

# Being Warm – Being Happy (BWBH)

Understanding Disability, Fuel Poverty and Energy Vulnerability for Adults with  
a Learning Disability

Final Report

March 2019



The BWBH Team: Jodie Bradley, Melanie Chapman, Chris Damm,  
Vicky Farnsworth Annie Ferguson, Jan Gilbertson, Alison Owen,  
Bernard Stafford, Beth Taylor, Angela Tod and Dan Wolstenholme

## Acknowledgements

The Being Warm Being Happy research team are very extremely grateful to all those who took part in the study. We would like to thank the people who agreed to share their homes and experiences with us in the household study. We are also thankful to those who attended the co-production workshops. Your input and enthusiasm were invaluable in moving us towards some tangible ideas for the future.

We are also grateful to the Project Advisory Group (Appendix 1) for all your input into the design, conduct and dissemination of the study. Your guidance was instrumental to the success of the project. BWBH is also grateful to Melanie Chapman who kept the team on message regarding social media.

A big thank you goes to our design colleagues, Remi Bec and Chris Redford. Remi helped with the co-production workshops and developed the graphics for the story boards. Chris has been involved from the beginning designing our logo and building the website. Chris also designed the card game, pen portraits and personae that were developed from the findings. The quality of their work has really helped drive the project forward.

The BWBH team would also like to express gratitude to all the final year graphic design students at Sheffield Hallam University who took part in the design challenge. Our thanks also go to James Corazzo, Principle Lecturer in Graphic Design, who made this possible. The ideas that the students developed, and their enthusiasm, innovation and hard work is much appreciated. Their contribution made a real tangible difference to the project.

Finally we would like to thank Eaga Charitable Trust for having faith in this project and providing the research grant. Without your funding and support the project would not have been possible.

Thank you to all for taking part in this project.

The Being Warm Being Happy research team.

*(Jodie Bradley, Melanie Chapman, Chris Damm, Vicky Farnsworth Annie Ferguson, Jan Gilbertson, Alison Owen, Bernard Stafford, Beth Taylor, Angela Tod and Dan Wolstenholme).*

# **Being Warm Being Happy: Executive Summary**

## **Introduction**

The Being Warm Being Happy (BWBH) project is a mixed methods study of fuel poverty experienced by adults with a learning disability (AWLD) in England. The project aimed to generate an understanding of why AWLD may be at risk of fuel poverty, examine rates of fuel poverty in households in which AWLD reside and develop recommendations and potential solutions to challenges and the problems identified.

## **Background**

There is a large body of evidence on the extent of fuel poverty, sometimes identified as part of a wider phenomenon of “energy vulnerability” or “energy poverty”. Living in a cold home is associated with premature death and a wide range of mental and physical illnesses. However, there is very little evidence of the nature and extent of fuel poverty in the disabled population, and virtually none at all for people with a learning disability. This is despite the fact that people with a learning disability are at a greater risk of material deprivation than the non-learning disabled population, and thus more likely to find it especially difficult to avoid living in a cold home. No research to date has examined the Fuel poverty experience and influences for AWLD. This project aimed to start to address this evidence gap. It is a participatory project where University academics worked with AWLD from a self-advocacy organisation.

## ***Aim***

BWBH is an exploratory study that aimed to understand and characterise the energy vulnerability from the perspective of people with a learning disability.

## **Methods**

This exploratory mixed-method study adopted a co-researcher model where people with learning disabilities were members of the research team. BWBH was also underpinned by co-production.

## ***Phase 1.***

Analysis of two national surveys were conducted the Understanding Society (US) Survey 2014-2015 and the English Housing Survey (EHS) 2013. The prevalence of fuel poverty was estimated in households in England in which someone with a learning disability lives relative to adults with other forms of disability reside and the general adult population.

## ***Phase 2.***

A household study comprising interviews and temperature measurements was conducted in 10 households with an AWLD. A contextual analysis of deprivation indicators of the households was conducted.

### **Phase 3.**

Two co-production workshops were held in a community venue in October 2018. Seventeen people from various stakeholder groups participated across the two workshops.

A design challenge was also conducted with students from Sheffield Hallam University to develop research ideas based on suggestions raised in the workshops.

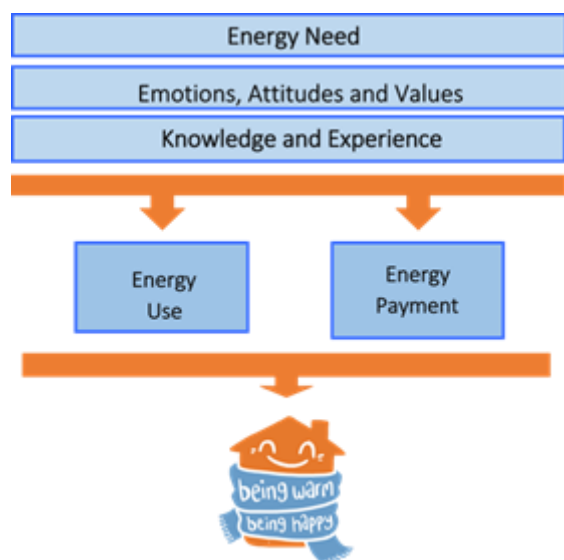
## **Key Findings**

### **Phase 1.**

- People with a learning disability living in private households are significantly more exposed to fuel poverty than their peers with other forms of disability, and the population of England as a whole. This result holds for both the US data and EHS data (using the Low Income High Costs (LIHC) fuel poverty metric).
- The set of *relative* rates of fuel poverty across five forms of disability (including learning disability) revealed by the US metric closely matches that revealed by the LIHC metric.
- The exposure of people with a learning disability to fuel poverty is significantly greater when measured by the LIHC rate than by the US rate.

### **Phase 2**

The household study developed unique understanding of the experience of fuel poverty and home heating from the perspective of AWLD. Three interrelated themes were identified: energy need; emotions, attitudes and values; and knowledge and experience.



The findings indicated that:

- Occupancy and characteristics of those sharing a home influenced energy need and use. For example, if the home was shared with others, their views on heating had to be considered.
- Those with health problems or additional disability, knew they needed to keep warm in order to maintain their health.
- Being able to keep warm at home was a cause of worry and anxiety for the participants, mainly because of cost. Roll out of Universal Credit, alongside other benefit changes (actual or threatened) aggravated existing financial worry.
- To manage this anxiety, and try and maintain control, people adopted a range of strategies including manually operating the heating, making trade-offs between fuel and other household expenses, paying by pre-payment meter, and restricting heating use.
- These strategies sometimes led to participants paying more for fuel because of their tariff or less efficient use of energy or suffered hardship such as being cold at home, or hungry.
- Approaches were adopted to stay warm without relying on heating systems e.g. hot drinks, limiting the use of appliances and being mindful of energy efficiency.
- Having family who could help with advice or advocacy was a key facilitator, as was access to an advocacy group such as Speakup.
- For most participants, prepayment energy meters offered a sense of control over finances that direct debit payments did not. People with sight and mobility problems experienced problems accessing the pre-payment meters.
- There was confusion about the role of smart meters; however, some participants were able to recognise the potential value of these.

### ***Phase 3.***

The co-production workshops and student designs identified a range of potential solutions. These were depicted graphically using personae, storyboards and design summaries (see full report). Solutions proposed included improved communication, development of training, raised awareness of fuel companies' Priority Service Registers (PSR), ensuring services are integrated across sectors, training of staff in energy efficiency and energy payment systems. Innovative technological solutions were also proposed.

### **Recommendations for practice**

- Raise awareness of the PSR amongst AWLD, but also advocacy organisations. Fuel companies have a responsibility to be proactive in making this happen.
- Develop accessible co-ordinated information and support that works across services and organisations. Easy read, accessible written information and energy bills were identified as a priority.

- There is a need to co-produce telephone and web-based advice systems that work for AWLD. However, reliance on web-based resources alone is not recommended as that would exclude some AWLD.
- Train services providers who help AWLD keep warm at home to enable them to effectively assess and respond to risk. There is potential for energy companies and other service providers to work in partnership with advocacy organisations to enable such training to be developed and delivered.
- Improvements are required to the user interface of smart meters and pre-payment meters. For example having a smart meter that spoke to you or had an easier to understand display. Energy companies can provide better advice and information on how to use them. Again, such interventions could be co-produced in partnership with AWLD and advocacy organisations.
- Further explore the potential of technological interventions including app based systems that provide accessible information and notifications about energy use and cost.
- New interventions should be implemented across sectors, to promote consistency of advice and streamlining of referral.

### **Recommendations for policy**

- Government should monitor the impact of the Universal Credit and Personal Independence Payments on the ability of AWLD to afford to maintain an adequate standard of living and avoid fuel poverty.
- Fuel poverty and energy efficiency interventions should be reviewed to make sure they do not inadvertently increase existing inequalities by disproportionately benefitting less disadvantaged. Review should occur before implementation.
- For new information resources and technological interventions to be Implemented across sectors, to promote consistency of advice and streamlining of referral (for example an information pack distributed by energy companies, tenancy agencies, advocacy groups and local government. See Joanna and Tom Appendix 8).

### **Recommendations for research**

This study begins to provide understanding of factors influencing the experiences of AWLD regarding fuel poverty and cold homes. It is just a start. Further research is required to:

- Test the generalisability of the qualitative findings amongst a larger population of AWLD.
- Develop evidence based interventions to improve the thermal comfort of AWLD.
- Evaluate the effectiveness of these interventions.

### **Conclusion**

BWBH has generated initial insight into the prevalence of fuel poverty risk and the extent and impact of fuel poverty experience amongst adults with a learning disability. It provides valuable understanding of the real world challenges faced by AWLD in today's society and the resourcefulness and resilience of many AWLD. However it also identifies the extent to which the existing energy system puts them at a disadvantage.

Existing policy often refers to people with disabilities as 'vulnerable' to fuel poverty, but fails to recognise the heterogeneity of disabled populations and the complex range of factors that conspire against them being able to keep warm at home. The BWBH study illustrates how policy based interventions, such as energy pricing and the roll out of smart meters, may make existing inequalities worse for AWLD.

The Being Warm Being Happy research team.

*(Jodie Bradley, Melanie Chapman, Chris Damm, Vicky Farnsworth, Annie Ferguson, Jan Gilbertson, Alison Owen, Bernard Stafford, Beth Taylor, Angela Tod and Dan Wolstenholme).*

### **Project report**

The full project report can be downloaded at:

<https://www.eagacharitytrust.org/warm-happy-understanding-disability-fuel-poverty-energy-vulnerability-adults-learning-disability-awld/>

**For further information**, please contact:

Professor Angela Tod, Professor of Older People & Care, School of Nursing & Midwifery, University of Sheffield. **Email:** [a.tod@sheffield.ac.uk](mailto:a.tod@sheffield.ac.uk)

# Contents

<b>Acknowledgements</b>	<b>2</b>
<b>Executive Summary</b>	<b>3</b>
<b>Contents</b>	<b>8</b>
<b>1. Introduction</b>	<b>10</b>
<b>2. Design and methods</b>	<b>13</b>
<b>3. Findings from Phase 1: The quantitative study of fuel poverty estimates in AWLD</b>	<b>23</b>
<b>4. Findings from Phase 2: The household study</b>	<b>31</b>
<b>5. Findings from Phase 3. Co-production</b>	<b>52</b>
<b>6. Discussion</b>	<b>63</b>
<b>7. Conclusion</b>	<b>70</b>
<b>References</b>	<b>68</b>
<b>Figures</b>	
Figure 1. The double diamond	20
Figure 2. Themes from workshop 1	21
Figure 3. An example of the '6 frame film strip' method	22
Figure 4. Deprivation in the nine BWBH household neighbourhoods	32
Figure 5. Deprivation and Fuel Poverty in the nine BWBH neighbourhoods	33
Figure 6. The BWBH thematic framework	37
Figure 7. Factors influencing energy/heating attitudes and behaviours	53
Figure 8. The Being Warm Being Happy challenges	54



## **Diagrams**

Diagram 1.	Rates of Fuel Poverty by Form of Disability (Understanding Society)	25
Diagram 2.	Rates of Fuel Poverty by Form of Disability (LIHC)	26
Diagram 3.	US and LIHC Fuel Poverty Rates and the Real Price of Domestic Fuel	28

## **Boxes**

Box 1.	Recommendations from Out in the Cold (Wealthy 2018)	66
--------	-----------------------------------------------------	----

## **Tables**

Table 1.	Sample characteristics for Phase 2. The household study.	18
Table 2.	BWBH household Study Evidence on Thermal Comfort and Fuel Affordability	35
Table 3.	Problems and Solutions identified from co-production	60

## **Appendices**

Appendix 1.	Project Reference Group	76
Appendix 2.	Examples of the BWBH Playing Cards	77
Appendix 3.	An example of a BWBH Pen Portraits	78
Appendix 4.	Fuel poverty under the Low Income High Cost indicator	79
Appendix 5.	US and EHS disability classifications	80
Appendix 6.	Analysis for Phase 1: the National quantitative study	81
Appendix 7.	An example of a BWBH persona	83
Appendix 8.	Storyboards from the BWBH co-production	84
Appendix 9.	Student design challenge ideas	87
Appendix 10.	Dissemination	88

# 1. Introduction

## Being Warm Being Happy

The Being Warm Being Happy (BWBH) project is a mixed methods study of fuel poverty experienced by adults with a learning disability (AWLD) in England. The project intended to:

- Build on the existing evidence base of the negative effects of fuel poverty and cold homes on physical and mental health and wellbeing, by focusing on AWLD.
- Generate an understanding of why AWLD may be at risk of fuel poverty, and what intrinsic and extrinsic factors contribute to this risk.
- Identify how the experience of AWLD regarding fuel poverty and affordable warmth connects to wider social and health issues.
- Generate recommendations and messages to inform policy and practice.

For the UK population as a whole there is a large body of evidence on the extent of fuel poverty, sometimes identified as part of a wider phenomenon of “energy vulnerability” or “energy poverty”. A principal motivation of researchers in this field is to provide evidence demonstrating how living in a cold home is associated with premature death and a wide range of mental and physical illnesses. But there is very little evidence of the nature and extent of fuel poverty in the disabled population, and virtually none at all for people with a learning disability. This is despite the fact that people with a learning disability are at a greater risk of material deprivation than the non-learning disabled population, and thus more likely to find it especially difficult to avoid living in a cold home. No research to date has examined the fuel poverty experience and influences for AWLD.

This project was conducted to start to address this evidence gap. It is a participatory project where University academics and AWLD, from Speakup Advocacy (referred to as Speakup in the report), worked in partnership. Speakup is a voluntary sector organisation based in Rotherham South Yorkshire.

## Background

Previous research has demonstrated that AWLD are at higher risk than the general population of unsafe home temperatures, and also more susceptible to related harm and consequent negative health impacts (Snell et al 2014). Reasons include, first, the higher prevalence of mental and physical co-morbidities, and sensory or cognitive differences in AWLD (Emerson 2014). Second, AWLD are also more likely to experience environmental adversity (material and social hazards) across the life course (Rudnick et al 2014, Gore 2011). Third, vulnerability is further enhanced by an increased likelihood of poorer household income and lower socioeconomic position (Emerson et al. 2012, 2013, Macinnes et al. 2014). Recent welfare reforms such as changing Incapacity Benefit (IB) to Employment Support Allowance (ESA), Universal Credit, and Disability Living Allowance (DLA) to Personal Independence Payments (PIP), and introduction of the ‘bedroom tax’ may have increased financial vulnerability for a person with a learning disability (Moffatt et al. 2015, Snell et al.

2014). Fourth, these socioeconomic disadvantages impact on emotional wellbeing. Self-esteem and psychological morbidity are exacerbated by experiences of bullying, hate crime and abuse, social isolation and poor living conditions. This cumulative effect can in turn impact on someone's resilience or capability to ask for or access help (Emerson 2013). Fifth, AWLD who are experiencing hardship are more vulnerable to the poverty premium, that is, the likelihood of having to pay more for basic household goods because of poverty, such as heating (e.g. having to pay more for fuel by a meter rather than direct debit). In addition, AWLD may experience physical, cognitive or sensory barriers and obstacles to detecting or communicating thermal comfort and being able to adjust home heating accordingly. Finally, due to cognitive and sensory impairment, AWLD are less likely to be able to respond to public health messages and/or information (Allerton & Emerson 2012; Emerson & Hatton 2011).

The complexity of influences extends beyond this report but the factors listed here serve to illustrate possible scenarios supported by existing evidence. However, little research has explicitly examined fuel poverty from the perspective of AWLD or sought to confirm rates of fuel poverty in this population.

In summary, a study of the fuel poverty experiences from the perspective of AWLD is justified for the following reasons.

*The very limited existing empirical evidence.* Whilst there is evidence on the prevalence of fuel poverty for the English population as a whole (BEIS, 2018), only one study has focused on the incidence of fuel poverty in the category covering all forms of disability and chronic long-term conditions, including learning disability (Snell et al. 2016). This study reported unexpected results. That is rates of fuel poverty were lower in households where someone with a learning disability lived, when compared to households without someone with a learning disability. This is a counter intuitive result when considering the evidence cited above. There are possible methodological explanations for this finding. For example, a sampling bias due to i) the English Housing Survey (EHS) may not access the more vulnerable households ii) the research may not be accessible to people with learning disabilities. However, this finding does merit further exploration. By conducting analysis across the EHS and Understanding Society data, BWBH aimed to overcome previous sampling and methodological problems.

In addition, we are aware of no existing qualitative evidence on the intrinsic factors which influence the lived experience of fuel poverty amongst adults with a learning disability.

*Consultation findings.* Two of the research team (AT and MC) conducted an extensive pre-protocol consultation with AWLD and the organisations, services and staff they interact with. This provided a clear indication that AWLD experience challenges in keeping warm at home. These concerns have been examined more systematically within BWBH. Key concerns raised by consultation participants included i) the lack of knowledge and awareness regarding energy payment systems, tariffs and support for customers at risk of fuel poverty, ii) the number of people who had experienced fuel debt or broken heating systems and not known

what to do iii) worry about the roll out of Universal Credit and other benefit changes that would compromise ability to pay for fuel.

*The greater risk of material deprivation faced by adults with a learning disability.* Relative both to adults with other forms of disability and the whole population of non-learning disabled adults, the employment profile of adults with a learning disability is greatly diminished. In England, there are estimates that as few as 7% of working age adults with a learning disability are in paid employment. Many of these jobs will be part-time or sheltered employment (Emmerson et al 2014). This compares to rates of between 25% and 50% for working age adults with other forms of disability and with a rate of just over 70% for the working age population as a whole (McRier et al 2016). This is reflected in the proportion of households where someone with a learning disability lives who finds difficulty in “making ends meet”, which was 57% in 2012-2014 compared with between 32% and 40% of hearing, vision and mobility impaired households, and 28% of non-disabled households (Mencap 2017). Other things being equal, these differences in extrinsic capabilities can be expected to translate through into excess rates of fuel poverty in households in which an adult with learning disability lives.

## **Aims and objectives**

### ***Aim***

BWBH is an exploratory study that aimed to understand and characterise the energy vulnerability from the perspective of AWLD, and identify the implications. Methods were adapted from those in previous research by the applicants (Nelson et al. 2014, Maidment et al. 2014, Tod et al. 2012,). The study was conducted with co-researchers with a learning disability and experience of research.

### ***Objectives***

The objectives of the BWBH project were to:

1. Compare the rates of fuel poverty in households in which AWLD reside relative to households in which adults with other forms of disability reside and the general adult population (Phase 1).
2. Understand the experience and risks of fuel poverty from the perspective of AWLD (Phase 2).
3. Identify the implications for policy and practice using methods of co-production (Phase 3).

## **2. Design and methods**

### **Design**

This is a participatory mixed-methods study in three phases, incorporating:

Phase 1. A quantitative study conducting secondary analysis of the English Housing Survey and Understanding Society databases to estimate the prevalence of fuel poverty in households in which an adult with learning disability resides relative to that in i) households in which adults with other forms of disability reside and ii) the general adult population.

Phase 2. A household study using temperature and humidity measurement and qualitative interviews in order to understand and characterise energy vulnerability from the perspective of AWLD.

Phase 3. A co-production phase working with stakeholders to identify implications for policy and practice from the findings and generate shared recommendations and solutions.

Before detailing the methods for the project we will briefly explain two activities upon which the proposed research was based. These are participatory research and co-production.

A project website was developed and maintained throughout (<https://beingwarmbeinghappy.org/>). This provided a way of sharing information and also engaging debate with a wider population. An active twitter feed facilitated this discussion (@BeingWarm).

### **Participatory Research**

Research using participatory methods improves the quality, relevance, and appropriateness of it. It also and contributes to broader democratization (Staniszewska et al. 2011). Central to public involvement is inclusive research, an umbrella term which includes participatory research carried out with, by and for, rather than on people who have traditionally been the subjects of research (Nind 2014). With regard to AWLD, inclusive research can be described as research that matters to people, improves their lives, and respects them (Walmsley & Johnson 2003).

