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<b>Contents</b>	<b>Page</b>
<b>Executive summary and recommendations</b>	<b>4</b>
<b>1. Introduction</b>	<b>9</b>
<b>2. At greater risk of fuel poverty</b>	<b>12</b>
2.1 Poverty and disability	12
2.2 Fuel poverty	14
2.3 Housing factors	17
<b>3. Essential energy needs</b>	<b>19</b>
3.1 Mobility problems	19
3.2 Other conditions	21
3.3 Families with disabled children	25
3.4 Illustrations	27
<b>4. Benefits and fuel poverty</b>	<b>35</b>
4.1 Fuel poverty calculations	35
4.2 Impact of benefits changes	36
<b>5. Conclusions and recommendations</b>	<b>41</b>
<b>References</b>	<b>43</b>
Appendix 1: Organisations interviewed	46
Appendix 2: Sources for illustrations	47

## Executive summary and recommendations

Over 10 million people have a limiting long term illness, impairment or disability in Britain, including an estimated 0.8 million disabled children. Many are at high risk of fuel poverty with potentially serious implications for their health, well-being and quality of life. This situation is likely to worsen in future as a result of rising energy prices and changes in the benefits system. Consequently, policy-makers should take concerted action to tackle fuel poverty among disabled people as a matter of urgency.

It is critical for government and regulatory policies and suppliers' practices to be underpinned by a good understanding of the range of circumstances and needs of disabled people in relation to energy. There is substantial evidence which demonstrates the strong relationship between disability and poverty/low incomes, and the additional costs faced by many disabled people, including those related to people's energy needs. The range and nature of these additional energy needs form the prime focus of this report.

The study also challenges how disability benefits are currently treated in the measurement of fuel poverty and in other official income statistics. In addition, it highlights concerns about a number of changes taking place in the benefits system which are likely to have adverse effects for many disabled people, including the ability to afford essential energy use. The aim is to help achieve a better understanding of the energy needs of disabled people to help break the link between disability and fuel poverty.

### Focus and methodology

The prime focus of the study was on the energy needs of people with physical, cognitive and sensory impairments and of families with disabled children. Due to time constraints, it was not possible to explore people's housing circumstances in detail, although the study recognises the importance of energy efficient homes as among the prime drivers for tackling fuel poverty.

The research consisted of a literature review, followed by interviews with a selection of organisations and with some individuals nominated by those organisations, in order to put together an authentic picture of the range of people's circumstances and energy needs. The findings were also used to construct illustrative 'case studies' and to inform the recommendations.

### At greater risk of fuel poverty

The study explores the key factors which mean that many disabled people face significant difficulties in affording essential energy use and are at particular risk of fuel poverty. These include the well-evidenced links between disability and poverty/low income, and the additional costs arising from disability including essential extra energy needs.

### **Poverty and disability**

Households with at least one disabled person are more likely than other households to be in relative income poverty (on an after housing costs basis). Conversely, people with lower incomes are more likely to have a long-term limiting illness than those in better-off households. Equally, families with disabled children are at greater risk of poverty or low income.

As the study points out, the reasons for this include the fact that disabled people are less likely to have paid employment and, where people are in paid work, they are more likely to be on lower pay. For instance, people's ability to work can fluctuate due to changes in the effects of conditions or as a result of medical treatment, affecting their earnings levels or jeopardising their ability to keep a job. Some disabled people have to take part-time work which tends to be lower paid. In addition, discrimination continues to place obstacles in the way of many disabled people in securing employment. Other factors affecting many disabled people include having to rely on benefits which may well be inadequate for their needs.

### **Extra costs of disability**

As well as the likelihood of being on a low income or in poverty, many disabled people face additional costs in order to secure their health and safety and to ensure they have a reasonable quality of life.

These costs include travel as many disabled people have to use accessible cars or taxis. Other costs associated with disability include home adaptations, mobility equipment and communications aids. But there are numerous other costs which often do not receive sufficient attention. These can include the need for extra clothes as a result of wear and tear or because of sudden weight gains or losses. Other additional costs relate to laundry and bathing needs, and the use of electronic communications (which offer important means of communication and ways of shopping and accessing services). The study also notes that some people's finances are being affected by reductions in local authority help for social care costs.

### **Fuel poverty and disability**

Official figures show that households with someone with a disability or a long-term illness are at heightened risk of fuel poverty. The research evidence demonstrates that many disabled people face difficulties in affording adequate energy consumption to meet their needs, including having to cut down on heating because of money worries. The negative health impacts of fuel poverty are particularly likely to affect disabled people and those living with long term conditions, among others.

### **Disabled children and young people**

Research evidence also shows that disabled children and young people are at high risk of poverty and disadvantage. It is also important to note that the number of children experiencing disability is rising. Families with one or more disabled children are likely to experience extra costs compared to those with no disabled children, and face difficulties in affording fuel and other essential costs.

### **People with mental health problems**

The study draws attention to the risks of fuel poverty among people with mental health issues. Research also shows that adolescents living in fuel poor homes are at greater risk of multiple mental health problems.

### **Housing factors**

There is extensive evidence about the importance of the energy efficiency of housing stock as a causal factor of fuel poverty. Research also shows that disabled people, and families with disabled children, are more likely than non-disabled people to live in poor housing. A warm and dry home is crucially important for many disabled adults and children. The consequences of cold housing are numerous and include increased risks of arthritis and respiratory problems, heightened risks to people's immune systems, and potential delays in recovery following treatment.

Other research findings highlighted in the study show how living in a cold home can potentially harm infants' and children's development, and increase children's vulnerability to respiratory problems. Pressures on household finances - including the invidious 'choice' of heat or eat - may also affect disabled adults' and children's nutrition and immune systems.

### **Essential energy needs**

The study explores a range of ways in which disability is associated with additional energy use or, to put it another way, why the health and well-being of many disabled people may be at risk if they cannot afford adequate energy consumption to meet their needs. The conditions discussed are by no means comprehensive but serve to illustrate that substantial numbers of people have high or additional fuel needs. They include conditions such as cancer, multiple sclerosis, HIV, spinal injuries, dementia, and incontinence, as well as some which are frequently overlooked, such as skin conditions.

Some physical impairments or conditions have more obvious energy-related consequences, others less so. For example, people with mobility difficulties often have to spend considerable periods at home, which adds to heating and lighting costs. However, they - and other disabled people - may well also need a higher ambient temperature. The effects of medical treatment and/or poor circulation, for example, can also contribute to people feeling colder than they would otherwise, and result in the need for heating at night and/or during the summer. Such factors may be long-standing, episodic or unpredictable, depending on changes in people's health, responses to treatment and household circumstances. Also, many disabled people face multiple factors which impact on their energy needs, such as living in energy-inefficient housing.

There are many other additional energy costs which arise in connection with disability, long-term medical conditions and/or the effects of treatment. These can include, for example, additional heating requirements due to physical inactivity and longer periods spent at home, laundry costs because of needing to wash clothes and bed linen frequently; extra costs of cooking

because of dietary requirements or nutritional needs; having to use electrical aids and equipment; and needing to charge batteries for electric wheelchairs and mobility scooters.

The study shows that many families with disabled children face a range of additional energy needs. As well as the need for a warm home, additional heating may be essential at night and/or during summer months because of the child's condition and to safeguard their immune system. As with adults, extra costs can include additional laundry and drying costs, clothing, and aids and equipment, including dishwashers and washing machines.

It should also be noted that others, such as grandparents, have caring responsibilities for disabled children and are likely to face similar costs, a fact which is often overlooked. Carers themselves may be on a reduced income or have had to give up work to care for - or help care for - a disabled grandchild, for instance. At the same time, they may well face extra energy costs because of their own health needs.

## **Benefits and fuel poverty**

The study highlights concerns about the inclusion of disability benefits as income in the measurement of fuel poverty and in other official income statistics. This means that the prevalence of fuel poverty among disabled people is likely to be under-estimated, and it runs counter to the purpose of disability benefits which is to help meet additional costs of disability. For the same reason, it is logical to exclude disability benefits as income in other official poverty and income statistics.

The need for a better understanding of the circumstances and energy needs of disabled people is underscored by the fact that major changes are taking place in a number of welfare benefits. These are likely to lead to reductions in the numbers of disabled people qualifying for some benefits, and also to possible reductions in the amounts received where people do qualify. These changes increase the likelihood of disabled people experiencing fuel poverty.

## **Conclusion**

Many disabled people and families with disabled children are at significant risk of fuel poverty. Difficulties in affording essential energy needs can result in potentially serious consequences for disabled people's health and quality of life. Moreover, a number of benefit changes are being implemented which are likely to exacerbate people's difficulties in affording essential energy consumption. Together with rising energy prices, this combination of factors is likely to lead to a rise in fuel poverty among disabled people and families with disabled children. Consequently the extent and nature of disabled people's energy needs require proper understanding and recognition in policy-making as a matter of urgency.

## Recommendations

- The Government should set up a taskforce - including DECC, the Department of Health, the DWP and Ofgem together with disability organisations - with a clear and urgent brief to audit the ways in which current and projected policies are likely to affect disabled people's ability to afford essential energy services. The results should be published together with a comprehensive and coherent action plan.
- The DWP should lead an examination of the adequacy or otherwise of the nature and levels of financial support for disabled people and families with disabled children which takes proper account of the various additional or extra costs arising from disability, including additional energy needs and fuel costs. This should inform the Government's welfare reform programme.
- Until there are fundamental changes in the financial support provided to disabled people and families with disabled children to help with energy costs, the energy suppliers should ensure that their eligibility criteria for the Warm Homes Discount (WHD) broader group include households in receipt of the disability-related components of the relevant benefits set out in the WHD regulations.
- The Department of Energy and Climate Change (DECC) should change its approach to measuring fuel poverty in England so that disability benefits are excluded as income. Similarly disability benefits should be excluded as income in other official income and poverty statistics.
- Ofgem should publish guidance to energy suppliers and network companies to inform their understanding of the varied energy needs of disabled people and households with disabled children, and to help ensure that they meet disabled people's needs. Ofgem should monitor suppliers' compliance with the guidance and be prepared to take appropriate regulatory action if suppliers fail to comply. This would be a logical step for Ofgem to take within the context of its proposed Consumer Vulnerability Strategy.
- Energy suppliers should review their policies and practices to ensure that disabled people do not face unnecessary barriers in being able to access assistance and advice about energy bills and help with energy efficiency. This should be done in a co-ordinated way which involves the trade association, Energy UK, and a specialist disability rights advisor.

## 1. Introduction

This report sets out the findings of a research study for eaga Charitable Trust project on the energy needs of disabled people and families with disabled children.

The objectives of the study were to:

- Help to achieve a better understanding of the needs and circumstances of disabled people and families with disabled children in relation to energy
- Highlight the likely impact of changes in benefits affecting disabled people and how disability benefits are regarded in fuel poverty calculations
- Help to improve government policies and industry practices so that they better meet the needs of disabled people, many of whom are in or on the margins of fuel poverty.

