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Research article

Being Warm Being Happy: Understanding factors influencing adults with learning disabilities being warm and well at home with inclusive research

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Abstract

The aim of the Being Warm Being Happy project was to understand and characterise fuel poverty and energy vulnerability from the perspective of adults with learning disabilities. Undertaken in community settings in South Yorkshire, UK, the study adopted an inclusive research approach, with three members of a self-advocacy organisation who have learning disabilities and/or autism working alongside academics as co-researchers. The study incorporated home temperature and humidity measurements and qualitative individual interviews. Ten households, all of which included an adult with learning disabilities participated in the research. Framework analysis identified four interrelated themes influencing decisions about energy use and payment method. First, energy need varied according to health status. Energy need was also influenced by the size, tenure and age of the participant's home. Second, emotions, attitudes and values, in particular a sense of control impacted upon energy use. Third, knowledge and previous experience could help or hinder participants keeping warm. Factors included prior first-hand experiences of support from self-advocacy organisations, energy companies and local authorities and the influence of parents' views and practices. Finally, concerns about affordability and challenges accessing the energy market also had an important impact on experiences and decisions. The research contributes to the limited evidence base about the nature and experience of fuel poverty amongst adults with learning disabilities highlighting the extent to which the existing energy system puts them at a disadvantage

and the resourcefulness and resilience of many adults with learning disabilities when facing these challenges.

Keywords: learning disability; inclusive research; fuel poverty and energy vulnerability; temperature; co-researchers and co-production.

Introduction

There are over one million people with learning disabilities in England (Hatton *et al.,* 2016), who are likely to be at higher risk of the potential health risks and consequences of cold weather and fuel poverty than the general population (Snell *et al*., 2013, Snell *et al*.,2014, Snell *et al*., 2015). However, there has been little research into the fuel poverty experiences of adults with learning disabilities and the causes and impact of living in cold, damp housing within this group. Often disabled people are treated as a homogenous group in fuel poverty data and statistics (Walker and Day, 2012), 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 (see Snell *et al*., 2016). To our knowledge no previous qualitative studies have looked at the intrinsic factors which influence the lived experience of fuel poverty amongst adults with a learning disability.

The Being Warm Being Happy (BWBH) project addressed this evidence gap. This paper presents findings from the qualitative interviews undertaken to understand and characterise energy vulnerability from the perspective of people with a learning disability. The research adds to work on hard-to-reach energy users (see Ambrose *et al*., 2020, Ashby *et al*., 2020), and takes an inclusive co-researcher approach. It provides evidence on how disability intersects with fuel poverty for adults with a learning disability increasing energy vulnerability and the likelihood of experiencing fuel poverty and cold homes. Improving knowledge in this area is particularly important and urgent within the context of the COVID-19 pandemic and the current energy crisis.

Literature Review

Initial research about cold homes focused on the extent of fuel poverty and the impact that fuel prices, household incomes and household energy efficiency had on whether people could keep warm at home (Boardman, 1991). More recently, fuel poverty or energy poverty as it is now commonly termed, has come to be regarded as a multi-dimensional problem with a range of drivers that can result in numerous kinds of vulnerability (see for example, Bouzarovski and Petrova, 2015; Middlemiss and Gillard, 2015, Gillard *et al*., 2017, Baker *et al*., 2018). This broader concept of 'energy vulnerability' has emerged from a burgeoning body of research examining the lived experience of fuel poverty which highlights the impact of energy needs and practices, including attitudes, values and the barriers experienced by those who are unable to access adequate energy services (Middlemiss and Gillard, 2015); research has focused on older people (Tod *et al*., 2013; Tod *et al*., 2012), adolescents and young adults (O'Sullivan *et al*., 2017; Butler and Sherriff, 2017), social housing tenants (Longhurst and Hargreaves, 2019), children with asthma (Tod *et al*., 2016) and disability (Cronin de Chavez, 2017). Together this research highlights the complex and systemic nature of energy vulnerability which often intersects with a range of factors and influences (see Middlemiss *et al*., 2019).

The link between energy poverty and disability has only received research attention relatively recently (Cronin de Chavez, 2017) with evidence suggesting that disabled people are likely to experience higher rates of energy poverty and have additional energy needs (Snell *et al*., 2015). Work undertaken by Ivanova and Middlemiss (2021) comparing energy use, income, poverty, and energy poverty amongst disabled households in the EU shows that these households consume around ten per cent less energy than other households, and that they are more likely to experience energy poverty.

However, there remains little evidence about the nature of fuel poverty amongst disabled people and virtually none about people with learning disabilities. One study indicated adults with learning disabilities were at higher risk than the general population of unsafe home temperatures and related negative impacts (Snell *et al*., 2014). However, a later study exploring fuel poverty and disabled people, found lower rates of fuel poverty in households including someone with learning disabilities (Thomson and Snell, 2016). These unexpected results, down to methodological differences in the collection of statistical data, are explored in detail in the BWBH report (Bradley *et al*., 2019), and as with Carolyn Snell and colleagues' important work, highlight issues with the way that information about disabled people is captured in energy poverty statistics.

To our knowledge, there is no research on adults with learning disabilities' lived experiences of fuel poverty, the intrinsic factors that may influence these experiences, or the appropriateness and accessibility of initiatives and interventions to provide energy advice and support.