This study embraced participatory research methods and added methodological insights, especially regarding the co-researcher model, in which a person with a learning disability is a member of the research team. This participatory approach increased the acceptability and trust for research participants and also helped to ensure that the findings were grounded in and reflected participants' experience. Participatory methods, and the trust generated, were important in recruitment to this project, especially for those who struggle to access support and services and may therefore become mistrustful.

A key methodological development due to the participatory nature of the study was the development of analysis techniques that were truly inclusive of AWLD. The co-researchers worked with the wider team to drive forward innovative approaches that included the development of pen portraits from the data (Appendix 3). These were used to summarise findings in an accessible way to enable understanding and discussion with AWLD. In addition, we developed playing cards, based on the initial themes from the analysis of the household interviews. The co-researchers used the cards to actively engage in analysis of the data.

The participatory nature of this study was achieved in the following ways:

1. Co-researchers who are AWLD and work as advocates at Speakup worked with academic researchers to conduct the household study. They led on recruitment and worked as peers on the data collection, analysis and sharing of findings.
2. The Reference Group met at key points during the study to provide expert advice and also comment on emerging findings. The co-researchers were integral to these meetings and provided vital insight and advice.

## **Co-production**

In the BWBH project, co-production provided an approach to involve all the key stakeholders. Co-production enabled real time synthesis, development and testing of knowledge from different sources and turning this learning into contextually specific, pragmatic outputs and solutions.

Co-production draws on the research literature relating to knowledge mobilisation, and reflects a shift from mode 1 to mode 2 forms of knowledge mobilisation. Mode 1 is the traditional approach where academics produce evidence and then 'translate' it into the real world. In contrast, mode 2, is where all stakeholders co-create knowledge together, leading to better solutions and ownership of the outputs, which in turn leads to increased chance of successful implementation (Rycroft-Malone et al 2016).

Co-production is not straightforward and comprises many stages, from knowledge generation to operationalisation. In BWBH we focused on earlier stages in the process. This involves knowledge generation, discovering and defining the problem and generating potential ideas for future development and evaluation.

Many of the tools and the overarching approach used in this study are described in 'The Better Services By Design' website ([bsbd.org.uk](http://bsbd.org.uk)) and the approach, using visual and creative methods, has worked with a wide range of different stakeholders (Cooke et al, 2016).

The methods adopted for each of the three phases will now be summarised, before presenting the findings.

## **Phase 1. Methods for the national quantitative study**

### ***Aim***

This component estimated the prevalence of fuel poverty in households in which someone with a learning disability lives, relative to that in i) households in which adults with other forms of disability reside and ii) the general adult population.

### ***Sample***

The estimates are confined to:

- Populations in England
- Adults with a learning disability living in unsupported private accommodation (rather than in nursing homes, long stay health care residential facilities and hospitals)

The estimates of prevalence were derived from data generated by two official national surveys:

- 1 The Understanding Society Survey 2014-2015  
(<https://www.understandingsociety.ac.uk/>).
- 2 The English Housing Survey 2013-2014  
<https://www.gov.uk/government/statistics/english-housing-survey-2013-to-2014-headline-report>

In the former, fuel poverty is measured subjectively, that is in terms of respondents' answers to the survey question "in winter are you able to keep this accommodation warm?" In the latter, fuel poverty is measured by the official Low Income High Cost (LIHC) indicator which is generated by a statistical modelling exercise, which in this sense is an objective measure. The use of data from the two surveys indicates whether a choice of an objective rather than subjective measure of fuel poverty changes the estimated prevalence of fuel poverty amongst adults with a learning disability.

### ***Analysis***

#### **Understanding Society (US) 2014-2015 data**

Understanding Society is a large scale longitudinal household survey. We calculated a set of cross tabulations between each US disability category and "no" answers to the US question "in winter are you able to keep this accommodation warm", from which prevalence rates of subjective fuel poverty by disability category are derived. In addition we estimated the rate of subjective fuel poverty for the population of England as a whole.

#### **English Housing Survey (EHS) 2013-2014 data**

The English Housing Survey is a large scale cross sectional household survey which is linked to the official Low Income High Cost fuel poverty data set. We calculated a

set of cross tabulations between each EHS disability category and households recorded as being in LIHC fuel poverty, from which prevalence rates of objective fuel poverty by disability category are derived. In addition we estimated the rate of objective fuel poverty for the population of England as a whole.

We also analysed possible causes of the difference between the national rates of subjective and objective fuel poverty derived from these two data sets.

## **Phase 2. Methods for the household study**

### ***Aim***

This exploratory study aimed to understand and characterise the energy vulnerability from the perspective of AWLD, and identify the implications for health literacy. Methods were adapted from those in previous research by the applicants (Tod 2011, 2012, 2014; Gilbertson 2014, 2012, 2007, 2006). The study was conducted with co-researchers with a learning disability and experience of research.

### ***Setting***

The BWBH household project was conducted in communities and homes in two local authority areas in Rotherham. This district provided an urban/rural and demographic mix. Rotherham also has a mix of housing types and tenure.

For context, the Index of Multiple Deprivation (IMD) scores for the small neighbourhoods in which the case study households are located is analysed together with the small neighbourhood rates of LIHC fuel poverty. This data shows that the case studies largely cover the spread of deprivation and fuel poverty in England as a whole. Further details of the contextual analysis are presented below in Chapter 4.

### ***Sample***

Individual interviews and household temperature measurements were conducted with households with an AWLD. Our focus was on householders with mild to moderate learning disability, who are living independently or with family members. Our inclusion criteria included consideration of consent under the conditions of the Mental Capacity Act (The Stationery Office, 2005), that the disability will not impair the ability to agree to participate or not. We therefore included participants who were able to:

- understand the information relevant to the decision,
- retain the information,
- use the information,
- communicate his or her decision (by any means) (Health Research Authority 2017).

We included households where the AWLD had some support or care at home, but we excluded people with severe disability, who receive intensive or 24 hour support or who live in residential care. Participants were included if they were able to



communicate without assistance or with the help of a translator or carer.

As the goal was to generate in-depth understanding, the sample size was 10 households (See Table 1). We obtained a mix of characteristics in terms of age, gender and type of disability, as well as type, occupancy level, rural/urban location, tenure and energy efficiency of home. Purposive sampling ensured the range of characteristics were included in the household sample.

### ***Recruitment***

Households were recruited through Speakup. Potential participants were identified using Speakup's community networks and their existing meetings and groups. The Speakup co-researchers made an initial approach, providing written and easy read information. They discussed the project with a potential household. If householders were interested in participating, a visit was arranged for both the academic and Speakup researcher to visit the home and explain the study in more detail. They went through the study and answered any questions. If the householder agreed to participate written or verbal consent was obtained, depending on the abilities of the participant.

### ***Data collection and analysis***

Data collection took place in winter months, between 18<sup>th</sup> December 2017 and 11<sup>th</sup> April 2018. This was to ensure homes were cold and the participants would be able to relate to the topic and heating. With informed consent, a device (Tinytag Ultra 2 Temperature / relative humidity recorder TT2) was placed into the living room and bedroom to log room temperature and humidity at hourly intervals for two weeks. The devices were then removed and the interview conducted. The device is small and unobtrusive. The temperature measurements provided an objective measure of home temperature. This was useful to compare to people's perception of warmth as described in the interviews and detect if people were able to accurately identify if their homes fell within recommended temperatures.

Semi-structured individual interviews were conducted in the participant's home using a schedule devised from energy vulnerability literature and the policy review. The reference group and advisory group also advised on the interview schedule. The focus for the interview was the person with the learning disability. If other members of the household, such as a family member, also wanted to be interviewed this request was accommodated. This occurred for 1 of the 10 interviews (Person 9, Table 1).

Interviews were conducted by the Research Team in liaison with the Reference and Advisory Groups.

The interview schedule included questions on factors influencing the person's ability to maintain safe home temperatures, their energy use, help and resources available and influences on accessing help if needed. Interviews were tape-recorded,

transcribed and anonymised before being entered onto Quirkos, a qualitative research software programme (<https://www.quirkos.com/index.html>).

Framework analysis was used to generate themes and issues that characterise fuel poverty and energy vulnerability for AWLD (Ritchie et al 2013). Framework Analysis has emerged from policy research and is a pragmatic approach to qualitative data analysis. It involves a systematic process of familiarization, sifting, charting and sorting the material into key issues and themes. It allows the integration of pre-existing themes into the emerging data analysis and provides a clearly defined analytical structure that contributes to the transparency and validity of the results (Ritchie et al 2013).

**Table 1. Sample characteristics for Phase 2. The household study**

	Age	Who else lives in the home?	Type of housing	Tenure	Time living here (years)	Decade home was built
<b>Person 1</b>	33	Partner, two daughters (age 9 and 15) and dog.	3 bed terrace	Home owner	11	1980s
<b>Person 2</b>	31	Dad (age 69) and cat	2 bed flat	Social housing	1.5	1970s
<b>Person 3</b>	49	Son (age 29) and dog.	2 bed maisonette	Social housing	1	1970s
<b>Person 4</b>	59	Husband	1 bed bungalow	Social housing	10	1970s
<b>Person 5</b>	59	Cat	1 bed bungalow	Social housing	2	1970s
<b>Person 6</b>	47	Four sisters and a niece	4 bed detached.	Social housing	'a long time'	1940s
<b>Person 7</b>	54	Mother (age 80) and cat	3 bed semi-detached.	Social housing	20	1950s
<b>Person 8</b>	44	Lives alone	1 bed flat	Social housing	7	1970s
<b>Person 9</b>	31	Husband (age 53)	1 bed bungalow	Social housing	5	1970s
<b>Person 10</b>	28	Mother, father and sister.	3 bed semi-detached.	Privately owned by parents	15 years	1970s

Framework analysis comprises five techniques with associated methods of data ordering. These are: familiarisation, developing a thematic framework, indexing, charting, and mapping and interpretation. After an initial thematic framework was generated these were tested in Reference Group discussions. Further analysis was conducted with the co-researchers to finalise the thematic framework prior to this. With the help of a designer we developed a set of playing cards and some pen portraits to help with the participatory analysis process (Appendix 2 and 3). These were also used in Phase 3, the co-production activity.

Analysis of the data from the Tinytag Ultra 2 Temperature / relative humidity recorder was conducted using the matching software. Actual temperature was compared to each participant's interview data to detect any mismatch between perceptions and reality in terms of room temperature. Reasons for this were then explored.

### **Phase 3. Methods for the co-production**

#### ***Aim***

The co-production phase of the project aimed to identify implications for policy and practice from the findings. It also aimed to generate potential solutions and innovative ideas to address the challenges identified in Phase 2.

#### ***Setting***

The co-production phase consisted of two workshops held in a community venue. A student challenge was also conducted, in which final year design students worked to develop research ideas based on suggestions raised in the workshops. This consisted of three sessions between students and the research team held in Sheffield Hallam University, where the students were studying.

#### ***Sample***

A wide range of stakeholders was invited to the co-production workshops including people from policy, practice, service provision, the voluntary sector and commissioning organisations (health, housing local authority and energy). AWLD and people from related advocacy groups were also invited.

Seventeen people participated across the two workshops, 14 attended the first and 11 attended the second. Participants included representatives from the core research team (including 3 co-researchers with a learning disability), the BWBH Advisory Board, a research funder, other academics, voluntary sector organisations, and NHS England. A designer attended the second workshop.

Eleven final year graphic design students from Sheffield Hallam University participated in the design challenge.

#### ***Methods***

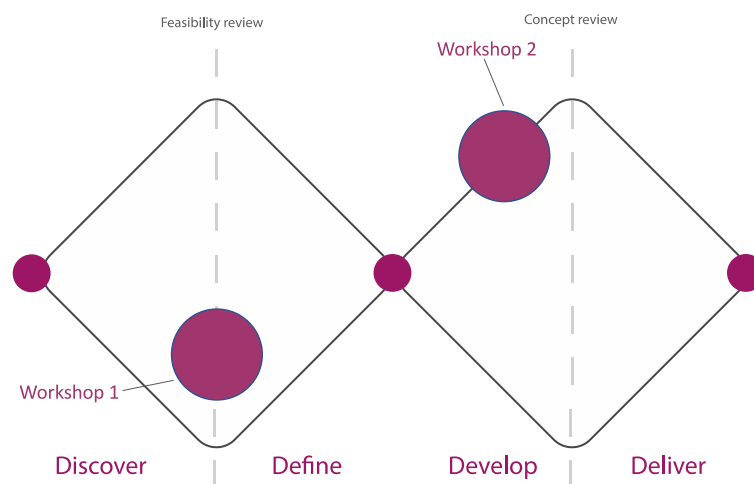
##### ***The co-design workshops***

The co-production phase in this project followed a process informed by the British Design Council's double diamond (see Figure.1) as adapted in previous work by the TK2A theme of the NIHR CLAHRC YH. This is a description of the process used by designers to discover and define a problem, and then work towards solutions. In this case these phases were undertaken as co-design in that all the participants

contributed to the process allowing different forms of knowledge to come to bear on the issue.

By using this approach, the knowledge gained from the qualitative and quantitative components of the project were able to be synthesised with the lived experience of the co-researchers and the wider stakeholders from fuel poverty and learning disability worlds.

**Figure 1. The double diamond**

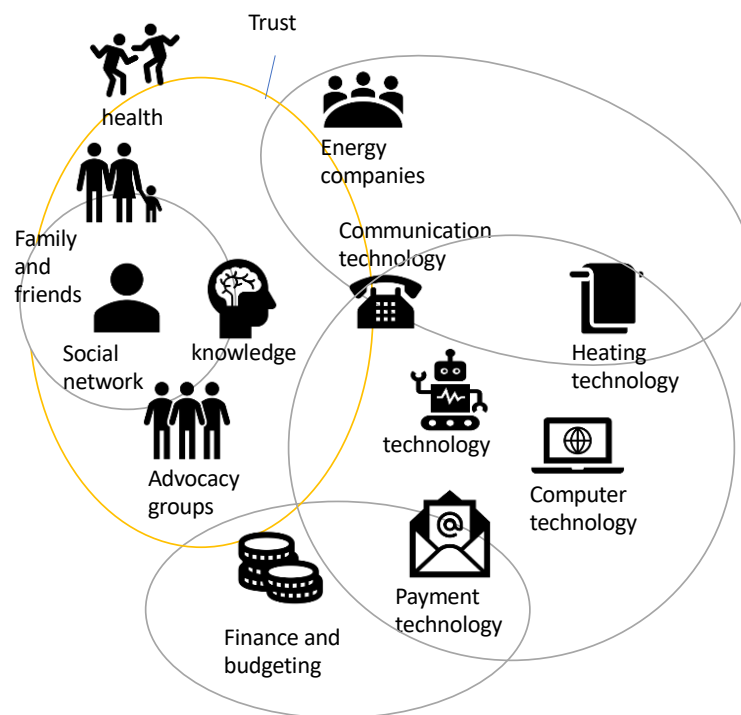


In the first workshop research knowledge and findings from Phases 1 and 2 of this study were used to develop a shared understanding of factors influencing fuel poverty and energy vulnerability for AWLD (The discover and define phases in Figure 1). Creative methods were adopted to allow and support equal involvement and discussion across participants. Prior to the workshop pen portraits of all the participants from the household study (Phase 2) had been developed (Appendix 3). Identifying data was removed from these. They highlighted key factors that influenced the energy of each household. The pen portraits were developed with graphics that were easy for workshop participants to understand, including AWLD.

The first activity in workshop 1 was to create a fictitious character (persona) loosely based on the pen portraits developed from the qualitative data. Quotes were used to express characters' feelings and attitudes towards keeping their home warm. The groups were encouraged to bring the characters to life by imagining their living circumstances and allowing reflection on the real challenges these characters might

face. The cards generated from the qualitative analysis were used as prompts to identify themes, summarised in the image below (Figure 2).

**Figure 2. Themes from workshop 1**



Workshop 2 built on this shared understanding and used a ‘6 frame film strips’ (Figure 3) technique to explore the characters responses to different scenarios. This allowed participants to reflect on what might happen to the persona now without any interventions or help to address their energy vulnerability. They then used the same process to imagine what could happen if the learning from the project was implemented in practice. This resulted in a series of stories that captured concrete examples of challenges and opportunities that would help and hinder AWLD in keeping their homes warm.

What emerged from this process were suggestions for:

- Policy and practice
- Related recommendations

- Emergent design ideas that may help to overcome barriers that AWLD experience that prevent them from keeping warm and accessing affordable warmth interventions.

**Figure 3. An example of the '6 frame film strip' method**



### *The student design challenge*

As shown in Figure 1 it was not within the remit of BWBH to move from the design concepts into the physical prototyping phase. However, during the project there was the opportunity to develop a design brief for final year graphic design students on the specific challenge of bills and smart meter interfaces. The project was pitched to a group of students in the form of a design brief, emailed to them by their tutor. The eleven students who expressed an interest were then invited to an initial meeting where the project and emerging findings were summarised by the project lead (Angela Tod) and co-production lead (Dan Wolstenholme). The students were given the choice of working individually or in groups. There were two groups of three students, two groups with two students and one student working alone.

A second meeting was held a week later when the students presented their emerging ideas to representatives from the project team including three co-researchers from Speakup. Feedback and suggestions were given to the students.

In the final meeting the students pitched their design solutions to members of the research team.

A summary of the findings and outputs from the co-production workshops and the student design challenge is provided in Chapter 6.

### **3. Findings from Phase 1: The quantitative study of fuel poverty estimates in AWLD**

#### **Introduction**

This chapter is divided into two sections. Section 1 presents estimates of the extent of fuel poverty amongst those with a learning disability who live in private households in England. Their exposure is compared with that of those with other forms of disability, and with that of the population of England as a whole. Two versions are presented by applying different metrics of fuel poverty. Section 2 follows on with an analysis of the difference in the estimates of fuel poverty that arises when one metric is applied rather than the other.

For this component of the study, fuel poverty is defined in very general terms as the condition of living in an inadequately warm home. It is measured as a prevalence rate, that is, the proportion of all households in the group in question which are counted as being in fuel poverty.

There are two national surveys for England which provide two different metrics by which such counts can be made, The Understanding Society (US) survey and The English Housing Survey (EHS). The annual US Survey asks householders the question “in winter are you able to keep this accommodation warm enough”. The answers to this can be tabulated by self-reported form of disability according to the US disability classification, and easily expressed as a prevalence rate. The US category that was adopted as an indicator of having a learning disability was ‘Memory or ability to concentrate, learn or understand’.

The EHS data set has an alternative metric for learning disability. This is provided by a link between the annually published EHS and the official annual Low Income High Cost (LIHC) fuel poverty data set. The latter provides a count of households in LIHC fuel poverty by self-reported form of disability, including learning disability. This is also easily expressed as a prevalence rate.

In both the US and EHS disability classifications, learning disability is part of a wider composite class which covers other cognitive problems. It is recognised therefore that these classifications are not an exact match for learning disability as they may also include people with, for example dementia or stroke. However, they are the best proxy for a learning disability.

It’s also the case that there are only five forms of disability that are common to both classifications; learning disabilities plus disabilities related to hearing, vision, mobility and dexterity.

#### **Measuring the Prevalence of Fuel Poverty: Self-Reported and Modelled Metrics**

The US metric is simple and straightforward. It is essentially the number of “no” answers to the US question “in winter are you able to keep this accommodation warm enough”, divided by the number of “no” plus “yes” answers.



The LIHC metric is a very different sort of construct. Under this metric a household is counted as being in fuel poverty if both of two conditions apply:

- that its *required* fuel costs are above the national average (the national median level) and
- that *if* that amount were actually spent, the household would be left with a residual income below the official income poverty line (which is 60% of median household income)

The diagram in Appendix 4 illustrates the LIHC fuel poverty metric.

Required fuel costs (which cover the energy needed for heating water, lighting, appliance usage and cooking as well as heating the home) are estimated by a complex statistical modelling exercise based on the following:

- The economic circumstances of householders (for example, if they are unemployed or retired or whether they will be at home for longer periods of the day)
- The heating system and the type of fuel(s) used, and
- The characteristics of the household dwelling

Built into this estimate of fuel requirements is a key threshold which presumes that all households enjoy the same prescribed standard of 21C for the main living area and 18C for other occupied rooms. This temperature standard is adopted in the wider public health field as a *health* threshold, below which the risk of cold related ill health increases. However, the evidence base for it is imprecise. Its origin can be traced back to a range of values presented in a 1987 World Health Organization report (World Health Organization 2007). More recent evidence on minimum home temperature thresholds for health suggests that, for occupied rooms in winter, a minimum of 18C rather than 21C is sufficient (Public Health England 2014). In a 2017 review conducted for the Scottish Government review there was a call for more evidence to the required temperature standard for health. This review also recommends a higher temperature standard of 23C for living rooms in vulnerable households (Scottish Government 2017).

The US and LIHC metrics relate to different aspects of fuel poverty. The former is an indicator of perceived thermal discomfort – of the experience of living in an uncomfortably cold dwelling. The latter is an indicator of the increased risk of ill health faced by those for whom the cost of heating the home to a prescribed standard is unaffordable.