### **Risks of fuel poverty**

Disabled people are at greater risk than non-disabled people of being on a low income and also of living in homes which are difficult to keep warm, both of which are widely accepted causes of fuel poverty. To compound matters, disabled people are likely to face additional financial pressures on top of everyday living needs, for example, to pay for accessible transport, dietary requirements, aids and equipment among many others.

Energy needs figure prominently in the essential additional costs which confront large numbers of disabled people and families with disabled children. The most obvious reason is the need to keep their home constantly warm, for example, due to physical and medical conditions or the side-effects of treatment.

However, the reasons why many disabled people have additional energy needs are far more varied than is often commonly understood. This report explores the nature of disabled people's energy needs and highlights some of the potentially serious consequences for their health and well-being if these needs are not adequately met.

### **Fuel poverty calculations and benefit changes**

The report also discusses the Government's plans for the way in which fuel poverty is measured in England, in particular, its intention to continue to include disability benefits, such as the current Disability Living Allowance (DLA), as income in the calculations. Unless this decision is reversed, this course of action will continue to result in under-estimates of the numbers of disabled people who are in fuel poverty. The policy also flies in the face of the intended purpose of disability benefits, which are aimed at meeting extra costs of disability, and should not therefore be treated as disposable income. The report also outlines a number of major benefit changes which are due to take effect in 2013. The consequences of these developments

are likely to be serious for many disabled people, including further straining the ability of households to afford to meet their essential energy needs.

### **Illustrations: household energy costs**

The report includes three illustrations which seek to show how households containing one or more disabled people can require more gas and/or electricity than other households. It is important to underline that the figures shown are intended to be purely illustrative in order to exemplify the potential extra amount. The situations and needs draw heavily from information obtained from the interviews for this research.

Making direct comparisons between households containing a disabled person and other households is a complex matter. In particular, this is because different physical impairments or medical conditions have different impacts on people's fuel requirements. For example, many people with arthritis or continence problems will need more hot water than people without these problems, while many with mobility and other problems are likely to need higher space heating consumption than people without these problems.

In addition, there is a wide range of ways in which disabled people seek to safeguard and improve their physical and mental health and quality of life. Some of this will derive from people's lives before the onset of disability. Others may arise from people's changed circumstances. For example, using IT equipment has become an integral part of people's lives in order to stay in touch and access services, while home entertainment such as games consoles may be vital to help people stay mentally or physically active.

There is also the potential impact on energy consumption arising from the use of equipment such as mobility scooters, stairlifts, communication aids, etc. Moreover, direct comparisons can be complicated further because of widely differing types of accommodation, including size of home, energy efficiency, location, access to mains gas, etc.

Bearing these caveats in mind, it is intended that the illustrations will help to exemplify some of the difficulties faced by disabled people and families with disabled children with regard to household energy consumption and bills. The sources and methods used for illustrations are explained in brief in the text, and listed in Appendix 2.

### **Focus and methodology**

Whilst the report outlines the broader context of fuel poverty, the prime focus is on the energy needs of people with physical, cognitive and sensory impairments and of families with disabled children. Where we refer to 'disabled people', the term is used as shorthand to cover households containing one or more disabled adults and/or disabled children. It should be noted that the underlying approach of this research rests on the social model of disability which takes account of how society is organised,

including external barriers. In contrast, the 'medical model' of disability focuses narrowly on what is 'wrong' with the person and not on their needs.

It is also important to note that, as a result of time constraints, it was not possible to explore people's housing circumstances in detail, although the importance of energy efficient homes is recognised in the report.

The study was based on a literature review which included, in particular, research material concerning the links between poverty/low income and disability, and the types of additional living costs faced by disabled people and families with disabled children including those related to energy needs. The initial findings from the review helped to inform subsequent interviews with a selection of organisations which advise disabled people and families with disabled children, and some individuals nominated by those organisations. These findings, plus additional material, were used to construct illustrative 'case studies'. The recommendations are based on the results of the literature review and the interviews.

## Outline of report

Chapter 2 sets out the links between disability and poverty/low income, the impact of the extra costs of disability on the ability of households to pay for energy bills, and the heightened risk of fuel poverty faced by many disabled people and families with disabled children, including factors associated with poor housing. Chapter 3 explores why many individuals and households have essential additional energy needs arising from disabilities and long-term medical conditions and side-effects of treatment in order to safeguard their health, safety and wellbeing. It also discusses the extra energy needs and extra costs faced by families with one or more disabled children.

Chapter 4 addresses the way in which certain disability benefits are treated for the purposes of measuring fuel poverty and more broadly in income statistics, as this issue is critical in ensuring accurate estimates of the numbers of disabled people in fuel poverty and more generally on low incomes. Chapter 4 also outlines a number of key changes in the benefits system which are likely to have significant consequences for many disabled people including the affordability of fuel bills. Conclusions and key recommendations follow in chapter 5. References are set out at the end of the report. Appendix 1 lists the organisations interviewed, and Appendix 2 lists the sources used for the illustrations.

## 2. At greater risk of fuel poverty

Disabled people and their families are in general at heightened risk of fuel poverty compared with non-disabled people. There are a number of often interlocking reasons for this. Firstly disabled people are more likely than many others to be in poverty or trying to get by on a low income, and are more likely to be living in poor housing. This combination of factors puts many at risk of experiencing fuel poverty. At the same time, disabled people frequently face additional costs of living arising from disability, including essential extra fuel costs (which are explored in detail in chapter 3).

### 2.1 Poverty and disability

Over 10 million people have a limiting long term illness, impairment or disability in Britain, including an estimated 0.8 million disabled children<sup>1</sup> (Office for Disability Issues, 2011a). However, other estimates put the total number at nearer 13 million depending on the definitions used. And, at any one time, 1 in 4 of the population experience mental health problems.

#### Low income levels

There is a substantial evidence base which shows that disabled people are at particular risk of experiencing poverty and low income. For example, 24% of people in families in the UK with at least one disabled member were in relative income poverty (on an after housing costs basis), compared to 20% of those in families with no disabled member (Department for Work and Pensions, 2012). Conversely, people with lower incomes are more likely to have a long-term limiting illness than those further up the income scale (Parekh et al, 2010, Laxton and Parckar 2009).

One of the key reasons is because disabled people are less likely to have paid employment and are more likely to be on lower pay than non-disabled people. For example, the employment rate gap between disabled and non-disabled people stood at 30% in 2012 (see Office for Disability Issues website reference).

Also, people's ability to work can fluctuate because of changes in the effects or severity of conditions such as cancer or multiple sclerosis (among many others) or as a result of medical treatment. This may mean that their earnings are unpredictable or lower than they would be otherwise, or that people are unable to find or keep a job because employers are reluctant to allow them to take time off.

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<sup>1</sup> This official estimate is described as covering the number of people with a longstanding illness, disability or infirmity and who have a significant difficulty with day-to-day activities.

For people of working age, disability generally ‘adds’ 30% to the likelihood of not being in employment, according to research for the Joseph Rowntree Foundation (Berthoud, 2007), which found that, for those who were disabled, the proportions not working were 46% for men and 53% for women. Among disabled lone parents, the proportion not in employment was 61%.

It is clear that many disabled people find it difficult to obtain paid employment in the first place. For those who have managed to get a paid job, job security may well be an issue. Some, for instance, have had to leave employment as a result of their condition or have to take unpaid leave because of periods of illness and/or treatment. This may well be accompanied by a decrease in savings (where people have managed to build up savings), and a concomitant rise in costs associated with disability or long-term medical conditions. At the same time, essential daily living costs such as rent and mortgage still need to be paid.

Furthermore, some disabled people have to take part-time work which tends to be lower paid. This may be because these are the only employment opportunities available. Other disabled people may well opt for part-time work because of fears that employers will not allow them time to go to medical appointments or take time off because their health fluctuates.

Discrimination among potential employers is another factor which continues to place barriers in the ability of many disabled people and those with long-standing medical conditions to secure employment. For instance, many people with HIV are especially vulnerable to experiencing precarious employment and fluctuations in income, for instance because of discrimination, loss of employment after diagnosis, or having to take long periods of sick leave.<sup>2</sup>

### **Extra costs of disability**

There is long-standing and extensive evidence showing that the additional costs of disability can be substantial (see, for example, Smith et al 2004; Chanfreau J and Burchardt T 2008). In addition, because of household budgetary constraints, estimates of potential extra costs may be higher than those of actual extra costs (Tibble 2008).

Many disabled people face extra costs that amount, on average, to approximately an extra quarter above normal expenditure compared to non-disabled people (Laxton and Parckar 2009). These include costs such as home adaptations, social care, mobility or communication aids. Interviewees emphasised how higher costs linked to disability routinely affect the amount of money that disabled people have available to pay for fuel and other essential bills. Transport costs are cited as a major factor. Many disabled people have to use accessible cars or taxis, which can add considerably to living costs.

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<sup>2</sup> According to interview findings.

Other additional costs can arise from the need to buy more clothes, for instance, as a result of wear and tear on clothing arising from particular conditions or impairments (for example, if people have to use prosthetics). Some conditions or medical treatments can result in people gaining or losing weight, again leading to the need to replace clothing.

Being able to prepare and cook food and other tasks, for example, is often critical for people's independence and self-worth, and also to enable them to keep active. Equipment such as larger fridges and freezers to store food may be a necessity not a luxury, for instance, if people have mobility problems and are unable to shop frequently. Similarly, equipment such as food processors may be essential if people have problems with poor dexterity or strength to chop food. Microwave ovens may be needed if people have difficulties in lifting kettles and other kitchen equipment.

Being online is becoming increasingly important to participate in society, and it can offer a vital means of communication and information for many disabled people. Also, shopping online is very important for many people who have mobility problems or those who have difficulties in carrying shopping or pushing a trolley. Again this helps to enhance people's independence. Moreover, there is growing pressure from government for people to use online methods to claim benefits and access services. However, being online adds another set of costs to everyday living.

Another increasingly significant factor which affects household finances stems from reductions in help available with social care costs (Scope et al 2013). As a result of local authority reductions in the extent of help available and tightening of eligibility criteria, more and more people are likely to have to try to fund their care needs in part or in full. In addition, family members may have to give up work to provide informal care, which has knock-on effects on household income.

Similarly, families with disabled children are at greater risk of poverty or low income. Going without essentials and getting into debt to pay for food, heating and clothes is the norm for most families with disabled children according to a Contact A Family survey (2012). 17% of families surveyed reported going without food, 21% go without heating, while 29% have taken out a loan to help pay for food and heating. Many parent carers consequently suffer from stress, from depression, anxiety, and guilt for not being able to provide enough and having nowhere to turn to.