This lack of research, and the contradictory messages from the research that does exist, is surprising, as people with learning disabilities are more likely to die at a younger age than the general population, with deaths rising throughout autumn and early winter (Heslop *et al*., 2019). They have a higher prevalence of health co-morbidities, including increased risk of cardiovascular and respiratory disease, which are common causes of death (Emerson *et al.,* 2014). Detecting or communicating thermal comfort and adjusting heating, accordingly, may also be hindered by physical, cognitive, sensory or communication impairments.

People with learning disabilities are more likely to experience poorer household income and lower socioeconomic position throughout their lives (Snell *et al.,* 2014*;* Emerson *et al*., 2012; Emerson *et al*., 2010; MacInnes *et al*., 2014; Moffatt *et al*., 2015). They are more vulnerable to the 'poverty premium', the likelihood of paying more for basic household goods, including heating, because of poverty (e.g., having to pay more for fuel by using a pre-payment meter rather than direct debit).

All these factors mean that people with learning disabilities are at greater risk of experiencing fuel poverty. They are also at a greater risk of, and more susceptible to, the health consequences of living in cold homes. The health consequences of such conditions are well documented elsewhere (see for example Marmot Review Team, 2011; Public Health England, 2014; NICE, 2015). A recent review of studies (Ballesteros-Arjona *et al*., 2022) examining the relationship between energy poverty and health shows that energy poverty is linked with worse physical, mental, and respiratory health. Energy poverty has a detrimental impact on chronic conditions resulting in higher levels of morbidity and mortality, higher use of health services and higher exposure to health risks. These poor outcomes particularly effect vulnerable groups including those with a long-standing illness or disability.

Whilst existing research has focussed on the health effects of fuel poverty, disability is also about other forms of impairment. The evidence outlined in the Ballesteros-Arjona *et al* (2022) review highlights how existing inequalities such as those faced by people

with a disability (and as outlined above) intersect with energy poverty coming together and interacting in such a way as to make the situation worse, multiplying detrimental effects. These interactions have been described as the 'triple effect of disability and energy poverty' (see Cronin de Chavez, 2017) whereby disability, in this case sickle cell anaemia, and ill health combine with a disabled person's reduced earning capacity and income *to 'send people into a spiral of worsening energy poverty'* (p.182).

The cumulative effect of these inequalities will have further impact on psychological and emotional well-being, resilience, and the capability to ask for or access help (Emerson *et al*., 2014). Finally, public health information and interventions may be inaccessible to people with cognitive or sensory impairments (Emerson and Hatton, 2011; Allerton and Emerson, 2012).

The Being Warm Being Happy Study

The BWBH research project was an exploratory mixed-method study consisting of three phases: analysis of two English national surveys to examine rates of fuel poverty in households in which adults with learning disabilities live; a household study to gather information about the experience of fuel poverty undertaken by and co-produced with adults with learning disabilities; and co-production workshops to identify potential solutions. This paper reports the household study findings; this phase comprised of qualitative interviews and temperature and humidity measurements in households that included an adult with learning disabilities, building on methods used in prior research (Tod *et al*., 2012; Tod *et al*., 2016; Cronin de Chavez *et al*., 2017).

Aims

The household study aimed to understand and characterise the experience and risks of fuel poverty from the perspective of adults with learning disabilities, to develop recommendations and potential solutions to the challenges identified.

Methods

Study approach

The BWBH project was an inclusive research project (Walmsley and Johnson, 2003; Nind, 2014), adopting a co-researcher model where people with learning disabilities were members of the research team. Inclusive research is conducted *by* or *with*, rather than *about*, *for* or *on*, the people that the research is about with the assumption that those affected by research are best placed to deliver it and have skills and knowledge of equal importance (Walmsley, 2001). Anticipated benefits of inclusive approaches include improved research quality and processes; for example, identifying relevant research topics (Strnadová *et al*., 2016), improving recruitment, designing accessible study materials, and contributing to data analysis and dissemination (Puyalto *et al*., 2016). Respondents may feel more comfortable being interviewed by another person with learning disabilities, leading to more honest and relevant responses, and interviewers with learning disabilities may know what questions to ask and how, and pick up on points that non-disabled interviewers would miss (O'Brien *et al*., 2014; Schwartz and Durkin, 2020).

Principles of co-production underpinned the project, with all stakeholders co-creating knowledge. As co-production with all stakeholders is believed to increase the likelihood

of successful solutions and implementation (Rycroft-Malone *et al*., 2016), a wide range of stakeholders was invited to attend. Those who attended the co-production workshops, included representatives from the core research team (including three 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.

The household study was in two local authority areas in South Yorkshire, providing an urban/rural and demographic mix. These areas experience levels of excess winter deaths and fuel poverty above the national average with old and non-traditional housing stock that create energy efficiency challenges. Analysis of Index of Multiple Deprivation (IMD) and Low Income High Costs (LIHC) fuel poverty data showed that the *neighbourhoods* where the households are situated are from across the spectrum of deprivation and fuel poverty for England as a whole. Although there is a close association between the level of deprivation and fuel poverty across the case study neighbourhoods, this relationship is less clear for the households in the study, and it is possible that a household could be more or less deprived than the neighbourhood in which it is located.

