

Driving down the extra costs disabled people face

Interim report

Chair

Robin Hindle Fisher



**Extra Costs
Commission**

Investigating costs faced
by disabled people



The Extra Costs Commission is generously supported by the Barrow Cadbury Trust.

The Barrow Cadbury Trust is an independent charitable foundation, committed to bringing about socially just change.

Extra Costs Commission

Driving down the extra costs
disabled people face

This is the interim report of the Extra Costs Commission. The Commission was set up in July 2014, in response to disability charity Scope's 2014 report *Priced Out: Ending the Financial Penalty of Disability by 2020*, which highlighted a lack of evidence or ideas about how to drive down the cost of products and services for which disabled people pay more.

The Extra Costs Commission is an independent inquiry, chaired by Robin Hindle Fisher. Its membership combines expertise across private, public, regulatory and consumer sectors. Seven of 15 Commissioners are disabled themselves.

- | | |
|----------------------------|--|
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Foreword

by Robin Hindle Fisher



Life costs more if you are disabled.

Research by the disability charity Scope estimates that on average, disabled people spend £550 a month on disability-related expenditure, including higher heating bills, buying specialised equipment, paying for taxis to get around or covering higher insurance premiums.¹

Government action to address these extra costs has focused on raising the income of disabled people through the welfare system, through extra costs payments (Disability Living Allowance, Attendance Allowance and the Personal Independence Payment). Until now, very little has been done by government, or any other group, to tackle the root causes of the problem – by looking at how to reduce disabled people’s outgoings in the first place.

This is a missed opportunity. As long as the gap in the cost of living between disabled and non-disabled people is so wide, it makes it harder for disabled people to contribute equally to society. It makes it harder for disabled people to save and build for the future. It ignores the potential for businesses and the economy of a large and growing consumer base whose earnings are eaten up simply by the basic cost of living. It stores up economic trouble for the future: the proportion of people in their 50s who are disabled or who have long-term health problems is predicted to increase from 43 per cent in 2004 to 58 per cent in 2020.² We cannot afford to price out this proportion of the population.

I, and my fellow commissioners, believe it is important – indeed critical – to improve the living standards of disabled people to understand more about what drives the additional costs disabled people face and to identify ways to start to reduce those costs.

This interim report sets out how the Extra Costs Commission believes that it can contribute to that process. We have identified three areas for change: empowering consumers, changing business practices, and market intervention. Our interim report should be seen as the start of a conversation with all those who might play a role in delivering change. Responses to the consultation questions included in this report will inform our final recommendations in June 2015. I very much hope that you will engage with our work in whatever way you can.

Robin Hindle Fisher

1 Brawn, E: *Priced Out*, Scope, 2014

2 Pillai R. et al: *Disability 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020*, IPPR, 2007

Executive summary

Disabled people and their families face expenses that others do not. They may need more of some goods and services than non-disabled people. In some cases they may pay higher prices for the same services because of their impairment or condition. These costs get in the way of disabled people and their families playing their full part in society. The Commission's research shows for example, that **69 per cent of disabled people are either struggling or falling behind with bills and credit commitments.**³

This report sets out new evidence about where extra costs lie. It also seeks your views on how to drive down the extra costs faced by disabled people and families with disabled children, asking a number of consultation questions to inform our final recommendations.

The Commission has identified those products and services where we can achieve rapid change and where disabled people and their families, the businesses that supply them and voluntary sector organisations who work to deliver social change are able to take immediate action. We are particularly interested in costs associated with: energy, clothing and bedding, specialised equipment, transport and insurance.

There are underlying barriers that must be tackled first. **Thirty per cent of disabled people have never used the internet, compared to seven per cent of non-disabled people.**⁴ To have the best chance of driving down costs, disabled people need better access to appropriate financial products and to be able to get online, where some of the best deals are to be found.

Disabled people and families with disabled children are a vital part of the solution. Various tools, information and offers exist to support them to make effective use of their spending power. However, our research shows that **less than half of disabled people and their families are satisfied with the information they have when making purchasing decisions.**⁵ More needs to happen to ensure that they are aware of resources that can support them in making informed decisions.

³ Extra Costs Commission: *Consumer survey*, March 2015

⁴ ONS: *Internet Access Quarterly Update*, Q1 2014, http://www.ons.gov.uk/ons/dcp171778_362910.pdf

⁵ Extra Costs Commission: *Consumer survey*, March 2015

Disabled people have a huge appetite for new tools to help them reduce extra costs. for example **over 90 per cent of disabled consumers saw value in membership discount schemes and peer-to-peer review platforms.**⁶ There is appetite too for disabled people to group together to obtain lower prices on goods through collective purchasing. We are keen to explore further how these initiatives could work in practice to improve competition and drive down costs.

A shocking three quarters of disabled people and their families have felt so badly treated because of their disability that they have left a shop or business.⁷ They tell us that their experiences as consumers are often frustrating and that they do not know where to go to be heard. Our evidence shows that they tend to choose not to return to the suppliers that have let them down – often taking away not only their business but also that of family and friends. We believe it is time that disabled consumers had a stronger, more effective voice. We want your views on how that could best be achieved.

We believe disabled people themselves have an important role to play in this – their voices can be heard only if they speak up. Tools will help only if disabled people seek them out, make use of them and feed back on how they can be improved. Businesses will tailor offers to their needs only if these needs are communicated. Our message to disabled people is: control what personal information you give, both about your impairments and about your preferences as a consumer, but where it could benefit you and other disabled people, do provide it. Finding a common identity for disabled consumers can help generate more consumer power.

From our initial investigations, it's clear that there is a huge opportunity out there for businesses that do, or might, supply disabled people: **there are over 12 million disabled people**⁸ who want to buy the value-for-money goods and services these businesses aim to supply, but who tell us they cannot find what they are looking for. **A recent estimate put the value of the 'purple pound' at £212 billion every year.**⁹

If there are challenges for businesses wanting to serve this market, we want to hear about them, as well as suggestions for how to overcome these barriers. Ideas we want to test include harnessing the information and networks that the voluntary sector has and developing these to meet business needs, so that new opportunities can be opened up. This has worked in specific cases: it can work much more widely.

6 Ibid

7 Extra Costs Commission: *Consumer survey*, March 2015

8 ONS: *Family Resources Survey 2012/13*, 2014

9 DWP press release on 'purple pound' figure, 27 August 2014: <https://www.gov.uk/government/news/high-street-could-be-boosted-by-212-billion-purple-pound-by-attracting-disabled-people-and-their-families>

The Commission believes that much can be achieved without additional regulation, by empowering disabled people and their families as consumers and feeding the entrepreneurial spirit of both disabled people and businesses. But in some markets there may still be structural barriers to reducing extra costs, requiring a potential contribution from regulators or legislative change. We have also been told of instances where rules and regulations may stand in the way of innovation that could reduce extra costs. We want additional evidence and views to support the development of specific recommendations on regulatory change.

Voluntary, public sector and trade bodies could do more to directly influence suppliers to drive down costs through incentives. Various approaches have been tried in other fields, for example accreditation, awards or challenge funding. We are conducting research on what might work best for extra costs. Pooling effort will be likely to lever the biggest impact. We want your thoughts on how best this could be made to work.

This report sets out the initial evidence, the analysis and our ideas for change. It asks for your response to a number of specific questions about our current thinking. Your responses will help us to refine our recommendations and identify who needs to act to make change happen.

We will publish our final recommendations in June 2015. That may be the end of the Commission, but with your help, we intend it to be the start of something big. A recurrent theme of this report is the importance of partnership: across disability organisations, between voluntary and private sectors, among disabled people, between disability charities, regulators, the public sector and public-spirited individuals. Government has a role in creating the conditions for these partnerships to thrive.

We seek a coalition of the willing to take forward the best of the ideas in this report we are yet to identify. Will you join this exciting project?

Recommendations

Our current recommendations are set out below, based upon the evidence we have so far. The thinking behind them and other options considered are set out in the body of the report.

1. Disability organisations should explore the creation of a hub through which disabled consumers can find the various market comparison sites, online marketplaces and review sites that already exist for the products and services they use, and undertake marketing to raise awareness of it. **(pg. 41)**
2. Trusted disability and/or consumer organisations should create a community platform to allow disabled people and their families to review disability-related goods and services, to encourage greater scrutiny of price, value and customer experience. **(pg. 41)**
3. Disability organisations, working in partnership, should pilot an affiliate scheme for disabled people that offers discounts on products and services through partnership with key retailers. **(pg. 43)**
4. Disability and consumer organisations should signpost disabled people and their families to appropriate switching schemes for services such as energy and insurance and develop new collective purchasing and switching schemes, with an aspiration to make disabled people the savviest consumers in the market. **(pg. 45)**
5. Disability and consumer organisations should coordinate to advocate for a new, stronger system to amplify the voice of disabled people dissatisfied with a supplier's services, and to improve the response to consumer complaints. **(pg. 47)**
6. Statistics should be developed on the 'purple pound' in consultation with business and with disabled people. These statistics should be readily updated, meet business needs and be recognised by disabled people as reflecting their experience. **(pg. 50)**
7. Representatives of business in collaboration with disability organisations should work together to identify and fill the most important gaps in information about disabled consumers available to business – considering for example, size and characteristics of the potential market, sector-specific analyses, individual customer data or evidence about potential wider benefits to business. **(pg. 51)**
8. Disability organisations, the Government and trade bodies should collaborate in developing incentives (such as awards, innovation prizes or accreditation schemes) to influence businesses to take actions that will reduce extra costs. **(pg. 60)**

Consultation questions

This report is designed to serve as a consultation exercise. We are interested to hear your views on the questions below. Information about how to respond can be found at the back of the report in Section 8.

Q1a: What are the current barriers to financial inclusion for disabled people? (pg. 36)

Q1b: What action could the Commission recommend to improve financial inclusion for disabled people and their families? (pg. 36)

Q2: What action could the Commission recommend that would close the digital gap between disabled and non-disabled people? (pg. 37)

Q3a: What additional evidence is there around the feasibility of a peer-to-peer review platform or coordination of tools available to support good consumer choices? What sources of support are available for disabled consumers? Where are the gaps? (pg. 42)

Q3b: What solutions could the Commission consider to ensure consumers who do not currently use the internet are equally empowered? (pg. 42)

Q4: What factors need to be considered in coordinating a joined-up retail affiliate scheme for disabled people and their families, e.g. eligibility criteria, marketing? (pg. 43)

Q5a: Is there a need for collective purchasing and switching schemes specifically targeted at disabled people and their families, e.g. for energy, insurance? (pg. 45)

Q5b: How feasible would it be to develop a collective purchasing model for clothing and bedding and/or specialised equipment? (pg. 45)

Q6: What systems or approaches would be most effective in strengthening the voice of the disabled consumer? (pg. 47)

Q7: What are the biggest factors that inhibit businesses from doing more to explore and take up opportunities to meet demand from disabled consumers? How could these be overcome? (pg. 49)

Q8: What has been effective in translating boardroom goodwill into reduced costs for disabled consumers? (pg. 52)

Q9: How significant a factor for businesses is the cost of getting the right information to the right disabled consumers, and learning about their preferences? What sort of information would be useful? What practical solutions would help to acquire this information? (pg. 53)

Q10: What characteristics would a project to fill gaps in information that would help supply disabled consumers more efficiently need to have, in order for it to be attractive to participate? **(pg. 53)**

Q11: What opportunities are there for disability organisations to support effective regulation? Which issues common across sectors, have the greatest potential to have impact on extra costs? **(pg. 55)**

Q12: What information would best help local authorities to ensure that licensing and enforcement of taxis and private hire vehicles serves the needs of disabled people, taking into account local circumstances? **(pg. 56)**

Q13: What are the risks of preventing insurers from taking into account disability when pricing insurance and how do these vary by insurance industry sector? **(pg. 58)**

Q14: Are there examples of suppliers being inhibited, or charging disabled consumers a higher price out of caution, because of rules and regulations? **(pg. 58)**

Q15: What evidence is there with regard to the effectiveness of different attempts to influence businesses to deliver policy objectives, in particular with regard to objectives benefiting disabled people? **(pg. 60)**

We are open to responses in any form and on as many or as few questions as concern you. Written responses should be emailed to ExtraCostsCommission@scope.org.uk or sent by post to:

Robin Hindle Fisher
Extra Costs Commission
c/o Scope
6 Market Road
London N7 9PW

The deadline for responses to this call for evidence and ideas is **15 April 2015**.