The operational difference between the two metrics would be much reduced if it's the case that a comfortable home temperature is also one that best protects the health of household residents. We return to this issue below.

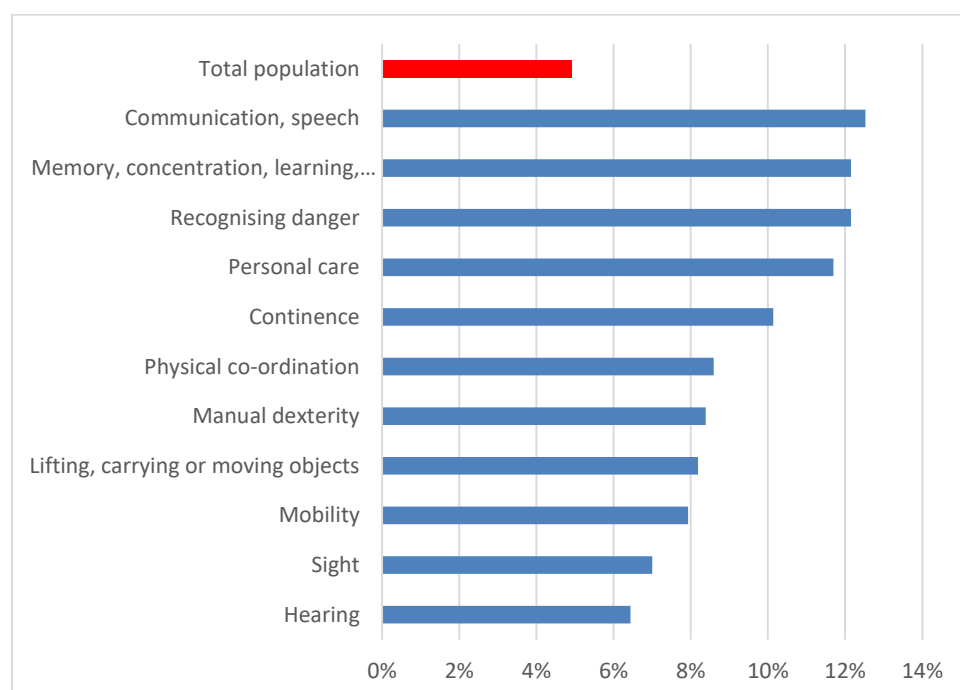
Although it is tempting to describe the US and LIHC metrics as 'subjective' and 'objective' it's more accurate to think of them as 'experiential' and 'modelled'. The US metric is wholly experiential as it is derived only from what people say about their lived experience. In contrast, the LIHC alternative is a complex statistical simulation

which is devoid of experiential data. This property of the LIHC metric has been criticised for ignoring the complex reality of living in fuel poverty (Middlemass and Gillard (2015)).

## Rates of Fuel Poverty by Form of Disability

Diagram 1 shows the prevalence of fuel poverty in all households in England and also by forms of disability according to the experiential US metric. Diagram 2 shows the same information according to the modelled LIHC metric. The former is for 2014/15 and the latter for 2013/14<sup>1</sup>

**Diagram 1 Rates of Fuel Poverty by Form of Disability and in all Households in England on the Understanding Society Metric, England 2014-15<sup>2</sup>**



Source: for the US data table and source see Appendix 5

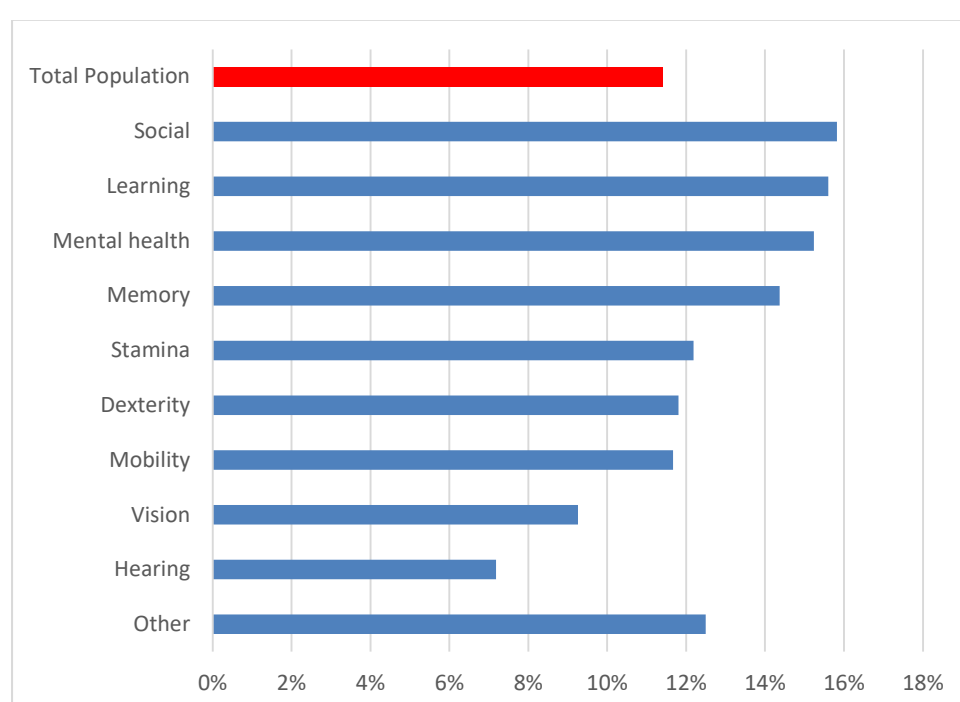
The rates of fuel poverty for people with a learning disability shown in these diagrams should not be interpreted as the result of having a learning disability rather than being disabled in some other way, that is, as representing a pure learning disability effect. This is because those with a learning disability typically have several other forms of disability as well. Thus, for example, the US data indicates that 18%

<sup>1</sup> Due to an unresolved technical fault affecting the 2014/15 LIHC and EHS data sets we have used the unaffected 2013/14 data sets

<sup>2</sup> Under the Chi square test all relationships between disability status and US fuel poverty are statistically significant to the 0.05 level, see Appendix 6

of households reporting an adult member with a learning disability also report having an adult member with speech or communication problems.<sup>3</sup>

**Diagram 2 Rates of Fuel Poverty by Form of Disability and in all Households in England on the Low Income High Cost Measure, England 2013-14<sup>4</sup>**



*Source; for the EHS data table and source see Appendix 5*

Under each metric the learning disability fuel poverty rate exceeds those for almost all other forms of disability and that for the population as a whole. This is a predictable result due to the severely diminished employment and income profile of adults with a learning disability.

Past studies have estimated that in England only about 17% of working age adults with a learning disability were in paid employment, which compares with 2016 rates of 47% for adults in Great Britain with any form of disability and just over 70% for the working age population in England as a whole

<sup>3</sup> This calculation on US data was conducted by the project team. We looked rates of other disability for those with a learning disability. The analysis is not presented here as it is not the focus of the report.

<sup>4</sup> Under the Chi square test all relationships between disability status and LIHC fuel poverty are statistically significant to the 0.05 level except for that involving hearing disability which is marginally insignificant ( $p=0.055$ ), see Appendix 6

(<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/getting-job-research-and-statistics>). In turn this is reflected in the proportion of households where someone with a learning disability lives in Great Britain finding difficulty in “making ends meet”. This was 57% in 2012-2014 compared with 42% for households with any form of disability and 28% for non-disabled households (Equality and Human Rights Commission (2017) table EF2.4).

However, what is not predictable is that each metric presents a similar picture of the **relative** rates of fuel poverty across the five forms of disability common to the US and EHS classifications. These are learning disability and disabilities affecting hearing, vision, mobility and dexterity.

Under *each* metric, the learning disability fuel poverty rate is about 50% greater than that for mobility disability and dexterity disability, about 70% greater than that for vision disability and in the region of twice that for hearing disability. This pattern is such that the rank order of fuel poverty rates across the five common disability forms is exactly the same under each metric. The learning disability rate is ranked 1 (the highest rate) and the vision disability rate is ranked 5 (the lowest rate).

In contrast, there is a very obvious difference between the metrics when it comes to the **absolute** rates of fuel poverty. For the population as a whole and for all forms of disability taken separately, the rate of LIHC fuel poverty is substantially higher than that revealed by the US metric. The right hand profiles in Diagrams 1 and 2 are of a similar shape, which indicates *relative* similarity. However, that for the LIHC metric lies much further to the right than that for the US metric. This indicates *absolute* difference. For the five forms of disability referred to above, the LIHC rates are between 20% and 50% greater than the corresponding US rates. For the population as a whole, the excess is 120%. It turns out that for all forms of disability and for the whole population, the rate of fuel poverty revealed by answers to a simple direct question about adequate warmth (US), differs from that revealed by a complex statistical simulation (LIHC). The latter exceeds the former in every case and by a great deal.

### ***Why are US Fuel Poverty Rates Less than LIHC Rates?***

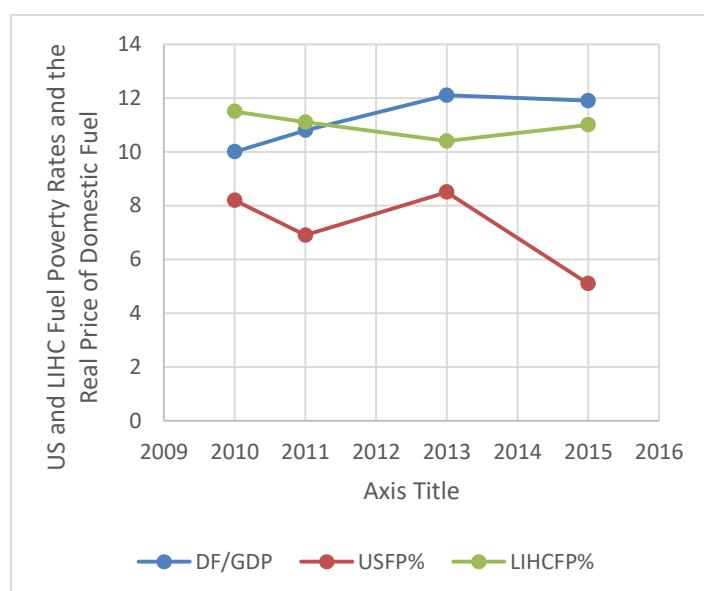
There are several possible explanations for the absolute differences between the LIHC and US rates of fuel poverty. These are as follows:

- *That inconsistent answers are given to the US question.* In order to avoid stigma someone who feels cold at home may answer “yes” to the question “in winter are you able to keep this accommodation warm enough”. Although we know of no direct evidence on the existence of an inconsistency of this kind it is hard to believe that this factor can account for the large year by year variation in the gap between the two metrics shown in Diagram 1.3 below
- *That different standards of adequate warmth are involved.* There is national evidence that the standard of perceived thermal comfort is less than the prescribed LIHC living room standard of 21C. Wong et al. (2009, Figure 1) report that low income households in England are comfortable with a living room temperature between 19C and 20C after energy efficient refurbishment.

However, these lower low living room temperatures may not reflect comfort but complex decisions made by people on a limited income. Many people on low incomes may ration their energy spend and as a result live in cold, under-heated homes. Others may maintain higher temperature standards at the cost of other household expenditure, such as food. Hamilton et al (2017. Table 4) report that English households not in fuel poverty according to the LIHC metric maintain a mean living room temperature of 18.9C during the winter period. Hills (2011. Table 2.3 and Figure 2.17) reports that financially unconstrained households in England heat their dwellings to a standard below that embodied in the LIHC metric. For a more detailed debate on this complex picture see the Scottish Government report *A new definition of fuel poverty in Scotland: review of recent evidence* (2017). The implication of this difference for the study presented here is that some households in the LIHC fuel poverty count will answer “yes” to the US question “in winter are you able to keep this accommodation warm enough”, and not appear in the US count

A fuller picture of the gap between the LIHC and US fuel poverty rates can be gained by inspecting the time trend of these counts for the population of England as a whole. Diagram 1.3 shows these trends (LIHCFP% and USFP% respectively) for the 2010-2015 period, together with that of the relative price of domestic fuel (the price of domestic fuel relative to those of all goods and services) expressed as an index with 2010=10 (DF/GDP).

**Diagram 3 US and LIHC Fuel Poverty Rates and the Real Price of Domestic Fuel, England, 2010-2015**



Sources:  
for DF/GDP <https://www.gov.uk/government/statistical-data-sets/monthly-domestic-energy-price-stastics>  
table 2.1.1  
for USFP% [https://www.understandingsociety.ac.uk/documentation/mainstage/dataset-documentation/wave/6/datafile/f\\_hhresp/variable/f\\_hheat](https://www.understandingsociety.ac.uk/documentation/mainstage/dataset-documentation/wave/6/datafile/f_hhresp/variable/f_hheat)  
for LIHCFP% <https://www.gov.uk/government/statistics/fuel-poverty-trends-2017> table 1

The key features of Diagram 3 are that:

- The LIHC rate exceeds the US rate in each year. This difference is broadly consistent with that estimated by Waddams-Price et al. (2012, Table 8 using 2011 data), albeit on differently constructed modelled and subjective metrics
- The LIHC trend is virtually flat whereas that of the US metric is clearly downwards
- The US trend is much more volatile than the LIHC trend.

The lack of variation in the LIHC trend is present by design. The LIHC metric was introduced in 2013 as a replacement for the previous so called “10%” metric whose sensitivity to changes in the relative price of domestic fuel was judged to be a misleading weakness as follows:

*“(under the 10% metric) as fuel prices change, the distribution of spending moves in relation to this fixed threshold and the number of households counted as fuel poor can change very rapidly..... While increasing fuel prices make the severity of fuel poverty worse (and have an affordability impact for every household), it is necessary to consider whether it is appropriate for the indicator of the extent of fuel poverty to be so responsive to fuel price changes..... the current indicator may mask the impact of changes to the energy efficiency of the housing stock and to income levels.”* (Department of Energy and Climate Change, 2011 pages 104 and 105).

It is argued that the LIHC replacement was sensitive to fuel price change but less prone to the extreme responses. However LIHC has been exposed to other critique in recent years (Robinson et al 2018, Middlemiss 2017). Criticisms include:

- The threshold is set incorrectly at 50%. This means there will always be 50% above and 50% below.
- The LIHC measure doesn’t take into account the size of homes. Thus people in smaller homes, who may be on lower incomes, are less likely to be classified as fuel poor.
- The LIHC measure creates a shift in homes classified as fuel poor away from those in rural areas and with lower housing costs

The US metric is not insulated from changes in the price of domestic fuel. The predicted effect of a rise in the fuel price is that the US fuel poverty rate will move in the same direction other things being equal. Although the fluctuation in US fuel poverty rate, shown in Diagram 3, will have arisen from the interaction of a range of factors, from 2011 onwards the US trend shows movements which are consistent with the expected relationship between changes in the price of domestic fuel and recorded fuel poverty.

There are conflicting arguments that can be made about whether the LIHC metric is more useful than the US metric as a measure of absolute rates of fuel poverty. In fact, it is claimed that neither the 10% indicator nor the LIHC indicator succeeds in accurately representing fuel poverty rates due to its multi-dimensional nature (Robinson et al 2018). An advantage of the LIHC metric is that it monitors both the

warmth of dwellings and the affordability of fuel bills. In contrast, the US metric monitors only the former. It could therefore be suggested that the LIHC metric thus based on a more complete account of fuel poverty. However, it suffers from various disadvantages and criticisms. This complex situation indicates that fuel poverty metrics should ideally incorporate both modelled and experiential approaches.

### ***Summary of Findings***

- Those people with a learning disability living in private households are significantly more exposed to fuel poverty than their peers with other forms of disability, and the population of England as a whole. This result holds under each of two differently constructed metrics – one (the US metric) based on self-reported experiential data and the other (the LIHC metric) generated by a formal statistical model with no experiential content.
- The set of *relative* rates of fuel poverty across five forms of disability (including learning disability) revealed by the US metric closely matches that revealed by the LIHC metric. Thus, in respect of the relative rates of disability fuel poverty there is nothing to choose between the experiential US metric and the statistically modelled LIHC alternative.
- The exposure of people with a learning disability to fuel poverty is significantly greater when measured by the LIHC rate than by the US rate, and this *absolute* difference also holds for all other forms of disability and for the population of England as a whole.
- An immediate cause of these *absolute* differences is that different temperature standards are in play. The evidence is that the standard of perceived thermal comfort that the US metric monitors is several degrees lower than the prescribed health related temperature standard embodied in the LIHC metric.
- The US fuel poverty metric varies much more over time than the LIHC metric.

## 4. Findings from Phase 2: The Household Study

### Introduction

This chapter presents finding from the household study, based in ten homes with an AWLD. However, these findings are prefaced by a section providing information on the levels of socio-economic deprivation and fuel poverty in the small neighbourhoods in which the ten households are located, and then moves on to evidence on levels of thermal comfort and fuel affordability in the households themselves. This information provides a useful context for the household study.

### Deprivation and Fuel Poverty

#### *Neighbourhoods*

Household fuel poverty can be thought of as a result of complex interactions between intrinsic and extrinsic factors. The former are characteristics of household residents, such as their beliefs and values about the need to keep warm at home and the behaviours and practices involved in the use of domestic fuel and in the management of home heating systems. The latter include the flow of income emanating from the labour market and the social welfare system, the thermal efficiency of the household dwelling and the price of domestic fuel. This sub-section presents a brief analysis of an extrinsic factor which is immediately local, that is the level of social-economic deprivation in the very small neighbourhood in which each of the ten households in this study are located, and how deprivation relates to fuel poverty at the neighbourhood level.

The official English Index of Multiple Deprivation (IMD)<sup>5</sup> provides a measure of all round deprivation experienced by people living in every small local area in England. These areas, often referred to as neighbourhoods, are formally “Lower-layer Super Output Areas” (LSOAs) and are designed to be of a similar size. On average they are approximately 1,500 residents and 650 households. There are 32,844 LSOAs in England all of which are placed in rank order of deprivation with one being the most deprived and 32,844 being the least deprived. The IMD is thus an indicator of *relative* not *absolute* deprivation – it tells us whether one neighbourhood is more or less deprived than any other but nothing about the size of the difference.

Although there are 10 study households there are only 9 study LLSOA neighbourhoods because 2 of the study households are located in the same neighbourhood. Figure 4 below shows the pattern of relative deprivation across the nine Rotherham case study neighbourhoods (N1-N9). The horizontal axis distinguishes between the Multiple Deprivation Index (IMD) and the seven socio-economic and environmental components of the multiple index. The key feature of the vertical axis is that, as the rank score *reduces* towards 1 the degree of

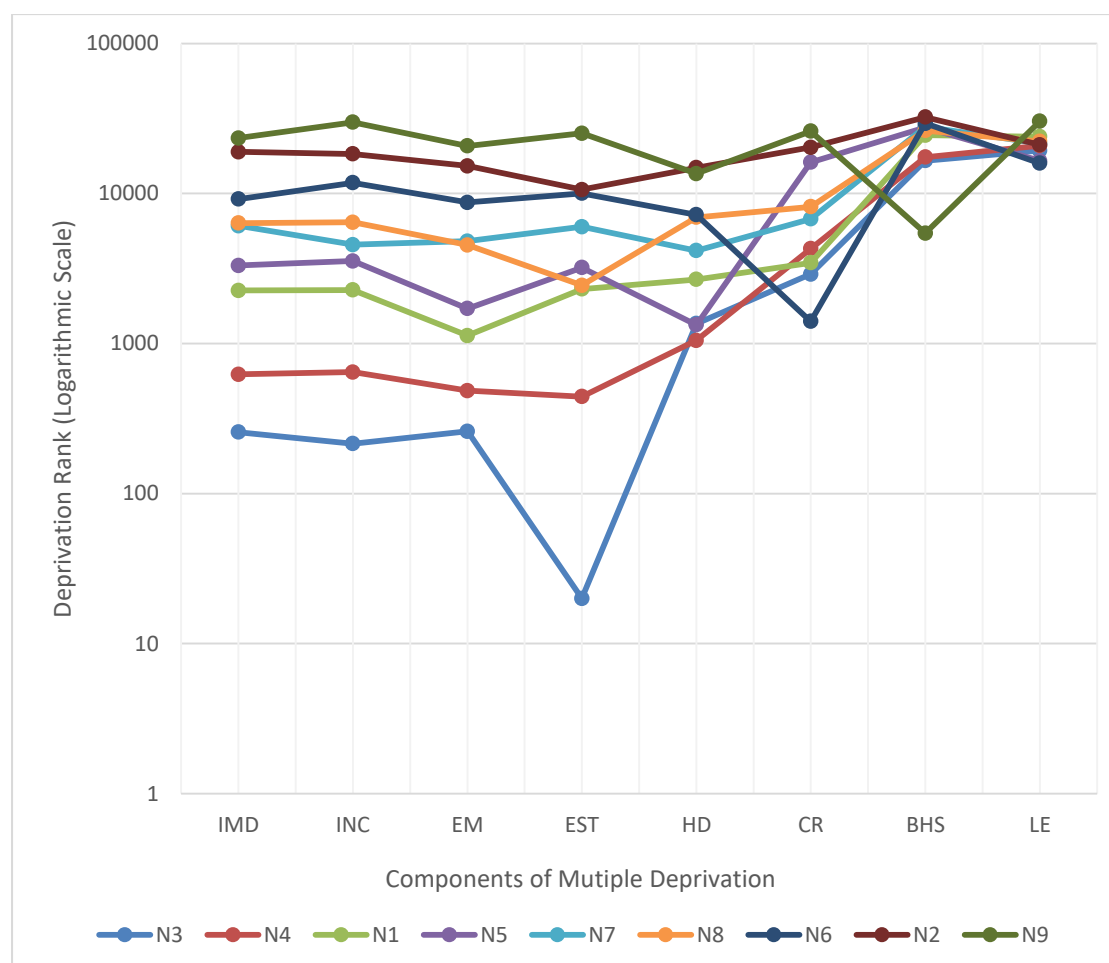
---

<sup>5</sup> The IMD is based on indicators of seven more-or-less distinct domains of deprivation, which are Income Deprivation (In); Employment Deprivation (Em); Health Deprivation and Disability (HD); Education, Skills and Training Deprivation (EST); Crime (CR); Barriers to Housing and Services (BHS); and Living Environment Deprivation (LE). Although these domain indicators are combined together statistically to calculate the overall Index of Multiple Deprivation separate Deprivation indices are provided for each of the 7 component domains



deprivation *increases*, and vice versa. Thus the higher is a curve the lower is the degree of relative deprivation.