## **2.2 Fuel poverty**

Throughout the period 2003 to 2010, households containing someone with a disability or a long-term illness had a higher rate of fuel poverty than other households (20% compared with 15%) according to the latest fuel poverty statistics (Department of Energy and Climate Change, 2012a). Other official survey findings show that households in Britain with at least one person with an impairment were less able to keep their home warm, compared with

households without anyone with an impairment (12% and 7% respectively (Office for Disability Issues, 2011b).

34% of fuel poor households contain someone with a disability, according to the final report of the Hills review (2012). However, it is crucial to note that official fuel poverty statistics are currently based on disability benefits being counted as income in these calculations. Figures on fuel poverty rates would be higher for disabled people if these benefits were not treated as income, as recommended in the Hills report (2012); we discuss this issue further in chapter 4.

The Hills Report (2012) also pointed out that the people most likely to experience particularly negative health impacts of fuel poverty are older people, infants, disabled people and those living with long term sickness. The problem is underlined by other findings. For example, households where at least one person had an impairment were less able to keep their home warm (12%) compared with households with no-one with impairments (Office for National Statistics, 2010a). Electricity and gas topped the list of areas where disabled people feel they spend a lot more than non-disabled people according to a Demos study (Wood C and Grant E, 2011).

For instance, nearly 1 in 5 people living with cancer reported that they had to turn the heating off over winter due to money worries, and 6 out of 10 people with cancer had to use more fuel since their cancer diagnosis (Macmillan Cancer Support 2009). Recent Macmillan research showed that around 27,000 cancer patients in the UK could be behind with paying their fuel bills and owe their fuel providers as much as £2.8 million in overdue payments (see Macmillan Cancer Support website reference).

It is also important to note that there are an estimated 6.4 million people in the UK providing unpaid care and support to friends and relatives, many of whom are in financial difficulties and at risk of fuel poverty. A Carers UK survey of over 4,000 carers found that 54% were in fuel poverty, needing to spend more than 10% of their incomes on heating bills (Carers UK undated). Many carers are forced to give up work to care, at the same time as they are faced with the considerable additional costs of disability, as Carers UK points out. Over 45% of those surveyed reported that they were cutting back on essentials like heating or food.

Other research confirms that people with a physical health condition were significantly more likely to have reduced their use of domestic fuel in the past year due to worry about cost than those without a physical health complaint (Harris J et al, 2010). According to this study nearly half of disabled people experienced at least one of the aspects of fuel related poverty.

### **Families with disabled children**

As with disabled adults, disabled children and young people experience higher levels of poverty and personal and social disadvantage than other children.

There are 770,000 disabled children under the age of 16 in the UK, or 1 in 20 children (Papworth Trust, 2011). Furthermore, the number of children experiencing disability is increasing, for example, as a result of medical advances at ante natal and neonatal stages.

The annual cost of bringing up a disabled child is three times greater than for a non-disabled child, and 29% of households with a disabled child live in poverty compared to 21% of households with no disabled children. (See Papworth Trust website reference)

According to an analysis of the Family Resource Survey (which includes data on a relatively large number of children and young people age 0-18), disabled children were more likely to live with low-income, deprivation, debt and poor housing than their non-disabled counterparts. This was particularly the case for disabled children from black/minority ethnic/mixed parentage groups and lone-parent households. Childhood disability was also associated with lone parenthood and parental disability. The study also found that disabled children were more likely to live with disabled siblings than non-disabled children, and also there was a relatively high prevalence of parental disability among parents of disabled children (Blackburn et al, 2011).

Families with disabled children were more likely than other families to report not being able to afford items and activities they wanted or needed, according to the above analysis. The study also concluded that being behind with payments for electricity, gas, council tax, water and telephone bills were the most commonly reported sources of debt.

### **People with mental health problems**

Fuel poverty is also commonly associated with mental health issues. For example 10% of people with common mental disorders are not able to keep their home warm enough in winter, compared with 3% of people without mental health problems. They are over twice as likely as others to under-consume fuel as a result of cost worries. And they are three times more likely than others to be seriously behind in paying for gas and electricity bills and/or being disconnected in the past 12 months (Harris et al 2010).

It should be noted that adolescents living in fuel poor homes in Northern Ireland are at significantly greater risk for multiple mental health problems when other contributory factors have been accounted for - an intriguing and worrying research finding (Liddell, Save the Children 2008). There is no reason to suppose that this does not apply to other young people in fuel poor homes elsewhere in the UK.

## 2.3 Housing factors

Disabled people's housing conditions, including of course their energy efficiency, are clearly of major importance in terms of the risk of fuel poverty and the risks to people's health, safety and well-being arising from cold and/or damp conditions.

As the Hills report (2012) pointed out, the energy efficiency rating of a property is a clear factor in driving high costs. It also emphasised that the risk of fuel poverty is affected not only by the thermal efficiency of buildings but also by the structure's ability to be adequately ventilated. In addition buildings without mains gas heating are generally much more expensive to heat due to the high costs of alternative fuels, such as electricity, heating oil, solid fuel and LPG.

There is also the issue of whether people are able to choose how best to secure space and water heating (typically accounting for 60% of energy consumption). For example rented or leased accommodation may incorporate only one main form of heating (except for, expensive, use of supplementary heaters). Furthermore, the choice of energy supplier may be in the hands of a freeholder, landlord or managing agent rather than the consumer.

As research by the Papworth Trust shows, disabled people are more likely than non-disabled people to live in poor housing, and there is a clear shortage of housing that is specifically designed to meet disabled people's needs (see Papworth Trust website reference).

According to a forthcoming analysis of the English Housing Survey for eaga CT, fuel poverty rates are highest in the private rented sector among households containing someone who is disabled or ill (35%-36% depending on the indicator used, using the basic income definition, that is excluding income related to housing such as housing benefit). Similarly the same research shows that, within owner occupiers, rates of fuel poverty are higher amongst households containing a member who is disabled or ill compared to households with no disabled or ill members (Thomson, Snell, and Bevan, forthcoming).

In addition, families with a disabled child are less likely to be living in a decent home compared to families with a non-disabled child (Beresford and Rhodes 2008). Those with a disabled child are 50% more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair, and to report problems with wiring, draughts and damp in the child's bedroom. Compared to other groups of disabled people, disabled children requiring specifically adapted homes are the least likely to be living in suitable accommodation.

Living in a cold home can potentially harm infants' and children's development, as pointed out in research on fuel poverty and children

(Liddell 2008). The more calories needed to keep warm, the fewer are available for growth and building a healthy immune system. In addition, the 'heat or eat' pressure on parents' finances is likely to affect children's nutrition and potentially affect their immune system. Children are also especially vulnerable to respiratory problems if they live in cold conditions.

Moreover, adolescents living in fuel poor homes are at significantly greater risk of multiple mental health problems when other contributory factors have been accounted for, according to the same research. One reason for this is that, where heating is limited to family rooms, this can limit teenagers' privacy and personal space, putting a strain on family relationships and causing them to spend more time in public places where they may be at greater risk (Liddell 2008).

### **Conclusion**

There is a substantial evidence base which shows that disabled people are at particular risk of experiencing poverty and low income. Moreover, many disabled people face extra costs which significantly restrict the amount they have available to pay for fuel and other essential utility bills. In addition, disabled people and families with disabled children face a high risk of living in poor housing. Consequently it is clear that households with one or more disabled members are at greater risk of being in or on the margins of fuel poverty than other households.

### 3. Essential energy needs

There is a wide and varied range of factors which result in many disabled people and families with disabled children having increased essential need for energy consumption compared to others in the population.

A warm home is crucially important for adults and children with physical impairments. As the Marmot review (2011) points out, chronic conditions may lower body metabolism so the body generates less heat, while stroke, Parkinson's disease and dementia restrict activity, slowing body heat generation and conservation. The consequences of cold housing highlighted in the report are many and include delays in recovery following hospital discharge. Also, for example, cold damp homes increase the risk of arthritic symptoms and, in general, a cold house increases the risk of falls in elderly people.

A more detailed explanation of how various conditions can affect people's energy needs follows. It is not an exhaustive list but does cover many of the most common conditions. The following findings are based on both material from the literature review and from information obtained through the interviews.

#### 3.1 Mobility problems

Many millions of people experience mobility problems to a greater or lesser extent. There is a plethora of conditions and impairments which can lead to reduced mobility, in the home and outside. With respect to energy use the primary impact is on space heating because, for most people, immobility or relative immobility leads to a lowering of metabolic rate (slowing body heat generation) and to a consequent need for a higher ambient temperature.

In addition, mobility problems are likely to increase the amount of time spent indoors. Moreover, lack of accessible or affordable transport often serves to restrict the ability of disabled adults and children to travel much and may render them effectively 'housebound'. For example, 74% of adults with physical impairments experienced restrictions in using transport compared with 58% of adults without impairments (Office for National Statistics 2010a).

##### **Arthritis**

One of the most common causes of mobility problems is arthritis, which affects 10 million people to a greater or lesser degree (see Arthritis Care website reference). A survey by Arthritis Care of people with osteoarthritis found that 81% of respondents experienced constant pain or were limited in their scope to perform everyday tasks. For some, the condition fluctuates and, when their arthritis is bad, 69% of those interviewed had difficulty carrying out daily household tasks and 53% struggled to get out of bed (Arthritis Care, 2012). Having a warm bath, soaking hands in hot water, etc.

are recommended as a way of self-managing the condition, which may well increase people's energy costs.

### **Back pain**

Chronic, fluctuating or episodic back pain is also a common cause of mobility problems and hence additional energy needs. Main causes include occupational injuries and strains, excess weight, and decrease in bone density. In addition, it can be associated with or result from other conditions such as multiple sclerosis.

### **Fibromyalgia**

Fibromyalgia causes widespread pain and extreme tiredness, and can affect people's mobility. People with fibromyalgia may also have difficulty sleeping, experiencing irritable bowel syndrome, and muscle stiffness. It is estimated that In England and Wales, there could be up to 1.8 million adults with the condition. Some people with ME can experience similar effects.

### **Cerebral palsy**

In the UK, cerebral palsy (CP) affects about one in every 400 children. CP is an umbrella term for permanent disorders of the development of movement and posture. Common features include muscle weaknesses and stiffness (and consequent fatigue), involuntary and uncontrollable muscle tone fluctuations, speech problems, tremors and balance problems. Some people with CP experience visual or hearing problems. CP can obviously affect people's mobility.

### **Stroke**

Every year an estimated 150,000 people in the UK have a stroke. The effects can reduce mobility as a result of paralysis, fatigue, poor balance, and spasticity. In addition some people's mobility can be reduced as a result of visual impairment, or cognitive or emotional problems. Some may also experience continence problems.

