

Driving down the extra costs disabled people face

Progress review
October 2016



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Foreword

by Robin Hindle Fisher



The average disabled person in the UK has to spend £550 a month on costs related to their disability.¹ These extra costs may include buying specialised equipment, having to spend more on heating bills, or being subject to higher insurance premiums.

Until recently much of the response to this problem has concentrated on raising the income of disabled people through extra cost payments – Disability Living Allowance (DLA) and Personal Independence Payment (PIP). This remains a critically important part of the solution. However, there are also other actions that can reduce some of the extra costs faced by disabled people.

I chaired a year-long inquiry, the Extra Costs Commission, from July 2014 – June 2015 that explored additional ways of reducing the financial burden on disabled people. A group of fifteen Commissioners,² seven of whom, including myself, were disabled, developed 16 recommendations to alleviate the additional costs experienced by disabled people.

One of our key findings was that disabled people themselves should do more to take advantage of the considerable spending power they have – estimated to be worth over £200 billion a year³ – the so-called ‘purple pound’. We recommended that disabled people should be ‘bold and loud’ as consumers, alongside a number of other initiatives to make markets function better for the almost 13 million disabled people in the UK.⁴

We identified that improving disabled people’s experiences as consumers will require actions from a number of different groups – namely **disabled people and their families, disability organisations,⁵ businesses, and regulators and government.**

1 Scope. (2014). Priced Out, <https://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Extra-Costs-Report.pdf?ext=.pdf>

2 The full list of Commissioners can be found at <http://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/commission/meet-commissioners-1>

3 Department for Work and Pensions, the Rt Hon Mark Harper MP and Office for Disability Issues. High street could be boosted by £212 billion ‘purple pound’ by attracting disabled people and their families. 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>

4 ONS (2016). Family Resources Survey 2014/15, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/531242/family-resources-survey-2014-15.pdf

5 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).

This report highlights some of the progress that has been achieved on our recommendations. We are very pleased to note that there have been a number of excellent examples of the groups we highlighted addressing the problem of extra costs. We have seen cases of disabled people demanding more as consumers, leading businesses such as Marks and Spencer developing products with disabled people in mind, and a number of disability organisations like Scope and Nimbus Disability supporting disabled people to capitalise more effectively on their spending power.

However, much more needs to happen – it is critical that we build upon these successes to reduce further the costs that disabled people pay for essential goods and services.

Though the Commission's work has now finished, we are handing over responsibility for taking our recommendations forward to Scope. I very much hope that the reflections and learnings captured in this report will inspire other organisations to work with Scope to drive change to tackle the financial penalty of disability.

Rohi Hindle Fisher

Executive summary

Life costs more if you're disabled.

On average, someone with a neurological condition will spend almost £200 a week on costs related to their disability.⁶ For someone with a physical impairment, these costs will be almost £300.⁷

There remains a critically important role for welfare in helping disabled people meet these additional costs. But there is also a need to find ways to tackle the financial penalty of disability by driving down the cost of goods and services for which disabled people pay more.

The Extra Costs Commission, a year-long independent inquiry running from July 2014 – June 2015, explored the issue of extra costs in detail. Fifteen experts from sectors including energy, financial services and consumer affairs, came together to identify solutions for tackling these costs (see Appendix A for full list).

We found that disabled people are often under-served across a number of key markets, resulting in extra costs – whether that is for disability equipment such as powered wheelchairs, or essential services such as energy. There is a strong business case for addressing this problem, as households with a disabled person spend £212 billion a year, the so-called 'purple pound'⁸ – meaning that disabled people are potentially a powerful consumer group.

One year on, Commissioners reconvened to review the progress made so far in driving down extra costs. It is good to see that there has been action by each of the groups we identified as having a part to play in tackling this problem – disabled people and their families, disability organisations, businesses and trade bodies, and regulators and government.

The Commission called for disabled people and their families to be 'bold and loud' as consumers. There have been positive examples of individuals encouraging businesses to consider disability when developing goods and services. In one case involving Marks and Spencer, this has led to the creation of a new specialist sleepwear range for disabled children.

There has been good work by disability organisations to support disabled people and businesses with driving down disability-related costs. For instance,

⁶ Extra Costs Commission (2015). Driving down the extra costs disabled people face – Interim report, <http://www.scope.org.uk/Scope/media/Interim-report/Interim-report.pdf?ext=.pdf>

⁷ Ibid

⁸ Department for Work and Pensions, the Rt Hon Mark Harper MP and Office for Disability Issues. High street could be boosted by £212 billion 'purple pound' by attracting disabled people and their families. 27 August 2014

Scope has created a new information resource to help disabled people manage their money more effectively, Nimbus Disability has started to offer discounts to users of its Access Card, and Rica has been carrying out research to increase businesses' understanding of the needs of disabled consumers.

A number of businesses, and organisations working with businesses, have also been thinking about how they can improve the experiences of disabled consumers. Uber has provided several of its drivers with in-depth disability awareness training and has also introduced wheelchair accessible vehicles to its fleet in London. The Business Disability Forum has developed an award for businesses that have taken steps to reduce extra costs for disabled people.

Lastly, regulators and government have been taking positive steps to intervene in specific markets to address the additional costs faced by disabled consumers. The Financial Conduct Authority has been looking in more detail at the customer journey of disabled people when purchasing insurance. There is growing political momentum to create a more equal and fairly-priced service for disabled people using taxis and private hire vehicles (PHVs).