**Figure 4. Deprivation in the nine BWBH household neighbourhoods**

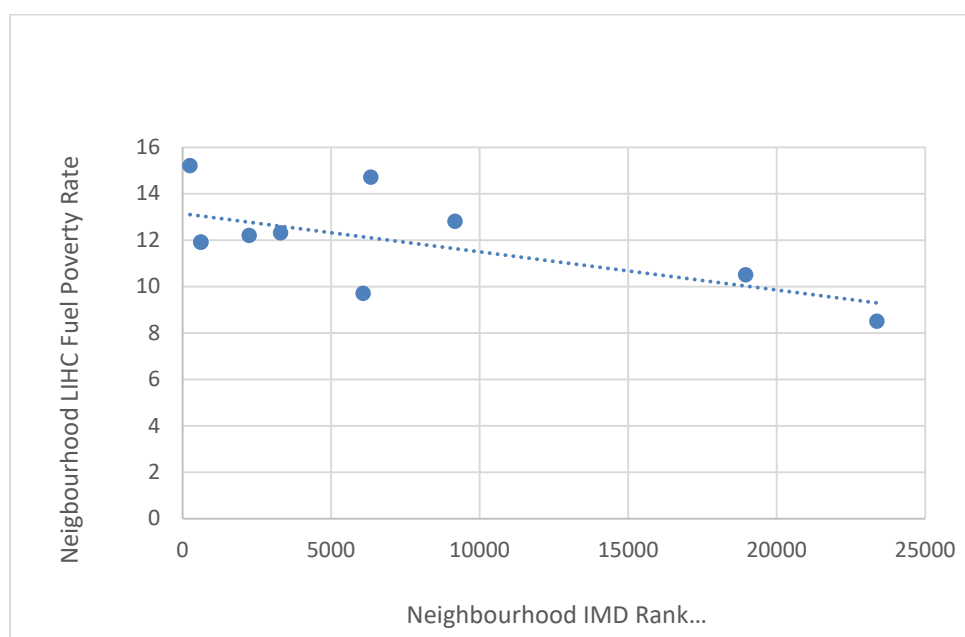


INC = Income, EM = Employment, EST = Education, skills and training, HE = Health and disability, CR = Crime, BHS = Barriers to housing and services, LE = Living environment  
Source: <http://imd-by-postcode.opendatacommunities.org/>

Figure 4 shows that the neighbourhood differences in Multiple Deprivation are largely accounted for by differences in the first three components: Income, Employment and Education, Skills and Training.

There is a close association between multiple deprivation and fuel poverty across the nine case study neighbourhoods, which is shown by the linear trend line in Figure 5. More deprived neighbourhoods (those of lower IMD rank) suffer from higher rates of fuel poverty as measured by the official Low Income High Cost Index and vice versa.

**Figure 5. Deprivation and Fuel Poverty in the nine BWBH neighbourhoods**



Source: for Neighbourhood IMD Rank as for Figure 2.1  
for Neighbourhood LIHC Fuel Poverty Rate <https://www.gov.uk/government/statistics/sub-regional-fuel-poverty-data-2017>

The key feature of Figures 4 and 5 is the width of the range of multiple deprivation and fuel poverty across the nine case study neighbourhoods. The black curve (N9) neighbourhood in Figure 1 is amongst the 30% *least deprived* neighbourhoods in England whereas the dark blue (N3) and orange (N4) curve neighbourhoods are amongst the 2% *most deprived* neighbourhoods in England, with the former being amongst the 1% *most deprived*. The rate of LIHC fuel poverty in the most deprived (N3) neighbourhood is 4.8 percentage points above the national rate (10.4%) whereas that in the least deprived (N9) is 3.9 percentage points less. Although the sample is small (10), the data shows that the case studies largely cover the spread of deprivation and fuel poverty in England as a whole.

The question that now arises is whether this clear link between multiple deprivation and fuel poverty at the **neighbourhood** level feeds down to the **household** level. Specifically, are the households where an adult with a learning disability lives located in more deprived neighbourhoods more exposed to fuel poverty than those in less deprived neighbourhoods? If this were generally the case, the officially measured Neighbourhood IMD score could be used as a device to target support to those households where an adult with a learning disability lives which are most vulnerable to fuel poverty. An answer to this question for the ten case study households can be derived from items of evidence from the household case studies, presented in the next section.

## Households

Two items of evidence from the BWBH household sample can be used to generate a plausible rule of thumb signal of household exposure to fuel poverty which is consistent with the official LIHC metric.

1. “yes/no” answers given by the ten study participants to the interview question “in winter are you able to keep this accommodation warm enough” combined with recorded winter day time living room temperatures.
2. Participants’ answer to the interview question “do you worry about paying for your energy?”

A combination of “yes” to question 1 and “no” to question 2 can be taken as an indication the participant is “not in fuel poverty”. This would be consistent with the LIHC fuel poverty metric. Such a household reports adequate warmth in winter, the cost of which is affordable. In contrast a “yes” / “yes” combination indicates *at least* a risk of fuel poverty. This household reports adequate warmth in winter the cost of which is *at least* close to being unaffordable, which is also consistent with the LIHC metric. A “no” answer to question 1 signals “fuel poor” regardless of the answer to question 2.

Column 2 in Table 1 shows a summary of the transcript of participants’ answers to the adequate warmth in winter question, together with the range of recorded winter day time living room temperature. Column 3 summarises the answers to the question about energy bills. Column 4 gives the plausible fuel poverty signal as defined above. Column 5 gives the IMD rank for the neighbourhood in which each household is located (1 = the most deprived neighbourhood in England and 32,844 = the least deprived). Household 1 is located in Neighbourhood 1 (in Figure 1 above), and so on. Households 4 and 6 are located in the same Neighbourhood (N4).

Four of the ten BWBH households are estimated to be in fuel poverty, which is over three times the 12% rate of LIHC fuel poverty in households where an adult with a learning disability lives in England as a whole (see Chapter 3 Diagram 1).

**Table 2. BWBH household Study Evidence on Thermal Comfort and Fuel Affordability**

<b>Case Study Household</b>	<b>Answer to the question “in winter are you able to keep this accommodation warm enough”, and range of winter day time living room temperature</b>	<b>Answer to the question “do you worry about paying for your energy”</b>	<b>Household Fuel poverty signal</b>	<b>Neighbourhood IMD rank (relative deprivation inversely related to IMD rank)</b>
<b>Household 1</b>	Yes, (at sometimes) 20C-22C	Not really	Not in fuel poverty	18 967/32 844
<b>Household 2</b>	Yes (unqualified) 18C-22C	Sometimes it's a worry	At risk of fuel poverty	2 256/32 844
<b>Household 3</b>	Yes (unqualified) 20C-23C	Not much of a worry	Not in fuel poverty	257/32 844
<b>Household 4</b>	Yes (unqualified) 25C-26C	No I don't worry about bills – I'm alright	Not in fuel poverty	623/32 844
<b>Household 5</b>	Yes (unqualified) 19C-23C	I do get worried	At risk of fuel poverty	3 309/32 844
<b>Household 6</b>	No (unqualified) 10C-15C	No	In fuel poverty	623/32 844
<b>Household 7</b>	Yes (unqualified) 23C	No	Not in fuel poverty	6 345/32 844
<b>Household 8</b>	Yes (unqualified) 21C-23C	Not really	Not in fuel poverty	6 089/32 844
<b>Household 9</b>	Yes (unqualified) 20C-24C	Not worried about bills	Not in fuel poverty	9 179/32 844
<b>Household 10</b>	No (in some rooms) 15C-18C	Not really	In fuel poverty	23 384/32 844

It is clear from Table 1 that in our sample households which include one or more people with learning disabilities located in more deprived neighbourhoods are **not** invariably more exposed to fuel poverty than those in less multiply deprived neighbourhoods. In that:

- Four of the six households not in fuel poverty are located in less deprived neighbourhoods (households 1,7, 8 and 9). However, the remaining two are in the two most seriously deprived neighbourhoods (households 3 and 4).
- The two households which are clearly locked in fuel poverty (households 6 and 10) are located in neighbourhoods at opposite ends of the spectrum of neighbourhood multiple deprivation. The former neighbourhood is seriously deprived by local and national standards (IMD rank = 623/32,844) whereas the latter is very emphatically not (IMD rank = 23 384/32,844).
- One of the two households located in the same neighbourhood is not in fuel poverty (household 4) whereas the other (household 6) is.
- Although household 3 is located in the most seriously deprived neighbourhood (IMD rank 257/32 844) it is not in fuel poverty.

Thus there is no evidence to match the pattern of fuel poverty across the ten households and the pattern of multiple deprivation across the small neighbourhoods in which the households are located. This lack of association could reflect a sampling issue. Because there are more and less deprived households in any neighbourhood it could be that the ten case study households are untypically deprived. That is they may be more or less deprived than the neighbourhood in which it is located. But there is a plausible alternative explanation of a very different kind. It may be that the pattern of fuel poverty in the BWBH households reflects the intrinsic within-household factors such as beliefs and behaviours related to energy use which are more influential than the extrinsic factor of neighbourhood deprivation.

### **Summary of findings on deprivation and fuel poverty related to the BWBH neighbourhoods and households**

- The case study neighbourhoods are drawn from a very wide spectrum of multiple deprivation.
- There is a close association between multiple deprivation and fuel poverty across the case study neighbourhoods.
- On a LIHC consistent basis the rate of fuel poverty in the households where an adult with a learning disability lives is over three times that in learning disabled households in England as a whole.
- There is no association between fuel poverty in the households where an adult with a learning disability lives and multiple deprivation in the neighbourhoods in which the households are located.
- This lack of association indicates that differences in fuel poverty across the case study households reflect differences in extrinsic determinants other than those associated with neighbourhood deprivation, or differences in intrinsic – within household – determinants of fuel poverty, or both.

The experiences and views of the BWBH households will now be presented.

# The experience and risk of fuel poverty from the perspectives of AWLD

## Introduction

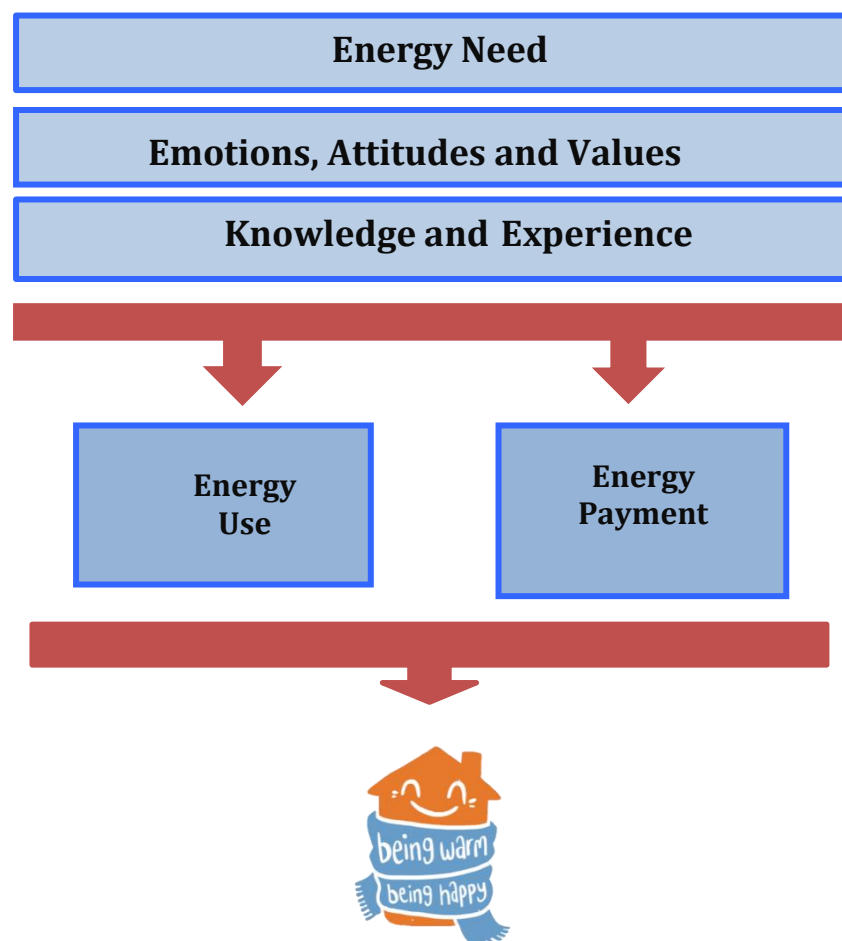
This section of the report presents the findings from the household study. The focus is on the qualitative interviews with AWLD. Information on temperature measurements is therefore woven into the qualitative interview findings, as well as being used in the pen portraits and personae developed for the co-production phase.

A thematic framework was developed from relevant policy reports, academic literature and initial analysis. This was then used to guide the ongoing analysis of interview transcripts after which a final thematic framework was produced. This was developed in consultation with stakeholders and the advisory group.

## Temperature measurements

Temperature and humidity measurements were taken but it was not the intention to report these in detail. Rather we wanted to identify if participant's thermal comfort matched their actual home temperatures. Table 2 demonstrates that participant's thermal comfort did match temperature recordings. Participants in the two coldest homes did report they were cold. Also, as there were only 10 households this is not sufficient to make any statistical claims regarding prevalence of high or low temperatures.

Figure 6. The BWBH thematic framework



## Interview findings

Figure 6 provides a visual representation of the thematic framework. This shows that i) energy need, ii) emotions, attitudes and values, and iii) knowledge and experience form the foundations from which households use and pay for energy. Ultimately, how people do or do not use and pay for energy contributes to whether AWLD are able to be warm and happy in their homes.

The following section considers each element of the framework in relation to the interview data obtained during the household study.

### **Energy need**

Energy need refers to levels of thermal comfort required in each household. Participants recognised that their personal circumstances impacted upon their energy need at home.

Table 1 (in Methods section, page 14) contains some contextual information alluding to the energy needs of each household. It is clear from the table that the type of accommodation varied across the sample in terms of size, tenure and age, all of which carry potential implications for the energy efficiency of the home and therefore energy need.

Regarding occupancy, energy need is likely to be influenced by the daily routine of those living in the household. For example, a family of four will understandably have different energy needs to a single occupant. With this in mind, only two participants (Person 5 and Person 8) lived alone while the remaining participants cohabited with family members.

The characteristics of occupants sharing the home also contributed to energy need. Living with children (Person 1 lived with her two daughters) or older people (Person 7 lived with his mother, aged 80) increased the energy need of the household. Participants recognised that if you had a health problems or co-morbidities your need for energy and heating was higher, illustrated in the data extracts below. Energy needs were also increased if people were at home a lot because of health or employment status.

*“‘cause with my arthritis I’ve got to keep my legs warm”. (Person 4)*

*“I have to put it [heating] on ‘cause of my health, ‘cause [support worker] told the company I’m epileptic... I’ve got to have the heating on ‘cause if I stays in cold, it could trigger a fit off with me trembling and stuff”. (Person 5)*

### **Emotions, Attitudes and Values**

Participants’ accounts illustrated how emotions, attitudes and values shaped their approach to energy use and payment. The following section therefore explores this in relation to how participants felt about their energy use and payment, the impact of family values and practices and attitudes towards technology.

## *Emotions*

Energy consumption was a cause of concern and worry for many participants, principally in terms of payment. They worried about not having enough money to meet their energy needs. Concerns were expressed about impending uncertainty regarding energy prices and the financial support available. Both were seen to be sensitive to regular changes, a view based on previous experience for some. A sense of control was important to help alleviate this worry and directly influenced how participants interacted with both their heating system and means of payment.

The majority of participants (all except Persons 7 and 8) opted to manually switch their heating on and off rather than use a thermostat or timer to control the temperature in their home. In this way, they felt more in control but may not have been the most efficient or cheapest way to heat their home.

*“It means you can put it on when you want it on and turn it off when you don’t want it on”.* (Person 4)

By manually adjusting their heating participants felt reassured that their use was more predictable and they would not waste energy or overspend on fuel costs. For this same reason, most participants (except Persons 7, 8 and 10) used a prepayment meter to pay for energy, again increasing the risk they paid more than necessary for their heating. The sense of control this provided justified the decision to use a prepayment meter, as illustrated in the data extracts below.

*Researcher: Is there anything else about paying for energy that worries you?*

*Person 1: Not really, apart from just really having the money for it and making sure that the bill’s being paid for and I’m not getting threatening letters from the company that I owe some money. So I go into the shop [to top up the prepayment meter]... I know it’s being paid for and I don’t have to worry about it.*

Participants portrayed a sense of pride in managing their own homes. They wanted to present themselves as independent, and were very conscious not to give the impression that they were unable to cope.

As explained at the beginning of this chapter, the majority of participants (8 out of 10) said that they were able to keep their accommodation warm in winter, when they were explicitly asked the question. However there was some suggestion that this was not always the case. For example, the Tinytag data suggested that the temperature in some households was below the recommended 18-21 degrees Celsius. The Tinytag data showed that the temperature in Person 6’s living room did not achieve temperatures of 15C or over during the two week period. Sometimes the temperature dropped to below freezing. Similarly, the temperature in Person 10’s



living room only entered the recommended 18-21C on two days over the two week period, remaining below this the remainder of this time.

It is possible that participants wished to give the impression that they were coping and able to keep their home warm when, in actual fact, sometimes they were not. The content of the interviews suggested that participants were aware of how they may appear and frequently tried to reassure the researchers that they managed their energy use and costs well. The following data extracts illustrate this.

*Researcher: And how do you pay for the heating and your energy bills?*

*Person 4: Oh I pay about...every fortnight...We put plenty on...we'll put plenty on heaters. Put plenty on water.*

*Person 5: Yeah. But I am still independent. I've only got...got to get that bit of support with my reading and stuff.*

There are potential implications of this sense of pride and determination. Maintaining the impression of coping in this way may delay people in accessing the support and information needed to be warm and happy at home. That is, people may delay recognising or admitting to a problem, and so encounter hardship.

In order to understand energy use and payment, it is necessary to look beyond the energy need of each household. This includes consideration of how AWLDs feel about using and paying for energy in their homes. The data showed that maintaining a sense of control and pride were important elements of this.

### *Family values and practices*

The values held by family members about energy use and payment shaped how participants interacted with energy. They tended to share similar attitudes towards energy use and adopted the same means of energy payment. Family members shared information about how to keep warm and happy at home and, in doing so, learned from one another.

Person 1 explained that her mother's experience had contributed to her choice to use a prepayment meter in her home.

*"And that's...the idea I got from [my mum] really, 'cause it taught me as well to make it a lot easier. I know it...I know the bill's paid for. I'm not going to get a letter through post.... You're not worrying about that bill coming through post, saying you owe so much money". (Person 1)*

Family was often the closest source of support for participants. It is therefore no surprise that family member values and practices influenced the AWLD towards keeping warm and happy in the home. Participants actively sought information about energy payment and energy saving tips from their family members.

*Researcher: So, where do you think you've learnt all those things from?*

*Person 10: I'd say it will be from my mum and dad, I think yes.*

### **Attitude toward technology**

Increasing use of technology was recognised as an important component of energy use and payment. Nearly all participants had smart phones and regularly used the Internet with some degree of confidence. However, this is not typical of all people with a learning disability (Abbott, 2007). All the BWBH participants demonstrated a lack of understanding and/or confidence in using the technology associated with energy use and payment, including smart meters, thermostats, direct debits and prepayment meters. For example, instead of topping up prepayment meters using a smart phone application, they chose to walk to the nearest shop to top up over the counter. In this way they engaged with a person rather than the available technology.

*"Cause you can't use these machines now. It's all machines. And you can't understand them. Like, I was struggling to try and find somebody to come and do it for you... They've taken that counter away. And you do it by computer".* (Person 5)

Person 1 reflected on using a thermostat to control the heating in her home. She decided it was easier to manually control the heating than rely on thermostat technology.