Patient and public involvement

Extensive consultation undertaken with adults with learning disabilities, their organisations, family members, and health and social care service providers helped to develop the BWBH application for research funding and the research protocol. We held workshops and interviewed people with learning disabilities with different cognitive and communication abilities and service providers. We explored whether people were keeping warm at home, the impact of being warm or cold at home, barriers and facilitators to maintaining adequate home temperatures, and if this was an important topic for research. This consultation confirmed that this was a worthy area for research especially for people living independently or with family, rather than those in supported housing who would receive support with heating and bills.

A self-advocacy organisation with knowledge of energy poverty and a background in research using a co-researcher model was actively involved throughout all stages of the application and study (see Bradley *et al*., 2019).

Sample and recruitment

Interviews and household temperature measurements were conducted with ten households that included at least one adult with learning disabilities. Our focus was on adults with mild to moderate learning disabilities living independently or with family members. We included people who had some support or care at home but excluded people with profound or multiple disabilities who receive intensive support or lived in residential care. The project gained ethics approval from the University of Sheffield. Inclusion criteria included consideration of consent under the Mental Capacity Act (Department of Health, 2005). We included participants if they were able to communicate without assistance or with support.

Recruitment of households was through the self-advocacy organisation. The co-researchers made an initial approach, providing written easy read information and discussing the project with potential participants. The academic and co-researchers gave more detail and answered questions at a follow-up visit and either written or verbal consent was obtained. Table 1 gives the sample characteristics.

Table 1: Sample characteristics

	Age	Who else lives in the home?	Type of housing	Tenure	Time living here (years)	Decade home was built	Payment method
Jenny	33	Partner, two daughters (age 9 and 15) and dog	3 bed terrace	Homeowner	11	1980s	Pre-payment meter
Kelly	31	Dad (age 69) and cat	2 bed flat	Social housing	1.5	1970s	Pre-payment meter
Annabelle	49	Son (age 29) and dog	2 bed maisonette	Social housing	1	1970s	Pre-payment meter
Frank	59	Husband	1 bed bungalow	Social housing	10	1970s	Pre-payment meter
Holly	59	Cat	1 bed bungalow	Social housing	2	1970s	Direct debit
Mark	47	Four sisters and a niece	4 bed detached	Social housing	'a long time'	1940s	Pre-payment meter
George	54	Mother (age 80) and cat	3 bed semi-detached	Social housing	20	1950s	Pre-payment meter
Megan	44	Lives alone	1 bed flat	Social housing	7	1970s	Direct debit
Laura	31	Husband (age 53)	1 bed bungalow	Social housing	5	1970s	Pre-payment meter
Adam	28	Mother, father and sister	3 bed semi-detached	Privately owned by parents	15	1970s	Direct debit

Note: All names are pseudonyms to maintain anonymity.

Data collection

Data collection occurred between December 2017–April 2018 to ensure that homes would need heating on to maintain adequate temperatures during the period of the research, enabling participants to relate to the topic. A Tinytag Ultra 2 temperature/relative humidity recorder (TT2) was placed into each household's living room and bedroom to log room temperature and humidity at hourly intervals for two weeks. After this monitoring period interviews then took place in people's homes. This approach was similar to other studies (Tod *et al*., 2013; Tod *et al*., 2012; Powell-Hoyland *et al*., 2016; Cronin de Chavez *et al*.,2017).

A co-researcher and academic researcher conducted semi-structured interviews using an interview schedule devised from existing fuel poverty literature and pre-protocol

consultation. It included questions on energy use, influences on ability to maintain safe home temperatures and help and resources. One interview included a family member; however, the focus of interviews was the person with learning disabilities.

Data analysis

Interviews were recorded, transcribed, anonymised and entered onto Quirkos, a qualitative research software programme. Framework analysis generated themes and issues that characterise fuel poverty and energy vulnerability for adults with learning disabilities (Ritchie *et al*., 2013). Framework analysis involves a systematic process of familiarization, developing a thematic framework, indexing, charting and mapping and interpretation. It allows integration of existing themes into the data analysis and provides a clear analytical structure that contributes to transparency of results (Gale *et al*., 2013).

An initial thematic framework was developed from policy reports, academic literature and initial analysis of interview transcripts by the university researchers. Analysis of temperature and humidity recorder data used the corresponding software generating visual representations (graphs) of actual room temperature and humidity for each participant. These visual representations were compared to each participant's interview data to explore the impact of energy beliefs and behaviours on home temperature, and to detect any mismatch between participants' perceptions of temperatures at home and objective measurements.

Playing cards helped to identify and describe key themes and issues from quotes from interview transcripts. A pen portrait for each participant summarised their living situation and influences on energy use. The playing cards and pen portraits summarised findings in an accessible way and were a way of actively including the co-researchers in the indexing, charting, mapping, and interpretation of the data. Figure 1 provides examples of the visual methods used to support the framework analysis.

The resulting thematic framework was developed further with stakeholders at two co-production workshops. Workshop participants developed personae from themes identified through the household study, then created storyboards to explore situations in which personae could experience fuel poverty crisis, and to generate potential solutions (Figure 2). These scenarios were used to test and refine the framework.