Whilst there has been substantial activity to take forward the Commission's recommendations, much more needs to happen to reduce the cost of living for disabled people. That is why we are calling upon the following groups to take further action to tackle extra costs:

- **Disabled people and their families** should continue to raise the profile of the 'purple pound' by ensuring businesses are aware of their needs as consumers.
- **Disability organisations** should work collaboratively with one another to drive down extra costs, exchanging knowledge and resources help develop and promote initiatives to empower disabled people as consumers.
- **Disability organisations** should explore how to use their brand profile and expertise to support businesses to understand disabled consumers better, and to raise awareness of products that would reduce extra costs for their audiences.
- **Company boards** should act as champions for disabled consumers, ensuring that the businesses they represent have a clear focus on serving disabled consumers effectively to help drive down extra costs for this group.
- **The Office for Disability Issues**, working with market regulators, should ensure there is a cross-governmental approach to help tackle the range of extra costs faced by disabled people.

The Commission's work has now formally concluded. We are passing on the baton to Scope, the organisation that first proposed the Commission, to keep alive the momentum we have created and ensure that lasting change is created from the positive beginnings set out in this report.

We call upon organisations across different sectors to work with Scope to build upon and champion the work of this inquiry.

Introduction

The Extra Costs Commission was an independent inquiry into the extra costs faced by disabled people and their families.⁹

According to the disability charity Scope, disabled people spend an average of £550 a month on costs related to their disability.¹⁰ For one in 10, costs of this sort amount to over £1,000 a month.¹¹

These costs have a substantial impact on the lives of disabled people. They make it harder for individuals to get a job, access education and training opportunities, as well as pay into savings and pensions.

What are extra costs?

The additional costs of disability are incurred in three main ways:

- **Paying for specialised goods and services.** This may include one-off, but expensive, purchases, such as assistive technology or mobility aids.
- **Greater use of non-specialised goods and services.** For example, someone with limited mobility may have to spend more on energy to keep warm, whilst a wheelchair user may have to use taxis more often if public transport is inaccessible.
- **Spending more on non-specialised goods and services.** This may include things such as higher tariffs for accessible hotel rooms, or having to pay higher premiums on insurance products.

Annabelle's story

I have to buy shoes far more frequently than I would do if I did not have cerebral palsy. My shoes wear out quickly because of the way I walk. For example, the shoes I wear for work – 9 to 5, five days a week – only last me two or three weeks. As a professional woman in my thirties buying shoes should be a thrill for me. Instead it's an expensive chore.

My job means I need to look smart, and this means that some things that others would see as treats are a necessity to me. For example, sometimes I struggle washing my own hair and need someone to help me, so I'll have to go to the hairdresser.



⁹ More information about the work of the Commission can be found at <http://www.scope.org.uk/get-involved/campaigns/extra-costs-commission>

¹⁰ Scope. (2014). Priced Out

¹¹ Ibid

Liz and Dan's story

Our daughter Ava is eight and has cerebral palsy, epilepsy and hydrocephalus, and is blind.



Ava loves music therapy and it really helps her, but there is no provision where we live so we have to pay £40 per week to go private. When we buy specialist toys, we have to go to companies that charge four times as much.

Her physiotherapy costs are currently £140 per week, which pays for two hours a week. Every time she needs a new wheelchair, we have to pay for the extras - a rain cover and sunshade can cost £500. We spend £50 a month on nappies, and Ava has food allergies so we spend roughly £25 to £35 extra each week on “free-from” food items.

Partly because disabled people face extra costs, they have the potential to be a hugely powerful consumer force. This is demonstrated by the fact that households containing a disabled person spend a colossal £212 billion a year, the so-called ‘purple pound’.¹²

However, disabled people are all too often under-served as consumers when it comes to choice of products and quality of service. This makes it harder for disabled people to capitalise effectively on the ‘purple pound’, with higher costs for essential goods and services as a result of a lack of competition in markets.

Better functioning markets for disabled people will not only benefit the consumer - they offer a valuable opportunity for businesses to grow by being able to reach a customer base of over 12 million people.¹³

Bringing together experts across a number of sectors, including energy, financial services and consumer affairs, the Commission sought to identify solutions for driving down the additional costs of disability.

In order for the Commission’s work to be worthwhile and meaningful, it is important that there is tangible action to reduce extra costs. Much has been happening since our inquiry ended, and this report will reflect on the progress that’s been made in delivering recommendations.



Disabled people’s households spend

£212 billion a year

¹² Department for Work and Pensions, the Rt Hon Mark Harper MP and Office for Disability Issues. High street could be boosted by £212 billion ‘purple pound’ by attracting disabled people and their families. 27 August 2014

¹³ ONS (2016). Family Resources Survey 2014/15

Overview of the Commission's work

The Commission considered new and existing evidence into the problem of extra costs, which involved speaking to disabled people about their experiences of the range and level of these costs.

In addition, we carried out a survey into disabled people's spending habits and preferences as consumers. A separate survey was also conducted to understand more about how businesses perceive disabled consumers.

