
	Physical impairment	15	40	25	60	60	70	0	2	7
	Neurological condition (MS)	30	0	30	20	30	64	0	20	0
Sensory impairment	4	0	8	One-off	49	0	0	One-off	0	

Disabled children

Impairment	Autism	0	50	38	0	30	65	21	20	0
	Learning disability	60	65	40	40	0	80	10	40	0
	Physical impairment	30	30	19	One-off	10	140	0	25	5

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