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Figure 1: The use of visual methods to support data analysis

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

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

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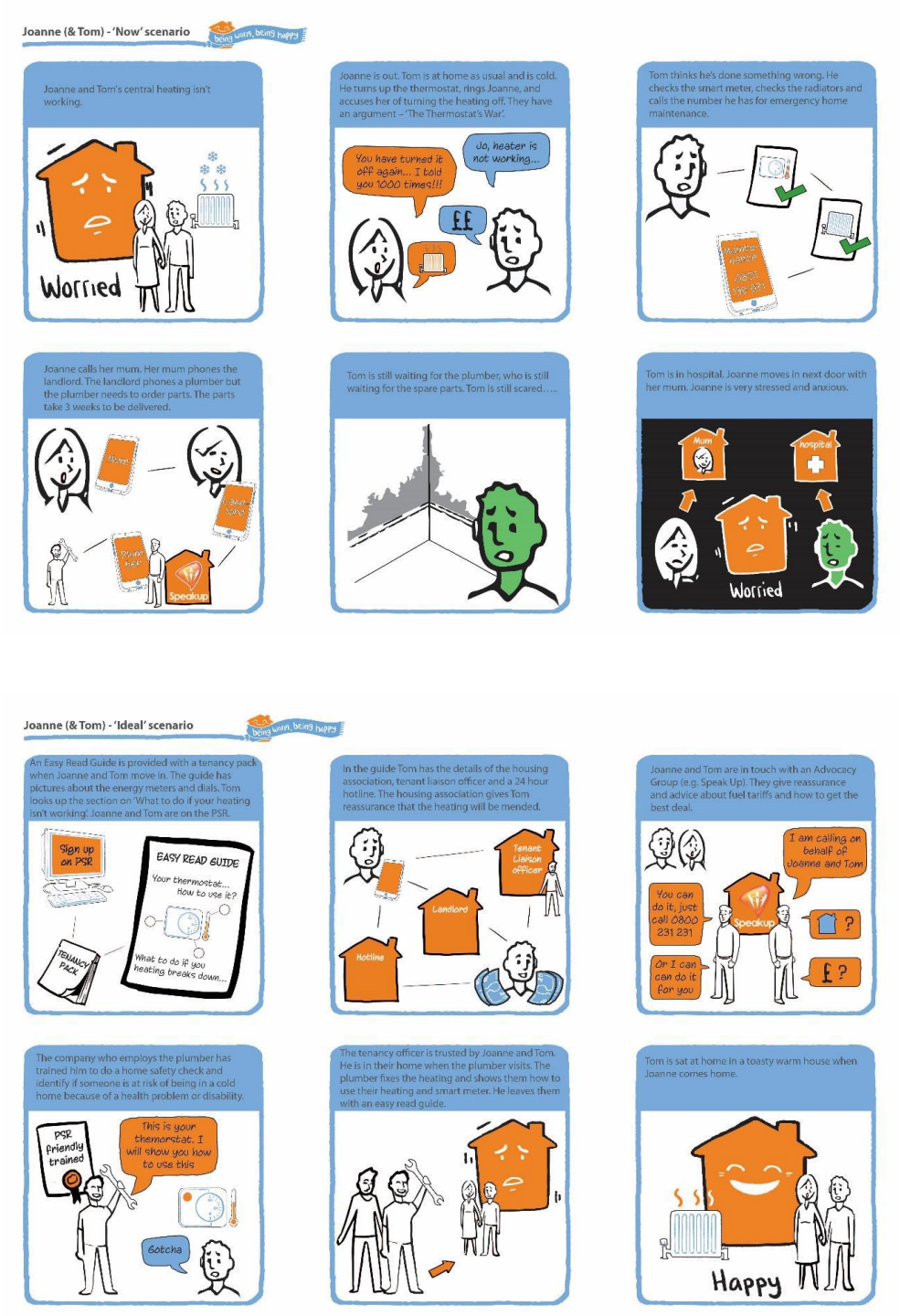
Figure 2: Storyboards used at the co-production workshops