Based upon this evidence, we identified specific areas of extra cost to explore further. These were selected on the basis of the likelihood of tackling these costs, the scale of the expected change, and where Commissioners felt they could add value. These areas were as follows:

- Energy
- Clothing and bedding
- Specialised equipment
- Taxis and PHVs
- Insurance



There are at least **833,000** fuel poor households in England with a disabled personⁱ



Over a third of disabled people spend additional money on clothing and bedding as a result of their impairmentⁱⁱ



1 in 3 disabled people spend money on specialised equipmentⁱⁱⁱ



2 in 3 wheelchair users say they have been overcharged for a taxi or private hire vehicle because of their wheelchair^{iv}



At least **half a million** disabled people have been turned down for insurance^v

Sources:

i) Department of Energy and Climate Change (2015). Fuel poverty detailed tables: 2013, <https://www.gov.uk/government/statistics/fuel-poverty-detailed-tables-2013> ii) Extra Costs Commission call for evidence from disabled people and their families (2014) iii) Extra Costs Commission call for evidence from disabled people and their families (2014) iv) Unpublished Department for Transport survey (2014) v) Ipsos MORI (2013). Disabled people and Financial Wellbeing, https://www.ipsos-mori.com/DownloadPublication/1583_sri-ews-scope-disabled-people-and-workplace-wellbeing-2013.pdf

Throughout the course of this inquiry, it became apparent that the issue of additional costs for disabled people cannot be solved by one group alone. The Commission's final report contained 16 recommendations for driving down extra costs targeted at four specific groups:

- Disabled people and their families
- Disability organisations
- Businesses
- Government and regulators

The role of extra cost payments

Extra cost payments – DLA and PIP – remain absolutely vital in helping disabled people to meet the additional costs of disability.

Whilst DLA and PIP fell outside the remit of our investigation, we recognise that action is needed on both income and costs to help reduce the financial penalty of disability. As such, until there is demonstrable evidence of a reduction in extra costs for disabled people, it is important that the value of these payments is protected.

Reviewing progress

In June 2016, a year after the Commission's final report, Commissioners reconvened to review the progress that's been made towards recommendations.

Seven organisations made specific commitments to take forward the Commission's recommendations in 2015 (see Appendix B). Six of these met with the Commission when it reconvened to share the successes and challenges they have experienced, and in some cases to share plans for further action.

The Commission is pleased that each of the organisations that returned to talk to us has taken steps to begin to tackle disability-related costs. It is also positive to see other organisations introducing products and services that will reduce the cost of living for disabled people and their families, and traction within government leading to progress on specific recommendations.

Our inquiry was only the start of the process of driving down the extra costs faced by disabled people. We hope that the case studies, learning and reflections captured in this report will inspire others to take similar action.

Progress towards recommendations

1. Disabled people demanding more as consumers

One of the Commission's strongest messages was to disabled people themselves.

We recognise that structural changes are needed to enable disabled people to obtain more affordable prices for key goods and services. However, we believe there is more that disabled people themselves can do to reduce the extra costs they face. There are over 12 million disabled people in the UK,¹⁴ whose households spend £212 billion a year, the so-called 'purple pound'.¹⁵ If disabled people are able to come together and make themselves more visible as a consumer group, then this has the power to influence how businesses act.

The Commission therefore called for disabled people and their families to be 'bold and loud' as consumers in order to build power behind the 'purple pound', ensuring businesses understand their needs and preferences when shopping, sharing information with one another about good deals and ways to drive down extra costs, and speaking out when they experience poor customer service.

Two brilliant examples of this happening are captured below, both involving parents of disabled children who have demanded more from major retailers when it comes to products for disabled people. The Commission hopes to see more instances like this of disabled people and their families exerting their consumer power to get a better service from businesses.

¹⁴ ONS (2016). Family Resources Survey 2014/15

¹⁵ Department for Work and Pensions, the Rt Hon Mark Harper MP and Office for Disability Issues. High street could be boosted by £212 billion 'purple pound' by attracting disabled people and their families. 27 August 2014

Case study: Rita Kutt and her grandson

My four-year old grandson Caleb has dystonic quadriplegia cerebral palsy, which means he is unable to sit, stand or walk and has little control of his head. He still uses nappies and is fed through a tube in his stomach, making it difficult to find clothes that fit him.



When Caleb reached the age of three, his mum, Zoe, and I started looking for suitable clothing for him. After searching the high street stores and internet, to my dismay, I found that there weren't any suitable products available. I realised that we could only buy them from specialist catalogues, charging between £12 and £15 for children's things like popper vests.

I began thinking whether high street stores could make popper vests a little bigger, which is when I decided to approach Marks and Spencer. I chose them because they're a global company – surely if they were able to order products in mass then these would be priced lower.

After writing to Marks and Spencer's customer services team, I received a response to say that they were interested in my proposal. They then developed a series of sample popper vests for Zoe and me to test with Caleb.

The company also worked with Scope for advice about developing these new products. Scope also arranged for parents of disabled children to trial and offer feedback on the popper vests.

Eventually, Marks and Spencer launched a specialist clothing range for disabled children that included not only popper vests but sleepsuits as well. The quality of the clothing is great, and all the items have easy accessibility for nappy changing and tube feeding.

I decided to tell other people about my work with Marks and Spencer on social media, and the response has been hugely positive. Lots of disabled people and their families have told me their own ideas for developing products for disabled people, and it's important that we encourage other high street retailers and businesses to take these up. After all, if we don't let them know what our needs are as consumers, how are they going to help?

Case study: Laura Rutherford and her son

My four-year-old son Brody has Global Development Delay, epilepsy, hypotonia and hypermobility. He wears the largest size nappies available in supermarkets (6+), but they are fast becoming too small for him.



Brody has been referred to the continence service, who hopefully will allocate a set number of nappies for him to use each day. Whilst this is a great service for many families, it varies according to where you live in terms of eligibility, waiting time and the number of nappies allocated. If you are ineligible or don't receive enough nappies to cover your needs, you are left with no option but to buy bigger nappies online - these come with a premium price tag.