### **Dementia**

Dementias are another set of conditions which can restrict activity and mobility, slowing body heat generation and conservation (see, for example, Alzheimers Society: 'The later stages of dementia'). About 800,000 people in the UK are estimated to have some form of dementia and the number is expected to double over the next 40 years (see Alzheimer's Society website reference).

As well as memory problems, difficulties encountered by people with dementia can include incontinence which will increase household use of energy for laundry etc. Also people with dementia may feel the need to walk repeatedly around the house, or get up and leave the house at any time during the day or night. Relatives and carers need to decide what level of risk is acceptable in order to maintain the person's quality of life and independence. In some instances, it may well result in a carer spending more time at home in order to help the person with dementia to feel and be

safe, again with potential consequences for increased energy consumption, for instance, for additional lighting and heating.

## **3.2 Other conditions**

### **Cancer**

More than one in three people will develop some form of cancer during their lifetime. People with cancer often find that the condition and/or medical treatments can make them less active, affect their appetite, making them feel the cold more. Night sweats as a result of treatment and poor circulation can also contribute to people feeling colder than they would otherwise. For these kinds of reasons, heating may well need to be on all night and/or during summer months. Spending more time at home during treatment or recovery also contributes to higher electricity and gas bills for heating and lighting.

Treatments such as chemotherapy and radiotherapy can weaken the immune system, making it easier to get an infection and harder to fight it. Living in cold or damp conditions can therefore be highly detrimental to people's well-being and ability to recover. Additional energy costs also arise because people may need to wash clothes and bed-linen frequently, for example, because of night sweats or sickness. As with many other conditions, people's energy needs may fluctuate due to changes in their physical condition or treatment. Worries about paying for fuel bills often add to what may be a very stressful situation, including periods when people are in remission from cancer.

And, alongside many other disabled people and those with long-term conditions, people with cancer are likely to have additional energy needs in order to be online and to have access to other communications services such as radio and TV. These services are often vital to people's quality of life, to reduce isolation and enable them to be in touch, and to have access to information, entertainment and services. For instance, online shopping can be an important service for people who have internet access and who are unable to go out to shops and want to keep their independence.

### **HIV**

In 2011, an estimated 96,000 people in the UK were living with HIV (see Terrence Higgins Trust website reference). Although the circumstances and energy needs of people with HIV vary - as with other people - there are specific factors that often result in additional energy needs arising from people's medical condition and also from the side-effects of medication. Moreover, people with HIV may have multiple factors which affect their energy needs, such as hepatitis or arthritis (as is the case for some people with other long-term conditions).

For example, having to spend more time at home due to mobility difficulties will add to energy costs. Also people may well need to ensure a constant level of warmth at home, which may also be necessary during the summer

period. Problems with immune systems mean that people with HIV are especially vulnerable to infections, and keeping warm is essential for people's physical health. Ensuring a good level of nutrition can often play a critical role as well in protecting people's immune system. Cooking fresh food may be essential but also adds to energy and other bills.

Extra laundry costs frequently arise because of single or double incontinence, for example, or as a result of night sweats associated with the side-effects of medication.

Another factor to consider is that more people with HIV are living into older age and are especially at risk of fuel poverty. Some may have been unemployed for long periods, and/or cashed in their occupational or private pension to cover their living costs, and are now struggling on low incomes. At the same time, they may be experiencing isolation, traumas and psychological problems which are likely to make it difficult to cope with energy bills.

### **Multiple sclerosis (MS)**

It is estimated that there are currently around 100,000 people with MS in the UK. People with MS may well require a constant temperature at home which is appropriate to their needs and does not cause them to become too hot or cold, as their symptoms may otherwise worsen. Similarly the use of equipment such as electric fans may be essential to enable people to maintain the right body temperature.

The condition can often reduce people's dexterity which may well mean they need to use electrical products routinely, for example to chop food. The need to charge other equipment such as electric wheelchair and scooter batteries, or to power electric hoists for example, can also boost their energy costs.

Good heating and hot water controls are essential for some as MS can severely reduce the sensation of heat and cold on the skin and result in the possibility of burns. Without adequate controls, people may end up 'wasting' hot and cold water in order to ensure that bath temperature is safe.

Other factors which are likely to increase people's energy needs include the need to be online in order to stay in touch, order shopping, and to access services etc. if people with MS have to spend more time at home. Devices such as games consoles can also play an important part in helping people with MS (and some other conditions/disabilities), and these can boost electricity consumption. Similarly, alongside many other people with physical impairments, the use of telecare devices is becoming an important feature of life for some people with MS (such as personal alarms, health monitoring devices, motion sensors which detect falls, etc.).

It is also important to note that MS is frequently unpredictable and the effects often fluctuate. At times people may need to use significant

amounts of energy, especially during periods when they may be housebound. Uncertainty about how the condition may change often makes it very difficult for people to manage their energy consumption and budget well.

### **Incontinence**

Continence problems are common. One in four people will have a problem with bladder control at some time, and one in ten will have problems with bowel control. Continence problems may be permanent or of limited duration, they may fluctuate, and they can also be progressive.

There is a wide range of conditions and causes, the Bladder and Bowel Foundation and the NHS identify the following (among others): urge incontinence (overactive bladder) which can be caused by diabetes, infection, bladder stones, neurological conditions (such as multiple sclerosis), Alzheimer's disease and spinal injury, and prostate problems. Stress incontinence is often associated with the consequences of childbirth and menopause; and bowel incontinence can be caused by neurological disorders, such as multiple sclerosis, spinal injury and tearing after childbirth.

Those experiencing incontinence are more likely than others to have additional washing requirements for clothes and bedding, baths and showers, which increases energy required for heating water and running appliances. In some circumstances people may spend more time at home as a result of incontinence, again leading to additional energy costs.

### **Skin conditions**

More than 15 million people have or are at risk of experiencing skin conditions, which are often overlooked as a factor which affects people's lives and their energy needs. Surveys suggest that around 54% of the UK population experience a skin condition in a given twelve month period, and nearly 13 million people go to GPs with a skin problem each year in England and Wales.

Skin conditions can lead to extra costs and also lower income. For example, some chronic skin conditions such as hand eczema may be associated with unemployment and resultant financial hardship (Finlay and Coles 1995, Meding et al 2005), whilst some people may experience prolonged periods when they are unable to work leading to financial costs. Many people with long-term skin conditions require care from family or paid carers.

Common skin conditions include:

Dermatitis & Eczema: contact dermatitis affects 9% of the UK population and is the most common type of work-related skin disease. Atopic eczema is the most common form of eczema in general. There are other types, such as gravitational eczema which is common later in life, particularly in women with poor circulation, those who have had a blood clot in their legs, and those with varicose veins. Some skin conditions are caused by or related to

allergy, and allergies themselves can result from a wide variety of environmental factors.

Other skin conditions include: impetigo, which is common in babies and children but which can affect anyone; psoriasis, which affects 2% of people in the UK; ringworm, which is common in children but which can affect anyone; vitiligo, which is experienced by one in 100 people in the UK, and of course acne, which is a common problem, affecting up to 8 in 10 people between the ages of 11 and 30.

Most forms of treatment involve keeping the skin moisturised using emollients (medical moisturisers) or barrier creams, with topical steroids commonly used to bring flare ups under control. This is likely to lead to increased laundry costs due to the need to wash clothes and bedding very frequently. In addition, damaged skin is vulnerable to infection, and people are advised to help keep skin clean by taking a regular bath or shower and by using emollients before and after (University of Nottingham 2009).

### **Sensory impairment**

Sensory impairments, particularly sight impairment which affects around 2 million people, can reduce mobility and lead to people being in their own home for longer periods. It may also be harder for people to use controls such as for central heating, and to read meters or other information about their energy consumption.

### **Spinal injury**

In a survey on heating the home, 97% of people with spinal injuries said they needed extra heating to help manage their condition and ensure they remain healthy (Spinal Injuries Association, 2010a). Just over a quarter said they had suffered health problems in the last 5 years because they could not afford to heat their home adequately.

Problems included pneumonia; aggravated arthritis; colds and flu; and circulation and cardiovascular problems. Over half of respondents said they had difficulty paying their fuel bills and had to turn heating systems down or off and/or go without family and social activities. 12.5% said they had to go without food. (As this was an internet survey, the percentages facing such difficulties are probably even higher among those without internet access who are more likely to be on low incomes.)

These difficulties are exacerbated by the fact that, as with many other people with physical impairments, those with spinal cord injuries (SCI) are likely to face additional energy costs such as:

- Electricity consumption to charge wheelchairs and electric hoists
- Increased gas or electricity heating costs. Many people with a SCI have limited or no body temperature control and are therefore very susceptible to temperature fluctuations (it is generally recommended

that people with SCI maintain their home environment at around 22 degrees Celsius)

- Higher vehicle fuel costs due to usage of a vehicle for an increased number of short journeys
- Increased water and electricity bills to cover the additional laundry costs arising from double incontinence.

### **Parkinson's**

One person in every 500 has Parkinson's: about 127,000 people in the UK (Parkinson's UK website). Most people who get Parkinson's are aged 50 or over but younger people can get it as well: 1 in 20 are under the age of 40. The main symptoms of Parkinson's are tremor, rigidity and slowness of movement. These are clearly likely to restrict people's mobility, leading to additional heating and lighting costs because of more time spent at home. Limited dexterity may well add further to people's energy costs, for example, because of the need for particular equipment or aids to carry out personal or household tasks.

Over half of interviewees in a survey of people with Parkinson's reported having additional spending requirements due to the condition, including additional costs of heating and laundry (Parkinson's Society 2008). As well as affecting movement, other issues, such as tiredness, pain, depression and constipation, can have an affect on people's lives, and make it more difficult to cope with energy bills or engage with the energy market.

### **3.3 Families with disabled children**

There are some 770,000 disabled children and young people in this country, and one third of disabled children live in lone parent households. Disabled children in the UK are more likely than non-disabled children to live in rented accommodation. 55% of families with disabled children are living in or at the margins of poverty. Parents of disabled children can spend up to twice as much on items as parents of non-disabled children. Lone parents are more likely than others to have no earned income, or be in semi-skilled or unskilled occupations (Papworth Trust 2011).

Cerebral palsy (CP) is one of the most common physical disabilities in childhood, and those with CP often have related problems including learning difficulties, incontinence, visual and/or hearing impairment, communication difficulties, scoliosis, and drooling. Autistic Spectrum Disorders are also relatively common, affecting about one in 100 children. Apart from communication and cognitive difficulties, children on this spectrum may experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

The energy needs of families with one or more disabled children obviously vary, for example because of the child's condition and possible effects of treatment, household income and home energy efficiency levels (as with other families). The factors which are likely to affect fuel needs and costs

include the basic need for a warm home. This may also require heating the home at night and/or during summer months because of the child's medical condition and treatment, such as the effects of chemotherapy, and the need to protect the child's immune system from infections.