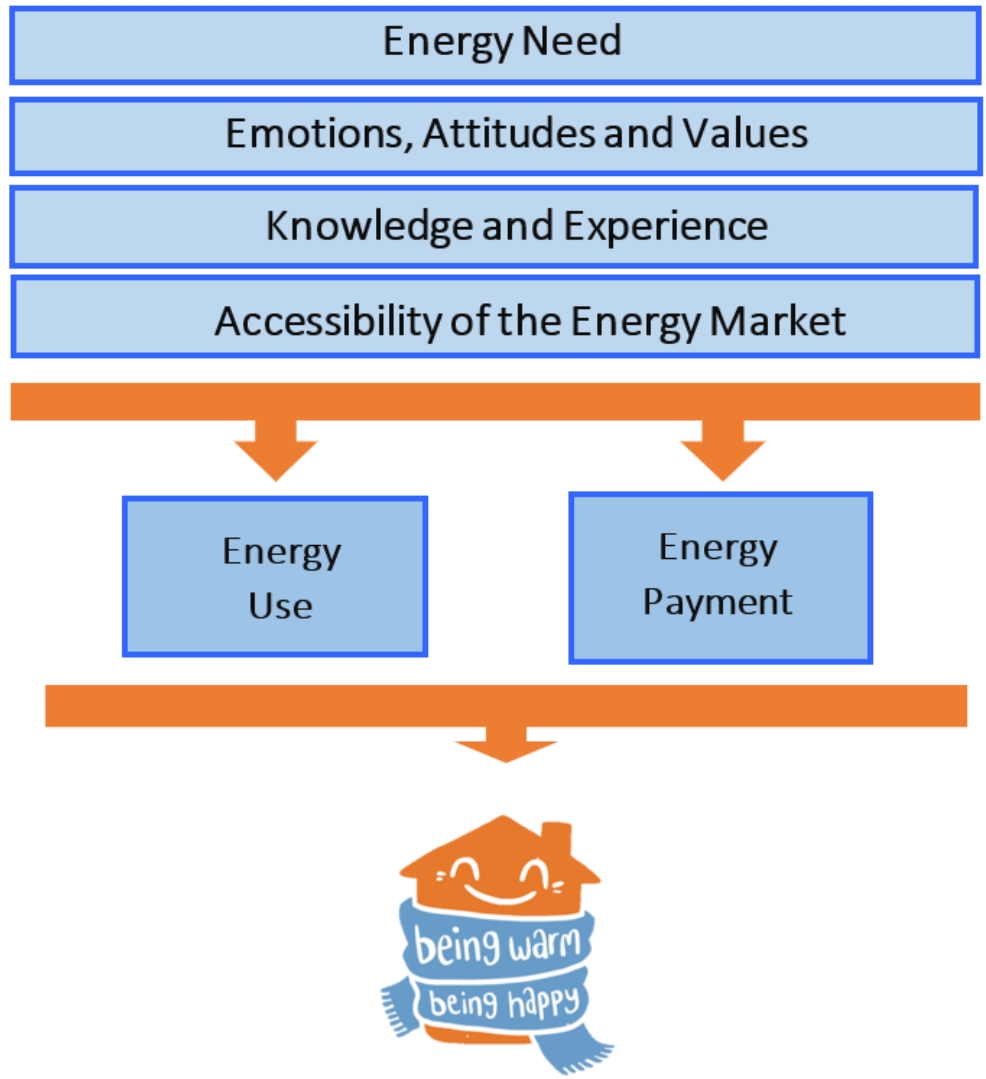


Results

The TT2 findings indicated that temperatures varied across the households. Most participants (8/10) said they could keep their accommodation warm in winter and mostly maintained temperatures of 18C and above. However, it was apparent that temperatures in some households fell below the recommended 18-21C. Mark's living room temperature did not achieve temperatures of 15C or over during the two-week period. Similarly, Adam's living room temperature only entered the recommended 18-21C on two days, remaining below this at other times. The home temperature data and experiences of the adults with learning disabilities interviewed came together (and to life) through the development of the personas in the co-production workshops. Attitudes to using and paying for energy were critical in understanding the recorded temperature data and how an adult with learning disabilities can 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 were reflected in the temperature data. Underpinning these attitudes was a range of influencing factors including 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.

Figure 3 provides a visual representation of the thematic framework developed from the qualitative interview data. Four themes, i) energy need, ii) emotions, attitudes and values, iii) knowledge and experience, and iv) accessibility of the energy market form the foundations from which households use and pay for energy and ultimately contribute to whether adults with learning disabilities are warm and well at home.

Figure 3: Thematic framework



Energy need

The energy need theme refers to levels of thermal comfort required in each household. Table 1 demonstrates variations across the sample regarding accommodation size, tenure, and age, all of which impact on energy efficiency and therefore the amount of energy required by a household to maintain temperatures. In Mark and Adam's homes this was not being met. The number of people living in the household and their daily routines influenced energy need; for example, increasing if people spent more time at home due to health or employment status. Only two participants lived alone; the others cohabited with family members. Living with children or older people also increased a household's energy demand. Participants recognised that their personal circumstances, in particular health problems or co-morbidities, created additional energy and heating needs to stay comfortable and healthy.

Frank: ''cause with my arthritis I've got to keep my legs warm'.

Holly: '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'.

Emotions, Attitudes and Values

Participants worried about having enough money to meet their energy needs, particularly as energy prices and financial support changed regularly. A sense of control was important to help alleviate worries about having enough money to meet energy needs, directly influencing how participants interacted with their heating system and means of payment. Payment methods for each household are detailed in Table 1. Most participants (8/10) manually switched heating on and off rather than use a thermostat or timer to control home temperatures. This helped them feel more in control as they felt that their energy use was more predictable, and they would not waste energy or overspend on fuel costs. Trying to maintain a sense of control explained most participants' (7/10) decision to use prepayment meters. They felt meters were the most cost-effective option, enabling them to budget and use energy accordingly by seeing how much money remained on the meter. Uncertainty regarding how much energy was being used, and therefore how much money was being spent, was perceived as a significant disadvantage to direct debits. One person paid by direct debit as this caused them least anxiety, and they believed this was more cost-effective.

Frank: 'It means you can put it on when you want it on and turn it off when you don't want it on'.

Jenny: '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'.

Holly: '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'.

Participants portrayed a sense of pride in managing their own homes, wanting to present themselves as independent, and able to cope.

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

This pride and determination to maintain an impression of coping may delay people recognising or admitting to problems with home heating or accessing support and information.