There are items like pull-ups and night-time pants, which are available in supermarkets and come in slightly bigger sizes. However, the absorbency of these isn't as good as they're designed for children who are potty training and have some bladder control. Not only this, but it would be very expensive to buy pull ups, as one pack may only last a day or two for a family with a doubly incontinent child.

Additionally, there is the option of cloth nappies; however, this isn't a 'one size fits all' solution.

Deciding to do something about this, I started a petition asking leading supermarkets to stock bigger nappies for incontinent disabled children. There are thousands of children like Brody in the UK, meaning there is a huge consumer group that supermarkets could be reaching – one that is all too often ignored.

The response to my campaign has been fantastic, with almost 16,000 supporters. I have also had some positive engagement with a couple of supermarkets.

In addition to these two case studies, we have also seen instances where disabled people have shared information and advice with one another to help reduce the extra costs they face.

For instance, the Disabled Living Foundation, a charity providing advice, information and training on independent living, has an online forum for disabled people called Youreable. This includes a specific section on specialised equipment, with a number of threads discussing different products and tips on how to obtain and service these at the best possible price.

Scope also facilitated a question and answer discussion on its online community with the grandmother Rita Kutt mentioned in the case study previously. A number of disabled people and parents of disabled children cited specific items for which they are charged a premium, e.g. clothing for children with a sensory impairment. In particular, Rita encouraged these individuals to set up online groups to identify others facing similar difficulties in obtaining these goods at an affordable price, using this as a way to show the scale of the problem to businesses.

Key observations

- Disabled people and their families have first-hand knowledge of the products that would help to reduce additional costs. This insight is invaluable for businesses.
- Online channels such as forums and social media provide extremely powerful tools for disabled people and their families to connect with one another and share their experiences of extra costs.
- Demonstrating the scale of the market for a particular product will help to create a more persuasive case for businesses to develop it.
- Where disabled people and their families share their experiences of being 'bold and loud' as consumers, this is helpful in encouraging other disabled people to take similar action.

Disabled people and their families are an important set of consumers that businesses should consider as an attractive target market. It is encouraging to see examples of individuals recognising their value as consumers and taking the initiative to ensure retailers develop products with disabled people in mind.

The Commission hopes that the stories listed here will encourage more disabled people and their families to be 'bold and loud' as consumers and see the positive impact that this can have on how businesses serve them.

Call to action: Disabled people and their families should continue to raise the profile of the 'purple pound' by ensuring businesses are aware of their needs as consumers.

2. Disability organisations empowering disabled people as consumers

Disabled people have the potential to be a powerful set of consumers by capitalising on the 'purple pound' and making their voice heard by the companies that they deal with on a daily basis. Disability organisations can play a part in making this happen by taking on a more prominent role as consumer advocates for the people they represent.

Many disability organisations have typically focussed on the part welfare has to play in helping to address the problem of disability-related costs. Whilst this is important, it is only one aspect of the solution – empowering disabled people as consumers is also important in tackling extra costs.

Disability organisations are in a strong position to take on this role. They are trusted and familiar amongst disabled people and their families, allowing them to successfully target information, products and services to enable disabled people to make best use of their spending power.

The Commission was pleased that several disability organisations committed to a number of recommendations, developing innovative ways to help reduce additional costs for disabled people. We hope that these cases studies will inspire others within the disability sector to follow suit.

Organisational commitment: Scope

Scope has worked with the Money Advice Service on developing a money advice hub, providing information to support disabled people to manage their money more effectively. The hub covers budgeting advice, an overview of price comparison websites and tips to navigate the insurance market effectively.

The charity has also been working with the consumer group Which? to include content on consumer rights issues, including information for disabled people about how to complain effectively and seek redress when they receive an inadequate level of service.

Scope already has substantial online information about welfare that is frequently accessed by disabled people. The work of the Commission has encouraged Scope to concentrate on consumer information alongside welfare support, to help disabled people strengthen their financial resilience.

There has been an 87 percent increase in views of the hub over the last year since it launched. However, one of the challenges will be to assess the impact this information has had in supporting disabled people as consumers and driving down extra costs for this group. Scope plans to start this process by capturing qualitative feedback from users of the hub. Commissioners also noted ways in which the hub might develop over time, in particular how businesses and government could signpost individuals to this resource where they themselves don't have detailed knowledge about extra costs. This would help to ensure that individuals are aware of, and can access, the breadth of information contained in the hub to help them feel more confident as consumers.

Scope will continue to develop its information offer on money and consumer issues.

Organisational commitment: Nimbus Disability

Nimbus Disability's Access Card allows disabled people to communicate requirements relating to their impairment through a series of easily understood symbols.

Nimbus has been working with the Ticket Factory to create an online booking system for events, whereby information regarding disabled people's access requirements is automatically provided where they have one of these cards. As part of this move, a number of venues have started acknowledging the need to provide free tickets for a disabled person's carer(s) or personal assistant(s).

The relationship with Ticket Factory has contributed to an increase in card users from 1,000 to 5,000. A growing customer base will enable Nimbus to build similar relationships with other ticket agencies and retailers, as they can provide these companies with the reassurance of a sizeable market of disabled people that they are able to reach.

Membership levels will be critical as Nimbus develops the card, to enable users to obtain discounts and deals from retailers. There has been progress in this area so far at a local level – growth of the card's customer base will help Nimbus take this to a national market.

Organisational commitment: Family Fund

Family Fund Trading is a subsidiary of Family Fund, providing emergency and discretionary goods and services through local authority and charity grant applications.