*"And I used to have it that way [use thermostat to control the heating system] and I...and me and [partner] stopped it because it was making...coming on in middle of night and we were getting too hot. And it wasn't coming on in the morning. So me and [partner] just stopped it".* (Person 1)

Person 9 was concerned about the prospect of getting a smart meter after experiencing difficulty using other devices.

*"Well I don't know how it [smart meter] works do I, with it like? ...Cause I had problems with my X-Box. I had to take it to my niece's husband to sort it out, 'cause I don't have a clue with them." (Person 9)*

Most households were aware of the technology associated with energy use and payment. However, their lack of confidence in using these devices acted as a barrier to embedding these into their energy use and payment practices. This could result in AWLD inadvertently not using the most energy efficient practices in the home as well as missing out on relevant information and the best tariffs for their fuel and energy.

## Knowledge and Experience

Alongside energy need and emotions, attitudes and values, participants' existing knowledge and experience informed energy use and payment. The following section will explore this in relation to past experiences, sources of support and decision-making.

### *Past experiences*

Participants frequently justified decisions and practices regarding energy use and payment by reflecting on past experiences. For example, all who paid by prepayment meter explained this by reflecting on negative past experiences of using direct debit payments.

*Researcher: So do you have any direct debits or is it all pre-payment?*

*Person 1: I used to, but it wasn't working out so well. I were forgetting to pay it and stuff, so cards is been easier for me because if they're in my purse, I remember to pay them, you see, and making sure that the bill's paid for and then I don't get a right high bill.... It were remembering to leave money in the bank account.*

The impact of past experience also influenced who people contacted for support.

*"Yeah. Or if I have any problems in the house, I ring, like you know, you know like if we hadn't got a radiator working, I ring the council. ... Yeah, they're brilliant the council, yeah, they're lovely yeah. They know me and [son], they know we've got a mild learning difficulty". (Person 3)*

This example highlights the importance of valued and trusted supportive relationships to prevent negative experiences.

### *Sources of support and decision making*

As already demonstrated in the section on family practices and values, family was an important source of support for many participants, in terms of both emotional and practical support. Another vital and trusted source of support widely accessed and praised was the self-advocacy organisation, Speakup.

*"Like, if I have a letter, and if I can't understand it, I always take it to Speakup... And if I'm a little bit worried, I take it to Speakup, and they help you. Speakup help us with letters and that. You know like, if we can't read, or if there's a letter we can't understand, they explain it better". (Person 3)*

This highlights the importance of the support provided by advocacy agencies, such as Speakup, in the lives of AWLD. In doing so, it raises concern for those who do not have access to the support of organisations such as Speakup. One participant

recognised the importance of accessing support from different sources rather than remaining solely reliant on a self-advocacy organisation.

*"I can hear what they're saying but they're speaking too fast, I can't make out what they're trying to tell me so that's why Speakup] or my partner... He speaks on my half, 'cause he...he's good at talking to them and understanding what they're saying ....he's the one who helps me pay the bills...., if I didn't have Speakup, I've got someone else I can turn to...(Person 4)*

Other sources of support were identified, including energy companies and the local council. Examples include accessing smart meter and 'stay warm' information from an energy company and practical help from the council when the heating isn't working. However, others felt unsupported, particularly at a time of crisis. Person 1 demonstrated this when she described her difficulty contacting the energy company when in need of support.

*"Yeah, when you're on hold or they might turn round, and say, you're sixth or seventh person in queue and you're waiting a while just to get in touch with someone, or it can just beep and be really busy.... in one day, you could have phoned about two or three times or four times just in one day to tell them you've got an issue with your boiler or your heater's not working properly. ... even if you do get in touch with them, they won't turn round and say, I'll come out next day, it might be about second or third day afterwards and you're could be sitting in house, freezing cold". (Person 1)*

The accessibility of trusted support and information is a potential barrier for AWLD in utilising that which is available. Accessibility carries meaning beyond the format of resources provided and includes how participants feel about engaging with support.

For those living in social housing, their local council was a source of support and help. For example the local council helped service and set up their boiler and heating system. However, there was reference to a lack of involvement in decision-making, implying an opportunity had been missed to enable someone to self-manage their home heating.

*"We've got council who comes out to set your boiler, see it's working okay. And they set everything, you know. (Person 4)*

*"They set it, they set it, council. We aren't to touch it". (Person 7)*

*Researcher: You're not allowed to?*

*"I think the council can be a bit strict with you. Say if you keep messing around with the boiler and the meters and all that, they can...they do tell you off and tell you not to mess about with them". (Person 1)*

Similarly, when a participant's family member managed energy use and energy payment on their behalf, the AWLD was not as well-informed or involved in decision making as those who managed this independently. For example, participants 10 and 6 did not know how their family members paid for energy. Although well-meant and helpful, ultimately this help reduced the energy knowledge, control and choice for the AWLD.

*"When I get a letter. I mean I usually get one with my bank statements on it, and I ring my dad up and I let my dad see it...Because he's in charge of my money, you see, because he's keeping an eye on what I'm spending". (Person 8)*

This absence of knowledge and choice carries potential implications for the future when family members may not be able to continue providing the same level of support.

The findings in this section shine a light on the delicate balance between support and independence in relation to energy use and payment. In order to address this balance, there is a need for accessible information and support for AWLD so that they are able to develop the knowledge and confidence needed to make decisions regarding energy use and energy payment.

## ***Energy Use***

This section focuses on how households used energy. It is clear that energy use is influenced by factors identified previously. This section will cover the trade-offs participants made in an effort to meet their energy need, strategies used to ration energy use and selective disconnection.

### *Trade offs*

Participants all described weighing up energy consumption with cost implications. Subsequently trade-offs were made to meet energy needs. For example, Person 2 traded personal space and independence to enable her to meet living and energy costs. She invited a family member to move in and contribute towards these costs as she was struggling to manage alone. Her struggle started following the introduction of Universal Credit, and a severe drop in income as a result.

*"He's [father's] paying for the roof over our heads so we're not on the street". (Person 2)*

Another household described sacrificing food so that they could cover energy costs.

*"It's a bit awkward. I'd rather have...be with pay meters like, 'cause we had that down at [previous house] didn't we?. ...if we wanted to go shopping or 'owt, there*

*weren't enough money for food, you know, like if you're using so much gas or electric and stuff". (Person 9)*

Trading off space for heat, spatial shrink, was another type of trade off evident across interview data. For example, Person 8 only switched the radiator on in the room she was using, turning this off when she left the room. In another example, Person 7 described how his mother slept downstairs because the living room was warmer than her bedroom.

*"She sleeps down here because it's too cold up there for her, in her bedroom, see". (Person 7)*

### *Restricting energy use*

All participants detailed strategies to limit the amount of time they heated their homes. Nearly all households (8/10) switched the heating on and off themselves, rather than rely on a thermostat or timer. This enabled households to switch the heating system and/or individual radiators on and off to restrict the time the heating was on. All households made sure the heating was off when they were not in the house and at night, resulting in a severe drop in temperature and excessive energy use to get the household up to a healthy temperature. The act of manually controlling energy use in the home meant that participants were able to easily able to ration energy use, and restrict heating so it was used only when considered absolutely necessary. The three data extracts below illustrate this across three households.

*"I **only put it on when it's right cold**. ... When I come home from work, if I know it's cold, I just put it on, a couple of minutes, to warm the place up, then I turn it off". (Person 3)*

*"I put it on when it's **right cold in here, you know, when it's right cold in winter**". (Person 4)*

*"Sometimes they [others in the house] have the central heating on but it's **probably only on, you know, a really cold day**". (Person 10)*

Another strategy used to restrict heating to when all members of the household were home.

*Researcher: what time do you tend to put the heating on in the evening?*

*Person 1: From I would say near enough four o'clock, because at that time we've all got in house.*

Tactics were used to delay or avoid heating use, including wrapping up in blankets, wearing extra layers of clothing, drinking hot drinks and using hot water bottles.

*“Well, sometimes waiting for Dad to come back I’ve actually got two hot water bottles and I’ll fill them both up, like one for my hands and one for my feet”.. (Person 2)*

Energy cost was a clear driver for rationing energy use in the home. For example, the only household that used a timer to operate their heating system used this to ration energy use. The timer was set to one hour in the morning and one hour in the evening.

*[this was] to save the, well, gas and electric really, 'cause obviously being a meter it...using the cooker and everything else it drains it out pretty quick”.* (Person 9)

There was evidence that people were selectively disconnecting from their energy because of cost. For example, Person 4 looked back on the previous winter and said *‘It was too much money.... [I] keep not putting heating on even in wintertime’*.

Participants described selectively disconnecting from their energy whilst waiting for money to enter their bank account. Most often this was by not topping up prepayment meters.

Limiting the use of appliances and being mindful of energy efficiency were also strategies used to restrict energy use. Participants talked about using energy saving lightbulbs, making sure the kettle was only filled with the amount of water needed, not leaving the tap running unnecessarily and only using the washing machine once a week. Considering the energy efficiency of the home in a broader sense, some households installed insulation and opted for carpets rather than laminated wood flooring to limit heat loss in the home and therefore limit energy use.

To summarize, each household used a range of methods to ration energy use in order to reduce financial costs. These included manually controlling heating systems to delay energy use until considered absolutely necessary. Strategies were adopted to stay warm without relying on heating systems e.g. hot drinks, limiting the use of appliances and being mindful of energy efficiency. For some participants the need to limit money spent on fuel meant they were sometimes in a cold home or were going without other essentials by making trade-offs.

### ***Energy Payment***

The following section considers how each household paid for their energy. It will consider the rationale and decisions for using direct debit or prepayment, the role of smart meters and how households managed their finances to allow for energy costs. How the factors identified above influence these decisions will be reflected upon.

#### ***Prepayment meter vs direct debit***

The majority of participants expressed a strong preference for using either prepayment meters or direct debit payments. Three households used direct payments (Persons 5, 8 and 10). Person 8 and 10 had no involvement in deciding how to pay for their energy because parents made these decisions on their behalf.

Person 5 opted to pay by direct debit because, for him, this caused least anxiety and he believed that this was the most cost-effective method. He was however the only person in the sample to express concern over the cost of using a prepayment meter relative to direct debit payment.

*Person 5: I just put it on direct debit you see, so I'm not worrying about it. Same with my council tax. So I do it direct debit so it gets paid automatically so I'm not worrying about it.... I had a meter put in, but I soon had it taken out because it was eating money. (Person 5) ...*

In contrast, participants who used a prepayment meter reported this to be the most cost-effective option for them because the meter enabled them to budget and use energy accordingly. The uncertainty regarding how much energy was being used, and therefore how much money was being spent, was perceived as a significant disadvantage to using direct debit methods. Participants thought it was vital to understand how much money was left on the meter so that they could budget accordingly.

*"Well it's just we don't have to worry about paying loads of money really. We can just top it up whenever we want to..." (Person 9)*

*"I'd rather be on meters than you're not getting surprise bills like say, they come out for a reading and then they send your estimate, not the proper thing, so you're either paying more or you're paying less. But most of time you're paying more than what they're saying, and you have to constantly keep phoning them up saying, no, this is wrong, it's nowhere near this". (Person 1)*

*Because I know I'm putting it on, and like I say, when it runs out, then I just top it up, and I know when I need to put it on, and I just put it on ... I prefer that instead of having bills coming through. Now, if I didn't have that [pre-payment meter], and I were paying bills, I would be a little bit, not worry worried, but I'd be worried in case, if one day I don't pay it, or if I not got right, money. (Person 3)*

In contrast, paying for water by direct debit was not considered problematic. The monthly bill for water was not perceived to be dependent on usage in the same way as energy, and so not as likely to fluctuate. Participants said that they could use water as and when they needed without receiving an unexpected bill, therefore paying for water via direct debit payment was considered low-risk.

*"Water's just direct debit but it's monthly. ... I'm not behind with it, I'm alright. I pay 41.40 a month and that's as much water as I want". Person 2)*



One criticism of prepayment meters raised by participants was accessibility. Person 5 explained how he found the prepayment meter difficult to use due to his visual impairment.

*“‘cause, you see, my eyes were bad. I couldn’t read it, it was that small. And it was going that quick. By the time I put my card in...terrible”.* (Person 5)

Similarly, Person 1 explained how the location of prepayment meters can reduce accessibility and their ability to monitor energy use.

*“Yeah, I do because before, in this house, the other meters, they’re down cellar, and the stairs aren’t very safe. It’s a bit dangerous. And you’ve got to go down there and then put a key in it or a card in it to go to the other meters. And I don’t like doing it that way, not because where it is but you’ve got to keep going up and down stairs”.* (Person 1)

Overall, for most participants prepayment energy meters offered a sense of control over finances that direct debit payments did not. Nevertheless, accessibility of prepayment meters was an issue for some depending on sensory disability and location of the meter.

### *Smart meters*

Some households (3/10) had smart meters installed in their homes. They liked and actively promoted the use of these. Nevertheless, there was a lack of clarity regarding the purpose of a smart meter. Participants 10, 9, 8 and 6 did not know whether they had a smart meter in their home. Person 9 confused the smoke alarm in their hallway for a smart meter, unaware of what a smart meter actually was. There was also some confusion amongst those who did have a smart meter because some are combined with prepayment meters and some are not. One participant with smart meter still seemed uncertain about their role, *‘I’ve got a smart meter, whatever they are.’* (Person 1).

Ease of use was a motivating factor to use a smart meter but barriers were also highlighted including difficulty accessing the meter. This data extract highlights the importance of location.

*“I can’t keep going in those cupboards....if it can go in there [if the smart meter can go by the side of the tv], I can just go over like that and put my glasses on and I can just look over. ... ‘Cause I can’t....kneel down and check the meter when it...where it is...”* (Person 4)

The potential value of a combined smart meter and prepayment meter was identified. Not having to look at different meters in different locations was a benefit. A combined device improved accessibility of the meters on a practical level. As well as this, several participants made recommendations regarding the accessibility of the interactive display on a smart meter. These included the need for larger font and buttons, simpler phrasing, audio instructions and use of a colour display.

*“These smart meters need to be bigger and more understandable. You can get a smart meter what could talk to you ... And say to you when to put your coat on and when to take it out... When to put the card in and when to take it out, when it’s taken the money or whatever”. (Person 5)*

Although there was some confusion about the role of smart meters in energy use and payment, participants were able to recognise the potential value of these, particularly as the display screen advances to become more user-friendly. There was a call for such improvements to meter design to happen as soon as possible.

### *Financial management*

Nearly all participants raised concerns about paying for energy. All managed their finances carefully, conscious of how much money was going in and out of their bank account. Topping up the prepayment meter regularly (weekly or fortnightly) helped with budgeting. Several participants (Persons 3, 4 and 9) described managing energy payments according to the day of the week they received welfare payments.

*“I know how much we’ve got ... count out his money when we gets it, it’s 64, so I give that lady the 64 in the shop and I know how much it is altogether for all the bills. So every fortnight I go and pay 64”. (Person 4)*

*“Well if it’s ESA<sup>6</sup> week, it’s £15, but when DLA<sup>7</sup> goes in it’s a bit more, like £25 on it.... We get paid every Tuesday, so we [top up] then”. (Person 9)*

*“I always try my best to top it up straight away. As soon as I get my money on a Wednesday, that’s when it really gets topped up”. (Person 3)*

Some households used the ‘emergency fund’ embedded in the pre-payment meters as a strategy to pay for energy. However, this tended to only be when ‘*in desperate need*’. (Person 9)

*“I mean most of the time I activated it [the emergency fund] before Dad moved in because like say it were either Friday or Saturday I were running low and I activate the emergency and then Monday coming around, get paid, so that when I get paid I’ll go and... “ (Person 2)*

---

<sup>6</sup> ESA: Employment and Support Allowance

<sup>7</sup> DLA: Disability Living Allowance

For those reliant on welfare, they reported being adversely affected by the recent changes to welfare payments in terms of being able to afford energy. The main change and source of anxiety was the roll out of Universal Credit (UC), and the associated reassessment. The uncertainty regarding UC and other financial support, including the Winter Fuel Payment, was a cause of concern.

*“Yeah, I did manage okay before because whilst I were getting my DLA and whatnot everything were cheap enough but now it's skyrocketed... so how the heck can I afford it now .... I'm just worried that for next year I won't be entitled to it [Winter Fuel Payment] again unless my benefits start again because the only benefit I'm getting is housing so I don't know if I'll be eligible for it again”. (Person 2)*

Those reliant on welfare payments to pay for their energy were more likely to budget according to these payments on a weekly or fortnightly basis, rather than monthly payments.

### **Summary of findings from the household study**

The findings from the household data indicated the following:

- Occupancy and characteristics of those sharing a home influenced energy need and use. For example, if the home was shared with others, their views on heating had to be considered.
- Those with health problems or additional disability knew they needed to keep warm in order to maintain their health.
- Being able to keep warm at home was a cause of worry and anxiety for the participants, mainly because of cost.
- To manage this anxiety and try and maintain control, people adopted a range of strategies including manually operating the heating, making trade-offs between fuel and other household expenses, paying by pre-payment meter, and restricting heating use.
- These strategies sometimes led to participants paying more for fuel because of their tariff or less efficient use of energy.
- Other strategies meant people suffered hardship such as being cold at home, or hungry.
- Approaches were adopted to stay warm without relying on heating systems e.g. hot drinks, limiting the use of appliances and being mindful of energy efficiency.
- Roll out of Universal Credit, alongside other benefit changes (actual or threatened), aggravated existing financial worry.
- Having family who could help with advice or advocacy was a key facilitator, as was access to an advocacy group such as Speakup.
- For most participant's, prepayment energy meters offered a sense of control over finances that direct debit payments did not. However, if people had

problems with sight and mobility, accessing the pre-payment meters could be problematic.

- There was confusion about the role of smart meters. However, some participants were able to recognise the potential value of these. Improvements to the user interface and better advice and information on how to use them were urgently requested by participants to overcome barriers, for example having a smart meter that spoke to you or had an easier to understand display.
- Participants worked hard to manage their household finances, keeping track of the flow of income and outgoings for the home. However, managing change was difficult, for example, when benefits were reduced or fuel costs increased.
- The three themes of i) energy need, ii) emotions, attitudes and values, and iii) knowledge and experience were all interrelated, thus creating a complex challenge for AWLD in being warm and happy at home.
- Multi-faceted and novel solutions are required within and across systems to overcome the challenges identified.

## 5. Findings from Phase 3: Co-production

### Introduction

This chapter summarizes the findings from the co-production workshops. The themes that emerged are critical in understanding the experience of AWLD regarding fuel poverty and home temperatures. The practical problems and solutions that were identified will then be summarised. The chapter will conclude with a précis of the work conducted by the graphic design students in response to the challenges identified in relation to smart meters, prepayment meters and energy bills.

### Fuel poverty and home temperatures for AWLD

The experience of AWLD was brought to life in the co-production workshops by developing personae from the themes identified in the phase two household study. Three personae were developed: John, Joanne and Bob. Attitudes to using and paying for energy were identified as critical in understanding how an AWLD may end up in a cold home or struggle to avoid fuel poverty and its negative impacts. Attitudes and behaviours varied enormously, from those who were cautious about using their heating to those who recognised the importance that keeping warm had on health and wellbeing.

Underpinning these attitudes was a range of influencing factors. These included knowledge and understanding of keeping warm and energy systems, social networks and availability of trusted advice, confidence and knowledge with technology (including payment, communication and heating technology). Underlying health problems also influenced the need for warmth and heating behaviour.

Many of the attitudes reflect the findings in the phase two household study, but the co-production methods enabled a better understanding to emerge about how factors interacted to compromise someone with a learning disability in being able to keep warm. These are summarised below for the different personae.