Extra laundry and drying costs often arise because of the need to wash and dry clothes and bedding frequently, for example, because of sickness, incontinence, eating difficulties, skin disorders such as skin blisters, and allergies. Separate washes may be needed if children require specialist clothing and/or bedding. Also, some children may have to change clothes very frequently during the day because of medical conditions or psychological needs.

Washing machines are often vital if a family can afford them, including tumble driers, and the running costs add to electricity bills. Dishwashers are often essential because mealtimes may take 2 or 3 hours and parents may not have time to wash up. It should be noted that having a quiet washing machine may be crucial because of sensory overload for autistic children, but they are often more expensive than other types or older machines. Also dishwashers can be essential if equipment, crockery and cutlery need to be sterilised.

Families with one or more disabled children are likely to be under financial and psychological stress, and often lack opportunities to have breaks and go on holiday. They are often firefighting to access education, medical services and support. Also, parents/carers are frequently on low incomes because they have had to give up work to care for their child or take up part-time jobs which tend to be lower paid.

Families are often in poverty and also frequently face barriers in finding out information, for instance, because of severe pressures on time, exhaustion and stress. Lack of sleep is a big issue for many parents. For example, parents may have to stay up during the night because of a child's medical or psychological needs. Worries and anxiety over a child's medical condition, management of treatment and prognosis, as well as possibly concern over the effects on siblings, can also add to people's stress and to demands on their time. This is clearly likely to restrict people's desire or ability or spend time comparing energy deals or switching suppliers for example.

It emerged during the interviews for this research that grandparents may also face similar problems and costs, which are often overlooked. They may be caring directly for disabled grandchildren and/or their adult children. This may arise possibly because a parent died, or cannot cope because of the complexity of a child's needs and income pressures, or the parents themselves may have a medical condition or physical or cognitive impairment.

Grandparents may be on a reduced income or have had to give up work to care for a disabled grandchild. At the same time, they may well need to ensure they can afford a warm home because of their own health needs.

Grandparents in this situation often find it hard to find out about and access help and support.

### **3.4 Illustrations**

The following illustrations were constructed using a combination of published material (for example, data on energy consumption) and interview material. They are intended solely to exemplify why additional energy can be required for disabled people's health and wellbeing.

#### **Illustration 1: older person, with arthritis**

Mrs A is an older person on her own, with circulatory problems and severe arthritis in her hands and other joints, especially her knees. She also has some sight impairment, due to age-related macular degeneration. She lives in a 1930s two-bedroom detached bungalow in a suburb, which she and her late husband bought many years ago. Care workers visit twice a day and she has meals-on-wheels once a day. Her daughter is over 200 miles away and she has no close relatives nearby.

She cannot get on the bus to go into town but a neighbour helps with shopping once or twice a week. Mrs A does what she can to keep the bungalow clean and in good order but she cannot tackle many domestic tasks which she used to take for granted (hence the care workers who, for instance, help with laundry).

Although her daughter has suggested that she replaces her old gas central heating boiler, gets her windows double-glazed, and the loft properly insulated, she has resisted because of concerns about the upheaval and mess. She is also worried about the cost but is embarrassed to mention this. A few years ago she did get some lightbulbs replaced with low energy compact fluorescents, but went back to the old bulbs because they weren't bright enough: she is very worried about having a fall as a result of inadequate lighting. She is on a Standard Credit tariff for gas and electricity.

Due to her restricted mobility she feels the cold and, when she gets cold, the arthritis gets worse. As for heating, the radiators in her living room, kitchen, bathroom and bedroom are on all the time. When the weather gets colder, her neighbour turns on the other radiators because the bungalow easily gets cold without them on (she finds it hard to do so herself). Her doctor advised that the heating should be turned up to reach 21-23 degrees. Even so, in cold weather she often has her fan heater on for a while in the sitting room, especially during the long evenings.

According to Which?, the typical cost of space heating and hot water for a bungalow with an older gas boiler stands at about £960 per annum (pa) (see Which? website reference).

- It is assumed that her space heating consumption is a little higher than Which?'s typical estimate, perhaps by 10% i.e. £1,056 per annum.
- Her fan heater for additional use costs in the region of 24p per hour to run, assuming that it is used for an average of 4 hours per day during the coldest four months of the year: the total cost would be £17 a year.
- As for lighting, it seems reasonable to suppose that a 100W and a 60W bulb would be on in the sitting room for some 6 hours per day, a 60W bulb in the hall for 12 hours per day (i.e. including the hours of darkness), a 60W bulb in the bedroom for 3 hours a day, a 100W bulb in the bathroom for 2 hours per day, and a 100W bulb in the kitchen for 4 hours a day. Over the course of a year this would amount to some £130.
- Heating her daily chilled lunch using the microwave would cost £34 a year. Using the electric hob to heat up a light tea every evening would cost perhaps £40 pa, and using the kettle 4-5 times a day would add another £20 a year. In addition, most mornings she makes toast - her toaster costs some £6 pa. These add up to £100 pa.
- Her dishwasher is used every other day, costing about £20 a year.
- Her fridge-freezer costs about £40 pa.
- Her carers fill and empty the washing machine every other day, so fuel costs are some £11 pa. She still tries to do the ironing, which costs about £15 a year. These add up to £26pa.
- Her LCD TV and her Freeview digibox, or DAB radio, are on for about 12 hours each day, costing around £90 a year.
- She uses a power shower every morning (not least because the hot water reduces the stiffness in her joints). The shower itself is rated at 4kW and costs around £21 a year to run.

(Not included in the above: use of vacuum cleaner, main oven, tumble drier, additional use of immersion heater in cold weather, hi-fi, ICT.)

**On this basis her annual energy bills are about £1,500, or £30 a week.**

#### **By comparison**

A widow in the same position but without arthritis and any significant sight impairment would be likely to face lower energy costs.

She does not have significant mobility problems; she can shop and cook. She is able to maintain a social life; she can do normal housework, and she has low-consumption lighting and finds it adequate. As a result she is out of the house for a number of hours about five days a week on average, and manages to visit and stay with her daughter for a break for about four weeks a year. She keeps warm by using the central heating system when needed and very seldom uses supplementary heating.

So what might her energy consumption (and bills) be?

- As she has a new gas boiler, it might be reasonable to assume that she uses a little less than Which?'s estimate for space heating and hot water, perhaps 15% or so less, which would result in annual cost of £815.
- Energy consumption per low-consumption bulb is about 15% that of an incandescent light and, assuming no difference in usage between her and her disabled counterpart, her lighting bill would reduce to about £20 per annum.
- It would be reasonable to assume that she would do about the same amount of cooking in general but, as she may have some meals outside the home, the cooking costs would probably be reduced to around £70pa instead of £100 a year.
- There is no reason to suppose that use of the dishwasher, fridge-freezer, washing machine and iron is any different to that of her non-disabled counterpart (with the exception of her visits away from home) which would then amount to some £77pa. For the same reason her use of the TV/digibox and radio would be likely to cost a little less, some £80pa.
- It is assumed that use of the power shower is similar to that of her non-disabled counterpart.

On this basis her annual energy bills are £1,080 a year, or £20-£21 a week.

*\*Consequently the extra costs of disability amount to some £420 a year, or an additional £9-£10 a week.*

### **Illustration 2: Lone parent with two disabled children**

Ms B is a lone parent with two disabled children. Her 9 year old daughter has cerebral palsy, and her 7 year old son is on the autistic spectrum. She has a part-time job and receives some benefits (e.g. Child Tax Credit, Working Tax Credit, Housing Benefit). They live in privately rented accommodation which is poorly ventilated and insulated. The children need separate bedrooms because her son can be hyperactive at night, and her daughter suffers from incontinence and is prone to asthma attacks. Both children are in school but often only on a part-time basis.

She manages financially - just. However, despite some help from relatives, she cannot afford to buy many of the 'normal' things that other children have which is very upsetting, and this includes any sort of holiday beyond the odd day outing. She is currently very worried about the financial impact of forthcoming changes in the benefits system. For example new housing benefit rules assume that children of their age should share a bedroom (any household deemed to have more bedrooms than required will lose 14% of their housing benefit for one extra room<sup>3</sup>).

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<sup>3</sup> Under the provisions of the Welfare Reform Act 2012.

In terms of fuel costs she has to spend more because of her daughter's incontinence (to wash clothes and bed-linen frequently), while her son's 'clumsiness' results in many spillages and lots of clearing up and mopping. She has to keep the flat warm, primarily because of her daughter's asthma, and she keeps more lights on at night for the sake of the children's safety. The TV stays on for many hours each day, on a low volume, not least because it helps to calm her son (and, to some extent, it masks noises from adjacent flats, which can seriously disturb him). She is not online as she's worried about the possible costs.

The flat has a conventional gas boiler serving wall-mounted radiators in all five living rooms (kitchen, sitting room, three bedrooms). On average, this is on for 16 hours a day during the coldest six months, and 8 hours during the rest of the year. It is on most days. The boiler also provides hot water; here too essential usage is likely to be substantial, and is supplemented by an immersion heater.

According to Which?'s 2012 guide (see sources) the heating and hot water demands of a three-bedroom, semi-detached, well-insulated house are £947 a year.

- Due to more extensive usage of the boiler and the fact that the flat is poorly insulated, it is not unreasonable to assume that the annual costs would be at least 15% more than the Which? estimate, namely some £1,100 a year.
- She has to use a supplementary low cost halogen heater whenever the day and/or night temperature is particularly low. If this is on for 3 hours for some 60 days a year, the resulting electricity consumption would cost £66pa.
- With regard to lighting, it would be reasonable to assume that a 100W and a 60W bulb would be on in the sitting room for some 6 hours per day, a 60W bulb in the hall for 12 hours per day, a 60W bulb in both bedrooms for 8 hours a day, a 100W bulb in the bathroom for 2 hours per day, and a 100W bulb in the kitchen for 4 hours a day. Over the course of a year this would amount to some £118.
- As for heating up food, using a microwave twice each day would cost around £68 a year. Using a gas hob 3-4 times a day would cost some £40 a year. Using the kettle 6 times a day for hot drinks would add another £24pa. Using the toaster 2-3 times a day would cost some £15 a year. In total, heating food and drink would cost £147pa.
- Her dishwasher is used every other day, costing £20 a year.
- The fridge-freezer costs her about £40 pa.
- She has to use the washing machine every day, so fuel costs are some £22 pa. The ironing costs about £15 a year.
- Her LCD TV and Freeview digibox are on for about 18 hours each day on average, and cost around £135 a year.
- Every day the bath and shower are used at least 3 times, requiring the immersion heater to be on for two hours daily, which would cost £105pa.