Whilst Family Fund Trading currently provides business-to-business services, it recognised that the unique discounted supply model provides an ideal opportunity to reach disabled people and their families directly, helping them access everyday and specialist goods and services. By expanding this business-to-business supply model into a business-to-consumer retail model, these consumers will be able to access similar discounts to those offered to organisations.

As items of specialised equipment can often be very expensive, it will be important that Family Fund Trading is able to get adequate discounts on these items from suppliers so that they can still offer a saving to disabled people. This will require building sufficient interest in Family Fund Trading amongst disabled people, to allow the organisation to make large purchasing orders for specialised equipment and therefore negotiate a cheaper price.

In addition, there needs to be the assurance that any discounted goods sold directly to customers reach disabled people, as intended. One way to test eligibility might be through using Nimbus Disability's Access Card, or a similar scheme, which could be used to enable disabled people to register with Family Fund Trading's website and shop for items.

Key observations

- As more disability organisations develop resources to support disabled people as consumers, it is important that there is ongoing evaluation to see how useful they are in enabling individuals to reduce the extra costs they face.
- When disability organisations are trying to secure discounts on products for disabled people, they need to demonstrate to businesses that there is a large enough consumer base to make this financially viable for them.
- There will often be opportunities for disability organisations to work together to help develop and promote initiatives to empower disabled people as consumers.

It is positive to see the progress that different disability organisations have made in developing tools and resources to enable disabled people to make effective use of their collective spending power, as well as save money on essential goods and services.

However, the disability sector is made up of a large number of diverse organisations - we are keen to see more disability organisations consider how they can support the disabled people they represent as consumers, and find opportunities to work together. This might include Scope using its money hub to make disabled people aware of Nimbus Disability's Access Card; or Family Fund Trading working with Scope and other disability charities to develop insight into items of specialised equipment frequently purchased by disabled people at a high cost.

Call to action: Disability organisations should work collaboratively with one another to drive down extra costs, exchanging knowledge and resources to help develop and promote initiatives to empower disabled people as consumers.

3. Partnership working between disability organisations and businesses

Our inquiry found that disabled people often have a poor experience as consumers: three quarters of disabled people have left a shop or business because of poor disability awareness or understanding.¹⁶

In the last year we have seen positive examples of businesses developing ways to improve their approach towards disabled consumers. For some, making this happen has involved working in conjunction with disability organisations.

When we spoke to businesses during our inquiry, six in 10 said that information about the consumer behaviour and preferences of disabled people would help them determine how to meet demand from this group.¹⁷ For others, there was uncertainty about the scale of the market they could potentially reach through targeting products at disabled people.



Three quarters of disabled people have left a shop or business because of poor disability awareness or understanding

Disability organisations are in a strong position to support businesses in both of these areas. Their reach amongst disabled people enables them to help gather the necessary customer insight to support businesses understand the needs, experiences and preferences of disabled consumers.

Businesses should be aware of the potential market of over 12 million disabled people¹⁸ to whom they can promote goods and services that aim to tackle extra costs. It is an opportunity that is too good to miss.

We are glad that there are several examples of change happening, illustrated by organisational commitments made by a number of organisations in our final report. Rica has been working with businesses to help them learn more about disabled consumers' shopping habits, whilst Really Useful Stuff has been exploring how it can work with disability charities to offer discounts on items of specialised equipment. The Business Disability Forum has also been providing businesses with a platform to raise the profile of their work to drive down extra costs.

The Commission hopes that this style of partnership working between disability organisations and businesses becomes ever more prominent.

¹⁶ Extra Costs Commission. (2015). Driving down the extra costs disabled people face – Final report, <http://www.scope.org.uk/Scope/media/Interim-report/Extra-Costs-Commission-Final-Report.pdf>

¹⁷ Ibid

¹⁸ ONS (2016). Family Resources Survey 2014/15

Organisational commitment: Rica

Rica has delivered research projects for a number of organisations to help them understand the needs of disabled consumers better, including British Gas, the Association of Train Operating Companies and O2. They have also supported the Business Disability Forum in providing similar research to its members.

One of the challenges for Rica has been getting businesses to see disabled consumers as a priority market, and understanding that this is a diverse group of individuals. Rica held an event last year with businesses to help address this, which outlined best practice in consumer research with older and disabled people.

Rica states that the work of the Commission has encouraged them to conduct more research into the cost of products disabled people buy, alongside looking at the overall customer satisfaction of this consumer group. We hope that Rica develops greater insight in this area to highlight the scale of the problem of extra costs to businesses in different sectors.

Organisational commitment: The Business Disability Forum (BDF)

The BDF has successfully developed a new Extra Costs award as part of its series of Disability-smart Awards. The winner of this award will be announced later this year.

It is positive that the BDF has committed to offer this award as part of its annual Disability-smart Awards. Whilst the number of applications for the award this year could have been higher, it is hoped that interest will increase as more businesses take steps to reduce additional costs.



Six in 10 businesses we surveyed would find information about disabled consumers useful

Organisational commitment: Really Useful Stuff

Following the Commission's final report, Really Useful Stuff has developed an online plug-in shop for charities to sell products that meet the needs of their service users.

They have worked with suppliers to obtain discounts of at least 10 percent of goods and have also enabled VAT-free shopping online, discounts that charities can then pass on to customers.

Action for ME is the first charity to have developed a plug-in shop via Really Useful Stuff. The Commission hopes that other charities will adopt this model for selling products at a cheaper price directly to disabled people.