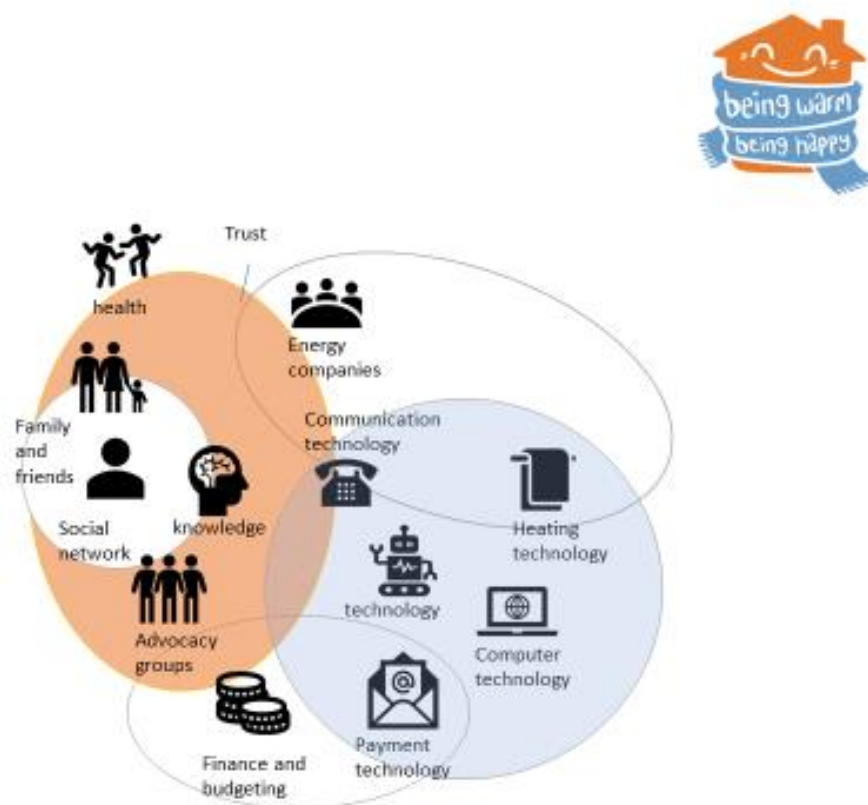
**John:** John is a 59 year old man who lives alone in a one bedroom housing association bungalow. He has been there for 2 years. His direct debit fuel payment was set up with the help of a support worker but he does not have a smart meter. John doesn't really understand how much fuel costs or how much he is using. He is an active, sociable person who lives near and helps care for his elderly mum. There are people in the neighbourhood he trusts for advice, like the lady at the post office. He knows he has to keep warm because the cold aggravates his epilepsy, and he likes his precious cat to keep warm. John does not like or understand computers and the Internet, partly because of his poor sight.

**Joanne:** Joanne is a 31 year old woman who lives with her partner Tom. They have been in their council home for five years and use a pre-payment meter. They do not have a smart meter as they do not really understand how they work or what they are for. They are cautious about their heating even though Tom has a chronic lung

condition which means he needs to keep warm. They limit having their heating on for an hour at a time and just 'manage' in between. However they do end up having 'thermostat' wars about when to turn the heating on or off. Joanne and Tom are worried about money as they rely on benefits for their household income. They are hoping to have a family sometime in the future when they can afford it. The pre-payment meter helps them avoid debt due to their energy costs. They have limited family nearby for support. They would need to have a high degree of trust in someone to ask for advice.

**Bob:** Bob is a 28 year old man who lives with his parents and siblings in a 3 bedroomed privately owned house. He has no involvement in the decisions to put the heating on, as his dad makes all the decisions. The household income is low so the heating is rarely on and his house tends to be cold as it's not very energy efficient. It is an ex-council house bought 15 years ago, but there is little money for maintenance. He is shy and relies on the family for company and advice. He would like to move out and be more independent but he does not know how he will achieve this, or run a home himself.

**Figure 7. Factors influencing energy/heating attitudes and behaviours**



The influencing factors not only affected heating behaviour, they also made the difference between identifying a problem and getting help, or not. For example, being socially isolated, not having access to an advocacy group and not being able to use information technology meant that, if a heating system stopped working or a big bill was received, an AWLD would struggle to get help. They may just try and muddle

through, thus being at risk of the negative mental and physical health impacts of a cold home.

In this way it was seen that AWLD could easily move from struggling to fuel poverty crisis, without anyone noticing or intervening. For Joanne, Bob and John, it became clear that if something went wrong with their existing system for accessing and using energy, they would face many challenges they were faced with to overcome the problem.

How things could go wrong and potential solutions to these emerged from the co-production exercises and the student design challenge (Table 3). The story boards developed are available in Appendix 8.

**Figure 8. BWBH challenges**



Using the expertise of participants, the themes identified and the co-production techniques (e.g. 6 frame film strip), scenarios were developed to describe why things

would go wrong for Bob, Joanne and John. The participants then discussed possible solutions.

### **Problems encountered by AWLD in being warm and being happy**

The problems to emerge from the co-production stage reinforce the findings from the household study. The key problems are summarised below and in Table 3. These explain why AWLD struggle in maintaining a healthy home temperature. They may mean AWLD end up in a cold home or in fuel poverty. The scenarios developed evidence the impact being cold at home has on both physical and mental health. In addition, worrying about or struggling to heat the home heating can have a cumulative impact on social connections and lead to people being more isolated.

#### ***Energy bills***

Energy bills are difficult to understand for AWLD. The bill is too crowded with information and focuses on how much money has been spent. Our participants said it was much clearer if there could be some mechanism to explain how much money people have left to pay for energy. In its current form, the energy bill does not give information that AWLD can engage with and understand easily.

#### ***Pre-payment and smart meters***

These provide a useful aid for some AWLD in monitoring their energy use, keeping track on how much money has been spent on fuel. Again, participants said it was more helpful to know how much money they had left for energy, rather than what they had paid. Pre-payment did provide a mechanism for some to avoid fuel related debt. However both meters provided challenges for some in terms of understanding the function of them, or the information on the screen. In addition, the fact that the smart meter has to change if you switch energy provider was a real disincentive, as people had developed trust in the smart meter they had got used to.

#### ***Priority service register (PSR)***

The PSR is a free service by energy suppliers and network operators to customers in need. Services vary between suppliers but include priority support in an emergency. There was little awareness of the PSR amongst the BWBH participants and this was recognised as a challenge in the co-production. It linked with the additional challenge for AWLD in communicating with energy companies.

#### ***Interaction between AWLD and energy companies***

A number of challenges emerged if AWLD needed to communicate with energy companies or ask them for help and advice. These included a reliance on telephone and the Internet. Phone advice was further complicated by being put on hold for long periods or navigating phone menu systems. Where advice was sought on the phone, advisers were time limited and relied on algorithms for support or signpost callers to the right information or agency. These systems meant that AWLD struggled to engage with them or were reluctant to use them. There was an additional challenge of whether energy companies were trusted by the AWLD.



### ***Trusted information and advice***

As with other populations, AWLD will turn to those they trust when they need help or are in difficulty. Family and people from the local neighbourhood were often in the circle of trusted people, but energy companies were not. The fact that information was not available **face to face** meant it was not trusted as easily.

### ***Information and training resources***

Information and written advice was difficult for AWLD to access and understand. There was a lack of easy read materials with clear 'calls to action' so people knew what to do and who to contact if things went wrong. Information was also lacking for support agencies so they knew how and why to respond to the needs of AWLD. For example, how to communicate with AWLD, how to assess for risk, respond and refer, provide energy coaching regarding fuel systems, payment and use, and why to conduct repairs quickly.

### ***Heating technology***

On the whole, heating technology was difficult for participants to understand. Boilers, thermostats and radiator valves were seen as complicated. In the personae, it became clear that if something went wrong there was no foundation of understanding to call on. As a result people may try and cope, rather than get help early on.

### ***Solutions for AWLD in being warm and being happy***

By using techniques such as the '6 frame film shots' and storyboards, some solutions to the challenges listed above were identified in relation to John, Bob and Joanne. Below a summary of some of the solutions is provided (also see Table 3). An important finding was that all these responses need to be integrated. In this way increased awareness of PSR, improved information resources, timely access to support and advice and improved technology can have a synergistic and cumulative impact.

### ***Awareness campaigns***

Awareness of the PSR needs to be raised amongst AWLD, but also advocacy organisations and service providers. Energy companies and network providers also need to be made aware that AWLD should be PSR customers and provided with the support they require. Energy companies and other services (e.g. landlords and plumbers) also need to raise their awareness of the communication requirements of AWLD and why current provision is inaccessible to them.

### ***Accessible co-ordinated information and support***

The availability of easy read materials across services would help provide accessible and acceptable information to AWLD. A priority for easy read accessible written

information and communication was energy bills. Having telephone advice systems that worked for AWLD would also help. Examples include avoiding call holds, advice lines under time pressure, and phone advice systems that need to follow an agreed algorithms. Instead, having systems that automatically phone people back if lines are busy, and training advice line staff to communicate effectively with AWLD would help overcome the constraints of current services.

In addition, the information given by services needs to be co-ordinated and coherent. Including support workers and advocates into information and support systems could help people slipping through the net. For example, if an AWLD has a support worker, making sure they are linked into relevant communication and information from services such as energy companies and landlords may help (e.g. energy bills).

### ***Training***

Training for services that help AWLD keep warm at home needs to be able to assess and respond to risk. In this way services will be more acceptable and trusted, but also more integrated. For example, plumbers, health professionals, support workers and Tenancy Liaison officers could be trained to detect if someone should be on a PSR but is not, and know what to do about this.

### ***Technology***

Several technological responses were identified. Some were picked up by the student design challenge and are reported below. From the co-production workshops the main proposal was for an 'Alexa' type device that would communicate with an AWLD and become a trusted source of knowledge and advice.

### **Student design challenge**

In this section we will summarise the proposals made by the students participating in the design challenge. Five different sets of solutions were submitted (Appendix 9). More details about them can be found on the BWBH website.

Here we provide an overview of the key proposals underpinning the solutions developed that responded directly to the themes to emerge from the BWBH findings. Whilst the proposals were developed with AWLD in mind, it should be stressed that the suggestions could be of benefit to all.

For ease, the work will be reported by referring to design group. The groups are listed below.

Design Group 1. Martyn Westsmith, Matt Burgess and Kelvin Davies

Design Group 2. Steph Evans, Pati Dlugosz and Jenae Walker

Design Group 3. Meghan Parry and Grace Whinfrey

Design Group 4. Matt Mycoe and Connor Nevin

### ***Technology***

All the students recognised that existing communication was not working, whether that was written information or technology. However, changing smart meters or prepayment meter interface was deemed too challenging, although some suggestions were provided by Groups 2 and 3. In addition, overcoming variation in smart meter design between companies was difficult. Instead the students focused on developing ideas for technology that would be a trusted intermediary between the meter and them.

Most of the solutions focused on mobile phones, as many people, including AWLD, already had a phone. Most of the BWBH participants liked and trusted their phone, although it is recognised that this may not be true for the wider population of people with learning disability.

The proposal from two groups (1 and 5) was a phone that could help with all aspects of energy at home and living with a meter. The app is linked to your smart meter (or energy meter if you don't have a smart meter) and will be set to display and notify the user in line with their requirements. Suggestions included:

- Budget: how much energy used over the preferred time (day, week etc.), how much energy is left that has been paid for.
- Energy: How much energy you have used or are using (in units that can be understood).
- Advice on when the room is cold and you need to put the heating on.
- Animated characters to give advice. The animation becomes a trusted character, 'an energy friend'.
- Dials to show in picture form how much energy is being used and how much budget is left, with timely notifications if running low on money so people can take action.
- Icons match the notifications/warnings e.g. blue icon for too cold, red icon for too hot.

Design group 5 had an additional suggestion of a printer. This could connect to the phone and print out snippets of relevant information at the push of a button. Printed records would then be kept by the AWLD to use as a reminder. For example, topping up their pre-payment meter. It could also be shown to service providers when asking for help. The graphics could explain in a simple fashion something an AWLD may struggle to explain in words.

One design group suggested a third party device that wasn't an app. This was an In Home Display (IHD) that had very easy to read graphic and key notifications. It had a tactile and sensory aspect as you could turn it to change the display. Different colours were used to display different types of information.

### ***Information from Energy Companies***

Design groups 2 and 3 did tackle information from energy companies. Group 3 suggested providing easy read bills with key information. They recognised the importance of clear, easy to read graphics and getting rid of the existing 'busy-ness' of the energy bill. Colour, fonts and graphics can be used to improve accessibility.

Design group 2 developed an innovative idea to help people understand energy bills. Instead of developing new easy read energy bills, which would have to be different for each company, they developed a guide. The guide would help people understand their bills without making a change to the existing system of communication. The guide would include a number of coloured sheets, each one with a small window. When placed on the energy bill a small chunk of information can be seen. Each sheet provides easy to read explanations of that information with arrows to the relevant text on the bill.

The same group also proposed an information pack to provide people with essential information about energy and their bill. The provision of this could be linked to the PSR e.g. given out when people go on the PSR. If people get the pack from elsewhere it could include a section saying how to get on the PSR.

This pack could also be distributed by tenancy agencies, landlords, support workers, advocacy groups and health professionals.

### **Summary**

- The co-production methods allowed the BWBH project to develop innovative ideas to overcome the problems raised by the project findings. The involvement of AWLD in the work increased the acceptability of the ideas proposed.
- The solutions proposed included improved communication, development of training, raised awareness of the PSR, integrated and trained services, including support agencies in energy provision and payment systems, as well as innovative technological solutions.
- The students brought to life some of the proposals, especially regarding technology. Their knowledge and use of graphics shows how colour, font, pictures and animation can increase accessibility of information, as well as how attractive, interesting and trusted it can be.

**Table 3. Problems and Solutions identified from co-production**

Person	Problem	Solution
John Ringo	<ol style="list-style-type: none"> <li>1. PSR: John or his support worker don't know about the PSR.</li> <li>2. Energy use: Doesn't understand how his energy use is calculated or how to get best tariff.</li> <li>3. Energy use and payment: Feels invisible. He has no control.</li> <li>4. Big bill: Doesn't know what to do or where to get help.</li> <li>5. Heating system: Doesn't understand how it works.</li> <li>6. Adjusting heating: Makes things worse when trying to change settings.</li> <li>7. Trade-offs: Cuts back on food.</li> <li>8. Self-disconnection and rationing: To try and save money.</li> <li>9. Getting advice: John or his support worker do not know where to get help</li> <li>10. Debt and health: When both decline John keeps to himself and doesn't know where to get help.</li> </ol>	<ol style="list-style-type: none"> <li>1. When sign up with an energy company there is an automated question about health/disability and people immediately put on the PSR.</li> <li>2. PSR support ideas: <ul style="list-style-type: none"> <li>• Support worker notified if client is put on PSR</li> <li>• Support worker or other is nominated advocate on PSR</li> <li>• 'Intro' pack: with telephone numbers and easy read materials.</li> <li>• Support worker gets 'Intro' Pack and updates.</li> </ul> </li> <li>3. GasElectrica: an Alexa type device that provides support and advice. People can ask GasElectrica for advice. GasElectrica will pick up if home environment is cold/hot and advise accordingly.</li> <li>4. Support Worker / advocate: <ul style="list-style-type: none"> <li>• Linked into support mechanisms</li> <li>• Included in communications from energy company to client</li> <li>• Trained in energy efficiency/switching.</li> </ul> </li> <li>5. Easy read materials: <ul style="list-style-type: none"> <li>• 'Intro' pack</li> <li>• Easy to read energy bill</li> </ul> </li> <li>6. Trust: Improved access and accuracy of communication mean that John Ringo is in a 'Circle of Trust' regarding being warm and happy at home.</li> </ol>

Joanne (& Tom)	<ol style="list-style-type: none"> <li>1. PSR: Joanne, Tom or their family) do not know about the PSR.</li> <li>2. Knowledge: Joanne and Tom cannot understand the information around them e.g. who to phone for help, and when.</li> <li>3. Energy system: They do not understand how the heating system or technology works.</li> <li>4. Energy needs: <ul style="list-style-type: none"> <li>• Tom is ill and at home a lot, so needs to keep warm.</li> <li>• Joanne is out a lot.</li> <li>• They often argue about the heating and home temperature because they like different things.</li> </ul> </li> <li>5. Getting help: <ul style="list-style-type: none"> <li>• Tom doesn't know who to call, tries various people but doesn't get help.</li> <li>• Joanne rings her mum, who also isn't sure what to do.</li> </ul> </li> <li>6. Service responses: <ul style="list-style-type: none"> <li>• Landlord and plumber do not know Joanne and Tom should be on the PSR and aren't trained to assess and notice they should be.</li> <li>• Landlord and plumber are not aware they should prioritise the repair because of Joanne and Tom's disability and Tom's health condition.</li> </ul> </li> </ol>	<ol style="list-style-type: none"> <li>1. When sign up with a new tenancy (private rented or social housing) there is an automated question about health/disability and people immediately put on the PSR.</li> <li>2. Tenancy Pack: <ul style="list-style-type: none"> <li>• Telephone numbers</li> <li>• Easy read guidance.</li> <li>• Telephone numbers for Tenant Liaison Officer (TLO), Landlord, 24 hour helpline, energy company</li> <li>• Clear guidance and call to action about who to phone in what situation.</li> </ul> </li> <li>3. Support worker / Advocate: <ul style="list-style-type: none"> <li>• Gets copy of Tenancy Pack</li> <li>• Linked into support mechanisms</li> <li>• Included in communications from TLO, Landlord, energy company etc.</li> <li>• Trained in energy efficiency/switching.</li> </ul> </li> <li>4. Plumbers (and home maintenance companies, especially those on contract for housing associations, councils and larger landlords): <ul style="list-style-type: none"> <li>• Trained to assess and work with people on PSR</li> <li>• Trained to assess if someone should be on PSR and isn't, and refer.</li> <li>• Liaise with trusted agency e.g. support worker/advocate.</li> <li>• Have a priority customer list so those on PSR don't wait for repairs.</li> </ul> </li> </ol>
----------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

	<ul style="list-style-type: none"><li>• Heating system: Does not understand how it works.</li></ul> <p>7. Health: Tom tries to cope and wait for repairs, keeps to himself and his health declines further.</p>	
--	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--

## 6. Discussion

This project aimed to address three objectives.

1. To compare the rates of fuel poverty in households in which AWLD reside relative to households in which adults with other forms of disability reside and the general adult population.
2. To understand the experience and risks of fuel poverty from the perspective of AWLD.
3. To identify the implications for policy and practice of using methods of co-production.

These objectives have been met. In the initial stage, evidence has been generated to demonstrate that people with a learning disability living in private households are significantly more exposed to fuel poverty than those with other forms of disability, and the population of England as a whole. The relative disability rates of fuel poverty for all forms of disability including learning disability are similar across the Understanding Society and the LIHC metrics. However, all fuel poverty rates are greater using the LIHC metric because the actual standard of perceived thermal comfort which the US metric monitors is likely to be several degrees lower than the prescribed temperature standard embodied in the LIHC metric. This raises concern as it implies that many AWLD responding to the US survey and saying they are able to keep adequately warm, i.e. not in fuel poverty, are likely to be living with home temperatures that pose a risk to their health.

A contextual analysis of neighbour deprivation and indicators of household fuel poverty points to the importance of home heating decisions made by AWLD and demonstrates that the range of deprivation in the neighbourhoods in which the participant households are located largely covers that in England as a whole.

The household study developed understanding of the experience of fuel poverty and home heating from the perspective of AWLD. Three interrelated themes were identified: energy need; emotions, attitudes and values; and knowledge and experience.

The findings reveal how AWLD make decisions about home heating and the factors that help and hinder their ability to be warm and happy at home. Home energy needs and use were influenced by household occupancy, views and practices of those who share the home, as well as health of those in the home. Participants explained the impact of difficulties in understanding existing information, heating and finance technology. These included initiatives that were meant to be supportive, for example smart meters and direct debits. Whilst some participants liked smart meters, there were problems across the sample in really understanding how to get the most useful information from them. This was compounded by variation in technology across energy companies.



Accessing support and information that was understandable and acceptable was challenging. Many participants relied on family or trusted agencies. Many of these sources of support had gaps in knowledge, for example few people knew about the Priority Services Register (PSR) compiled by energy suppliers and networks.

Managing money, household income and paying for energy was a huge worry for participants. Participants worked hard to manage their household finances, keeping track of the flow of income and outgoings for the home. However, managing change was difficult, for example, when benefits were reduced or fuel costs increased. This worry was enhanced for some by the pending roll out of Universal Credit and an associated anticipated drop in income. Strategies to manage this anxiety, whilst trying to maintain control, included manually operating the heating, making trade-offs between fuel and other household expenses, paying by pre-payment meter, and restricting heating use. Some strategies increased risk of hardship, such as being cold at home, or hungry. Many examples of rationing and selective disconnection from heating were cited.

BWBH shows how multi-faceted and novel solutions are required within and across systems to overcome the challenges identified. The co-production phase successfully generated a number of potential solutions, many related to improved access to more acceptable information, or the development of technology that was more user-friendly.

In brief, the BWBH project has produced unique findings that give an overview of the fuel poverty and home heating experience of AWLD, and how the vulnerability of AWLD to fuel poverty appears under different metrics. These findings provide insight into the challenges for AWLD when trying to keep warm at home. They indicate that AWLD are disadvantaged in many ways regarding current policy and practice, for example in relation to accessing and using energy payment systems, energy efficiency and fuel poverty strategies. There is an indication that intervention generated inequalities (IGIs) (Lorec et al. 2013) may apply for AWLD in relation to fuel poverty. IGIs increase existing inequalities by disproportionately benefiting less disadvantaged groups. In the BWBH study some participants struggled with smart meter technology and engaging with systems that supported the cheapest fuel tariff. These and other interventions are sometimes promoted in policy to help low income households and those experiencing inequalities. The BWBH findings indicate that the opposite occurs. A policy reliance on interventions such as smart meters and online or direct payments for fuel may disadvantage those AWLD who feel more in control with a pre-payment meter and struggle to use the Internet. A recommendation is that all fuel poverty and energy efficiency policy interventions should be reviewed for their potential for creating IGI's.