**On this basis her annual energy bills are £1,633 a year or £31 a week.**

**By comparison:**

A lone parent with two non-disabled children of the same age would:

- Spend at least a third less on space heating (newish boiler and the children are out of the home more, and they need lower ambient temperatures during day and night) i.e. £737pa
- Use only 40% of the total lighting as the children are out more for example, namely £47pa
- Probably use about the same energy consumption to prepare food and drink, i.e. £147pa
- Use the dishwasher and fridge-freezer to the same extent, namely £60pa
- Be able to reduce use of the washing machine by about a third, reducing the cost to £15, but possibly use the iron by the same amount (about £15 a year)
- Probably have the LCD TV and Freeview digibox on for no more than about 6 hours a day, costing around £45pa
- Use the immersion heater occasionally, reducing the cost to, say, £20pa

**On this basis her annual energy bills are £1,086 a year or £20.90 a week.**

***Consequently the extra costs of disability amount to some £547 a year, or an additional £10 a week.***

**Illustration 3: Couple in their early 40s, he is disabled**

Mr and Mrs Smith live in a 3-bedroom 1930s house, they have one grown up son who lives elsewhere. Until two years ago they both had reasonably well-paid jobs but then Mr Smith had a rugby accident (he played as an amateur for many years) which resulted in a spinal cord injury (SCI). This caused paralysis of his legs and affected other functions.

He returned home after hospital and a period in rehabilitation but in the meantime he had to give up the idea of resuming his job, and his wife (as his main carer) had to find part-time work. In addition, they had to arrange for the installation of a specialised downstairs bathroom, and to have the living room converted into a bedroom, which was quite costly. He uses a manual wheelchair for indoor use and a mobility scooter outdoors, both of which they bought. Apart from the sudden onset of severe physical problems, both had to face up to major changes in many aspects of their lives, and experience emotional stresses and strains. In particular Mr Smith is now prone to depression.

They had previously installed a condensing boiler, double glazing, loft insulation, low energy bulbs, and had bought the most efficient fridge-

freezer (A++) they could find, and used a gas hob and gas oven. On the other hand, the household's energy needs have now increased, not only because they both now spend a lot more time at home than previously. This is because like a number of people with spinal injuries (SCI) he is doubly incontinent. Similarly, like most in this position, he can no longer properly regulate his body temperature (the ability to constrict blood vessels and other autonomic functions which aid the body's temperature regulation are all affected by SCI).

Many conventional methods of keeping warm such as electric blankets and hot water bottles are not recommended due to the risk of burns and thermal injuries that may result from the body's lack of sensation. Therefore they were recommended by doctors to keep their home at a minimum temperature of 22 degrees. Otherwise significant health problems could ensue, such as frostbite, pneumonia, circulation and cardiovascular problems, brittle bones, and swelling of the legs.

Mr Smith was persuaded by his 20 year-old son to use the PC more and to try out some Xbox-based sports games. He found these to be mentally stimulating and they have helped him to maintain and develop hand dexterity. However, some games consoles do consume a significant amount of electricity.

- As indicated in previous illustrations, the typical heating and hot water demands of a three-bedroom, semi-detached, well-insulated house amount to £947 a year or, with a condensing boiler, £770 per annum.
- Bearing in mind the additional hours spent in the home, the need to maintain a steady and reasonably high ambient temperature, and extra hot water/washing needs, it is reasonable to add some 25%, taking the annual heating bill to £962pa.
- While the amount of lighting required is also likely to be higher, their low energy bulbs help. As with the previous illustration it would be reasonable to suppose that the low-energy equivalent of a 100W and a 60W bulb would be on in the sitting room for some 6 hours per day, a 60W bulb in the hall for 12 hours per day, a 60W bulb in both bedrooms for 8 hours a day, a 100W bulb in the bathroom for 2 hours per day, and a 100W bulb in the kitchen for 4 hours a day. Over the course of a year this would amount to some £17pa.
- As for heating up food, using a microwave twice each day and the gas oven every other day would cost around £55 a year. Using a gas hob 3-4 times a day would cost some £40 a year. Using the kettle 6 times a day for hot drinks would add another £24pa. In total, heating food and drink would cost £119pa.
- The TV and PC stay on for many hours each day, the former (a fairly small plasma TV) costs around £100pa, the latter typically uses 3.2 kilowatts per day (8 hour daily usage, rest on standby) and would cost around the same. So these cost about £200 a year. Added to this the

Xbox is used on average 5 hrs per day for 300 days a year, which costs £198 per annum.

- Their energy efficient fridge-freezer costs about £20pa to run, about the same as the dishwasher (every other day), and daily use of the washing machine and iron run to £35pa.

(Not included in the above: other possible likely additional costs such as charging the scooter battery.)

**On this basis their annual energy bills are £1,570 a year or just over £30 per week.**

### **By comparison**

If his injury and subsequent changes to their lives had not occurred:

- It is likely that they would have been at home for fewer hours each day with lower space heating and hot water requirements; it would be reasonable to assume that the heating cost would be reduced to some £770pa.
- Similarly, the amount of lighting required would be perhaps 60% less, namely £10 a year. Food preparation is likely to be less, possibly by about the same amount, resulting in costs of £71pa.
- TV and PC use would be likely to be less, perhaps by as much as half during the course of a year, bringing the cost down to £100. In addition it is reasonable to take games consoles out of the equation.
- Finally, while use of the fridge-freezer and dishwasher is unlikely to be any different (namely £40pa), use of the washing machine and iron might be about a third lower, costing £25pa.

**On this basis their annual energy bills would be about £1,016 a year or £19.54 a week.**

***Consequently the extra costs of disability amount to some £554 a year, or an additional £10.46 a week.***

### **Conclusion**

There is a wide span of factors which result in many disabled people, including families with disabled children, having increased essential need for energy consumption compared to others in the population. These include:

- Needing to use additional lighting and heating because of spending considerable periods at home
- Needing to heat more rooms than would otherwise be the case (e.g. two young disabled children, each of whom has to have a bedroom)
- Needing to maintain constant high temperatures in one or more rooms, and for substantial periods during the day (or the night) and during summer periods

- Needing access to additional heating (e.g. use of supplementary heating in the living room for substantial periods)
- Living in poorly-insulated and/or damp housing
- Needing additional hot water for baths and showers
- Additional use of washing machines and/or driers for clothes and laundry
- Having to use other domestic equipment such as dishwashers
- Needing to use communications and entertainment devices such as TVs, computers and games consoles to stay in touch and keep actively engaged
- Needing to charge electric wheelchairs or mobility scooters, and use gadgets, alarms, telecare and other aids and equipment in the home and outside.

It is also vital to take account of the potentially considerable psychological, physical and emotional strains and pressures which affect many disabled people, families with disabled children and carers. This combination of factors has serious implications for people's ability to afford energy bills, consume adequate amounts of energy for their needs, and to engage with the energy market.

## 4. Benefits and fuel poverty

Firstly, we consider the way in which the Government's assessment of fuel poverty is affected by its assumptions about Disability Living Allowance (and its successor). We then highlight changes taking place in the benefits system which will affect large numbers of disabled people, and are likely therefore to increase the prevalence of fuel poverty among disabled individuals and households.

### 4.1 Fuel poverty calculations

Disability Living Allowance (DLA) is currently counted as income in official calculations of income involved in determining fuel poverty figures, and the Government is proposing that DLA and Attendance Allowance should continue to be included in this calculation (DECC 2012b).

However, the Hills review of how fuel poverty is measured in England had concluded that DLA should be excluded from assessments of household income:

*“Our starting point is that removing DLA from the income calculation would be appropriate, reflecting more general arguments about the way in which its inclusion leads to understatement of the proportion of disabled people who have low incomes.”*

(Hills 2012, op cit)

At the time of writing, we are awaiting the Government's final proposals on changes to the way in which fuel poverty is measured in England. However there is a convincing argument for removing disability benefits from income calculations for measuring fuel poverty. Disability benefits are intended to cover additional costs associated with disability which impact on disabled people over and above everyday living costs. It is also illogical to treat disability benefits as 'disposable income' for fuel poverty calculations as they are excluded from income assessment when calculating entitlement to means-tested benefits (Consumer Focus 2012).

Similarly Macmillan Cancer Support (2011) noted that DLA is not considered as income in social care assessments, as well as for means-tested benefits. The organisation also highlighted how, if income is not considered before DLA, it could distort the numbers of disabled people who are seen to be living in fuel poverty, with undesirable outcomes in terms of whether support is targeted at disabled people. And, in its latest annual report, the Fuel Poverty Advisory Group (2012) has set out concerns that the inclusion of disability benefits such as DLA in the income calculation makes it look as if those households in receipt of disability benefits are on higher incomes, and excludes more of them from the fuel poverty calculation.

Forthcoming research based on a secondary data analysis of the 2010 to 2011 English Housing Survey (EHS) confirms that the way in which disability

benefits are treated in the calculation of fuel poverty is likely to underestimate levels of fuel poverty amongst disabled people (Thomson, Snell, and Bevan, forthcoming). For example, this research shows that the effect of the inclusion of DLA as income in fuel poverty calculations is particularly pronounced among very low income households containing a disabled person. Here, if income is adjusted by the removal of DLA, the 43% of households containing a disabled person who are below the poverty line<sup>4</sup>, and in fuel poverty would be very likely to increase. On the basic income definition (that is excluding income related to housing such as housing benefit) this figure increases to 56.4%.

In addition, as Consumer Focus pointed out (2012), disability benefits are not adequate for covering the additional fuel costs that many households containing a disabled person face, notwithstanding whether they are adequate for covering other disability costs.

The Government currently includes disability benefits as income in other mainstream income statistics. Consumer Focus has recommended that all income and fuel poverty statistics should therefore be reformed to exclude disability benefits, rather than fuel poverty statistics alone (Consumer Focus 2012). We support this recommendation which reflects the fact that disability benefits are intended to cover additional costs experienced by disabled people, and should not therefore be treated as income which is available to meet everyday costs of living.

## 4.2 Impact of benefits changes

Many disabled people have been under increasing financial pressure as a result of benefit changes over the last few years, even before other changes take effect this year. These include, for example, the abolition of incapacity benefit and its replacement by Employment and Support Allowance (ESA), and capping the rate at which a number of benefits are uprated below the rate of inflation. It is also worth noting that disabled people under pension age do not currently qualify for winter fuel payments. At the same time, many disabled people and families with disabled children are having to fund all or part of their social care needs due to cuts in help by local authorities and/or narrowing of eligibility criteria.

Findings from Demos research (Wood 2011) chart the cumulative effects for a number of families including disabled people and carers of cuts in benefit rates and reductions in local services over the last couple of years. Financial losses, growing isolation, and increasing strains on people's mental health have clear repercussions for the ability of households with disabled members to cope with the costs of energy bills and other essential services. Some of the participants in the Demos research reported having to choose between fuel and food, to cancel hospital appointments as they were unable to afford travel costs, and to let their houses fall into disrepair.

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<sup>4</sup> This is commonly accepted as below 60 per cent median household income.