Key observations:

- Disability organisations should not underestimate the rich insight they can provide to help businesses understand the needs of disabled consumers better. This will enable businesses to take action to help drive down extra costs.
- Disability organisations should explore how they can use their digital and marketing channels to raise the profile amongst their audiences of products from businesses that are targeted at disabled people.

It is positive to see a number of cases where disability organisations and businesses have recognised the value of working together to help improve disabled people's experiences as consumers. This highlights the Commission's message that the problem of extra costs cannot be solved by one group alone.

Call to action: Disability organisations should explore how to use their brand profile and expertise to support businesses to understand disabled consumers better, and to raise awareness of products that would reduce extra costs for their audiences.

4. Businesses serving disabled people better

It became clear during the course of the Commission's inquiry that businesses have a pivotal role in driving down the extra costs of disability.

Disabled people will often be disadvantaged in markets when shopping for essential goods and services. For example, over a third of disabled people the Commission surveyed said that they face additional costs for clothing and bedding as a result of their impairment.¹⁹

The more businesses think about how they can best serve disabled consumers, the greater the opportunity to increase choice and competition for this group when making purchases. If markets function better, the extra costs faced by disabled people could be reduced. At the same time, there are financial benefits for businesses who take action – by failing to meet the needs of disabled people, businesses could be missing out on a share of £420 million in revenue each week.²⁰

We are pleased that leading businesses like Marks and Spencer and Uber have responded positively to the Commission's work by developing products with disabled consumers in mind.

We want to see more businesses across different sectors follow suit. The Commission hopes that the two case studies featured here will encourage other businesses to consider how they could incorporate a focus on disability as part of their customer offer, and tap into disabled people's spending power of over £200 billion a year.²¹

19 Extra Costs Commission. (2015). Driving down the extra costs disabled people face – Final report
20 Ibid

21 Department for Work and Pensions, the Rt Hon Mark Harper MP and Office for Disability Issues. High street could be boosted by £212 billion 'purple pound' by attracting disabled people and their families. 27 August 2014



Businesses could be missing out on a share of **£420 million** a week by failing to meet the needs of disabled people

Case study: Marks and Spencer

Our range of specialist bodysuits came about when a customer contacted us with the suggestion. As a business we spend a lot of time gathering customer feedback and adjusting our products accordingly but this email in particular struck a chord, as Rita talked to us not only about her family but all of the other families who would benefit too. The fact that she had identified a wide customer base that Marks and Spencer had the opportunity to support was something we couldn't ignore.

We worked with Rita and a number of other families to develop the specialist bodysuits and sleepsuits, and when they launched online we had the most fantastic response – customers left us lots of reviews explaining the difference that the product made to their child, ideas of what else we could do, and most importantly a very strong sense that this was something they wanted to be more widely available.

The range itself was an extension of a product we currently stock at the moment, which meant that although the development was a little more complex than our current range of bodysuits, we knew we would be able to deliver it and that it could become a sustainable part of our business.

The response has been overwhelming, and has led us to explore new ideas. This year, working with the National Autistic Society, we launched an Easy Dressing schoolwear range - we're now looking at further adaptations to this product that will support parents who are asking us for adaptive clothing for their children.

What's been key for us is the realisation that as a business we have all the tools we require to be able to do this – the understanding of what's comfortable for a child and what makes life easier for a parent, and suppliers who have the capability to adapt the product – and we can therefore make this into a permanent part of our Kidswear ranges that we know will be sustainable rather than a one-off project. It has helped us to extend our product offer for customers with disabled children and really opened our eyes to more opportunities in the future.



Case study: Uber

Following the work of the Commission, Uber – which allows people to book licensed PHVs through its app – has worked to further develop their service for disabled passengers. This progress forms an important part of our overall aim to extend the availability of safe, affordable and convenient transport to all.

The first step was to better understand the range of challenges faced by disabled people when using existing taxi and PHV services. Through working with Scope – and other disability organisations, we found the list of challenges included drivers with little experience of how to provide a good service to disabled passengers, instances of overcharging, and a lack of wheelchair accessible vehicles.

In response to these challenges, we launched two new options on their app, uberASSIST and uberWAV.

uberASSIST – launched in October 2015 – allows disabled passengers to book a PHV driven by a highly rated Uber partner-driver who has completed a special disability equality course, designed and delivered by disabled trainers.

This option is now available in five UK cities. To overcome price discrimination, it always costs the same as the lowest option on Uber's app.

In response to the specific extra costs faced by wheelchair users, we then launched uberWAV in May 2016. Launching with 55 fully wheelchair accessible vehicles (growing to over 100 vehicles by late 2016), uberWAV has now completed thousands of journeys since its launch. As with uberASSIST, uberWAV is always priced at the same level as the lowest available option on Uber's app.

Together these benefits have resulted in great consumer feedback and a growing and thriving service in London. In future, we plan to continue to improve – and grow – these services, aiming to serve many more disabled people across the UK in the coming months and years.



Key observations:

- The rationale for creating products with disabled people in mind will need to be clear.
- Customer insight from disabled people and disability organisations is critical to identifying and developing products that would benefit disabled consumers.
- A 'test and learn' approach is useful for businesses looking to give greater consideration to the needs of disabled consumers.

The Commission is pleased that businesses like Marks and Spencer and Uber have made a concerted effort to reduce extra costs for disabled people.

These case studies represent changes in two markets – the retail and taxi and PHV markets. Our inquiry looked at five extra cost areas, so it is important that other businesses within other markets think about how they can develop products to meet the needs of disabled consumers better.

Later this year, Scope will be holding two roundtables with the energy and insurance industries to discuss the issue of extra costs further. This will provide an opportunity to explore in more detail how companies can support disabled people in paying an affordable price for energy and insurance.