Our survey of businesses will open soon and will be available at **www.extracosts.org**

1. The Commission's role in driving down extra costs

1.1 Our remit

The Commission was set the following question in its terms of reference:

What are the key drivers of the additional costs faced by disabled people and their families in England and Wales and what can be done to reduce them?

In answering that question, our aims are to:

- Promote better understanding of the key social and market-based drivers of extra costs;
- Develop a suite of recommendations for business, the voluntary sector, Government and disabled people on how to drive down these extra costs.

The terms of reference for the Commission tasked us to look at three main areas:

A. How to empower disabled consumers

The Commission is interested in what action can be taken to support disabled people to make the best value purchasing decisions. We focus on ways to foster consumer empowerment and how to build the capacity of individuals to make best use of their spending power.

Our inquiry is considering whether disabled people have access to the right tools and confidence to navigate markets effectively, to secure value-for-money purchases and to source information and advice to help in managing extra costs.

We are equally interested in the potential of any initiatives that could reduce extra costs for disabled people, such as collective purchasing schemes for essential products and retail partnership schemes that reward loyalty.

B. How to ensure the efficient supply of products and services to disabled people

How businesses operate has a large impact on the extra costs faced by disabled people and their families. Where there is a lack of supply to meet consumer demand, or insufficient competition or innovation in a market for a particular product or service, the price disabled people pay may be higher than it needs to be. Where businesses fail to recognise disabled people as a sufficiently valuable customer base, efforts are unlikely to be made to serve them. Recognition of the potential market does not always translate into provision of services, for example if structural barriers – real or perceived – would make this costly. Suppliers, distributors and manufacturers have a pivotal role to play in driving down costs.

The Commission is exploring how businesses can be encouraged to engage further and more effectively with disabled people, both those already supplying this consumer base and those not yet active in this area. We are considering the barriers that restrict this from happening and how these could be overcome.

C. Where there is a need to intervene in markets to drive down costs (and where there isn't)

We make no assumption that greater regulation is needed in order to drive down costs to disabled people. Indeed, less intervention in some areas may be the answer. Nevertheless, the Commission is giving consideration to whether better enforcement or changes to regulation and incentives to business may play a part in particular markets serving disabled people. We ask whether removing over-protective regulation could enable wider choice and lower costs for disabled consumers, and if/where financial incentives could most effectively leverage investment in the supply of goods and services to disabled people.

1.2 A focused approach

Disabled people face multiple extra costs. The factors that drive these are complex. The Commission has decided to focus on those areas where we expect impact to be most significant. The criteria we have used to assess the likely impact of the change we want to see, include:

- the scale of the expected change:
 - how many disabled people will be affected;
 - how large a reduction in extra costs can be expected for those disabled people who would benefit;
 - the extent to which the change will be felt by those currently most disadvantaged.

- the likelihood of achieving change:
 - political, economic and cultural barriers to implementation;
 - the need to balance the desire for quick wins against the need to see lasting societal change.
- the value that the Commission can add:
 - the opportunity to support existing initiatives that may lead to action without the need for further recommendations;
 - using the particular knowledge, expertise and experience of the Commissioners to best effect.

There are many effective voluntary sector organisations working to promote the interests of people with a particular impairment or health condition. To minimise duplication, the Commission is focusing on action to address the needs of disabled people in general, or of a number of different groups of disabled people.

The Commission recognises that inaccessibility of the physical environment is a significant contributor to extra costs.¹⁰ When a wheelchair user cannot get into a shop because there is no ramp for example, this can limit their choice or force them to use more expensive substitutes for their chosen product. However, the issue of physical accessibility is one that has received much attention, and where campaigns for improvements are well-organised.¹¹ In consequence, the Commission is not intending to make recommendations about medium or long-term improvements to infrastructure that will improve accessibility.

The same applies to other areas of social policy that have a significant impact on disabled people's outgoings. Many disabled people face high social care costs. Provision of social care for working-age disabled adults is underfunded by at least £1.2 billion,¹² leaving individuals to pay for this support themselves or go without it. Families with disabled children will incur significant expenditure for childcare, paying eight times more towards these costs compared to other families.¹³ There are however, a number of organisations campaigning for changes to legislation and policy on both of these issues. The Commission's collective expertise does not make us best placed to add weight to existing action in this area.

10 A survey by DisabledGo in December 2014 assessed 30,000 shops and restaurants and found that a fifth of shops had no wheelchair access, <http://www.disabledgo.com/blog/2014/12/disabledgo-study-shocks-the-government-with-evidence-of-inaccessible-british-high-streets/>

11 The Office for Disability Issues initiative – *Accessible Britain Challenge* – is encouraging communities to be inclusive and accessible for disabled people. It was launched in September 2014.

12 Fernandez, J. et al: *Implications of setting eligibility criteria for adult social care at moderate needs level*, PSSRU, 2013

13 Contact a Family: *Childcare Affordability Trap*, 2014

Perhaps because our combined expertise and experience is heavily weighted to the non-statutory sector, we begin from the premise that action by businesses, disability and consumer organisations¹⁴ and by disabled people themselves will go a long way to driving down the costs disabled people face, without the need for significant new regulatory powers or changes to government policy.

1.3 The role of welfare benefits

Extra cost payments – Disability Living Allowance (DLA), Attendance Allowance (AA) and Personal Independence Payments (PIP) – provide crucial help with the additional costs incurred by disabled people. However, while these payments can make a contribution, they are not sufficient to cover all costs. In 2015/16, the maximum award for DLA or PIP of around £360 a month would not cover costs for the average disabled person,¹⁵ let alone those facing the highest costs.

The level and nature of welfare payments is outside our remit. But the discrepancy between average extra costs and levels of benefits leads us to conclude that action on both income and costs is needed if we are to level the playing field. Until there is demonstrable evidence that the extra costs faced by disabled people have begun to fall, we believe that the value of DLA/PIP should be fully protected. And given the likelihood that some extra costs cannot be quickly or easily reduced, the Commission does not believe that its work should provide any justification at this time for changing the purpose or scope of these extra cost payments.

¹⁴ By disability organisations, we refer to organisations of disabled people (disabled people's and user-led organisations) and organisations for disabled people (disability charities such as Scope).

¹⁵ Brawn, E: *Priced Out*, Scope, 2014

2. Extra costs: the evidence

2.1 Categorisation of extra costs

The Commission issued a call for evidence to disabled people and their families seeking their experiences of extra costs (see Appendix A). Our analysis of over 400 responses from individuals and interested organisations shows that costs fall into three broad categories:

A. Specialised goods, often with an added premium

This category includes disability-related equipment that can be a one-off, but expensive, purchase, including for example assistive technology, wheelchairs and other mobility aids, screen readers or adapted household items and furniture.

Disabled people told us that not only do these purchases create a financial shock that other people may not have to confront, but the products also often seem to be over-priced or to differ wildly in price from supplier to supplier.

B. Greater use of non-specialised goods and services

Extra costs occur in a number of areas where disabled people consume more of certain non-specialised goods and services than non-disabled people because of their impairment or condition. While the products themselves may be low-cost and would be recognisable to non-disabled people as necessary expenditure, needing to buy them more frequently results in disabled people spending more over time.

For example, children with a mobility impairment may wear through their shoes fortnightly, whilst wheelchair users may find that they get cold more quickly because they move around less, requiring constant heating for their home even during the summer months.

C. Higher cost for non-specialised goods and services

This category includes anything that costs more to disabled people than non-disabled people for an equivalent product or service. In some cases, this is because the cost of a reasonable adjustment is passed on to the individual rather than being absorbed into the costs of the product or service for all of its consumers.

A few examples of this were raised in our call for evidence, including higher taxi rates for larger or adapted vehicles and higher tariffs for accessible hotel rooms. A number of disabled people and their families also report having to pay a lot to insure themselves or their children, particularly for holidays and to drive.

2.2 Impact of extra costs

Disabled people are already less likely to be in work than non-disabled people: nearly 80 per cent of non-disabled people have jobs compared to less than half of disabled people.¹⁶ Coupled with this, when in work, disabled people on average earn over £1 an hour less than non-disabled people.¹⁷ Along with having to manage the extra costs they face, and despite the provision of DLA and PIP, disabled people have less disposable income.

This has significant consequences. On average, disabled people are less likely to save, holding £108,000 less in assets and savings than non-disabled people over their lifetime.¹⁸ Our research has shown that over 60 per cent of disabled people and their families are either struggling or falling behind with bills and credit commitments.¹⁹



Extra costs can prevent disabled people from contributing fully to society. For example, some disabled people who want to work find that they cannot afford the related transport costs, and many parents of disabled children encounter the same difficulty in meeting childcare costs to allow them to work. This reduces the productive capacity of the economy. Where disabled people are using their income inefficiently to meet unnecessary extra costs, fewer resources are spent on goods and services of greater economic benefit. Reducing extra costs can release suppressed demand, providing more opportunities for businesses.

16 ONS: *Labour Market Statistics*, February 2015

17 ODI Indicator B7: <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php>

18 McKnight, A: *Disabled people's financial histories: uncovering the disability wealth penalty*, CASE paper 181, 2014

19 Extra Costs Commission: *Consumer survey*, March 2015

2.3 Evidence from previous studies

There is consensus across the available research that disabled people face significant extra costs, though there is a wide range of estimates of the total value of those extra costs, which reflects different approaches to calculation. Appendix B summarises the evidence that we have reviewed.

We identified relatively few studies that broke down costs by area of expenditure. Again, different approaches produced different results. However, areas of extra cost where disabled people appear to spend more than non-disabled people are food and drink; housing, fuel and power; health and personal care; and recreation, culture and holidays.

There is very little evidence about what elements of disabled people's lifestyles, experiences or needs affects the extra costs they face. Some limited data exists on extra costs according to impairment type. Smith et al. attempt to illustrate the extra costs faced by people with a visual or hearing impairment,²⁰ whilst more recent research indicates that partially-sighted working-age adults would have to spend £50 more each week than a non-disabled person to achieve the same minimum standard of living.²¹ For a severely hearing-impaired person, this figure rises to £163.

2.4 New research

Cost by area of expenditure and impairment type

Given the limited amount of specific research on cost by area of expenditure and across different groups of disabled people, we conducted online focus groups to investigate further. Our aim was to develop a more comprehensive framework of data to describe the extra costs disabled people face. Seven groups consisting of a total of 51 people who were disabled themselves, parents of disabled children or individuals speaking on behalf of a disabled family member were asked about their extra costs. Table 1 and charts 1-10 (note, specialised equipment is not included as either this didn't feature as a cost or was a one-off cost. Nonetheless, these one-off costs were high) show estimated relative extra costs for people with different impairments or conditions.

Different extra costs are shown to be spread across several areas for people with different impairments. Transport emerges as the greatest extra cost; the costs of health and personal care are also high for several groups. It is worth noting that for specialised items, many people had one-off costs, such as for wheelchairs or hearing aids.