We outline below a number of the critical changes that are due to take place in welfare benefits and some of the key implications for disabled people. This is not a comprehensive list - it is intended to indicate some of the scale and scope of the planned changes which are likely to impact on many disabled people and their families.

### **Impending benefit changes**

#### April 2013

- Local council tax support will replace council tax benefit - there are concerns that some hard-pressed local authorities are likely to reduce the help provided to pay for council tax.
- Community care grants and crisis loans for general living expenses (including rent in advance) will be abolished and replaced by new local provision. Again there are concerns about possible reductions in support by some local authorities.
- There will be a total benefits cap applying to many benefits for working-age households, of £500 per week for couples and lone parents, and £350 per week for single adults. Although the caps do not apply to households receiving Disability Living Allowance, many disabled people do not receive DLA and are reliant on other benefits.
- Personal Independence Payments will begin to replace DLA for new claims in parts of the north of England; there are serious concerns that new eligibility criteria will penalise some disabled people.

#### June 2013

Personal Independence Payments will be introduced nationwide to replace DLA for new claims.

#### October 2013

Universal Credit will begin to be rolled out from then to 2017. One of the purposes of UC is to rein in the total costs of a wide range of benefits and tax credits.

(see for example, Hardest Hit Campaign 2012)

### **Disability Living Allowance (DLA)**

DLA is due to start to be replaced by Personal Independence Payment (PIP) in April 2013 for people with a health condition or disability aged between 16 and 64. There will be two components, mobility and daily living, which will be paid at two different rates.

The reasons given by the Government for this change is *'that the complexity and subjectivity of the benefit [DLA] has led to a wider application than originally intended'* and the numbers of people qualifying need to be reduced in order for the benefit to be *'sustainable and affordable'* and focused on those who *'need the greatest help to live independently'* (Department for Work and Pensions, 2010a).

According to the most recent estimates (in a House of Commons Library briefing), the change will mean that, by 2018, around 607,000 fewer people will receive PIP than would have got DLA, which equates to a 28% reduction in the caseload and a cut in spending of 27% by 2018 (Kennedy 2013).

According to a group of national disability organisations and advice agencies (Scope et al 2012), this cut could well see those who face particularly high barriers and disability costs, which are not captured by a medical assessment process, lose out on a vital lifeline of support and be pushed further into poverty as a result. These organisations also describe the planned assessment process for PIP as not fit for purpose as the approach is highly medical (focusing solely on an individual's needs arising from physical impairment, without sufficient consideration of the social model of disability (which instead takes account of external barriers arising from social, practical and environmental factors)).

At present about two-thirds of DLA recipients qualify for an 'indefinite' award which means that their impairment/ medical condition is not expected to improve. Under PIP, regular reassessments will be part of the system except for those with a terminal diagnosis.

Recent survey research by the Hardest Hit Consortium of disability organisations (2012) demonstrates the importance of DLA for many people to help meet the hidden extra costs of disability. For example, respondents reported that they often spent more on heating their homes especially in winter, and people were well aware of the help that DLA gives in helping to meet their energy bills.

Nine in ten people surveyed in the above research reported that their everyday living costs are significantly higher because of their illness or disability. According to one of the research participants quoted in the report: *'I've got a pre-pay meter in my flat, and it's really expensive. I always wear lots of layers at home - sometimes I even sit and watch television with my coat on - just to avoid having to put the central heating on.'* Household equipment was identified as an extra cost for many, with washing machines in particular identified as being in almost constant use by several people (Hardest Hit Consortium 2012). Similarly, 68% of respondents in a Disability Alliance survey highlighted how their DLA helps with heating/laundry bills (Disability Benefits Consortium, undated).

### **Universal credit**

The Government intends that universal credit will replace all income-related benefits and tax credits for people on a low income.

Disability organisations have voiced very strong concerns about the effects of the introduction of universal credit. For example, in future, cuts to the child disability additions and the severe disability premium as a result of universal credit are likely to lead to disabled people and their families struggling to pay for basic essentials such as food and heating, according to

research by Citizens Advice, The Children's Society and Disability Rights UK (2012). This analysis estimates that:

- 100,000 disabled children stand to lose up to £28 a week
- 230,000 severely disabled people who do not have another adult to assist them could receive between £28 and £58 a week less than currently
- Up to 116,000 disabled people who work could be at risk of losing around £40 per week.

In a survey carried out for the above research, among those eligible for the severe disability premium, 83% said a reduction in benefit levels would mean they would have to cut back on food and 80% said they would have to cut the amount they spent on heating.

As Citizens Advice has highlighted, at present there is no equivalent of the severe disability premium within the elements of universal credit, which is intended to help with the additional costs of disability for those without someone to assist them (Citizens Advice 2013). Once Universal Credit has been fully implemented, severely disabled people with no adult to assist them, and who are eligible for the limited capability for work element, will be entitled to about £58 less a week than in the current system and even the most disabled adults entitled to the 'limited capability for work related activity' element will be entitled to £28 less a week than in the current system, according to CA's analysis.

#### **Housing benefit and help with council tax**

From April 2013, council tenants and housing association tenants under pension age will have their housing benefit entitlement reduced if the council decides that their home is large for their needs, described as the under-occupancy rule, or 'bedroom tax'. The amount of rent used to calculate how much housing benefit someone is entitled to will be cut by a fixed percentage. People will not be able to claim housing benefit for rooms above this limit that are used for disabled adults, for example, or a separate bedroom needed because of illness. Some disabled adults living in adapted or specially designed properties will face cuts in their benefits but it may not be practical or affordable for them to move. (See for example, Shelter website reference).

In addition, council tax support will replace council tax benefit, council tax discounts, exemptions and reductions in April 2013. Local authorities will set their own rules to suit the needs of their local area, and will decide which groups of people to help. Some rules will still be set by the UK Government, including help for pensioners. In particular, many working age people on benefits will be affected.

#### **Other financial support: Warm Homes Discount**

The Warm Homes Discount (WHD) is a statutory scheme in Britain to help some 'vulnerable' energy consumers with electricity bills through rebates

from suppliers (financed by energy consumers in general rather than taxpayers). In addition to the Core Group of eligible customers, suppliers are required to provide an annual rebate to a wider group of customers who are fuel poor or in a group at risk of fuel poverty: 'the Broader Group'.

Eligibility for the Broader Group is determined by the suppliers based on the framework set out in the Warm Homes Discount Regulations, which give a predefined list of benefits which suppliers may use for their eligibility criteria. Ofgem must approve the use of these predetermined criteria; or suppliers may opt to use their own Broader Group eligibility criteria on condition of approval from Ofgem.

Note that the predefined list of benefits currently set out in the regulations consists of income support and disability premiums but they do not include receipt of disability benefits.

### **Conclusion**

The extent of fuel poverty among disabled people is likely to be underestimated, in particular, due to the inclusion of disability benefits such as DLA as income. This policy does not reflect the purpose of disability benefits which is to help meet the additional costs borne by disabled people on top of everyday living costs. For this reason it is also logical that disability benefits should be excluded in all other official statistics regarding poverty and income levels as well as in fuel poverty calculations. More broadly, the effects of benefit cuts which have taken place in recent years, together with impending changes in benefit structures and levels, give rise to deep concerns about the impact on many households with disabled members, including their ability to afford essential energy consumption.

## 5. Conclusions and recommendations

Many disabled people and families with disabled children are faced with a combination of being in poverty or on a low income, living in poor housing and of facing additional essential costs of living, including energy costs. Consequently, they are at significant risk of fuel poverty, as the research evidence shows. These linkages and their potential impact on people's health and well-being are profoundly important and merit far greater attention by policy-makers and the energy industry. Failure to do so serves to compound the financial and other difficulties faced by large numbers of disabled people and places at risk people's health and quality of life.

The research shows that the energy needs of disabled people are affected by a range of factors which are likely to lead to additional essential energy consumption, including the need for heating and lighting if people spend a considerable amount of time at home. The choice of 'heat or eat' faces an increasing number of people in the population who are struggling with their energy bills. This 'choice' is especially stark for disabled people whose health, safety and well-being may be severely jeopardised if they cannot afford essential energy use to meet their needs. In addition, this situation is likely to be contributing to significant extra costs for the NHS and social care services.

As well as heating and lighting, many other factors impact on household energy use which relate to disabled people's physical and mental health needs, as this report explores. These factors may be long-standing in nature or fluctuate over time, depending on changes in people's health, responses to treatment and household circumstances. Many disabled people face multiple factors which impact on their energy needs. This subject therefore merits far more comprehensive and in-depth attention in policy-making and research than has been the case so far.

Moreover, at the broad policy level, there is little coherence about the ways in which the income levels of disabled people are measured, notably how disability benefits are treated in calculations of income in fuel poverty figures and other official statistics. The inclusion of these benefits as income goes against their intended purpose which is to help meet the additional costs of disability, not everyday living costs. Whilst official figures show that many disabled people are in fuel poverty, these numbers are likely to be even higher than officially estimated once disability benefits are excluded as income, which should be the case.

At the same time a number of benefit changes are due to be implemented which will in practice impact negatively on many disabled individuals and households, compounding their financial difficulties and ability to afford essential energy consumption. Taken together with rising energy prices, the inevitable result will be a rise in fuel poverty and an ever-strengthening link between disability and fuel poverty unless urgent action is taken - see recommendations below.

## Recommendations

- A taskforce should be set up - including DECC, the Department of Health, the DWP and Ofgem together with disability organisations - with a clear and urgent brief to audit the ways in which current and projected policies are likely to impact on disabled people's ability to afford essential energy use. The results should be published together with a comprehensive and coherent action plan.
- The DWP should lead an examination of the adequacy or otherwise of the nature and levels of financial support for disabled people and families with disabled children which takes proper account of the various additional or extra costs arising from disability, including additional energy needs and fuel costs.
- The Department of Energy and Climate Change (DECC) should change its approach to measuring fuel poverty in England so that disability benefits are excluded as income. Similarly disability benefits should be excluded as income in official income and poverty statistics.
- Ofgem should publish guidance to energy suppliers and network companies to inform their understanding of the varied energy needs of disabled people and households with disabled children, and to help improve company policies and practices. Ofgem should monitor suppliers' compliance with the guidance and be prepared to take appropriate regulatory action if suppliers fail to comply. This would be a logical step for Ofgem to take within the context of its proposed Consumer Vulnerability Strategy.
- Energy suppliers should ensure that their eligibility criteria for the broader group category within the Warm Homes Discount are sufficiently comprehensive to include disabled people and households with disabled children.
- Energy suppliers should review their policies and practices to ensure that disabled people do not face unnecessary barriers in being able to access assistance and advice about energy bills and help with energy efficiency. This should be done in a co-ordinated way which involves the trade association, Energy UK.