Any business - in any sector – that wants to expand should consider how they can cater to the needs of disabled consumers more effectively. Marks and Spencer and Uber are examples of businesses that are thinking about a long-term strategy to reach this section of the market. Buy-in for such an approach at boardroom level is integral to driving change forward, with a need for Non-Executive Directors to outline the business case for targeting disabled people.

Call to action: Company boards should act as champions for disabled consumers, ensuring that the businesses they represent have a clear focus on serving disabled consumers effectively to help drive down extra costs for this group.

5. Raising the profile of extra costs within government and amongst regulators

In certain instances, there will be a need for government and regulators to step in to complement the actions of disabled people, disability organisations and businesses.

In its final report, the Commission identified a number of areas where market forces alone cannot address the challenges disabled people face in accessing essential goods and services at an affordable price. The interventions we have outlined for government and regulators have concentrated on how particular markets work for disabled people, reviewing the effectiveness of legislation designed to empower disabled consumers, and introducing stronger legal requirements to ensure disabled consumers are treated fairly.

We have seen some good progress by regulators and by government following our report last year, most notably in relation to the insurance and taxi and PHV markets. There is now a need to build upon this so that these markets, and others, function effectively for disabled consumers.

The Financial Conduct Authority (FCA) and insurance

One area of extra cost identified by our inquiry was insurance. Evidence suggests that as many as two and a half million people feel they are overcharged for insurance because of their disability, whilst at least half a million disabled people feeling they have been denied cover for the same reason.²²

Insurance firms and disabled people may present different reasons as to why this is happening - there is a need to understand the relationship between these two groups further, and to test whether disabled people have access to insurance products that have been fairly priced.

FCA, in its role as market regulator, is well-placed to carry out such a piece of work.

²² Ipsos MORI (2013). Disabled people and Financial Wellbeing, https://www.ipsos-mori.com/DownloadPublication/1583_sri-ews-scope-disabled-people-and-workplace-wellbeing-2013.pdf

Organisational commitment: The Financial Conduct Authority (FCA)

In September 2016, the FCA published its results following a review into the impact of Big Data in general insurance, specifically motor and home. This included looking at how Big Data may impact on how insurance products are priced for consumers – we are pleased that this involved a specific focus on the experiences of those deemed to be ‘non-standard’ risk, including disabled people.

The FCA took the decision to carry out a Call for Inputs (Cfi) for its work on Big Data, rather than a market study. A Cfi is a less intensive review than a market study – however, this has enabled the FCA to ascertain specific areas in relation to Big Data that would be worth exploring in more depth.

This Cfi looked at five years of application and quote data from two comparison websites, as well as data from a survey of 150 brokers serving disabled people, older consumers and ex-offenders. The findings indicate that Big Data does not currently adversely affect these consumer groups, which is positive.

Alongside this, the FCA earlier published a report on access to financial services. This considers in detail the challenges faced by disabled consumers in accessing affordable insurance.

Following the two pieces of work mentioned above, we are pleased that the FCA is keen to continue discussion on financial inclusion, including on the issue of access to insurance and extra costs for disabled people.

Digital inclusion for disabled people

Building upon the work of the Commission, Scope has been engaging with government on a number of issues relating to the extra costs of disability.

One of these areas is the digital exclusion experienced by disabled people – 25 percent of disabled adults have never used the internet compared to six percent of non-disabled adults.²³ The Commission identified that tackling this problem will require ensuring that digital platforms are fully accessible when disabled people are shopping online.

The Equality Act places an obligation on service providers to put in place reasonable adjustments to allow individuals to overcome barriers that would prevent them from accessing goods and services. Digital accessibility should be covered as an adjustment, but based upon the evidence gathered by the Commission into the difficulties faced by disabled people in using the internet, it is not clear what impact the Act has had in delivering improvements in this area.

²³ ONS (2016). Internet Users in the UK: 2016, <https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016>

The 2015 – 16 Lords review of the impact of the Equality Act²⁴ on disabled people has raised awareness of the digital divide between disabled people and non-disabled people. The Government's new digital strategy offers an opportunity to make the case further to address this.

Improving disabled people's experiences of taxi and PHV services

Another aspect of Scope's work has involved driving forward the Commission's recommendation to create a more equal service for disabled people when using taxis and PHVs.

It has been promising to see companies like Uber, alongside other taxi and PHV firms, consider disability awareness training for drivers and the provision of wheelchair accessible vehicles as part of the core service they offer.

Within government we have seen progress through the review of the Equality Act in relation to disabled people. Following the call for evidence, the review's final set of recommendations picked up several of the Commission's calls to government relating to taxis and PHVs. These included making compliance with the Equality Act and disability awareness training a condition of licensing, as well as increasing the number of wheelchair accessible vehicles.

It is positive that the Government has said that it will look further at these recommendations. In particular, the Department for Transport's Accessibility Action Plan, currently under development, is an opportunity to consider disabled people's experiences of using taxis and PHVs in more detail.

At the same time, Guide Dogs UK, as part of a wider coalition, has introduced a Private Members' Bill that would make disability awareness training compulsory for taxi and PHV drivers.

Key observations:

- Regulators and government have begun to recognise the issue of extra costs for disabled people. However, much more needs to be done to build upon this progress.
- Beyond insurance, taxis and PHVs and digital inclusion, there are other areas where interventions may be needed by government or regulators to help drive down additional costs.