Knowledge and Experience

Past experiences informed decisions and practices regarding energy use and payment, such as paying by prepayment meter rather than direct debit, and who to contact for support.

Jenny: 'I used to [have direct debits], 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'.

Annabelle: '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'.

Participants and their family members tended to share attitudes and practices regarding energy use and use the same means of payment. This was often because the participants had learnt from their parents and adopted the same energy behaviour.

Jenny: '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'.

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

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

In addition to family, local self-advocacy organisations could be another vital, trusted source of support.

Annabelle: 'Like, if I have a letter, and if I can't understand it, I always take it to [self-advocacy organisation] … And if I'm a little bit worried, I take it to [self-advocacy organisation], and they help you. [Self-advocacy organisation] 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'.

This raises concern for those without access to such organisations and demonstrates the importance of accessing support from different sources.

Frank: '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 [self-advocacy organisation] or my partner… He speaks on my [be]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 [self-advocacy organisation], I've got someone else I can turn to… '

Other sources of support included information from energy companies. However, people could feel unsupported, particularly at times of crisis. One participant described her difficulty contacting the energy company when in need of support.

Jenny: '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 could be sitting in house, freezing cold'.

For those living in social housing, their local council was a source of practical support and help; for example, fixing heating, servicing and setting up heating systems. However, references to a lack of involvement in decision making imply missed opportunities to enable someone to self-manage their home heating.

Frank: 'We've got council who comes out to set your boiler, see it's working okay. And they set everything, you know'.

George: 'They set it, they set it, council. We aren't to touch it.

Researcher: You're not allowed to?'

Similarly, participants whose family members managed energy use and payment on their behalf were not as well-informed or involved in decision making as those who managed this independently. Participants Adam and Mark did not know how their family members paid for energy.

> *Megan: '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'.*

Although well-meant, ultimately this reduced energy knowledge, control and choice, with potential implications for the future when family members may not be able to continue providing the same level of support.

Accessibility of the energy market

All participants struggled with the interface between themselves and the energy market. A key factor was that they lacked understanding and/or confidence in using technology and technical processes associated with energy use and payment, including smart meters, thermostats, direct debits and prepayment meters. Nearly all had smartphones and used the Internet with some degree of confidence; however, instead of using a smartphone application to top up prepayment meters, they chose to visit a shop and engage with a person rather than technology.

> *Holly: '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'.*

One participant decided it was easier to manually control their heating using a thermostat than rely on thermostat technology and timers.

> *Jenny: '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'.*

Another was reluctant to get a smart meter after difficulties using other devices.

> *Laura: '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'.*

There was a lack of clarity regarding the presence and purpose of smart meters. Four participants did not know whether they had a smart meter, and one of these confused a smoke alarm for a smart meter. There was confusion amongst the three households with smart meters because some are combined with prepayment meters. One participant with a smart meter still seemed uncertain about their role, *'I've got a smart meter, whatever they are.'* (Jenny).

One criticism of both prepayment and smart meters raised by some participants was accessibility. Meters could be difficult to use for people with visual impairments, and their location could limit ability to monitor energy use.

> *Holly: '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'.*
>
> *Jenny: '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'.

Several participants made recommendations regarding the accessibility of interactive displays on smart meters, including larger font and buttons, simpler phrasing, audio instructions and use of a colour display.

Holly: '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'.

Another factor linked to the interface with the energy market related to energy use. All participants weighed up energy consumption with cost implications, making trade-offs to meet energy needs. One participant traded personal space and independence following a drop in income after the introduction of Universal Credit (UC) by inviting a family member to move in and contribute towards living costs.

Kelly: 'He's [father's] paying for the roof over our heads so we're not on the street'.

Another household sacrificed food to cover energy costs.

Laura: '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'.

Participants trading space for heat was evident. For example, one participant only switched the radiator on in the room she was using, turning this off when she left the room; another participant's mother slept in the living room as it was warmer than her bedroom.

All participants limited the amount of time they heated their homes, using energy only when considered essential. All households ensured heating was off when they were not in the house and at night, and most households manually switched heating on and off when people were at home. In cold weather this would have led to a severe drop in temperature and excessive energy use to get the home up to a healthy temperature on return or in the morning. Another strategy was to restrict heating to when all household members were home.

Annabelle: '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'.

Adam: 'Sometimes they [others in the house] have the central heating on but it's probably only on, you know, a really cold day'.

The only household that used a timer to operate their heating system used this to ration energy use, setting the timer to one hour in the morning and one hour in the evening. There was evidence that people were selectively disconnecting from their energy because of cost; by not using heating or not topping up prepayment meters whilst waiting for money to enter their bank account.

Frank: 'It was too much money [last winter] …. [I] keep not putting heating on even in wintertime'.

Tactics to delay or avoid heating use, included wrapping up in blankets, extra layers of clothing, hot drinks and hot water bottles.

> *Kelly: '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'.*

The third factor relating to the participants' interface with the energy market related to payment for energy. As mentioned, most participants expressed a strong preference for using prepayment meters or direct debit payments. Whilst three households used direct debit payments, two participants in these households were not involved in decision making around energy payment because parents made these decisions on their behalf.

Almost 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. Those reliant on welfare benefits budgeted around the timing of when payments arrived.