²⁰ Smith et al: *Disabled people's costs of living*, 2004

²¹ Hill et al: *The additional cost of disability- a new measure*, 2015

Table 1: Median weekly extra costs (£) reported by focus groups by impairment type and areas of cost

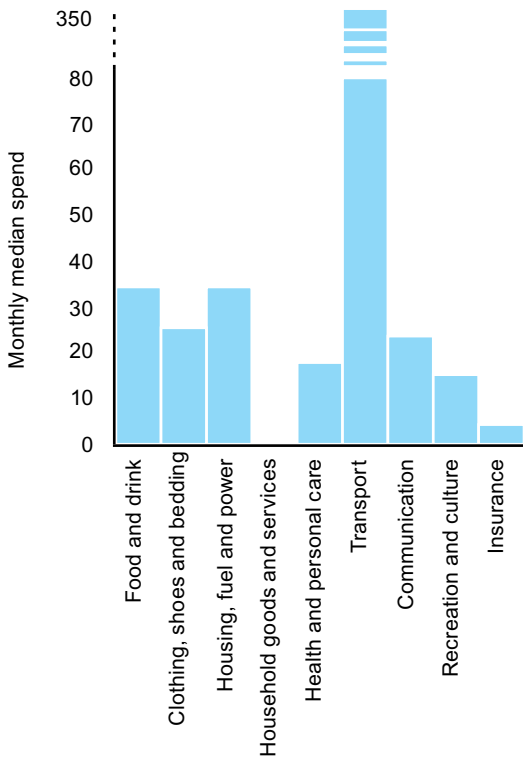
		Extra cost area								
		Food and drink	Clothing, shoes and bedding	Housing fuel and power	Household goods and services	Health and personal care	Transport	Communication	Recreation and culture	Insurance
Disabled adults	Autism	35	25	35	-	18	350	24	15	4
	Chronic condition	40	25	30	65	50	55	0	30	2
	Learning 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

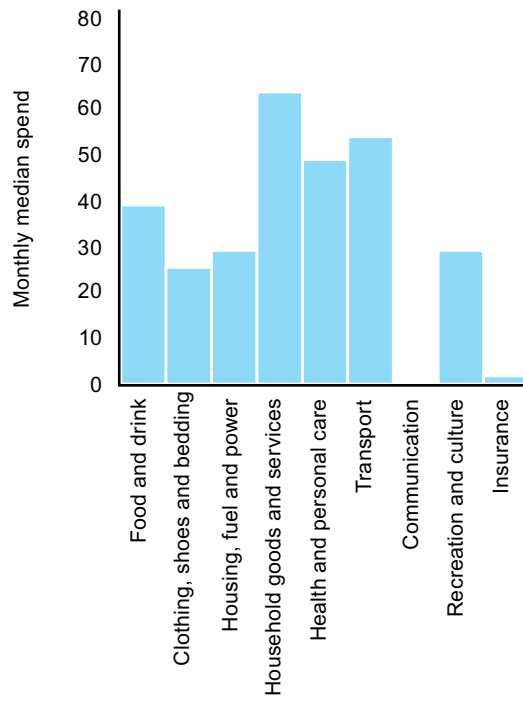
Impairment	Autism	0	50	38	0	30	65	21	20	0
	Learning disability	60	65	40	40	0	80	10	40	0
	Physical impairment	30	30	19	One-off	10	140	0	25	5

Charts 1 to 7: Median weekly extra costs (£) reported by focus groups for different groups of disabled adults, according to impairment type

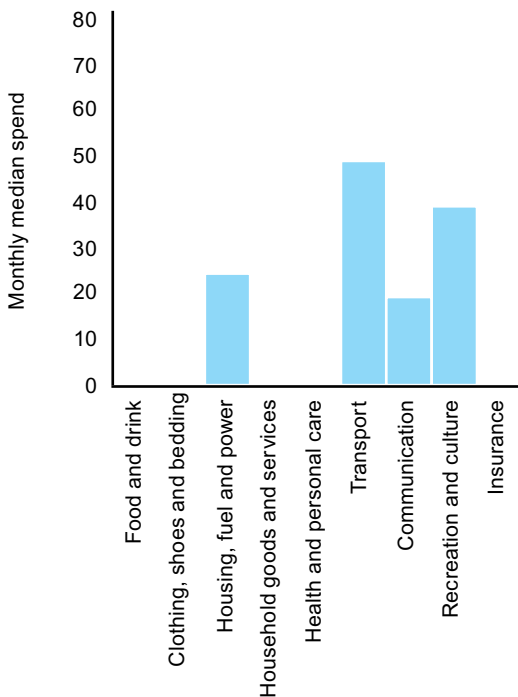
1. Autism



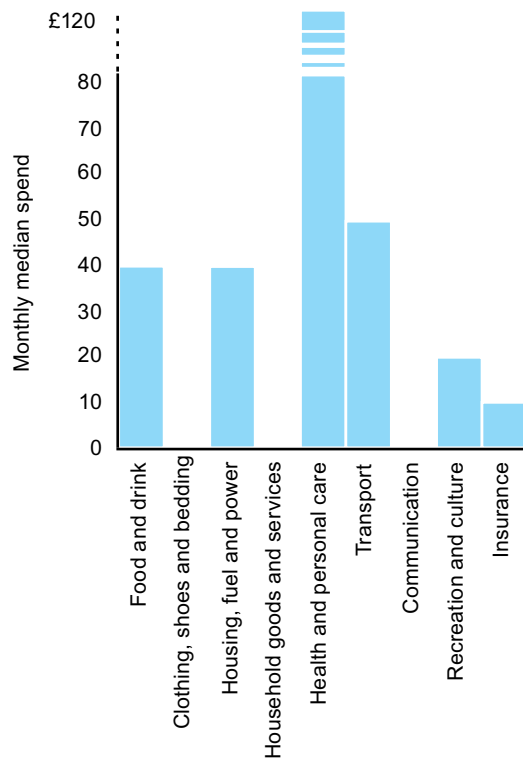
2. Chronic condition



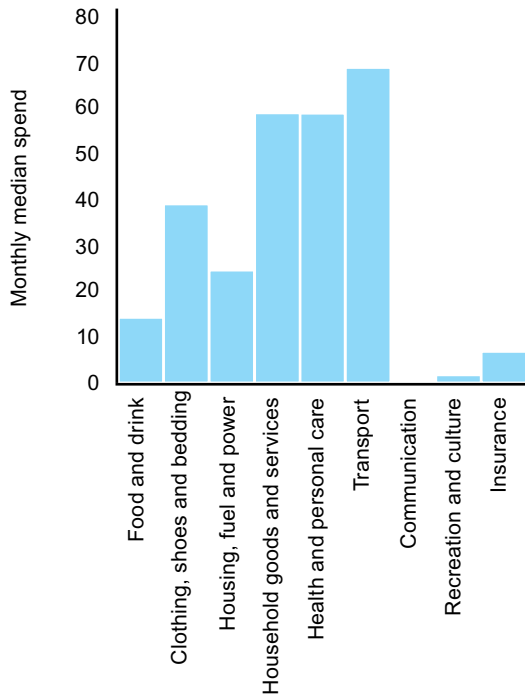
3. Learning disability



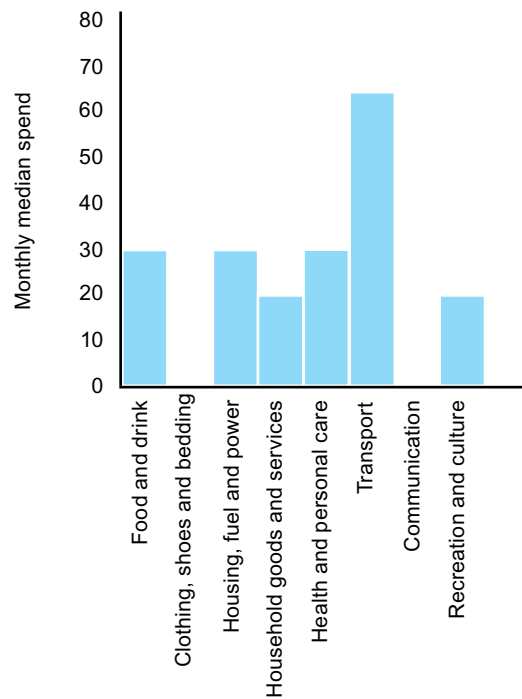
4. Mental health condition



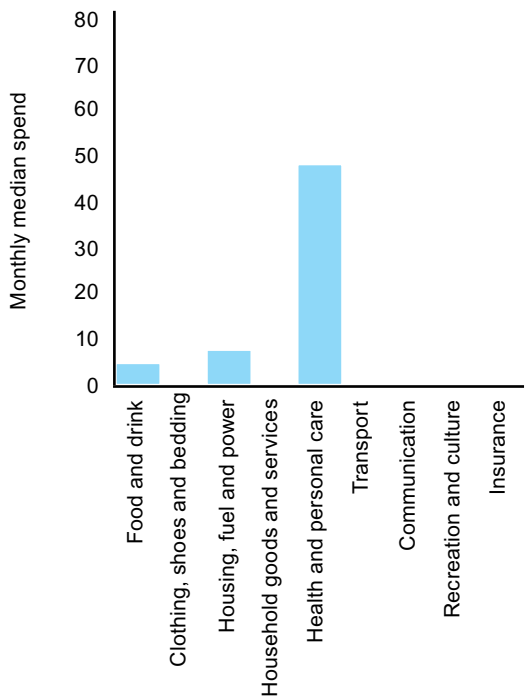
5. Physical impairment



6. Neurological condition (MS)

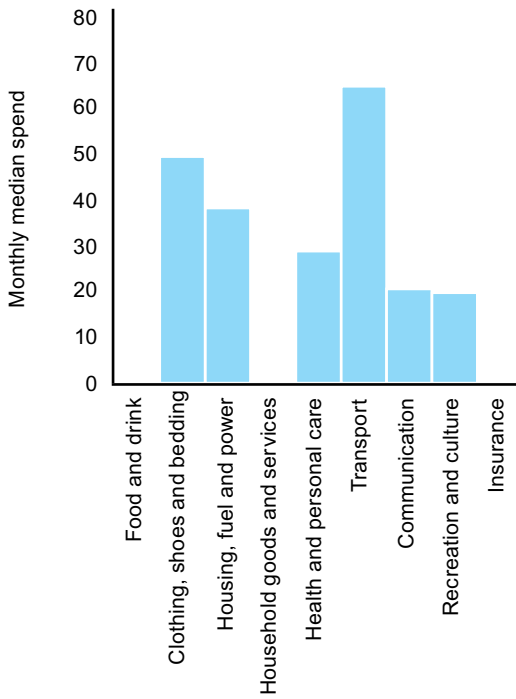


7. Sensory impairment

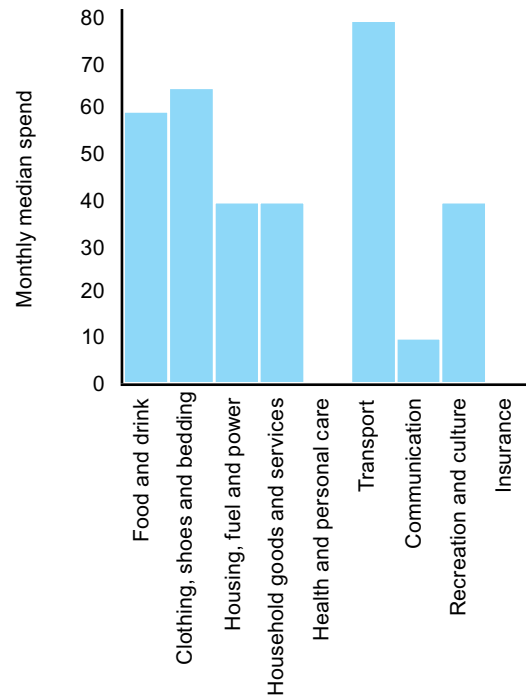


Charts 8 to 10: Median weekly extra costs (£) reported by focus groups for different groups of disabled children, according to impairment type

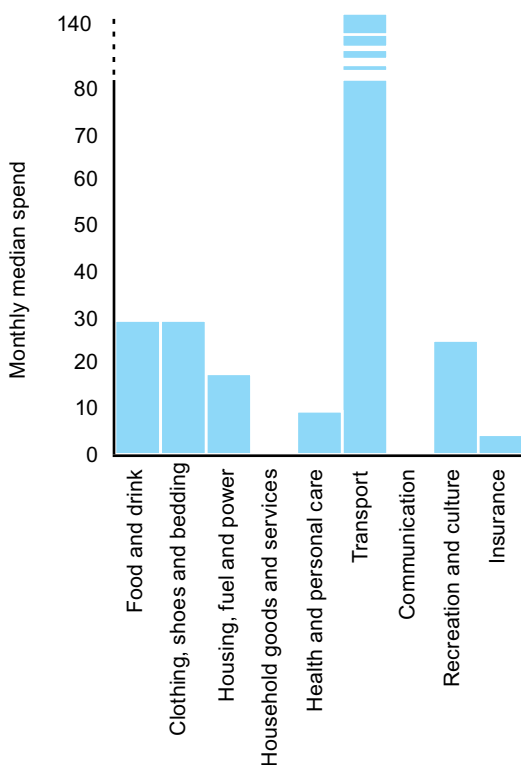
8. Autism



9. Learning disability



10. Physical impairment



Perceived impact of extra costs

We also asked disabled people whether they felt each cost to be ‘high’ or ‘low’, so that we could establish how they perceived the costs they face. This dimension can reflect wider factors that can help in assessing priorities, for example how the cost compares with what one would expect to pay for a given product or service. Table 2 shows these results: they confirm that estimates of cost shown in the graphs generally reflect how people feel about their extra costs, with transport being the greatest. They also indicate that disabled people tend to feel that what they pay for housing, fuel and power represents a relatively high cost and that there are unmet needs for recreation, culture and insurance.

Common extra costs across groups of disabled people

Some costs were common to most disabled people, suggesting that there is a mass consumer market in these areas of up to 12 million people who are paying over the odds:

- **Transport** was a high extra cost for almost all groups. One factor that affected many was public transport not being accessible, resulting in use of expensive 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.

‘Had to give up my life insurance policy due to costs imposed...trying to patch that hole costs around £400-500 per month, probably more realistically £1,000-1,200 per month.’