We welcome the fact that some regulators and government departments have started to address some of the challenges faced by disabled people in relation to extra costs. It is essential that this progress is built upon. At the same time, it is important that we don't ignore other markets where action by government or regulators would help to tackle disability-related costs.

24 More information about this review can be found at <http://www.parliament.uk/equality-act-committee>

For instance, over 35 percent of fuel poor households contain a disabled person.²⁵ Another example is the specialised equipment market, where disabled people frequently told the Commission that there was a lack of choice when shopping for items of this sort.

A number of government departments and regulatory bodies should be involved in tackling extra costs, such as the Department for Business, Energy and Industrial Strategy and the Department for Transport.

The Office for Disability Issues - which sits within the Department for Work and Pensions - is well-placed to support this work through a more strategic focus on extra costs. Its remit is to support the development of policies to remove inequality between disabled people and non-disabled people, which would fit well with our mission to tackle the financial penalty experienced by disabled people.

Call to action: The Office for Disability Issues, working with market regulators, should ensure there is a cross-governmental approach to help tackle the range of extra costs faced by disabled people.

²⁵ Department of Energy and Climate Change (2015). Fuel poverty detailed tables: 2013. <https://www.gov.uk/government/statistics/fuel-poverty-detailed-tables-2013>

Conclusion

When the Commission started its inquiry in July 2014, we set out to achieve meaningful impact on driving down the extra costs faced by disabled people.

Since the publication of our final report last summer, we are immensely pleased to see a range of different organisations and individuals taking our recommendations forward. Disabled people and their families are demanding more as consumers, businesses are recognising the value of the 'purple pound', and more disability organisations are supporting disabled people and businesses in their efforts. There has also been an increased focus within government and amongst regulators on the issue of disability-related costs.

We would like to thank all those that have responded positively to our work so far, as well as all those that helped us develop our solutions for reducing additional costs.

In addition, we would like to thank the Barrow Cadbury Trust for their financial support for this project, as well as Scope up for setting up the Commission and providing the secretariat.

The Commission's work has now come to an end. But it is vital that the momentum is not lost. We are handing the baton over to Scope to take forward and develop the work of this inquiry. To support Scope, we call upon disabled people, disability organisations, businesses, regulators and government to work with the charity to address the problem of extra costs for disabled people.

Appendices

Appendix A

Disabled people and their families should be 'bold and loud' and build consumer power behind the 'purple pound'.

1. Disabled people should adopt the identity of disability positively to attract the interest of businesses.
2. Disabled people should share information about good deals and ways to reduce costs with other disabled people through online disability communities and forums.
3. Disabled people should demand more as consumers and speak out when companies or disability organisations do not fully meet their needs.

Disability organisations should improve information and services to disabled people and businesses to allow them to drive down the extra costs of disability.

4. Disability organisations should develop information resources and peer-to-peer platforms that have a greater focus on disabled people's needs as consumers.
5. A disability organisation should set up an affiliate scheme for disabled people to attract discounts and deals.
6. Disability organisations should develop and promote collective switching and group purchasing schemes for energy and insurance, and explore creating bulk purchasing schemes for clothing, bedding and specialised equipment.
7. Disability and consumer organisations should coordinate to strengthen the consumer voice of disabled people.
8. Disability organisations should support businesses to develop intelligence on the consumer needs and expectations of disabled people.

Businesses should improve the customer experience of disabled people and recognise the power of the ‘purple pound’.

9. Businesses should use data capture techniques and relationships with disability organisations to reach disabled people and learn more about their needs as consumers.
10. Businesses should improve website accessibility and use customer feedback from disabled people to improve service and address unmet need.
11. The insurance industry should make efforts to understand how the market is working for disabled people and take practical steps to support individuals who are unable to obtain affordable insurance.
12. Organisations representing businesses should develop incentives to influence businesses to reduce extra costs for disabled people.

Regulators and government should intervene where features of markets result in unfair extra costs for disabled people.

13. The UK Regulators Network, with disability organisations and the Competition and Markets Authority, should capture and act upon disabled people’s experiences across different regulated markets.
14. The Financial Conduct Authority should investigate whether disabled people and similar potentially under-served groups have access to insurance that fairly reflects risk.
15. The Government should review the impact of the Equality Act in improving web accessibility and take action when service providers fail to meet their obligations.
16. The Government should adopt the Law Commission proposals on taxis and private hire vehicles that support disabled people in obtaining a more equal and fairly-priced service.

Appendix B

A range of organisations committed to taking forward recommendations in the Commission's final report:



Recommendation 4: **Scope** will develop information and online community resources to include a specific focus on the needs of disabled people as consumers.



Recommendation 5: **Nimbus** plans to develop its Access Card to allow users to obtain discounts, offers and incentives from a wide range of service providers and retailers.



Recommendation 6: **Family Fund**, in conjunction with Family Fund Trading, will explore how it can build a partnership with a disability organisation to extend negotiated rates on essential products to disabled people, such as specialised equipment.



Recommendation 8: **Rica** will conduct research to further inform businesses about the needs of disabled consumers.



Recommendation 9: **Really Useful Stuff** will build relationships with strategic partners and use market data to extend its reach and proposition to disabled consumers.



Recommendation 12: **The Business Disability Forum** will develop a specific award targeted at businesses that have made a concerted effort to drive down extra costs for disabled consumers in 2016.



Recommendation 14: **The Financial Conduct Authority** is committed to further engagement with the disability sector during the scoping stage for its market study on big data and accessibility.

For more information on the Extra Costs Commission, please visit scope.org.uk/get-involved/campaigns/extra-costs-commission

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