> *Frank: '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'.*

> *Laura: 'Well if it's ESA* (Employment Support Allowance) *week, it's £15, but when DLA* (Disability Living Allowance) *goes in it's a bit more, like £25 on it…. We get paid every Tuesday, so we [top up] then'.*

Some households used the pre-payment meters 'emergency fund' as a strategy to pay for energy when *'in desperate need'*. (Laura)

> *Kelly: '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… '*

At the time, changes to welfare payments adversely affected being able to afford energy. The uncertainty regarding UC and other financial support, including the Winter Fuel Payment, was a cause of concern and anxiety.

> *Kelly: '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'.*

Discussion

This research makes an important contribution to the limited evidence base about the nature and experience of fuel poverty amongst adults with learning disabilities. Fuel poverty statistics and other research data often fail to recognise the diversity of disabled people's experiences and lifestyles (see Ivanova and Middlemiss, 2021). Our work provides much needed evidence on the lived experience of people with learning disabilities which adds to the understanding of the way that disability intersects with fuel poverty. These insights are even more important to consider following the challenges faced by people with learning disabilities during COVID-19 and due to rising energy prices and increases in the energy price cap.

The study design incorporates creative and methodological techniques and demonstrates the importance and benefits of taking an inclusive and participatory

approach. It provides invaluable learning for researchers and others who are engaging and working with hard-to-reach groups.

Whilst the coping strategies employed by the adults with learning disabilities to manage their heating use and stay warm tend to reflect those employed by the broader fuel poor population (Ambrose *et al*., 2021), and the issues they are experiencing in accessing energy advice and support resonate more widely with those encountered across hard-to-reach groups (Ambrose *et al*., 2020), our study gives further insight into how the energy market plays an important part in shaping approaches and attitudes to energy use and practice of those who are particularly disadvantaged by it. Although some adults with learning disabilities are aware of the importance of being warm at home for their health, the energy market is often inaccessible and difficult to navigate. Participants struggled with the range of providers, frequent changes in tariffs and offers, difficulties contacting energy companies for advice and support, and energy technology, and billing and payment systems that are difficult to understand.

Our evidence demonstrates how accessibility carries meaning beyond the format and content of resources and includes how participants feel about engaging with services and support. This finding supports other evidence on the lived experience of energy poverty which shows that emotions play a part in shaping energy vulnerability, with factors such as stigma, embarrassment and trust either facilitating or preventing the receipt of support for energy vulnerable households (Longhurst and Hargreaves, 2019). Other recent research has demonstrated that the way people interact with the energy market is relational and influenced by their relationships with friends, families, intermediaries, and energy companies themselves (Middlemiss *et al*., 2019; Ambrosio-Albala, 2020). Our study illuminates how relationships and experiences can influence and mediate access to the energy market for people with learning disabilities.

The importance placed on appearing independent was a significant finding in that it may mean that adults with learning disabilities are particularly reluctant to access support except from trusted sources such as family or self-advocacy organisations, who may have limited or inaccurate knowledge themselves. Opportunities to become more knowledgeable and in control of energy use and payment, could be missed through well-intended actions of families, or restrictions imposed by councils.

Our findings show how adults with learning disabilities are disadvantaged in many ways regarding current energy policy and practice, for example in relation to accessing and using energy payment systems, accessing energy efficiency and fuel poverty strategies. Although vulnerable hard-to-reach groups face similar issues when trying to access energy advice, the extent to which adults with learning disabilities experience inaccessible energy services and support is likely to be more extreme, acting to increase their risk of experiencing cold homes and fuel poverty which in turn poses a much greater risk to their health, and in some cases their independence. Adults with learning disabilities frequently face additional cognitive, sensory or communication impairments that make information and support inaccessible. It was clear that accessing support and information which was understandable and acceptable was extremely challenging for participants in our study. A 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 adults with learning disabilities can get a consistent and appropriate level of support and help with energy services (Wealthy, 2018).

When considering the way disability intersects with fuel poverty, our evidence points to the challenge of engaging with energy services faced by adults with a learning

disability as being an additional factor (to those already outlined by Cronin de Chavez, 2017) that acts to spiral them into worsening energy poverty.

Our study took place before the COVID-19 pandemic; however, the findings are particularly relevant and timely as the ongoing pandemic has highlighted how important it is to protect people at additional risk from the coronavirus. Maintaining safe home temperatures over the winter months is likely to play an important part in this. People with learning disabilities (and older family members who often support them) are at greater risk of contracting the coronavirus and having a severe reaction, or dying, as they have a higher prevalence of health co-morbidities, including respiratory disease (Hatton, 2020). The COVID-19 pandemic has also disrupted services and support, and restricted contact with family and friends who might usually provide help and advice, exacerbating existing barriers and creating additional barriers to maintaining a warm home.

The impact of austerity measures and benefits changes also means that people with learning disabilities, an already socioeconomically disadvantaged group, are even less financially secure. The COVID-19 pandemic may have created even more difficult trade-offs between heating and other essentials over winter, as many people were required to spend more time at home due to national and local restrictions and faced a drop in income. The current cost of living crisis and significant rises in energy bills will exacerbate the situation. Beliefs about energy practices, technology and payment methods may lead to a greater sense of control; however, these beliefs mean that people with learning disabilities are often spending more on energy than necessary and using strategies to ration energy use. This increases the likelihood of being in a cold home or going without other essentials by making trade-offs, with the potential negative impacts on health and wellbeing. Similar findings have been found in studies examining the experiences of fuel poverty for older people and families with children (see Tod *et al*., 2012; Tod *et al*., 2016).