- 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.’

Table 2: Perception of median weekly extra costs (£) reported by focus groups, by impairment type and areas of cost

Perceived difficulty: Low Moderate High Can't afford

		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	Autism				-					
	Chronic condition									
	Learning disability									
	Mental health condition									
	Physical impairment									
	Neurological condition (MS)									
	Sensory impairment									

Disabled children

Impairment	Autism									
	Learning disability									
	Physical impairment									

- 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.’

Key differences for different groups of disabled people

Some costs differed across different groups of disabled people, suggesting that there are more specialised markets for some products and services, which will require a more bespoke response and/or more targeted marketing:

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

‘Extra costs incurred are: specialised amplified screen phone, which is £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 £1,500 – very high cost.’

- Some groups of disabled people face extra costs for **food and drink** because they require special diets or are unable to cook with the level of support they receive.

‘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. Extra costs depended on whether the person’s impairment required them to buy specialised clothing and the rate of wear-and-tear.

‘Footwear is the bane of my life! Shoes for ‘normal’ wear last 3 days max. Estimate £100 per month.’

- Some groups felt that they had relatively high costs for **household goods and services** because they needed care and support at 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... we have little choice 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 psychological therapy, carers or personal assistants.

‘£120. 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 Key areas of focus

The Commission has decided to explore five areas of cost from the evidence in more detail. These goods and services between them reflect the variety of issues raised by the evidence we have gathered so far. The five areas are among those where we also consider changes could have most impact, bearing in mind the criteria set out in section 1.2, and where solutions might have widest applicability. These areas are as follows:

- energy;
- clothing and bedding;
- specialised disability equipment (for the home or to improve mobility);
- taxis;
- insurance.

We will now discuss these in turn.

2.6 Energy

There are an estimated 4.5 million households in fuel poverty in the UK.²² Government figures tell us that of all fuel poor households, 35 per cent contain someone with a long-term illness or disability, equivalent to 798,000 homes.²³ In the extra costs framework, this emerged as a moderate to high cost for disabled adults and families with disabled children. In research carried out by the charity Contact a Family, 36 per cent of families with disabled children have needed a loan to pay for heating.²⁴

‘My husband is chronically disabled with MS. Being immobile he feels the cold in the winter, but is also affected by heat in the summer, so most of the year we have heating on all day, or cooling fans in the summer.’

‘I have multiple disabilities. One major issue for me is controlling my environment, namely temperature...Given this specific problem my energy bills are considerable, during the colder times of the year my heating is on 24 hours a day.’

Although the impact of higher energy bills is felt by a number of groups of people, including older people and those out of work, the reason for bills

22 Department of Energy and Climate Change: *Annual Fuel Poverty Statistics Report 2014*, 2014
Note that the official statistics are likely to underestimate the number of disabled people in fuel poverty, because DLA, AA and PIP are counted as income although they are not an income replacement benefit, but provided to support disabled people with the extra costs they face. This could lead to too few people’s income registering as impoverished.

23 Department of Energy and Climate Change: *Detailed tables (England) on fuel poverty, 2012*, <https://www.gov.uk/government/statistics/fuel-poverty-detailed-tables-2012>

24 Contact a Family, *Counting the Cost 2014*, 2014

being higher is different in the case of many disabled adults and children. Our call for evidence showed how some disabled people who are less mobile as a result of their impairment require additional heating consumption in order to stay warm. For others, a warm home is an important factor in helping to manage their condition, because their impairments are aggravated by the cold. Others said that they rely on devices that need to be regularly charged or continually powered, such as assistive listening devices, leading to higher energy costs. In these cases, needing more energy – and paying more as a result – is a direct result of disability. Meeting extra energy costs is an essential form of support to maintain wellbeing and independence.

It is thus not surprising that energy was one of the most frequently mentioned areas of extra cost in our call for evidence.

2.7 Clothing and bedding

There were moderate extra costs for clothing, shoes and bedding in our framework depending on the impairment group, in particular for people with autism, people with chronic conditions, children with a learning disability and those with physical impairments. However, clothing and bedding emerged as the most frequently mentioned extra cost area in our call for evidence.

‘On top of catering for [my son’s] very picky diet, we have the cost of travelling to his appointments and nappies, regular new clothing due to soiling and clumsiness, regular new bedding and the expensive accessories that cannot be bought on the high street.’

‘I have to buy shoes far more frequently than I would do if I did not have cerebral palsy. My shoes wear quickly because of the way I walk.’

Two trends appeared in the evidence. Some submissions mentioned the wear and tear to garments that get caught on wheelchairs, and where someone’s impairment causes them regularly to become agitated and rip their clothes. Incontinence or other personal hygiene issues can lead to frequent changes of clothing and bedding. In these cases, disabled people are purchasing more of a non-specialised item than non-disabled people would.

In other submissions, people mentioned the additional cost of specialised items of clothing to accommodate different body shapes or particular functional needs – here the drivers of extra costs relate to the price of specialised clothing or bedding and whether the market operates sufficiently well to deliver the best price to customers. These two situations will require different fixes in order to drive down cost to the disabled consumer.

Encouraging businesses to do more for disabled consumers in the area of clothing and bedding not only requires a deeper understanding of the size of the market and the consumer habits of this group, but the business case has to be compelling as well.

2.8 Specialised equipment

This extra cost category was the second most cited in our call for evidence. Our framework shows that specialised items cause high one-off costs for some groups in particular – those with a chronic or neurological condition, physical or sensory impairment.

‘I have to buy specialised software to enable me to use a computer, so as to magnify whatever appears on the computer screen. This can cost up to £1,000.’

‘My son’s trike is about to cost us £1,650.’

Mobility vehicles were regularly reported as an area of extra cost. Research from the consumer group Rica shows that some powered wheelchairs can cost over £40,000, with additional costs for servicing and maintenance.²⁵

Several families with disabled children told us of expensive toys, including an adapted bike costing approximately £1,000. Action on Hearing Loss reported a higher cost for flashing doorbells and amplified telephones/textphones compared to non-specialised items.²⁶

Sense told us that a tablet with built in-screen reader software costs around £400, whereas other tablets that require separate screen reader software cost in the region of £850.²⁷ Here, the driver of costs seems to be either simply a lack of innovation (limited understanding or awareness of the potential market for new products, leading to poor supply to consumers) or the lack of flexibility of mainstream hardware, which is in turn hindering innovation.

Much specialised equipment is essential to support disabled people to live independently. The high price tag often associated with purchases of this sort can swallow up a large proportion of the income of disabled people and their families. As with energy, the critical importance of disability equipment to the lives of disabled people makes it an important area to look at. We are interested in whether these prices are justified, and whether there are instances where costs can be reduced, for example through the impact of shopping around or even collective purchasing and bulk buy schemes.

²⁵ Rica: *Powered wheelchair user survey report*, 2014

²⁶ Formal evidence submission to the Commission from Action on Hearing Loss

²⁷ Formal evidence submission to the Commission from Sense

A report by the Helen Hamlyn Centre for Design at the Royal College of Arts argues that as much as possible, mainstream technology should be enabling for a wider number of users from the outset, rather than creating separate assistive devices.²⁸ This can help to minimise costs for the individual consumer, as the development and production cost of mainstream device components is spread over a larger number of units rather than a small number of assistive devices.²⁹

There are varying estimations of the size of the UK disability equipment market but it is a market that is large in scope. Keynote Ltd estimates the market to be worth around £501 million, whilst the British Healthcare Trades Association sets the value at £720 million.³⁰ More research is needed to understand the size and make-up of the different parts of this market, but it seems clear to us that there is a sizeable market opportunity for business.

2.9 Taxis and private hire vehicles

The call for evidence demonstrated that transport is a regular source of extra cost for disabled people. This was also a high extra cost for almost all impairment groups in our framework.

‘I often have to use taxis to and from home and work, as living in a rural area, and not driving, there are no buses and trains... This has cost me hundreds of pounds over the thirty years of having epilepsy.’

‘I am always charged a lot extra for taxis...I am expected to pay, on average, £10 extra for a taxi journey...that’s if you can get one.’

Some disabled people require support from a personal assistant when travelling on public transport, but their discount or concessionary fare will not always cover both people. Many disabled people face parking charges at hospitals when attending appointments (although recent guidance issued to NHS organisations on parking has advised that concessions, including free or reduced charges or caps, should be made available to disabled people).³¹

If public transport is inaccessible, or in some areas in short supply or lacking altogether, disabled people will rely more on taxis and private hire vehicles or their own personal vehicles to get around.

28 The Helen Hamlyn Centre for Design: *Enabling Technology*, 2013

29 Ibid

30 Consumer Focus: *Equipment for older and disabled people: an analysis of the market*, 2010

31 Department of Health: *Guidance on NHS patient, visitor and staff car parking principles*, August 2014, <https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles/nhs-patient-visitor-and-staff-car-parking-principles>

Of the various issues raised by disabled people and organisations, we believe that the cost of taxis and private hire vehicles is the area where we can have most impact. Attention is being given to accessibility in the public transport system. For example, there are accessibility requirements³² placed upon bus and coach operators, and work to improve accessibility of trains and train stations is in hand. For taxis and private hire vehicles, reform is now being considered, but we are less advanced in terms of delivering change.

In May 2014, the Law Commission completed a review of the legal framework on behalf of the Department for Transport. The Government expects to issue an interim response shortly.

The Law Commission's evidence reveals that:

- disabled people use taxis and private hire vehicles approximately 67 per cent more than non-disabled people, as often this is the only option for local travel or to reach another mode of transport;³³
- only three per cent of private hire vehicles are wheelchair accessible;³⁴
- an estimated 58 per cent of taxis in England and Wales meet the current definition of 'accessible'.³⁵ There is an urban/rural divide: 100 per cent of London's taxis are accessible with urban areas outside London also having a high proportion of accessible taxis;³⁶
- When London is removed, only 41 per cent of taxis are accessible.³⁷

Other problems include varying attitudes and standards amongst taxi and private hire vehicles with regards to disability, which can lead to difficulties for disabled people in using these services.

A shortage of accessible vehicles in some areas inhibits the presence of a competitive market for disabled passengers similar to that from which non-disabled passengers benefit.

32 See The Public Services Vehicles Accessibility Regulations 2000 and subsequent amendments: <http://www.legislation.gov.uk/uksi/2000/1970/contents/made>

33 Disabled Persons Transport Advisory Committee: *Attitudes of Disabled People to Public Transport – a research study conducted for the Disabled Persons Transport Advisory Committee*, 2001

34 Department for Transport: *Taxis and Private Hire Vehicles Statistics: England and Wales 2013*, 2013

35 Ibid

36 Ibid

37 Ibid

The Law Commission recommends:

- accessibility reviews every three years by licensing authorities;
- a rethink of rank design to ensure compliance with the Equality Act 2010;
- disability awareness training for drivers as a pre-condition for granting or renewing a license;
- making information about complaint procedures more readily available as a means for disabled passengers to challenge ineffective service.

We are keen to explore how we can build on the Law Commission's analysis from the perspective of driving down extra costs to disabled people;

2.10 Insurance

Insurance protects consumers against financial shocks – a particularly acute need for many disabled people. Disabled people tend to have lower levels of savings and wealth available for a rainy day. Insurance was the financial service most frequently mentioned in response to our call for evidence, with many in our focus groups saying they found insurance so expensive it was simply unaffordable, rather than an extra cost actually incurred. Some respondents felt that they had been dealt a real injustice in the way that the market operates, with travel and motor insurance the most common areas of complaint.

'Our annual travel insurance is £220 for our family of four. If our daughter had no disability it would be a quarter of this price!'

'We do not get the opportunity to shop around for insurance on the car – due to modifications for the wheelchair a lot of companies won't even quote.'

Research conducted for Scope by Ipsos MORI found that 22 per cent of disabled people feel that they pay more for insurance,³⁸ and a further 8 per cent said they had been turned down for insurance, of whom the majority felt that this was due to their disability or pre-existing health condition.³⁹ The industry has told us that in many cases, disability is not taken into account in pricing some types of insurance and disabled people are on a level playing field, which tallies with the Ipsos MORI research. However, translating percentages into people indicates that there are two and a half million disabled people who feel they pay too much and at least half a million unable to get insurance who attribute this directly to their disability. It is for this reason that the Commission considers it important to consider whether any change might make insurance more accessible and affordable for disabled people.