Responses to the challenges identified in BWBH need to be developed to prevent, not add to, existing inequalities experienced by people with a disability (Equality and Human Rights Commission, 2017). Such existing inequalities relate to education, work standard of living, health, access to care, community participation and social isolation (EHRC 2017). For example, it has been suggested that as few as 7% of people with a learning disability are in employment (Parkin et al. 2017). The worry and anxiety associated with being able to keep warm at home adds an additional mental health burden to existing physical and sensory challenges that may already be experienced by many people with a learning disability (EHRC, 2017, Liddell & Guiney, 2015 Emerson et al. 2012). This is additionally important to recognise when considering the potential impact of Universal Credit and other benefit changes on household income, as described by participants of BWBH and the previous consultation.

A recent House of Commons briefing paper raised a concern that support for people with learning disabilities is 'patchy' within communities, highlighting the risk that someone can easily slip from struggling to crisis regarding keeping warm at home (Parkin et al. 2017). This reinforces the requirement for reform of the Priority Services Register, so that AWLD can get a consistent and appropriate level of support and help (Wealthy, 2018).

With its focus on AWLD, the findings from BWBH add to and strengthen the existing evidence base on energy vulnerability and energy justice, but with a focus on AWLD. The study demonstrates that AWLD are disproportionately affected by three distributional injustices, high energy prices, low incomes and inefficient housing (Gillard et al. 2017). The potential relationship between energy practices and stigma also play out in some of the accounts from BWBH (Hards 2014). Where people are struggling to heat their home, and seeking to avoid feeling inadequate because of this, there is a risk of isolation and preventable hardship (Hards 2014). This can be aggravated when people have already experienced bullying, negative attitudes or even hate crime (EHRC 2017). Thus there is a risk that social isolation and suffering can increase for AWLD who are struggling to keep warm in winter.

## **Strengths and limitations**

There are limitations to the BWBH study, mainly related to size and capacity. This was an initial exploratory study, with a small budget. However, within those constraints, it delivered a range of outputs.

One limitation in phase one was the available data. There was an unresolved technical fault affecting the 2014/15 LIHC and EHS data sets. Therefore the unaffected 2013/14 EHS data set was used. This difference in years was accounted for in the analysis. In addition, the US category that was adopted as an indicator of having a learning disability was 'Memory or ability to concentrate, learn or

understand'. This is open to challenge and may be seen as being imprecise. However, there was no other dataset that provided a better indicator or sample size. As an initial exploratory study to examine prevalence of fuel poverty for households, it proved adequate to demonstrate the increased fuel poverty risk for households where an AWLD lives.

Another limitation was that people taking part in the household study were recruited through Speakup, who have expertise and interest in providing advice regarding keeping warm at home. The participants' experiences may not, therefore, reflect those of people not in touch with such an informed self-advocacy organisation. Others are likely to be experiencing even more barriers to keeping warm and well at home. There was also relatively high use of mobile phone technology amongst some of the participants. This is not reflective of the wider community of people with learning disability. Caution is therefore required in adopting any one technological solution to overcome the barriers identified in BWBH.

The participatory and co-production approaches embedded within the study provided active engagement of AWLD within the research team. This strengthens the claim that the findings are grounded in the real world experience of AWLD. The trust and honesty that was engendered between researchers and the households produced findings from the household study that resonated with wider audiences. As a result, the team at Speakup won a Celebrating Inclusivity award by National Energy Action. The co-production methods did enable generation of mode 2 knowledge where all stakeholders co-create knowledge together. This did, as intended, lead to solutions with an increased chance of successful implementation and ownership by AWLD.

The triangulation of different methods provided addition strength and rigour to the findings. At each phase the findings from the previous stage were tested and challenged. In this way, there is confidence that the findings truly reflect the experience of AWLD. The resonance with other literature, as indicated above, also supports the transferability of the household study findings to other UK settings.

## **Recommendations**

A recent survey by SCOPE produced a series of recommendations to deliver a shift in approach from Government, Ofgem and energy suppliers in order for the energy market to work for people with a disability (Wealthy 2018). The BWBH findings reinforce those recommendations, suggesting they can be adopted as a whole and be applied to AWLD (Box 1). The suggestions to emerge from the co-production phase of BWBH mirror these recommendations, highlighting, the urgent need to raise awareness of the PSR, improve information strategies and resources, and develop new accessible technological solutions for equal engagement in the energy market for AWLD. BWBH findings reinforce the relevance of these recommendations in relation to people living with a learning disability. It is important to recognise that AWLD are included under the umbrella 'disability' term.

## **]Box 1. Recommendations from Out in the Cold (Wealthy 2018)**

### ***Government***

- Review the impact of the Equality Act in improving web accessibility to ensure disabled people are not disadvantaged when accessing information and support related to their energy costs.
- Work with Ofgem, suppliers, local councils and disability organisations to run an awareness campaign about the support that is available to help disabled consumers with their energy bills.
- Review the core eligibility criteria for the Warm Home Discount to ensure support is targeted at disabled people who face extra energy costs more effectively.
- Work with Ofgem and energy suppliers to reform the Priority Services Register so that disabled people receive a consistent level of service to support them with their energy costs.
- Amend the Digital Economy Act to enable more 'vulnerable' consumers to benefit from Ofgem's safeguard tariff, evaluating the impact of any changes to data sharing on supporting disabled people who face additional costs for energy.

### ***Ofgem***

- Assess the quality of service that energy suppliers provide to disabled consumers to support disabled people when choosing a supplier.
- Amend its definition of a 'vulnerable situation', as part of its Customer Vulnerability Strategy, to include situations where disabled people face extra costs for energy because of their impairment or condition.

### ***Energy suppliers***

- Explore ways in which smart technology and data – with consent of individuals – could be used to more effectively support disabled customers.
- Improve how they gather information about the needs of their customers to ensure they are successfully identifying and supporting disabled people who may struggle to engage in the market, including individuals who face additional costs for energy.

In addition to the recommendations from Wealthy (2018), specific recommendations from the BWBH project have been generated for practice, policy and research.

### **Recommendations for practice**

- Raise awareness of the PSR amongst AWLD, but also advocacy organisations. Fuel companies have a responsibility to be proactive in making this happen.
- Develop accessible co-ordinated information and support that works across services and organisations. Easy read, accessible written information and energy bills were identified as a priority.

- There is a need to co-produce telephone and web-based advice systems that work for AWLD. However, reliance on web-based resources alone is not recommended as that would exclude some AWLD.
- Train services providers who help AWLD keep warm at home to enable them to effectively assess and respond to risk. There is potential for energy companies and other service providers to work in partnership with advocacy organisations to enable such training to be developed and delivered.
- Improvements are required to the user interface of smart meters and pre-payment meters. For example having a smart meter that spoke to you or had an easier to understand display. Energy companies can provide better advice and information on how to use them. Again, such interventions could be co-produced in partnership with AWLD and advocacy organisations.
- Further explore the potential of technological interventions including app based systems that provide accessible information and notifications about energy use and cost.
- New interventions should be implemented across sectors, to promote consistency of advice and streamlining of referral.

### **Recommendations for policy**

- Government should monitor the impact of the Universal Credit and Personal Independence Payments on the ability of AWLD to afford to maintain an adequate standard of living and avoid fuel poverty.
- Fuel poverty and energy efficiency policy interventions should be reviewed for their potential for creating intervention generated inequalities (IGIs). IGIs are interventions that inadvertently increase existing inequalities by disproportionately benefiting less disadvantaged groups.
- For new information resources and technological interventions to be Implemented across sectors, to promote consistency of advice and streamlining of referral (for example an information pack distributed by energy companies, tenancy agencies, advocacy groups and local government. See Joanna and Tom Appendix 8).

### **Recommendations for research**

The BWBH study begins to provide understanding of factors influencing the experiences of AWLD regarding fuel poverty and cold homes. However, this is just a start. Further research is required to build on these findings and provide more detail on the prevalence and impact of fuel poverty and cold homes for AWLD.

The influence of benefit changes on the mental wellbeing of AWLD and their ability to heat their home raises worrying questions about the broader impact of welfare reform. Further exploration of this is also required in further research.

The BWBH study findings do help us to understand factors that influence decisions of AWLD regarding home heating and energy efficiency. However, due to the small sample of the household study further research is required to test the generalisability of the qualitative findings amongst a larger population of AWLD.

A number of potential solutions emerged from the BWBH study, including some early prototypes for technological solutions. Further research is required to develop evidence based interventions to improve the thermal comfort of AWLD and to evaluate the effectiveness of these interventions. Where possible cost effectiveness should be incorporated.

## **7. Conclusion**

The Being Warm Being Happy (BWBH) project is a mixed methods study of fuel poverty (FP) experienced by adults with a learning disability (AWLD) in England. It has generated initial insight into the prevalence of fuel poverty risk and the extent and impact of fuel poverty experience amongst adults with a learning disability. It provides valuable understanding of the real world challenges faced by AWLD in today's society and the extent to which the existing energy system puts them at a disadvantage.

The study's accounts portray the resourcefulness and resilience of many AWLD. However, they also highlight the limitations of existing policy, and the intervention generated inequalities that apply to some policy, for example energy pricing and roll out of smart meters.

A range of recommendations and outcomes has been generated, alongside ideas for two applications for Energy Redress Funds. The study provides an excellent platform for further research related to energy poverty, energy justice and AWLD.

## References

- Abbott C. (2007) E-inclusion: Learning difficulties and digital technologies. On: <https://www.nfer.ac.uk/media/1829/futl66.pdf> Accessed January 2019
- Allerton, L & Emerson, E 2012, 'British adults with chronic health conditions or impairments face significant barriers to accessing health services' *Public Health*, vol 126, no. 11, pp. 920-927. DOI: 10.1016/j.puhe.2012.08.003
- Department of Business, Energy and Industrial Strategy (2018) Fuel Poverty Statistics Report 2018  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/719106/Fuel\\_Poverty\\_Statistics\\_Report\\_2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/719106/Fuel_Poverty_Statistics_Report_2018.pdf) Accessed November 2018
- Critchley, R; Gilbertson, J., Grimsley, M. and Green, G. (And the Warm Front Study Group) (2007) Living In Cold Homes after Heating Improvements Evidence from Warm Front, England's Home Energy Efficiency Scheme. *Applied Energy*, 84, pp. 147-158.
- Department of Business, Energy and Industrial Strategy (2018) Fuel Poverty Statistics Report 2018  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/719106/Fuel\\_Poverty\\_Statistics\\_Report\\_2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/719106/Fuel_Poverty_Statistics_Report_2018.pdf) Accessed November 2018
- Department of Energy and Climate Change (2011) John Hills Fuel Poverty: The problem and its measurement Centre for Analysis of Social Exclusion (Case) Report 69 2011. <http://sticerd.lse.ac.uk/dps/case/cr/CASereport69.pdf> Accessed November 2018.
- Equality and Human Rights Commission (2017) Being disabled in Britain: A journey less equal. On <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> Accessed November 2018
- Emerson E, Robertson J, Baines S, Hatton C. (2014) The self-rated health of British adults with intellectual disability', *Research in Developmental Disabilities*, 35(3) 591-596 <http://dx.doi.org/10.1332/175982714X14007697173759>
- Emerson E, Baines S, Allerton L, Welch v. (2012) Health inequalities and people with learning disabilities in the UK: 2012. Improving Health and Lives: Learning Disabilities Observatory. On: [http://cdn.basw.co.uk/upload/basw\\_14846-4.pdf](http://cdn.basw.co.uk/upload/basw_14846-4.pdf) Accessed June 2017
- Emerson E, Hatton C. (2011) Health inequalities and people with intellectual disabilities. Cambridge University Press. Cambridge.
- Equality and Human Rights Commission (2017) Being disabled in Britain: a journey less equal 2017



Gilbertson, J., Stevens, M., Stiell, B. and Thorogood, N. (For the Warm Front Study Group) (2006) Home is where the hearth is. Grant recipients views of the Warm Front Scheme. *Social Science and Medicine*, 63, pp. 946-956.

Gilbertson, J., Grimsley M and Green, G. for the Warm Front Study Group (2012) Psychosocial routes from housing investment to health gain. Evidence from England's home energy efficiency scheme. *Energy Policy*, 49, pp. 122–133.

Gore N. (2011) Support and research gaps in learning disability. On: <http://www.communitycare.co.uk/2011/01/13/support-and-research-gaps-in-learning-disability/> Accessed November 2018

Hards SK (2012) Status, stigma, and energy practices in the home *Local Environment* 18(4), 438-454 doi.org/10.1080/13549839.2012.748731

Health Research Authority (2017) Questions and Answers – Mental Capacity Act 2005 On: <http://www.hra.nhs.uk/resources/research-legislation-and-governance/questions-and-answers-mental-capacity-act-2005/> Accessed November 2018

Hamilton IG, O'Sullivan A, Hubner G, Oreszczyn T, Shipworth D, Summerfield A, Davies M. (2017) Old and cold? Findings on the determinants of indoor temperatures in English dwellings during cold conditions *Energy and Buildings* 141; 142-157

Health Research Authority (2017) Questions and Answers – Mental Capacity Act 2005 On: <http://www.hra.nhs.uk/resources/research-legislation-and-governance/questions-and-answers-mental-capacity-act-2005/> Accessed November 2018

Hong SH, Gilbertson J, Oreszczyn T, Green G, Ridley I. (2009) A field Study of thermal comfort in low income dwellings in England before and after energy refurbishment. *Building and Environment* 44: 1228–36.

Lorenc T, Petticrew M, Welch V, et al (2013) What types of interventions generate inequalities? Evidence from systematic reviews? *J Epidemiol Community Health* 2013;67:190-193. <http://dx.doi.org/10.1136/jech-2012-201257>

Maidment. C., Jones. C.R., Webb. T.L., Hathway. A.E. and Gilbertson, J.M. (2014) The Impact of household energy efficiency measures on health: A Meta-Analysis. *Energy Policy*, 65, pp 583-593.

MacInnes T, Tinson A, Gaffney D, Horgan G, Baumberg B. (2014) Disability, long term conditions and poverty. New policy institute. On: <https://www.npi.org.uk/publications/income-and-poverty/disability-long-term-conditions-and-poverty/> Accessed November 2018

McTier C, Macdougall L, McGregor A, Hirst A, Rinne S. (2016) Mapping the employability landscape for people with learning disabilities in Scotland. Scottish Commission for Learning Disability <https://www.sclcd.org.uk/wp-content/uploads/2016/08/SCLD-Report-Web-1.pdf> Accessed November 2018

- Mencap (2017) Getting a job: Research and statistics. On: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/getting-job-research-and-statistics> Accessed November 2018
- Middlemiss L. (2017) A critical analysis of the new politics in fuel poverty.37(3), 425-443 Critical Social Policy. doi.org/10.1177/0261018316674851
- Middlemass L, Gillard R. (2015) Fuel poverty from the bottom-up: Characterising household energy vulnerability through the lived experience of the fuel poor Energy Research & Social Science 6; 146-154
- Moffatt S, Lawson S, Patterson R, Holding E, Dennison A, Sowden S, Brown J. (2015) A qualitative study of the impact of the UK bedroom tax. Journal of Public Health, Vol. 38:2; 197–205 doi:10.1093/pubmed/fdv031
- Nind M. (2014) What is inclusive research? London: Bloomsbury Academic.
- Parkin L, Bate A, Bellis A. (2017) Supporting and safeguarding adults with learning disabilities. CPD-2017-0179. House of Commons Library.
- Public Health England (2014) Minimum home temperature thresholds for health in winter – A systematic literature review
- Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R. (2013) Qualitative Research Practice. Sage. London
- Robinson C, Bouzarovski S, Lindley S. (2018) 'Getting the measure of fuel poverty': The geography of fuel poverty indicators in England. Energy Research and Social Science 3, 79-93 doi.org/10.1016/j.erss.2017.09.035
- Rudnick A, Montgomery P, Coatsworth-Puspoky R, Cohen B, Forchuk, C, Lahey P, Perry S, Schofield R. (2014) Perspectives of social justice among people living with mental illness and poverty: a qualitative study Journal of Poverty and Social Justice, Volume 22, Number 2, June 2014, pp. 147-157(11) Journal of Poverty and Social Justice 22(2) 2147–57 doi.org/10.1332/175982714X14007697173759
- Scottish Government (2017) A new definition of fuel poverty in Scotland: review of recent evidence On: <https://www.gov.scot/publications/new-definition-fuel-poverty-scotland-review-recent-evidence> Accessed January 2019
- Snell C. Bevan M. Thomson H. (2016) Fuel Poverty and Disabled Adults: the Impact of Policy Change EAGA Charitable Trust On: <https://www.eagacharitabletrust.org/app/uploads/2016/03/yorkunifinalreport.pdf> Accessed November 2018
- Staniszewska S, Brett J, Mockford C, Barber R (2011) The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research International Journal of Technology Assessment in Health Care, 27:4 391–399. doi:10.1017/S0266462311000481

The Stationery Office (2005) Mental Capacity Act 2005  
[https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga\\_20050009\\_en.pdf](https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf) Accessed November 2018

Tod AM, Lusambili A, Cooke JM, Homer C, Abbott J, Stocks AJ, McDaid KA. (2013) Barriers to keeping warm in later life *Nursing Older People* 25(10) p22-29

Tod AM, Nelson P, Cronin de Chavez A, Homer C, Powell-Hoyland V, Stocks A. (2016) Understanding influences and decisions of households with children with asthma regarding temperature and humidity in the home in winter: a qualitative study. *BMJ Open*. 6:e009636. doi:10.1136/bmjopen-2015-009636

Tod AM, Lusambili A, Homer . Abbott J, Cooke JM, Stocks AJ, McDaid KA. (2012) Understanding factors influencing vulnerable older people keeping warm and well in winter: a qualitative study using social marketing *BMJ Open* 2012;2:e000922 doi:10.1136/bmjopen-2012-000922

Waddams-Price C, Karl Brazier K, Wenjia Wang W. (2012) Objective and subjective measures of fuel poverty *Energy Policy* 49 (2012) 33-39

Walmsley J, Johnson K (2003) Inclusive research with people with learning disabilities: past, present and futures. London: Jessica Kingsley.  
Wealthy B. (2018) Out in the cold. On <https://www.barrowcadbury.org.uk/wp-content/uploads/2018/03/Out-in-the-cold-Scope-report.pdf> Accessed November 2018

Wong SH, Gilbertson J, Oreszczyn T, Green G, Ridley I. (2009) A field Study of thermal comfort in low income dwellings in England before and aftWorld Health Organization Housing, Energy and Thermal Comfort: A review of 10 countries within the WHO European Region 2007

Rycroft-Malone J, Burton CR, Bucknall T, Graham ID, Hutchinson AM. (2016) Collaboration and Co-Production of Knowledge in Healthcare: Opportunities and Challenges. *International Journal of Health Policy Management* 5(4):221–3.

## **Appendix 1. BWBH Reference and Advisory Groups**

### ***Project Reference Group***

A Reference Group of AWLD from Speakup Rotherham met at critical times within the study to ensure the experiences of AWLD are considered.

The Reference Group members were co-researchers (Jodie, Vicki and Annie, (Annie will also sit on the advisory group)) plus other people at Speakup.

The Reference Group will provide ongoing advice and support regarding the project, for example to discuss data collection, data analysis, emerging findings and plan the co-production event. Reference Group members will participate in the co-production workshops.

### ***Project Advisory Group***

The project Advisory Group met three times during the course of the project.

The Advisory Group kept the project on task, time and provided support and advice as problems emerged. They advised on recruitment, interpretation of emerging findings and helped develop the dissemination and impact plan.

#### ***Members of the BWBH Advisory Group***

1. Angela Tod (School of Nursing and Midwifery (SNM), University of Sheffield (UoS).
2. Beth Taylor (SNM, UoS). Lead for the household study (Phase 2).
3. Jodie Bradley, Alison Owen and Vicky Farnsworth (Speakup Rotherham) Co-researchers from Speakup
4. Annie Ferguson (Speakup Rotherham)
5. Jill Thompson (SNM, UoS).
6. Melanie Chapman (Manchester Community Adult Learning Disability Services (Up to January 2017), Research Fellow, Manchester Metropolitan University).
7. Jan Gilbertson. (Centre for Regional, Economic and Social Research (CRESR), Sheffield Hallam University)
8. Dr Bernard Stafford (SNM, UoS). Lead for Phase 1.
9. Dr Chris Damm (CRESR, SHU) Analyst for Phase 1.
10. Prof. Juliet Goldbart (Disabilities Studies, Manchester Metropolitan University)
11. Dr Liz Croot, (School of Health and Related Research (SCHARR), UoS)
12. Dan Wolstenholme, (CLAHRC YH) Lead for Phase 3.
13. Kate Chadwick (SNM, UoS). Administration and management.

## Appendix 2. Examples of the BWBH Playing Cards



## Appendix 3. An example of a BWBH Pen Portrait



### Joanne

#### Attitude to using energy:

"We usually have the heating on for an hour and then turn it off to save money. My husband has a lung condition so it's important he stays warm to stay well."

#### Attitude to paying for energy:

"We tried using direct debits but it used to upset me that I didn't know how much we would owe and I got very stressed about this. Now we put money on the meter every week when ESA or DLA go in the account."