## References

- Action Against Allergy  
[http://www.actionagainstallergy.co.uk/index.php?option=com\\_content&view=article&id=105&Itemid=524](http://www.actionagainstallergy.co.uk/index.php?option=com_content&view=article&id=105&Itemid=524) accessed 30.2.13
- Aldridge et al, *Monitoring poverty and social exclusion 2011*, New Policy Institute and the Joseph Rowntree Foundation.
- Alzheimer's Society: <http://www.alzheimers.org.uk/infographic>  
Accessed 4.2.13
- Arthritis Care: <http://www.arthritiscare.org.uk/AboutArthritis> website  
accessed 12.11.13
- Arthritis Care, *OANation 2012*:  
<http://www.arthritiscare.org.uk/LivingwithArthritis/oanation-2012>
- Alzheimers Society, *The later stages of dementia*,  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=101](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101)
- Berthoud R (2007) *Work-rich and Work-poor, Three decades of change*, Joseph Rowntree Foundation
- Beresford B and with Rhodes D (2008) *Housing and disabled children*, Joseph Rowntree Foundation
- Blackburn C M et al (2011) *Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey*, BMC Pediatrics 2010, 10:21.
- Bladder and Bowel Foundation:  
<http://www.bladderandbowelfoundation.org/about/about.asp>  
accessed 19.7.12
- British Skin Foundation: <http://www.britishskinfoundation.org.uk>  
accessed
- Carers UK (undated) *The Cost of Caring: How money worries are pushing carers to breaking point*
- Chanfreau J and Burchardt T (2008) *Equivalence scales: rationales, uses and assumptions*
- Citizens Advice Bureau (2013) *Briefing: House of Commons First Delegated Legislation Committee 11 February 2013*
- Citizens Advice Bureau, Disability Rights UK and The Children's Society (2012) *Holes in the safety net: The impact of Universal Credit on disabled people and their families*
- Consumer Focus (2012) *Consumer Focus response to DECC consultation on fuel poverty measurement*
- Contact a Family (2012) *Counting the Costs*
- Department for Communities and Local Government (2012) *English Housing Survey: Household Report 2010-11*
- Department of Energy and Climate Change (2012a) *Annual Report on Fuel Poverty Statistics*
- Department of Energy and Climate Change (2012b) *Fuel Poverty: changing the framework for measurement*
- Department for Work and Pensions (2012) *Households Below Average Income An analysis of the income distribution 1994/95 - 2010/11 United Kingdom*

Department for Work and Pensions (2013) *EXPLANATORY MEMORANDUM TO THE SOCIAL SECURITY (PERSONAL INDEPENDENCE PAYMENT) REGULATIONS 2013*

Disability Benefits Consortium (undated) *Benefiting disabled people?*

Fuel Poverty Advisory Group for England (2012) *Tenth Annual Report 2011-12*

Hardest Hit Coalition (2012) *The Tipping Point: The human and economic costs of cutting disabled people's support*

Harris J et al (2010) *Health, mental health and housing conditions in England*, National Centre for Social Research and eaga Charitable Trust.

Hills J Professor (2012) *Getting the measure of fuel poverty Final Report of the Fuel Poverty Review*, Hills J, CASE and Department of Energy and Climate Change.

Kennedy S (28 January 2013) *Draft Social Security (Personal Independence Payment) Regulations 2013*, House of Commons Library

Laxton C and Parckar G (2009) *Fuel poverty and disability*, Leonard Cheshire Disability.

Leonard Cheshire Disability (2008) *Disability Poverty in the UK*

Liddell C (2008) *The impact of Fuel Poverty on Children*, Save the Children

Macmillan Cancer Support (2011) *Hills Fuel Poverty Review 2011 -*

*Macmillan Cancer Support response to Interim Findings*

Macmillan Cancer Support: [www.macmillan.org.uk](http://www.macmillan.org.uk)

[www.macmillan.org.uk/Aboutus/News/Latest\\_News/Macmillanrespondstorieinnumberofpeopleunabletopayfuelbills.aspx](http://www.macmillan.org.uk/Aboutus/News/Latest_News/Macmillanrespondstorieinnumberofpeopleunabletopayfuelbills.aspx) accessed 19.7.12

[http://www.macmillan.org.uk/Aboutus/News/Latest\\_News/Newyearseseedramaticfuelbillhighforcancerpatients.aspx](http://www.macmillan.org.uk/Aboutus/News/Latest_News/Newyearseseedramaticfuelbillhighforcancerpatients.aspx) accessed 28.1.13

Marmot Review Team (2011) *The Health Impacts of Cold Homes and Fuel Poverty*, Friends of the Earth. **Check publisher and author**

Morris J *Rethinking disability policy Viewpoint* (2011) Joseph Rowntree Foundation

MS Trust: **check ref**

<http://www.mstrust.org.uk/information/publications/factsheets/bowel.jsp>

National Eczema Society

<http://www.eczema.org/> accessed

NHS Choices

<http://www.nhs.uk/Livewell/skin/Pages/Commonconditions.aspx>

<http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Introduction.aspx>

<http://www.nhs.uk/Livewell/incontinence/Pages/Breakingthetaboo.aspx>

NHS Livewell

<http://www.nhs.uk/Livewell/incontinence/Pages/Breakingthetaboo.aspx>

Office for Disability Issues (2011a) *Disability prevalence estimates 2009/10*.

Office for National Statistics (2010a) *Life Opportunities Survey - Interim Results 2009/10*, Office for National Statistics

Office for Disability Issues (2011b) *Life Opportunities Survey Wave one results, 2009/11*

Office for Disability Issues:

<http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#imp> accessed 6.2.13

Parekh A, MacInnes T and Kenway P (2010) *Monitoring poverty and social exclusion 2010*, New Policy Institute and the Joseph Rowntree Foundation.

Parkinson's Society (2008) *Life with Parkinson's today - room for improvement*

Papworth Trust, *Disability in the United Kingdom 2010*  
[http://www.papworth.org.uk/downloads/disabilityfactsandfigures2010\\_100202152740.pdf](http://www.papworth.org.uk/downloads/disabilityfactsandfigures2010_100202152740.pdf)  
[http://www.papworth.org.uk/page.php?urlid=children\\_disability\\_and\\_poverty](http://www.papworth.org.uk/page.php?urlid=children_disability_and_poverty)

Scope et al (2012) *The Future of PIP: a social model-based Approach*

Scope et al (2013) *The other care crisis: Making social care funding work for disabled adults in England*

Scope: <http://www.scope.org.uk/help-and-information/cerebral-palsy/further-info-on-cp>

Shelter:  
[http://england.shelter.org.uk/get\\_advice/paying\\_for\\_a\\_home/council\\_tax/council\\_tax\\_support#2](http://england.shelter.org.uk/get_advice/paying_for_a_home/council_tax/council_tax_support#2), accessed 30.1.13

Smith N, Middleton S, Ashton-Brooks K, Cox L and Dobson B (2004) *Disabled people's costs of living More than you would think*, Joseph Rowntree Foundation

Spinal Injuries Association (2010a) *Heating Your Home (internet) Survey Final Report*.

Spinal Injuries Association (undated) *Spinal Injuries Association response to Disability Living Allowance Reform - a consultation by the Department for Work and Pensions*

Stroke Association: <http://www.stroke.org.uk/about/common-problems>

Centre of Evidence Based Dermatology (2009) *Skin Conditions in the UK: a Health Care Needs Assessment*, University of Nottingham

Thomson T, Snell C and Bevan M (forthcoming) *Fuel Poverty and Disability: a statistical analysis of the English Housing Survey*, Department of Social Policy and Social Work and the Centre for Housing Policy, University of York

Tibble M (2005) *Working Paper No 21 Review of existing research on the extra costs of disability*, Department for Work and Pensions

Wood C and Grant E (2010) *Counting the Cost*, Demos

Wood C (2012) *DESTINATION UNKNOWN:SUMMER 2012*, Demos

## **Appendix 1:**

### **Organisations interviewed**

Bowel and Bladder Foundation  
Disability Rights UK  
Family Fund  
Macmillan Cancer Support  
Mental Health North East  
MS Society  
Parkinson's UK  
RNIB  
Scope  
Spinal Injuries Association  
Terrence Higgins Trust

## Appendix 2

### Illustrations: key sources of information on consumption and costs

Centre for Sustainable Energy

[http://www.cse.org.uk/downloads/file/advice\\_leaflet\\_room\\_heaters.pdf](http://www.cse.org.uk/downloads/file/advice_leaflet_room_heaters.pdf)

[http://www.cse.org.uk/downloads/file/advice\\_leaflet\\_what\\_uses\\_watt.pdf](http://www.cse.org.uk/downloads/file/advice_leaflet_what_uses_watt.pdf)

<http://www.bbc.co.uk/news/uk-england-devon-19544952>

Blackburn et al. BMC Pediatrics 2010, 10:21, see

[www.biomedcentral.com/1471-2431/10/21](http://www.biomedcentral.com/1471-2431/10/21)

[http://wrap.warwick.ac.uk/3202/1/WRAP\\_Blackburn\\_Prevalence\\_childhood\\_disability.pdf](http://wrap.warwick.ac.uk/3202/1/WRAP_Blackburn_Prevalence_childhood_disability.pdf)

<http://www.carbonfootprint.com/energyconsumption.html>

<http://www.confusedaboutenergy.co.uk/index.php/domestic-fuels/fuel-prices>

<http://www.energysavingtrust.org.uk/In-your-home/Water>

<http://www.energysavingtrust.org.uk/scotland/In-your-home/Water>

[http://www.papworth.org.uk/downloads/disabilityfactsandfigures2010\\_100202152740.pdf](http://www.papworth.org.uk/downloads/disabilityfactsandfigures2010_100202152740.pdf)

National Autistic Society

Which?

<http://www.which.co.uk/energy/creating-an-energy-saving-home/guides/home-heating-systems/gas-central-heating/>

Spinal Injuries Association, in evidence provided to the Energy and Climate Change Committee, 2010 (see

[http://www.spinal.co.uk/userfiles/SIAs\\_evidence\\_on\\_fuel\\_poverty\\_to\\_energy\\_and\\_climate\\_change\\_committee\\_3\\_.pdf](http://www.spinal.co.uk/userfiles/SIAs_evidence_on_fuel_poverty_to_energy_and_climate_change_committee_3_.pdf)

Estimate of incidence from Aspire, the SCI support charity, see

<http://www.aspire.org.uk/>

<http://ecogeek.org/efficiency/3376-wii-crushes-other-game-consoles-in-energy-efficiency/>

Which?

<http://www.which.co.uk/energy/creating-an-energy-saving-home/guides/home-heating-systems/gas-central-heating/>

<http://www.parkgateit.co.uk/articles/computer-power-consumption.html>

<http://www.which.co.uk/home-and-garden/heating-water-and-electricity/guides/boiler-energy-efficiency/>)



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