38 Ipsos MORI: *Disabled People and Financial Wellbeing*, 2013

39 Ibid

3. Financial and digital inclusion

Our inquiries have identified two factors that cut across a number of areas of cost and that are therefore relevant to our inquiry: financial inclusion and digital inclusion. These are factors that are necessary in enabling disabled consumers and their families to achieve lower costs for a number of goods and services.

To ensure disabled people are equipped to secure a lower price for products, we need to overcome barriers that limit either the financial capability of disabled people and their families, or their ability to access and use the internet.

3.1 Financial inclusion

Financial inclusion is essential for disabled people to enjoy financial stability and financial resilience on a par with non-disabled people. A lack of access to appropriate mainstream financial products can accentuate the extra costs experienced by this group: over half of disabled people and their families are either sometimes or constantly struggling to keep up with their bills and credit commitments, on top of which another 13 per cent are failing to meet some bills and credit commitments.⁴⁰

Disabled people need to have a bank account into which income can be paid and securely held in order to set up payment for services via direct debit. Direct debit is often a cheaper method of payment for services such as energy compared to cash options such as paying by cash in arrears, or prepayment. Customers on low incomes often like the control of paying by cash and in the case of prepayment, paying as they use energy as it can help with budgeting and removes the worry of shock energy bills. However, data from the Wealth and Assets Survey show that 87 per cent of disabled people have a current account compared to 94 per cent of non-disabled people.⁴¹

Banks are required to offer basic current accounts. The introduction of credit union current accounts has also contributed to improvements in this area. As the provision of these accounts develops to meet the needs of people on low incomes, it will be important to better understand the barriers to take-up of these products and tackle them accordingly.

40 Extra Costs Commission: *Consumer Survey*, March 2015

41 Scope: *Disabled people and financial well-being – credit and debt*, 2013

Availability of affordable credit is also important. Disabled people are more likely to be represented among high cost credit users – 18 per cent compared to 5 per cent of non-disabled people.⁴² When disabled people are able to access credit, it is more likely to be high-cost or in the form of doorstep or payday loans.⁴³ High interest charges exacerbate the impact of other extra costs. The Commission acknowledges the role that credit unions and community development finance institutions play in providing loans at affordable rates of interest to those that are excluded from mainstream sources of credit. We are aware of the necessity of funding and partnership working to facilitate the expansion of these services.

It is unclear to what extent disabled people have adequate information about the range of banking, credit and saving options that could help increase their financial inclusion and resilience. The Commission is therefore eager to ensure that financial inclusion initiatives, including the work of the Financial Inclusion Commission and the Money Advice Service's Financial Capability Strategy, consider the financial needs of disabled people. This is fundamental to increasing their consumer power and influence.

Consultation question 1a: What are the current barriers to financial inclusion for disabled people?

Consultation question 1b: What action could the Commission recommend to improve financial inclusion for disabled people and their families?

3.2 Digital inclusion

Advances in digital technology have had a huge impact on how consumers obtain information and access goods and services. Increasingly, a 'savvy' consumer needs access to the various online offers, price comparison tools and review information. For some disabled people access to the internet has provided very significant consumer benefits in the form of easier transactions than by telephone or by avoiding long and costly trips to purchase goods and services.

However, there continues to be a significant digital divide between disabled and non-disabled people – 30 per cent of disabled adults have never used the internet compared to only seven per cent of non-disabled adults.⁴⁴

⁴² Personal Finance Research Centre, University of Bristol: *The impact on business and consumers of a cap on the total cost of credit*, 2013

⁴³ Ibid

⁴⁴ ONS: *Internet Access Quarterly Update*, Q1 2014

The Government has been working to address this digital gap through its Digital Inclusion Strategy,⁴⁵ which aims to reduce the number of people without basic skills and capabilities by a quarter over the next two years.

The Commission is pleased that the strategy recognises the needs of disabled people as being different from those of non-disabled people – firstly because disabled people are less likely to have acquired digital skills compared with non-disabled people, and secondly because not all web content or technology is accessible and compatible with assistive technology such as screen readers.

Some disabled people's limited capacity to understand and use the internet, along with inaccessible websites, can severely hinder disabled people's ability to get the most from being online. We therefore welcome the fact that the Digital Inclusion Strategy has enlisted voluntary and private sector organisations to help improve the accessibility of web content and to support people to acquire digital skills. It is important that these initiatives continue and that disabled people are fully aware of sources of support available to help them become tech savvy.

In the first instance though, it is important that disabled people have the opportunity to connect to the internet. ONS data indicates that 11 per cent of households do not have internet access due to access costs being too high and 12 per cent due to equipment costs.⁴⁶ Given the impact of extra costs on what disabled people can afford, these barriers are particularly likely to affect disabled people.

We would like internet providers to take on the challenge of reducing the gap in the digital divide between disabled and non-disabled internet users so that by 2020 we have equality. The Commission notes that BT provides a basic phone and broadband package at a reduced rate to customers in receipt of certain benefits including Employment and Support Allowance. Other internet providers should offer similar deals to low-income households; the eligibility criteria for these services should include those in receipt of DLA or PIP.

Consultation question 2: What action could the Commission recommend, which would close the digital gap between disabled and non-disabled people?

⁴⁵ More information about the Government Digital Inclusion Strategy can be found at <https://www.gov.uk/government/publications/government-digital-inclusion-strategy/government-digital-inclusion-strategy>

⁴⁶ ONS: *Internet Access- Households and Individuals 2014*, 2014

4. Solutions by area of cost

We have identified a number of potential solutions that could drive down the costs faced by disabled consumers in our five areas of focus. These solutions fall into the following broad areas:

- a) Empowering consumers
- b) Supplying unmet needs efficiently
- c) Market intervention and regulation

We discuss the range of solutions in these areas in sections 5, 6 and 7.

Some of the possible solutions identified are only relevant to one or two of the areas of extra cost and some possible solutions are relevant to all areas. Table 3 provides a high level summary.

Table 3: Solutions for driving down extra costs according to extra cost areas

		Extra cost area				
		Clothing and bedding	Energy	Specialised equipment	Taxi / private hire vehicles	Insurance
Solution for addressing extra costs	Improved consumer information (Section 5.1)	✓	✓	✓		✓
	Affiliate schemes (Section 5.2)	✓				
	Collective purchasing (Section 5.3)		✓			✓
	Stronger disabled consumer voice (Section 5.4)	✓	✓	✓	✓	✓
	Better information for businesses (Section 6.2)	✓	✓	✓	✓	✓
	Regulation (Sections 7.1–7.3)		✓		✓	✓
	Deregulation (Section 7.4)	✓		✓		
	Incentives (Section 7.5)	✓	✓	✓	✓	✓

✓ Extra cost area covered by solution

5. Delivering change: empowering consumers

5.1 Providing consumers with better information and advice

Consumer empowerment tools

As with all consumers, disabled people and their families are faced with choices when shopping for goods and services. A number of mainstream and well known, largely web-based, comparison sites exist today which help consumers to identify goods and services that are available, compare prices and terms and go on to make a purchase if they wish. Among well known (and Confidence Code accredited by Ofgem) examples are moneysupermarket.com and uSwitch. These tools should be able to provide important information to disabled people on how to get the best price for items that both disabled and non-disabled people require, such as energy and insurance.

However, it is not clear how far these mainstream comparison services are used by disabled consumers or whether they provide sufficient information on disability-specific product terms. Almost half of disabled people and their families have felt they have not had the necessary information in order to make the right choices when shopping online.⁴⁷



To support those that feel they do not get the right information, either we need new online information services that better meet the needs of disabled people as consumers, or we need to raise awareness of existing resources, or both. Any existing or future tools need to be well publicised and easy to find and use in order to allow disabled people to make good choices as

⁴⁷ Extra Costs Commission: *Consumer survey*, March 2015

quickly and simply as possible – whether they are targeted exclusively at disabled consumers, or not. We are interested in exploring how to make individuals more aware of the various websites available through better marketing and coordination.

The Commission is also interested in what sites currently provide information about specialised products such as technological equipment and mobility aids. We discovered some online marketplaces that have been set up and geared towards providing specialised products in one place for disabled people. For example, Ability Superstore stocks a variety of mobility aids.

There are currently several tools designed to help disabled people in making decisions when shopping for specialised products. These include price-comparison resources such as DLF Data. Run by the Disability Living Foundation, this is a database available via subscription that enables users to find extensive information on daily living equipment.⁴⁸

There is also some support available in the form of expert advice and/or help in person to assist disabled people and their families in choosing and using specialised goods and services.⁴⁹ Examples include Aidis Trust, a charity that guides disabled people in selecting and using computer technology, and Which?, which includes reviews of mobility technology products, such as stair lifts.

Lastly, there are websites that contain user-generated content reviewing disability-related items. Technology is a prominent area here, but often content is in the form of discussion forums that are impairment-specific, blogs or closed email lists exchanged between technology professionals.⁵⁰ Reviews of mobility/everyday living aids and assistive technology products stocked on sites such as Amazon are useful only if the user knows what they are looking for, and will be of limited value unless it is clear that the reviewer has a similar perspective and requirements to the prospective customer.⁵¹

Some online communities targeted towards disabled people share information effectively. One is Enabled by Design, where users can create an account and discuss independent living products and services, with a focus on adapting these to meet the needs of disabled adults and children in a process termed ‘hacking’. Similarly, Euan’s Guide allows individuals to assess the accessibility of different venues and locations. The site contains over 1,000 user reviews, demonstrating the enthusiasm for peer-to-peer review.

In all, the Commission was pleased to find a number of existing initiatives that could help disabled people and their families in making choices as consumers. However, data gathered from our survey into the shopping

48 Scope: *Maximising disabled people’s use of technology – the landscape for advice, support and funding, draft interim report*, Feb 2015

49 Ibid

50 Ibid

51 Ibid

habits of disabled people and their families show strong support for the development of additional online tools to enable them to become savvier shoppers.

Respondents were asked to comment on a number of ideas for resources geared towards helping disabled people navigate markets better. A membership discount scheme for disabled people was the most popular: this is discussed in section 5.2. The second most popular idea was a website for disabled people to share reviews and other information on products and businesses: nine in ten respondents answered that they would find this useful or very useful.⁵² Respondents said when seeking guidance, the most important factors were that the advice comes from someone with similar experiences to themselves and was independent.⁵³

We believe that there is potential in establishing a platform for disabled people and their families to use to assist each other in making choices about a range of disability-related goods and services. This could be achieved by allowing users to post reviews on products, answer consumer queries and share details on quality and value-for-money deals, similar to the role that TripAdvisor serves for holiday destinations, hotels and restaurants.

Trust was the factor rated highest in looking for advice or information when buying things: over three quarters of respondents in our consumer survey rated it as very important.⁵⁴ This points to any platform that is seen to be independent of specific suppliers and run by an organisation that has, or can establish quickly, a strong reputation for being trustworthy.

We appreciate that online choice tools and comparison sites will not be accessible for all disabled consumers. It is therefore important that there is adequate support offline to assist disabled people through the different stages of making key purchases, particularly with regards to specialised equipment.

Recommendation 1: Disability organisations should explore the creation of a hub through which disabled consumers can find the various market comparison sites, online marketplaces and review sites that already exist for the products and services they use, and undertake marketing to raise awareness of it.

Recommendation 2: Trusted disability and/or consumer organisations should create a community platform to allow disabled people and their families to review disability-related goods and services, to encourage greater scrutiny of price, value and customer experience.

⁵² Extra Costs Commission: *Consumer Survey*, March 2015

⁵³ Ibid

⁵⁴ Ibid

Consultation question 3a: What additional evidence is there around the feasibility of a peer-to-peer review platform or coordination of tools available to support good consumer choices? What sources of support are available for disabled consumers? Where are the gaps?

Consultation question 3b: What solutions could the Commission consider to ensure consumers who do not currently use the internet are equally empowered?

5.2 Negotiating lower prices or better value for money

Affiliate schemes

Providing disabled people with the necessary information and guidance to make considered choices as shoppers is one aspect of empowering them as consumers. However, even when this group are able to secure the best price on a particular item, costs will still mount up on frequently purchased items or those things disabled people use more, like taxis, energy or clothing and bedding.

Many retailers already have schemes to reward customer loyalty, such as the Nectar card that allows users to collect points on purchases at a number of stores to then redeem on subsequent purchases, or the tastecard that offers discounts at a series of restaurants. This model – which benefits the supplier by attracting return custom – may work well as a means of distributing discounts for disabled people on the products they like, trust and buy often.