#### People would describe me as:

Joanne is careful and cautious, she is caring for her husband Tom who has COPD. She is a bit of a worrier and is stubborn. They are planning a family, but waiting till they have enough money to afford a bigger house. They don't understand what a smart meter is or why people have one

#### Things that are important to me:

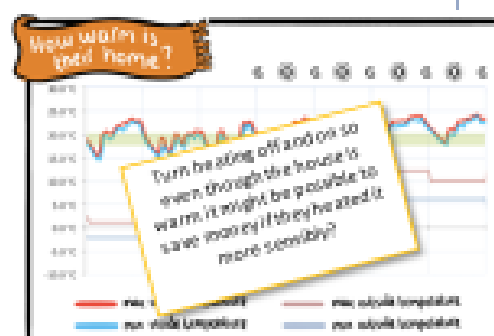
Keeping the home warm for her husband (within reason) for his health. She enjoys socializing and attend the advocacy group, visiting friends, inviting friends to her home. Her mother lives next door – close to her mum. No other family nearby. She does enjoy her routine.

#### Something I enjoy

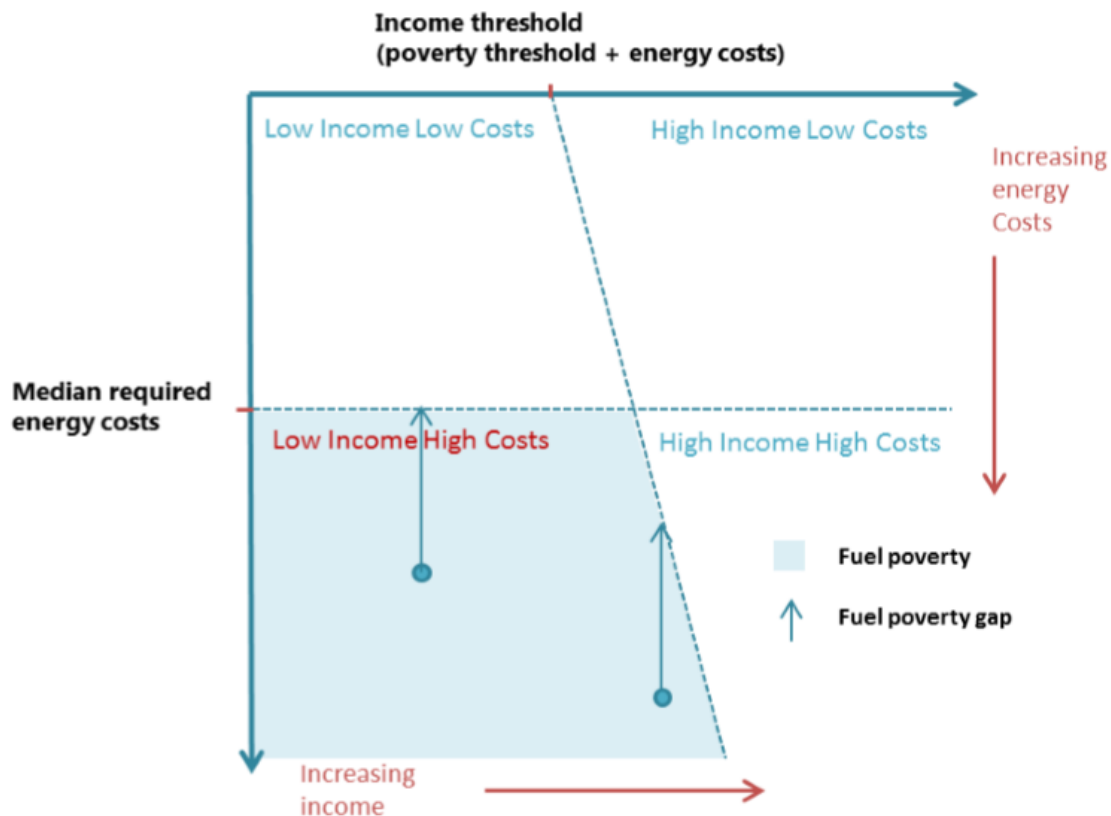
Cooking, baking, walking, travelling – locally using her mobility pass for the train and bus. Her husband stays at home as with his chest he is not as active, he might stay at home (with the heating on) or wander down to the allotment.

#### Something I dislike

'an off' thermostat wars with her husband, arguing with Tom about money



## Appendix 4. Fuel poverty under the Low Income High Cost indicator



Source:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/719106/Fuel\\_Poverty\\_Statistics\\_Report\\_2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/719106/Fuel_Poverty_Statistics_Report_2018.pdf)

- The vertical axis measures required fuel cost, downwards.
- The horizontal axis measures residual household income rising from left to right – the income left over once required fuel has been paid for.
- The sloping vertical line marks the 60% income poverty threshold and the horizontal line the average (median) required fuel spend.

Only households located in the blue south west quadrant are in LIHC fuel poverty. The prevalence of fuel poverty is the number of households located in the blue quadrant divided by the number located in all four quadrants.

## Appendix 5. US and EHS disability classifications

### The Understanding Society disability classification

1	Mobility(moving around at home and walking)
2	Lifting, carrying or moving objects
3	Manual dexterity (using your hands to carry out everyday tasks)
4	Continence (bladder and bowel control)
5	Hearing (apart from using standard hearing aid)
6	Sight (apart from wearing standard glasses)
7	Communication or speech problems
8	<b>Memory or ability to concentrate, learn or understand</b>
9	Recognising when you are in physical danger
10	Your physical co-ordination (e.g. balance)
11	Difficulties with own personal care (e.g. getting dressed, taking a bath or shower)

Source:

[https://www.understandingsociety.ac.uk/sites/default/files/downloads/documentation/mainstage/questionnaire/wave-6/Wave 6 Questionnaire Consultation v02.pdf?q=9558304d7af4598006c470cda6c94ef4fabe3668](https://www.understandingsociety.ac.uk/sites/default/files/downloads/documentation/mainstage/questionnaire/wave-6/Wave%206%20Questionnaire%20Consultation%20v02.pdf?q=9558304d7af4598006c470cda6c94ef4fabe3668) page 173

### The English Housing Survey disability classification

1	Vision (for example blindness or partial sight)
2	Hearing (for example deafness or partial hearing)
3	Mobility (for example walking short distances or climbing stairs)
4	Dexterity (for example lifting and carrying objects, using a keyboard)
5	<b>Learning or understanding or concentrating</b>
6	Memory
7	Mental Health
8	Stamina or breathing fatigue
9	Socially or behaviourally (for example associated with autism, attention deficit disorder or Asperger's syndrome)
10	Other (please specify)

Source:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/534640/EHS Questionnaire 2013-14.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/534640/EHS_Questionnaire_2013-14.pdf) page 42



## Appendix 6. Analysis for Phase 1: the National quantitative study

**Understanding Society 2014/15 cross tabulation data (weighted household level): disability category by “no” answer to adequate heating question and Chi square test result**

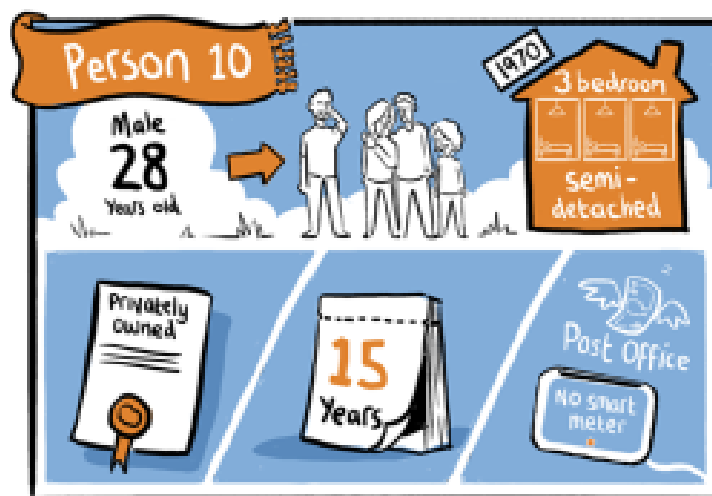
		adequate heating				ChiSq
		yes		no		
		Count	Row N %	Count	Row N %	
mobility (moving around at home and walking)	not mentioned	13795	95.6%	630	4.4%	0.000
	mentioned	3574	92.1%	308	7.9%	
lifting, carrying or moving objects	not mentioned	13987	95.6%	636	4.4%	0.000
	mentioned	3382	91.8%	301	8.2%	
manual dexterity (using your hands to carry out everyday tasks)	not mentioned	15937	95.2%	807	4.8%	0.000
	mentioned	1432	91.6%	131	8.4%	
continence (bladder and bowel control)	not mentioned	16465	95.2%	836	4.8%	0.000
	mentioned	904	89.9%	102	10.1%	
hearing (apart from using a standard hearing aid)	not mentioned	16403	95.0%	871	5.0%	0.055
	mentioned	966	93.6%	66	6.4%	
sight (apart from wearing standard glasses)	not mentioned	16581	95.0%	879	5.0%	0.012
	mentioned	787	93.0%	59	7.0%	
communication or speech problems	not mentioned	17040	95.0%	891	5.0%	0.000
	mentioned	328	87.5%	47	12.5%	
memory or ability to concentrate, learn or understand	not mentioned	16159	95.4%	771	4.6%	0.000
	mentioned	1209	87.8%	167	12.2%	
recognising when you are in physical danger	not mentioned	17136	95.0%	906	5.0%	0.000
	mentioned	233	87.8%	32	12.2%	
your physical co-ordination (e.g. balance)	not mentioned	15979	95.2%	807	4.8%	0.000
	mentioned	1390	91.4%	131	8.6%	
difficulties with own personal care	not mentioned	16527	95.2%	826	4.8%	0.000
	mentioned	842	88.3%	112	11.7%	

**English Housing Survey 2013/14 cross tabulation data (weighted household level): disability category by LIHC fuel poverty status and Chi square test result**

Fuel poverty flag low income high cost

		measure				ChiSq
		Not in fuel poverty		In fuel poverty		
		Count	Row N %	Count	Row N %	
DsVision2_hh	.00	7659660	88%	998058	12%	0.00
	1.00	539608	91%	55056	9%	
DsHearing2_hh	.00	7643292	88%	1010099	12%	0.00
	1.00	555976	93%	43015	7%	
DsMoblty2_hh	.00	6334801	89%	806748	11%	0.00
	1.00	1864468	88%	246365	12%	
DsDexterity2_hh	.00	7274014	89%	929244	11%	0.00
	1.00	925254	88%	123869	12%	
DsLrnDf2_hh	.00	7739831	89%	968206	11%	0.00
	1.00	459437	84%	84908	16%	
DsMemory2_hh	.00	7680461	89%	966076	11%	0.00
	1.00	518807	86%	87037	14%	
DsMental2_hh	.00	7570069	89%	939981	11%	0.00
	1.00	629199	85%	113132	15%	
DsStamina2_hh	.00	6732032	89%	849531	11%	0.00
	1.00	1467236	88%	203583	12%	
DsSocial2_hh	.00	7908954	89%	998558	11%	0.00
	1.00	290314	84%	54555	16%	
DsOther2_hh	.00	8009813	89%	1026053	11%	0.00
	1.00	189455	88%	27060	12%	

## Appendix 7. An example of a BWBH persona



### Bob Barley

#### Attitude to using energy:

"My parents decide when to have the heating on. Occasionally I ask them if we can switch it on when I'm cold but I usually just put an extra jumper on."

#### Attitude to paying for energy:

"My parents take care of energy bills. I'm not sure how much they spend. I guess I don't need to worry about that grown up stuff until I move out."

#### People would describe me as:

Tall and shy, he likes to cook. He is efficient and organized hard working and reliable, works in a café. Bob lives at home with his family. Marjorie his mum, who he describes as over protective / loving, a librarian. His younger sister Meg who he doesn't get on with as she is a teenager. Dave his dad who is the decision maker in the home, he is a poorly paid civil servant and is constantly worried about money and being in debt. The family bought the council house 15 years ago but have never had any money to 'do it up'.

#### Things that are important to me:

Being warm, house is always cold. He would like a girlfriend, he would like to get a place of his own, but feels he has lots to learn about money and bills. He enjoys going out for a drink with his mates.

#### Something I enjoy

He likes video games, likes numbers, going to the movies and he is a football fan.

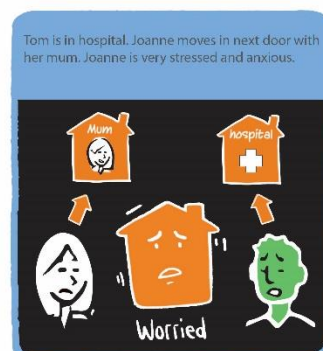
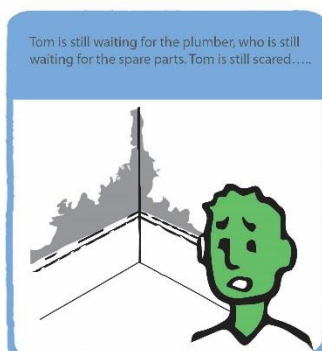
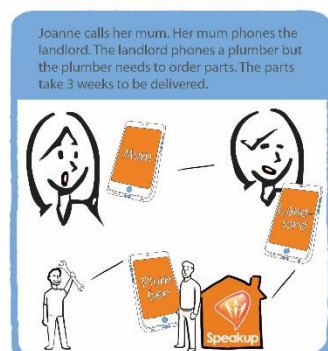
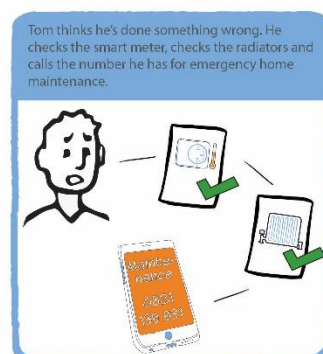
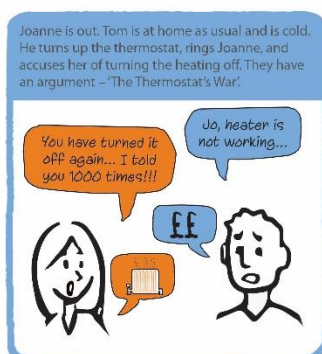
#### Something I dislike

He doesn't like the fact its cold at home, he doesn't like Bananas, Glitter, spiders, Christmas jumpers and jelly in that order

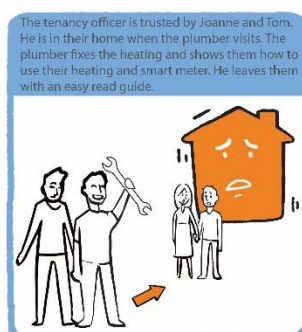
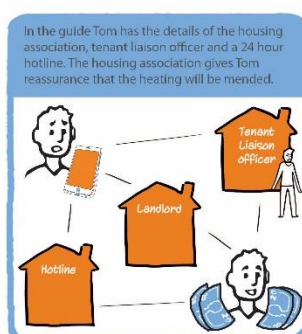
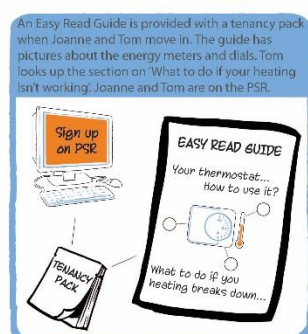


## Appendix 8. BWBH storyboards

### Joanne (& Tom) - 'Now' scenario



### Joanne (& Tom) - 'Ideal' scenario



## John Ringo - 'Now' scenario



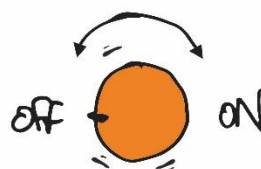
John gets a really expensive bill.



He is shocked and frightened. He doesn't know that his bill is an estimate and therefore isn't accurate.



Not knowing how much he is paying makes John panic. He doesn't know what to do so tries to alter the boiler and thermostat settings. He messes things up.



John ends up turning off the heating. He also doesn't eat much so he can save money. Only the cat eats and goes out.



John's support worker visits John. He tries to sort things out and contacts the energy company. The support worker isn't really sure what to do, what to ask for or what steps to take.



Over time John gets into debt and becomes depressed. He is hungry. The support worker is busy and stressed trying to sort things out...



## John Ringo - 'Ideal - Low Tech' scenario



There is more information around about the PSR so support workers, advocacy agencies and John Ringo knows about the PSR. John Ringo is put on the PSR.



When service user signs up > automatic question > a 'yes' answer nominates an advocate (at energy company) & send intro pack to John & his support worker.



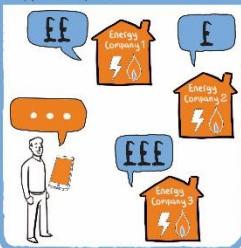
The PSR 'intro' pack is in easy read and people can find a telephone number to call for help. If John rings the number he isn't put on hold. He can leave a message and is called back.



Support worker gets regular instructions, intro pack, updates, actions, PSR contact at EON.



The support worker puts John on the cheapest tariff. He is trained in how to do this. The support worker reviews the tariff every year and switches energy supplier if required.



Must be sent an 'Easy Read Bill' when on PSR - E.g. how the user is doing, what has been changing supported by clear visuals and light information.



Monthly statements to be sent to service user and support worker.



John can relax in his armchair with his cat. They are happy, warm and John has money for himself.





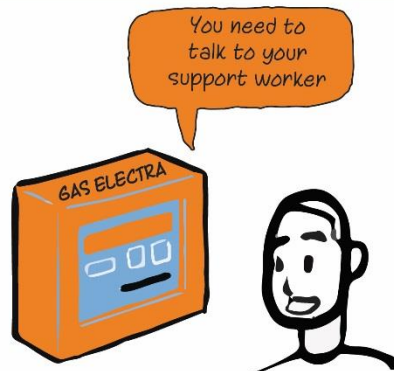
## John Ringo - 'Ideal - High Tech' scenario



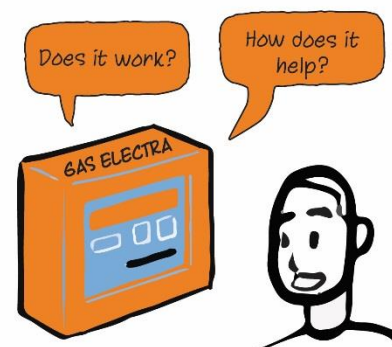
PSR automatic sign up for all with a learning disability. Allocated a 'GasElectrica' by the energy company.



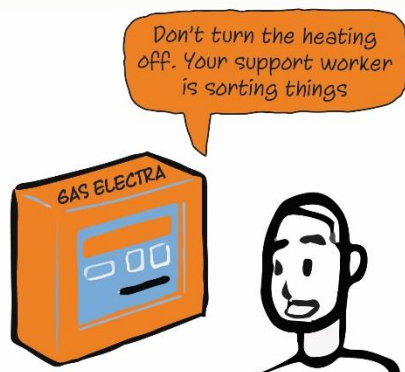
"Gas Electra" gives clear instructions to John



"Gas Electra" gives feedback to John



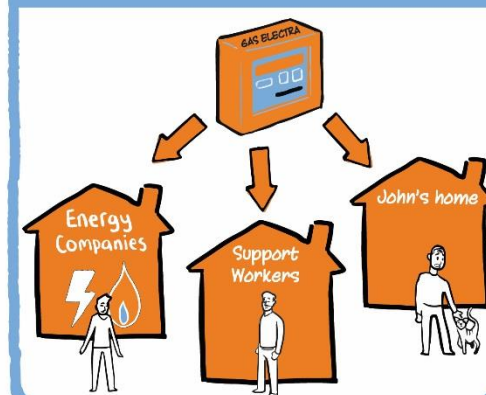
"Gas Electra" gives reassurance



"Gas Electra" gives a history record about the conversations "Gas Electra" has had with John and his potential actions.



To be a trusted technology, Gas Electra has to give feedback continuously to John, support worker, and gives alerts to gas company.



## Appendix 9. Student design challenge ideas



## **Appendix 10. Dissemination**

### **Dissemination and Impact**

September 2018 Celebrating Inclusivity Award, National Energy Action.

September 2018 NEA National Conference Stall and Video Presentation on BWBH

November 2018. Understanding fuel poverty and health. Fuel Poverty Research Network Conference. Sheffield. 8-9 November Being Warm Being Happy. Fuel poverty and health for adults with learning disabilities. Taylor B. Tod AM. *(Invited speaker)*

August 2019. World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, *(To be submitted by Mel Chapmen)*

September 2019 Royal College of Nursing International Research Conference, Sheffield *(To be submitted by the team)*.

### **Web/Social media**

Website <https://beingwarmbeinghappy.org/>

Twitter @beingwarm

### **Redress funds**

Speakup have used the findings to work with different partners to apply for Energy Redress Funds. Two projects are being submitted. One, 'Promise Me', aims to develop and deliver multi agency training using easy read and accessible materials for AWLD. The second aims to develop the proof of concept of a new technology to support the AWLD in the home, in line with the GasElectrica idea that emerged from the co-production.