A major strength of the BWBH study was the participatory, inclusive approach, with researchers from a self-advocacy organisation and universities working together. We feel this increased the acceptability of the project to people with learning disabilities, helped to develop trust with participants, and facilitated recruitment. An important methodological development was the design of novel, creative techniques for data analysis and developing solutions; the co-researchers reported that these were accessible and inclusive. The use of creative methods at the co-production workshops supported a variety of key stakeholders to develop a range of potential solutions (Table 2). The self-advocacy organisation applied for funding to take forward selected findings and has since developed a ‘Prioritise Me’ training resource about the energy market for people with learning disabilities ([see Speake and Gilbertson, 2020). This demonstrates the importance of co-production throughout the research process; from planning the research to taking forward the recommendations.

Table 2: Potential solutions

Awareness-raising
• Information about the Priority Services Register (PSR) for people with learning disabilities, advocacy organisations and service providers. • Information about how to improve provision, how to detect risk of fuel poverty amongst people with learning disabilities, and how to signpost/ refer to appropriate support (including PSR) for energy companies, health and social care providers, tenancy liaison officers and plumbers.
Accessible co-ordinated information and support
• Easy read information and energy bills • Improved telephone advice systems (e.g., avoiding call holds, advice lines with no time pressure, call-back systems to avoid waiting at busy times, training for advice line staff about effective communication with people with learning disabilities). • Ensuring support workers, advocates and family members are linked into relevant communication and information from energy companies and services.
Technology
• Improved meter design. • An accessible device to control heating, access up to date information about household energy use and cost, get information about energy efficiency, energy deals etc (e.g., similar to voice operated virtual assistant AI technology, talking smartphone application).

Limitations

Temperature measurements in ten households are not sufficient to make any statistical claims regarding the prevalence of high or low temperatures in households containing adults with learning disabilities. Although our ten qualitative interviews do permit us to make analytical generalisations, all the participants were recruited through one self-advocacy organisation with expertise in energy advice. Therefore, the participants' energy experiences, knowledge and practices may not be so typical of other people with learning disabilities. The reported confidence in smartphone use is not typical of all people with learning disabilities (Chadwick *et al.,* 2018). We focused on people who would be considered to have mild or moderate learning disabilities who were living independently or with family; there are likely to be different experiences and influences for people with profound and multiple learning disabilities, people receiving intensive support or living in residential care. None of the people with learning disabilities were younger than 28 and the oldest were 59, although family members were aged up to 80 years.

Implications and conclusions

As stated, this study adds to the evidence base on the lived experience of fuel poverty and contributes to the understanding of how disability and fuel poverty intersects, and plays out, in the lives of adults with a learning disability.

The insight into the influences on whether adults with learning disabilities can keep warm at home raises implications for clinicians and policy makers. Whilst participants talked about local authorities, self-advocacy groups and family influencing their energy practices, there was no mention of support from other third sector, health or social care

service providers (e.g., Citizens Advice Bureau, community learning disability teams). This could be because many adults with learning disabilities are unknown to, or not using, specialist services (Hatton *et al.,* 2016). However, it may indicate that providers do not recognise the potential likelihood and impact of living in cold housing for adults with learning disabilities, or that they do not view involvement as part of their role. Given the likely impact on physical and mental wellbeing, and potential reluctance to seek help, it is important that there is awareness-raising amongst service providers and commissioners. Guidance is needed on how to identify adults with learning disabilities who may be at risk, appropriate interventions, and whose role it is to do this.

Table 2 outlines solutions for energy companies and energy services which would improve the advice and support available for adults with learning disabilities and hard-to-reach energy customers more generally. For especially vulnerable consumers like those with learning disabilities, ensuring support workers, advocates and family members are linked into relevant communication and information and enhancing the accessibility of information and technology is vital. The lack of clarity about the presence and purpose of smart meters and the poor accessibility reported by participants is concerning and demonstrates how the potential benefits of smart meters are not being realised by vulnerable consumers who are less able to respond to information provided which could help them reduce their energy bills (see Citizens Advice, 2015). More recent research has highlighted that support such as home visits, face to face delivery of advice and further demonstration of smart meter functions is crucial when supporting vulnerable consumers to benefit from their smart meters (Hodges, *et al*., 2018).

Our findings lead to further questions and areas for future research. It is important to identify whether these findings are unique to this sample or reflect the experiences of adults with learning disabilities more generally, and if so, how to effectively support people to be warm and well at home. Whilst we did not include people who receive intensive support or live in residential care, as it was expected that they would receive support to keep warm at home, discussions during the consultation phase suggested that there may be issues around household temperatures and consequent impacts (e.g., around over-heating for example). Research exploring the perspectives of commissioners, third sector, health and social care providers would be beneficial. In the context of the COVID-19 pandemic and escalating energy prices, further research is even more important, and prospective studies on the impact of energy price increases would be particularly valuable.

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