From surveying disabled people and their families, it is clear there is appetite for some form of membership discount card for disabled people. This would help disabled consumers to identify the traders in the market place, whether online or on the high street, that would provide a good service, and potentially a very good deal, to disabled consumers. Over 90 per cent⁵⁵

55 Extra Costs Commission: *Consumer Survey*, March 2015

selected this as their preferred idea for a consumer empowerment tool, by far the most favoured option. The design of any scheme would need to be such that it created a sufficiently large consumer group of disabled people so that retailers could see the benefits of being part of it in terms of the number of people to whom they could market and the extent to which being part of the scheme would grow their business (whether through reach to new customers or increased sales to existing customers).

Whether there would need to be eligibility criteria to access some or all of the scheme benefits is an open question. Voluntary sector organisations that currently engage with disabled people and their families may be well placed to create an appropriate simple route to enable supporters and service users to join such a scheme.

A scheme of this sort would, if successful, also provide retailers with an invaluable insight into the ways in which disabled people and families of disabled children shop and the types of purchases they make. Such information would be beneficial in understanding better how to develop and market products to this consumer group, discussed (along with associated data issues) in more detail in section 6.

The Commission believes that there is sufficient potential to explore such a scheme. It is likely to work best where its user base and coverage of goods and services is large enough to achieve critical mass. This points to collaboration among potential providers. We are open to other ideas on how better to facilitate mutually advantageous deals between suppliers and disabled consumers that reward consumer loyalty.

Recommendation 3: Disability organisations, working in partnership, should pilot an affiliate scheme for disabled people that offers discounts on products and services through partnership with key retailers.

Consultation question 4: What factors need to be considered in coordinating a joined-up retail affiliate scheme for disabled people and their families, e.g. eligibility criteria, marketing?

5.3 Collective purchasing

We believe that disabled people and their families represent an under-recognised but nevertheless significant consumer force. However, disabled people are an extremely heterogeneous group – geographically dispersed, encompassing people with a wide array of different impairments and conditions, who have different needs and lifestyles, and varying spending power.

We know that harnessing the collective voice of disabled people and their families could give this group more negotiating power. In practice, this could mean individuals banding together as part a large collective to purchase goods or services, receiving a reduced rate due to the volume of the order.

A sector where this is especially common is energy, where people already switch energy provider together. For example, the collective switching site iChoosr, brings together groups of consumers for whose custom energy suppliers then compete. Working with local authorities, it has helped over 43,000 households save more than £6.5 million on their energy bills since 2012.⁵⁶

The nature of disability means that in many cases, disabled people will have to use more energy than non-disabled people as a direct result of their impairment. Measures to help people to reduce their energy bills such as home insulation, energy-efficiency boilers and switching energy provider, may not alone be sufficient to offset extra costs.

When asked about collective switching for energy, 33 per cent of disabled people and their families said that they would definitely be interested in such an initiative, 32 per cent did not know and 35 per cent were not interested.⁵⁷

The evidence above raises the question as to the extent to which this group are aware of these collective switching schemes and the benefits they could potentially provide. The regulator for the energy industry, Ofgem, sees trust as a key barrier to engagement with the market and as such, has recognised the potential role that third sector organisations with trusted brands could play to encourage people to engage. Disability organisations could play a pivotal role here, using their brand and reputation to bring disabled people and their families to secure a better deal on their energy supply.

There are other industries where consumers can use collective purchasing power to obtain a lower price on products. Insurance is one area where collective purchasing is starting to develop to meet specific requirements. For example, Bought By Many offers a platform to bring together people with similar needs for insurance – ranging from people with specific medical conditions to people who own particular breeds of dog – in order to purchase insurance products that meet their needs at a good price.

The concept of collective purchasing might also allow disabled people and their families to access clothing and bedding at reduced prices, or permit an organisation or group of individuals to bulk-buy specialised equipment at a lower price.

⁵⁶ Data taken from iChoosr website, <http://ichoosr.co.uk/who-is-ichoosr/>

⁵⁷ Extra Costs Commission: *Consumer Survey*, March 2015

However, the collective buying process here is not as straightforward as it is for an energy or insurance service. Goods purchased in bulk may need to be stored and distributed to the end consumer making the proposition of collective purchasing of specialised goods and services more challenging operationally compared to negotiating a discount on a standard tariff with an energy supplier. The specialised equipment market also consists of diverse items that will be relevant to different groups of disabled adults and children. This could also present a challenge in achieving the necessary scale of purchasing to be able to secure significant discounts on products.

'Affinity' deals between a supplier and an organisation – for example a disability organisation – can bring goods and services to the attention of supporters of that organisation, which may represent improved value for money, for example through better quality of service. Within such an arrangement, the disability organisation may act to select the supplier and the supplier would appreciate savings from a new route to market. The charity may also earn referral fees or commission. We are interested in schemes like this that expressly offer reduced cost for the same level of service. These are most likely to work where market knowledge and infrastructure are exploited effectively, for example to minimise distribution costs.

Recommendation 4: Disability and consumer organisations should signpost disabled people and their families to appropriate switching schemes for services such as energy and insurance and develop new collective purchasing and switching schemes, with an aspiration to make disabled people the savviest consumers in the market.

Consultation question 5a: Is there a need for collective purchasing and switching schemes specifically targeted at disabled people and their families, e.g. for energy, insurance?

Consultation question 5b: How feasible would it be to develop a collective purchasing model for clothing and bedding and/or specialised equipment?

5.4 Strengthening the voice of disabled consumers

We have found that far too often, disabled consumers face costs that are over the odds. On top of the poor experiences that any consumer might encounter, over three quarters of disabled people and their families have felt so badly treated because of their impairment or condition or that of their child, that they have left a shop or business.⁵⁸ Whilst we are pleased that disabled consumers are exercising their right to exit, this finding is very disappointing. It shows that not enough is done to learn from and correct bad practice. Overcharging may not be the immediate issue, but when a disabled customer withdraws from a purchase, there is often an extra cost straightaway in going elsewhere. This also reduces the number of potentially acceptable suppliers, therefore tending to push up cost.



We believe that action is needed to strengthen the voice of the disabled consumer. Effectively done, this can be in the commercial interests of business. It improves customer feedback providing important information on how better to meet customer needs while protecting reputation. A critical customer may do proportionately more damage than an advocate does benefit. Businesses with little record of complaints from disabled customers should not be complacent. Disabled customers have told us of times when they have complained and felt that they were not listened to: this inhibits further complaint and others may not even bother to try. Lack of information, understanding or support were all cited as significant factors detracting from the consumer experience.

Businesses acting on their initiative can make a difference. They ought to be able to anticipate the needs of disabled customers – but if they fall short, disabled people who want to see their own needs and those of others in their position addressed must be prepared to speak up. If this is to happen more, disabled consumers need to have the confidence that they will be listened to and that there is a reasonable prospect something might change as a result. The Commission believes that more can be done to build consumer confidence for disabled people.

⁵⁸ Extra Costs Commission: *Consumer Survey*, March 2015.

Currently disabled consumers turn to a range of disability and advice organisations for advice, support and advocacy. However, our survey suggests that these sources of advice are not as widely used as they might be. Other than gov.uk, which provides information on benefit entitlement, the advisory services about which we asked were each used by less than a third of disabled consumers.⁵⁹

We believe that elements of an effective system include:

- pooling experiences from customers to achieve more power and therefore profile so that consumers know where to come;
- a constructive approach but with sufficient independence and authority to create incentives for the least responsive suppliers to think twice;
- appreciation of the perspectives of disabled people and of businesses.

There are several options for achieving a stronger voice for disabled consumers – whether a new body (e.g. champion, ombudsman, panel of advocates) or better linking up of existing mechanisms; whether gentle and discreet or ferocious and strident in style; whether resource intensive or light touch. We invite views on the most promising options.

In our view, an improved outcome will require coordination, and an active contribution from the voluntary sector.

Recommendation 5: Disability and consumer organisations should coordinate to advocate for a new, stronger system to amplify the voice of disabled people dissatisfied with a supplier’s services, and to improve the response to consumer complaints.

Consultation question 6: What systems or approaches would be most effective in strengthening the voice of the disabled consumer?

⁵⁹ Extra Costs Commission: *Consumer Survey*, March 2015

6. Delivering change: supplying unmet needs efficiently

6.1 The opportunity for business

Large, under-served market sectors provide **an exciting opportunity for businesses**. The Commission believes that disabled people and their families form such a group.

Disabled people – a large group⁶⁰ with high total spending power⁶¹ – have told us that they often cannot find what they are looking for at a price that is reasonable. Sometimes they cannot find it at all. More suppliers competing to meet this demand would contribute to a reduction in extra costs.

At the same time, products created according to inclusive design principles could benefit an even larger market, including but not exclusive to disabled people. For example, the design company OXO has produced a series of cooking tools and utensils with handles that have enhanced grip and which do not rotate or strain the hand. These have been proven to be particularly useful for individuals with arthritis, but also popular with a much wider set of consumers.⁶²

Businesses are normally motivated to seek out and satisfy unmet demand. Why then, are disabled customers not better served? We have been offered several theories:

- information is not available that is sufficiently compelling to divert resources into investigating demand from disabled consumers and developing a business case to meet it;
- there are unavoidable costs because disabled consumers represent a diverse market made up of different groups with different impairments;
- disabled customers may be peripheral to an organisation's strategic focus;

60 ONS: *Family Resources Survey 2012/13*, 2014

61 DWP press release on 'purple pound' figure, 27 August 2014: <https://www.gov.uk/government/news/high-street-could-be-boosted-by-212-billion-purple-pound-by-attracting-disabled-people-and-their-families>

62 System Concepts, *The Benefits of Inclusive Design*, 2011 <http://www.system-concepts.com/articles/industrial-ergonomics-articles/2011/the-benefits-of-inclusive-design.html>

- there are strong legal or regulatory barriers, for example with regard to personal data.

We are interested to hear further views on the significance of these and other barriers, in general and in the five areas of extra cost on which we are focusing.

Consultation question 7: What are the biggest factors that inhibit businesses from doing more to explore and take up opportunities to meet demand from disabled consumers? How could these be overcome?

6.2 Providing information that will help businesses to spot opportunities

One barrier to businesses spotting opportunities to meet demand from disabled customers – both in terms of specialised products and non-specialised products that disabled people are more reliant upon – is a lack of readily accessible information, such as:

- the size of the potential market;
- relevant customer data, for example about spending power or willingness to stick with a supplier that has provided a good service;
- developments, for example in innovative design or technology, which reduce the cost of supplying to disabled consumers;
- examples where investing in meeting the needs of disabled customers has brought spin-off benefits, together with information on the factors that generated such benefits and how they might apply to other products and services.

Initial work has identified that businesses need information at two levels:

- headline information – which can implant the idea that there may be value in doing more to meet demand from disabled customers;
- supporting information – which can result in the idea of doing more for disabled customers being taken forward actively, for example because it makes clearer how that could be done in the particular circumstances of a supplier.

The total size of the ‘purple pound’ – the amount that disabled people spend each year – is an example of headline information. The Department for Work and Pensions recently estimated that the purple pound is worth £212 billion.⁶³ More can be done to produce statistics that are readily updated,

⁶³ DWP press release on ‘purple pound’ figure, 27 August 2014: <https://www.gov.uk/government/news/high-street-could-be-boosted-by-212-billion-purple-pound-by-attracting-disabled-people-and-their-families>

that meet the needs of businesses and that disabled people recognise as reflecting their experience. Putting a value on the spending power of disabled people draws attention to the issue and provides a building block for more detailed information that businesses can apply to their specific circumstances.

An example of supporting information is research by the Helen Hamlyn Centre for Design on how suppliers of technology can best meet demand from disabled customers,⁶⁴ and guidance for small businesses on taking up the opportunities presented by disabled customers.⁶⁵ However, the evidence that we have so far gathered suggests that these examples are rare and that there is little granular market information that could help businesses assess the opportunities offered by disabled consumers.

National statistics are likely to be the best starting point for such work but may need to be augmented with further analysis or research.

Recommendation 6: Statistics should be developed on the ‘purple pound’ in consultation with business and with disabled people. These statistics should be readily updated, meet business needs and be recognised by disabled people as reflecting their experience.

Disabled people can help to improve the information available that will help businesses identify efficient ways of providing a choice of goods and services tailored to customer needs. Disabled people are rightly wary of their personal information being misused, so the purpose for which information is sought must be clear, and confidence provided that data will be used only for that purpose. Dialogue is needed to extract the benefits of information sharing while protecting against the risks.

With the right safeguards, sharing data both about disability and about individual consumer habits and preferences can help. As well as enabling an individual consumer to benefit from tailored offers, this can have a wider benefit to disabled people in strengthening evidence that disabled customers represent part of a market large enough to merit attention. The Commission believes that the fact that each individual’s circumstances are different should not inhibit disabled people from banding together for convenience, to get the same kind of attention achieved by other groups who share a common identity.

Disability organisations may hold vital intelligence, information and knowledge about groups of disabled people that would help businesses to improve their understanding of potential markets. The offer to a business of a partnership in which the disability organisation brings knowledge

64 The Helen Hamlyn Centre for Design: *Enabling Technology*, 2013

65 Office for Disability Issues: *Growing your customer base to include disabled people: A guide for businesses*, 2012

and expertise could persuade businesses to test opportunities to serve disabled consumers. Disability organisations could also help to address the potentially fragmented nature of the market by assisting with marketing and potentially distribution, so that businesses can reach a wider market more effectively.

Potential ways forward

Options for disability organisations to provide businesses with better information to help to meet the needs of disabled customers include:

- setting out how businesses can get the most from existing information;
- coordinating information from different sources;
- developing advisory services for businesses – for example on how to design services tailored to individual needs, drawing on the knowledge of disabled people;
- developing specific information (headline or supporting) that fills gaps;
- facilitating collaboration between businesses and the voluntary sector.

There are opportunities here that individual businesses can take forward. However, the Commission believes that some of the biggest wins need collaboration, for example to share costs or make use of complementary experience.

Recommendation 7: Representatives of business in collaboration with disability organisations should work together to identify and fill the most important gaps in information about disabled consumers available to business – considering for example, size and characteristics of the potential market, sector-specific analyses, individual customer data or evidence about potential wider benefits to business.

There are likely to be specific information gaps and opportunities in each of the key areas on which we are focusing. For example, insurers may need better information in order to profile risk effectively. Disability organisations have, or may be able to obtain, relevant information that could reduce the cost of accurate risk profiling.

The Commission expects to recommend that insurance companies and insurance trade bodies such as the Association of British Insurers should work in partnership with disability organisations to ensure risk profiling of disabled people is based on accurate information.

6.3 Business systems which deliver aspirations

Throughout our inquiries, we have met an encouraging number of business leaders already convinced that it is worth thinking about disabled customers. To translate this leadership commitment into a good deal for disabled consumers, the right systems and processes must be in place. Initial consultations suggest that systems vary in practice for serving disabled customers. We want to develop the evidence base to help businesses – including in our key areas of focus such as clothing and bedding and taxis – to review their internal processes in ways that can improve customer experience.

Options for recommendations include:

- specific recommendations on good practice, for example on how to ensure that those allocated responsibility for disabled consumers within an organisation have the means to meet their responsibilities;
- recommendations on the development of tools to assist businesses in organising to meet their goals for disabled customers. Such tools might include for example, recognised standards of good practice or audit services.

Consultation question 8: What has been effective in translating boardroom goodwill into reduced costs for disabled consumers?

6.4 Helping businesses to reduce the costs of supplying disabled customers

In some markets, businesses are good at spotting opportunities to meet demand from disabled customers and have the systems that enable them to maximise these opportunities. As a result customers have a choice between several suppliers. Prices can nevertheless be high. This can happen where factors increase the cost of supply in a way that is difficult for any one supplier to address.

Two factors have been cited in our discussions to date with business leaders: costs of marketing and distribution costs. We have decided as a priority to look at whether costs of marketing can be reduced. It has been suggested that these costs are high because the diversity of disabled people as a group means there is no one single efficient communication channel.

Any place where disabled people go for information is a marketing opportunity. Recommendation one is for the development of a hub to which disabled consumers go when looking for tools to assist them in buying goods and services. There is potential within the scope of that recommendation to consider opportunities for reducing costs of marketing to disabled people.

Consultation question 9: How significant a factor for businesses is the cost of getting the right information to the right disabled consumers, and learning about their preferences? What sort of information would be useful? What practical solutions would help to acquire this information?

Consultation question 10: What characteristics would a project to fill gaps in information that would help supply disabled consumers more efficiently need to have, in order for it to be attractive to participate?

7. Delivering change: market intervention

Much can be done to reduce extra costs by empowering consumers and by businesses seizing the opportunities the market presents. However, there may be circumstances where even the most empowered consumers are unable to secure reductions in the extra costs they face, perhaps signifying a market failure that may justify intervention or regulation.

There may be issues upon which regulators can work across sectors, supported by disability organisations, to reduce costs to consumers, for example in developing a better understanding of disabled consumers. We would be interested in views on this. However our considerations so far have focused primarily on sector-specific regulatory issues, as set out below.

7.1 Regulation and energy

Energy is a key area of extra cost that is subject to regulation specific to the sector in addition to the application of general consumer law. Sector regulation centres on customer service, access to the market and fair presentation of choices rather than price per se, but could also help to reduce extra costs. The context of specific duties on energy suppliers to support customers placed in vulnerable situations is helpful; the effect of extra costs will contribute to placing disproportionately more disabled people in such situations.

At Ofgem's instigation, the Competition and Markets Authority (CMA) is currently investigating the supply and acquisition of energy in the United Kingdom. The issue of possible market failures and how to address them is therefore under consideration. In its updated issues statement of 18 February 2015, the CMA highlighted that between 2012 and 2014, over 95 per cent of the dual fuel customers of the six large energy firms could have saved by switching tariff and/or supplier with an average saving of between £158 and £234 a year (depending on the supplier).⁶⁶ The CMA also highlighted that those customers on the standard variable tariff who have never switched supplier stand to gain the most in terms of reducing their costs and that these customers are more likely, amongst other factors, to be disabled or not to have internet access.⁶⁷ These findings underline our view

⁶⁶ Competition and Markets Authority: *Energy market investigation: Updated issues statement*, February 2015, https://assets.digital.cabinet-office.gov.uk/media/54e378a3ed915d0cf7000001/Updated_Issues_Statement.pdf

⁶⁷ Ibid

of the importance of disabled consumers exercising their choice so as to lower their energy costs.

Since 2013, standards of conduct have been in force, aimed among other things at making sure that suppliers take into account customers' needs. Powers exist to enforce these standards if necessary. We are interested in whether disabled customers working with the regulator could do more to ensure these standards are enforced so as to help ensure fair treatment.

Smart meters with separate energy displays are due to be introduced by 2020 and are expected to bring benefits to customers, for example through better information that can help people identify energy-saving measures and budget more easily. It is important that meters and displays are available that are designed so disabled people can secure full benefits. For example, some disabled people using prepayment may gain particular benefit from not having to physically access the meter to top-up, or travelling to a pay-point to credit their meter. Instead well-designed options should enable people to top-up easily by phone, online or via their energy display.

Consultation question 11: What opportunities are there for disability organisations to support effective regulation? Which issues common across sectors have greatest potential to have impact on extra costs?

7.2 Regulation and taxis and private hire vehicles

Another of our key areas of extra cost that is subject to regulation, notably in the form of licensing, is taxis and private hire vehicles. The Law Commission's review concluded that, "it is clear that disabled passengers continue to suffer severe difficulties in obtaining and using these services". Among its recommendations were changes to the licensing system and how it is implemented by local authorities, and a new duty on taxis to stop for disabled people where it is safe and reasonable to do so. The report also raised questions about the effectiveness of enforcement.

We welcome the interest in this subject, which is timely. We are interested in both regulatory and other options for reducing extra costs for disabled customers arising from scant provision of taxis and private hire vehicles. We should like to hear further evidence relevant to whether regulatory change is needed before taking a view on lead recommendations. Possible recommendations include:

- how the voluntary sector and local authorities might collaborate to ensure licensing is implemented and enforced in a way which helps to address the extra costs faced by disabled people without placing disproportionate burdens on reputable operators;

- recommendations to Government on the importance of reducing extra costs to the Law Commission’s legislative proposals, for example with regard to national standards and to the obligation to stop for disabled customers.

Consultation question 12: What information would best help local authorities to ensure that licensing and enforcement of taxis and private hire vehicles serves the needs of disabled people, taking into account local circumstances?

7.3 Regulation and insurance

Regulation is by no means the only tool that might help to reduce costs in the insurance sector and we have discussed other options elsewhere in this report. The evidence we have sought from the sector about its approach to ensuring a fair deal for disabled customers that accurately reflects risk is relevant both to regulation and to other tools.

Responding to our call for evidence, disabled people expressed frustration at their experience in seeking insurance of several types. Our framework research also identified insurance as sometimes priced so high as to be unaffordable. Reported experiences included:

‘Cover for my son’s condition made the insurance more than 5 times what it would have been – even though his condition is extremely unlikely to have caused any additional risk.’

‘I have a ball on the steering wheel costing £25...every single insurance company tried to charge me more because my car is adapted. I phoned one of them and demanded why they wanted to charge me £££s more, they said it was to cover the cost of repairing the adaptation.’

High prices may reflect high risk: for health or travel insurance for example, some disabled people may represent a higher risk for insurers. Adapted vehicles or expensive disability-related equipment could legitimately justify higher motor or home insurance premiums on the grounds of higher replacement cost. High prices could also be caused by some form of market failure, potentially requiring regulatory intervention.

The insurance sector is one with sufficient suppliers that a competitive market is possible. It has taken some steps to consider the needs of disabled customers. For example, a number of insurers have put effort into making their services accessible. One insurer we spoke to explained that for travel insurance, the tool on which it relied was subject to constant refinement by a team of doctors and nurses to ensure that decisions reflected the most current medical underwriting position. The RSA provides an insurance scheme linked to the Motability scheme that helps disabled people to lease cars, scooters or powered wheelchairs. This achieves high customer satisfaction ratings (+80 on the Net Promoter Score, an indicator that looks at how far customers who promote a supplier outweigh detractors).

The evidence from disabled people is largely qualitative. Insurers can point to the incentives on them to price accurately assuming economically rational behaviour in a competitive market. However, an individual insurer may hesitate to make public the detailed information that would demonstrate accurate pricing since that could be commercially sensitive. To address this understandable absence of transparency, there is a case for the Financial Conduct Authority to review the position.

In a market with many suppliers, we do not expect that all insurers will seek to provide insurance to every consumer, risk or market segment. Some insurers, for example focus on high volume sectors that require a minimum of information so as to reduce costs of underwriting and increase the pool of consumers sharing risks. These may be among the most heavily advertised and best known services. A disabled customer receiving a high cost quotation from such a source is in a disadvantageous position. Some insurers take the initiative to advise such customers where they can find help – this good practice should happen systematically.

We welcome the positive engagement we have had from insurers. However, we are not confident that all is well on access and pricing for disabled consumers. Greater use of signposting may not be enough to address the protection gap for disabled consumers or deliver the best possible deals for them. For this reason we intend to explore further the case for a range of measures, whether on consumer empowerment or increased regulatory scrutiny.

Our current analysis points towards the following recommendations:

- where a disabled person is either refused insurance or offered it at a high cost, insurers should be obliged to signpost the customer to insurers that offer fair quotes, or to an effective brokerage service that they can easily use;

- the Financial Conduct Authority should investigate how effective competition is in the insurance market for disabled people, taking into account in particular the extent to which disabled consumers are engaged or financially included from an insurance and protection perspective.

Consultation question 13: What are the risks of preventing insurers from taking into account disability when pricing insurance and how do these vary by insurance industry sector?

7.4 Deregulation

We share the concern voiced in responses to our call for evidence that either direct regulation or the existence of safety standards may sometimes have an inhibiting effect on supply. For example, in our call for evidence, we received a number of submissions that cite regulated orthopaedic footwear as being significantly more expensive than non-specialised footwear. We are interested to explore how regulation in these areas may result in reduced choice for disabled customers.

We have heard anecdotal evidence that in some cases suppliers may be put off from offering lower cost options to disabled consumers because of ‘rules and regulations’. A related risk is that professionals advising disabled people may not be at liberty to suggest anything but the most gold-plated options. For example, an occupational therapist advising on mobility aids who may be held responsible in the event of an accident involving any equipment recommended may feel obliged to recommend the option with maximum safety features, to the exclusion of considerations of convenience and cost. If this is happening, the effect may be to prevent disabled customers from making choices about the balance between safety and price that would be open to non-disabled people. If it is widespread, it may mean that it is not worth suppliers offering lower cost options at all.

We think that this is a credible hypothesis. However, we have little evidence as to how widespread this is in practice. We should therefore like to strengthen the evidence base to help assess specific changes to deregulate so as to free up businesses and disabled consumers to achieve lower costs.

Consultation question 14: Are there examples of suppliers being inhibited, or charging disabled consumers a higher price out of caution, because of rules and regulations?

7.5 Ways to provide incentives for suppliers to satisfy demand from disabled consumers

Regulation is not the only tool for addressing market failures. Incentives can act as a catalyst for improvement. For example, where information is lacking, incentives that encourage information gathering can lead to long-term change. Assistance with up-front costs can tip the balance of an investment decision, opening up new service offers which if viable can by demonstration draw in competition. Such incentives may be financial or not, and can take the form of rewards or of sanctions. If effective, rewards that elicit a voluntary response may have greater impact in terms of generating commitment and a positive culture than regulations that force what may, at least initially, be reluctant action.

In the course of our initial work, a number of potentially exciting ideas have been suggested for encouraging businesses to take the next steps to providing more cost-effective goods and services to disabled customers. Accreditation with reference to standards of best practice can spur innovation, particularly where consumers recognise the achievement. The Armed Forces corporate covenant⁶⁸ offers a model in which businesses are invited to make a voluntary pledge to act in support of the principles of the national covenant, and is supported by grant funding, an employer recognition scheme and authorised logo. Other ideas include challenge or seedcorn funding, prizes, awards, rankings and kitemarks. Such ideas could be targeted to a particular sector, or could take a wider approach.

The voluntary sector and Government have made various creditable efforts through provision of incentives to influence businesses to meet the needs of disabled people more effectively. We are interested in what could be done to boost the impact of existing initiatives. However, evidence on the factors that help or hinder the success of such initiatives does not appear to be readily available in one place. Our initial examination suggests that those wishing to influence businesses lack robust information that would help in identifying and designing effective schemes.

We have commissioned a short research project to scan for relevant information. We are also interested in any evidence that others hold that might be relevant.

Recommendations could concern specific initiatives, perhaps targeted on encouraging businesses to adopt some of the ideas set out in section 6. There may also be a case for research to further strengthen the evidence base.

⁶⁸ Ministry of Defence: *Corporate Covenant*, 2013 <https://www.gov.uk/government/policies/fulfilling-the-commitments-of-the-armed-forces-covenant/supporting-pages/corporate-covenant>

We believe that there is broad consensus between a range of voluntary and public sector bodies on what it would be good to see businesses doing to help to improve provision and reduce extra costs. We also believe that incentives that have widespread backing, whether financial or in other forms, are more likely to be influential. We do not expect that by the time of our final report we shall have all the answers on what works. Therefore we make a recommendation about the process for taking this forward along the lines set out below. We are interested in whether such a recommendation could be made more specific, for example in suggesting priorities for experimentation.

Recommendation 8: Disability organisations, the Government and trade bodies should collaborate in developing incentives (such as awards, innovation prizes or accreditation schemes) to influence businesses to take actions that will reduce extra costs.

Consultation question 15: What evidence is there with regard to the effectiveness of different attempts to influence businesses to deliver policy objectives, in particular with regard to objectives benefiting disabled people?

8. Next steps

8.1 Engagement: developing recommendations

In developing our recommendations, we want to hear from you. This report has posed questions, listed on pages 12-13. We are open to responses in any form and on as many or as few questions as concern you. Written responses should be emailed to ExtraCostsCommission@scope.org.uk or sent by post to:

Robin Hindle Fisher
Extra Costs Commission
c/o Scope
6 Market Road
London N7 9PW

The deadline for responses to this call for evidence and ideas is **15 April 2015**.

Our survey of businesses will open soon and will be available at www.extracosts.org

8.2 Engagement: implementing recommendations

In the next phase of our work, we are particularly keen to hear from those who may play a part in implementing any of our recommendations. We are interested both in expressions of willingness to take forward and develop ideas, and in reservations about ideas as currently expressed. If there are challenges to be overcome, we want to know about them.

In the period to June 2015, we expect to approach a range of organisations to whom our recommendations will be addressed. If you believe you may have a part to play, there is no need to wait to be asked: we are keen to hear from you. If you have not already been in contact, email us at ExtraCostsCommission@scope.org.uk.

Among those from whom we would like to hear are:

- voluntary organisations with products, services, tools or information in place or in development that could play a part either in smarter purchasing by disabled consumers or more efficient supply to disabled consumers;
- businesses with products, services, tools or information in place or in development that could play a part either in smarter purchasing by disabled consumers or more efficient supply to disabled consumers;
- sponsors who would be interested in supporting the implementation of recommendations in one or more areas;
- researchers with an interest in developing analysis and filling in evidence gaps.

8.3 Final report

We will publish our final recommendations in June 2015. Our final report will be publicly available on the Commission website: www.extracosts.org Details of supporting activity, including a launch event, will be announced nearer the time.

We would greatly welcome offers of support in ensuring that the messages of the final report reach the right audience. To offer support or to apply for an invitation to the launch event, please email ExtraCostsCommission@scope.org.uk

Appendix A: Methodology

The Commission launched an open call for evidence in July 2014, inviting relevant organisations to share any relevant information around disability-related costs, and seeking the experiences and ideas of disabled people and families of disabled children facing extra costs.

The response to the call for evidence from disabled people demonstrated to the Commission just how important the issue is. Alongside over 350 formal responses from disabled people, the issue struck a chord with users of Scope's social media channels, through which the call for evidence was disseminated, with many more people adding their stories. The personal evidence we received is a powerful reminder of why tackling extra costs matters and has helped us gain better understanding of ' instead of 'to understand better the types of disability-related costs that affect disabled people most. The highest ranking 15 extra costs areas are shown in the table below.

Table A1: Top 15 extra cost areas in call for evidence

	Extra cost area
1	Clothing and bedding
2	Specialised equipment
3	Energy
4	Vehicles and petrol
5	Food and drink
6	Transport
7	Health products and services
8	Personal care
9	Housing
10	Household goods and services
11	Holidays
12	Insurance
13	Parking charges
14	Recreation, culture
15	Communication

Evidence to support the Commission's work has also been received from a number of organisations.⁶⁹

To supplement the call for evidence, a roundtable was held to seek expert views on how best to empower disabled people and their families as consumers.

The Commission has undertaken a **review of relevant existing literature**, and is undertaking a number of pieces of primary research to enhance the existing literature on extra costs. These include the following:

- a number of **focus groups** with disabled people and families with disabled children to better understand the categories and extent of extra costs faced by people across a number of impairment types. The findings have been used as the basis for a framework which better explains the nature of extra costs disabled people and their families face.
- **a consumer survey** to gather evidence about the spending habits and preferences of disabled people and their families, focusing on the areas of costs prioritised by the Commission. The survey also looks at the tools that could help improve decision-making. Over 2,500 responses were received.
- **a business survey** to seek out good practice, understand the motivations behind business decisions that may affect the supply of goods and services to disabled people, and test ideas that may drive down the price of relevant products.
- commissioning **two papers**, on the intangible benefits to business of improving the supply of products and services to disabled consumers; and what business incentives might change the behaviour of suppliers of products and services to disabled consumers, both to be completed by Long-Run Economics.

In the second phase of the inquiry, the Commission will hold a range of meetings and interviews to engage with representatives from the voluntary sector and business sector to ensure that our final conclusions are robust, realistic and understood by those expected to deliver against them.

69 Action on Hearing Loss, Association of British Insurers, AXA UK, Bournemouth University, British Insurance Brokers' Association, Business Disability Forum, Centre for Consumer and Essential Services, Citizens Advice, Community Navigator Services, Contact a Family, Co-operatives UK, Department for Business, Innovation & Skills, Direct Line Group, Disability Rights UK, Dosh, Energy UK, Epilepsy Society, Family Fund, Financial Inclusion Commission, Hiscox, Insurance Lloyds Banking Group, Joseph Rowntree Foundation, Lloyds Market Association, London School of Economics and Political Science, Loughborough University, Macmillan Cancer Support, Money Advice Service, National Autistic Society, New Policy Institute, Newlife Foundation, North Staffs Users Group, Ofcom, Ofgem, Parkinson's UK, Prudential, RICA, RSA, Sam Jewell, Scope, Sense, Smarterbuys, Thurrock Coalition, Town and Country Planning Association, Whizz-Kidz

Appendix B: Previous research on extra costs

The total amount that disabled people spend, or need to spend

We identified fourteen studies conducted since 1988 which have attempted to quantify the extra costs faced by disabled people and their families. Table B1 shows some of the weekly overall extra costs – based either on actual expenditure or on need – estimated by a range of different sources.

Table B1 shows that there is a wide range of estimated extra costs:

- for disabled adults, these estimates of extra costs range from £17 to £2,087 per week.
- for a disabled older person, estimates of extra costs range from £42 to £380 per week.
- for a parent of a disabled child, estimated extra costs range from £15 to £483 per week.

Caution is advised in comparing these figures, since they come from a variety of sources which have used different methods. For example, some studies used statistical modelling techniques to estimate extra costs (e.g. Morciano et al., 2012), while others conducted focus groups or interviews with disabled people (e.g. Smith et al., 2004). Other variations in methodology include what areas of extra costs people have been asked about.

It is also worth noting that previous calculations of extra costs are often estimations of *all* of the costs disabled people and their families face. Scope's research, based on data from Demos, indicates that disabled people spend an average of £550 a month on costs directly associated with their disability.⁷⁰ This figure has been formulated by asking disabled people to approximate their overall spend on a series of items; it does not distinguish the proportion of this spend that is extra compared to that which non-disabled people spend on a monthly basis.

The Commission is primarily interested in the *additional* amount of expenditure that disabled people and their families incur as a result of disability – that is, the premium or penalty disabled people face that might be reduced in order to level the playing field between disabled and non-disabled people's financial stability.

⁷⁰ Brawn, E: *Priced Out*, Scope, 2014

Table B1. Overall weekly extra costs (£) according to previous research (2014 prices)⁷¹

	Group		
	Disabled adult	Disabled older person	Parent of disabled child
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

All figures given rounded to nearest £.

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

- 71 Martin and White, as cited in Tibble, M: *Review of existing research on the extra costs of disability*, 2005
 Disablement income group, as cited in Tibble, M: *Review of existing research on the extra costs of disability*, 2005
 McKay, S: *Further analysis of the OPCS survey of disabled adults*, 1990
 Berthoud, R: *Meeting the Costs of Disability*, 1991
 Philips, as cited in Tibble, M: *Review of existing research on the extra costs of disability*, 2005
 Smith et al: *Disabled people's costs of living: more than you would think*, 2004
 Zaidi, A., & Burchardt, T: *Comparing incomes when needs differ: equalization for the extra costs of disability in the UK*, *Review of Income and Wealth*, 51(1), 2005
 Wood, C., & Grant, E: *Counting the Cost*, 2010
 Morciano, M; Hancock, R & Pudney, S: *Disability costs and equivalence scales in the older population*, ISER Working Paper Series (No. 2012-09), 2012
 Hancock, R., Morciano, M., & Pudney, S: *Nonparametric estimation of a compensating variation: the cost of disability*, ISER Working Paper Series (No. 2013-26), 2013
 Smyth, M. and Robus, N: *The Financial Circumstances of Families with Disabled Children Living in Private Households* (OPCS Report 5), 1989
 Dobson, B. and Middleton, S: *Paying to care: the costs of childhood disability*, 1998
 Dobson, B., Middleton, S., & Beardsworth, A: *The impact of childhood disability on family life*, 2001
 Contact a family: *Counting the Cost 2014*, 2014

The costs that have the most significant effect

We have also examined evidence that might help us identify the most significant drivers of the extra costs faced by disabled people. There has been less research into this area. We identified three studies from 2004 and 2012 which looked at the extra costs disabled people experienced with a range of goods and services from food and drink to recreation and holidays. Table B2 shows the compiled results. Because of the different methodologies and approaches of these studies we have not been able to draw firm conclusions on the value of any specific areas of extra costs. However, the research has suggested the types of goods and services that might be significant in driving the extra costs.

Table B2 shows that there is a lack of consensus over the level of expenditure across different cost areas. Particular areas of extra cost where disabled people appear to spend more than non-disabled people though, are food and drink, housing, fuel and power, health and personal care and recreation, culture and holidays. In research by Smith et al., the level of costs rises as the level of an individual's needs increases.

Table B2. Weekly extra costs (£) for disabled people (including data by high to low need) across areas of cost⁷²

		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

72 i. Smith et al: *Disabled people's costs of living: more than you would think*, 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, C., & Grant, E: *Counting the Cost*, 2010

iii. ONS: *Living Costs and Food Survey (LCF)*, 2012



For more information on the Extra Costs Commission, please visit www.extracosts.org

Call **020 7619 7375** if you'd like this report in a format that is accessible for you.

