









The Being Warm Being Happy Project: an exemplar of participatory research

Tod AM, Taylor B, Wolstenholme D, Chapman M, Ferguson A, Bradley J, Owen A, Farnsworth V.

Background

Being cold at home can kill. The Cold Weather Plan for England expects nurses to prevent such avoidable, cold related harm. Adults with Learning Disabilites (AWLD) are more vulnerable to the risk of cold related harm.

Aims

The Being Warm Being Happy (BWBH) aimed to understand influences on the ability of AWLD to keep warm at home, how this impacted upon their health, and what could be done to facilitate keeping warm at home.

Method

Data collection and analysis were conducted collaboratively with researchers who had a learning disability. The study took place in 2017/2018. Participatory methods were used to conduct an in-depth interview study with 10 households with an AWLD. A coproduction stage translated the household findings into solutions, with involvement from a range of stakeholders. Co-production methods included developing pen-portraits, storyboarding.











Findings

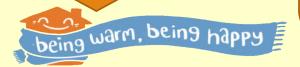
The findings provide understanding of the energy needs and experiences of participants as well as their emotions, attitudes and values related to energy. Impacts on physical and emotional health are considered. Co-production findings identified solutions to improve awareness of strategies and services to prevent cold related harm.

Increased need for heating
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".

Struggling with technology "Cause you can't use these machines now. It's all machines. And you can't understand them.

Restricting energy use

"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) "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)



Sources of support

"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".

Conclusion

The study used novel participatory approaches to generate a unique understanding of how AWLD can keep warm and well at home. Some practical solutions and recommendations were generated, including messages for nurses caring for AWLD. These included Examples include:

- Raising awareness of the Priority Services Register amongst AWLD, NHS and advocacy organisations.
- Develop accessible co-ordinated information. Easy read, accessible written information and energy bills were identified as a
 priority.

Marmot Review Team (2011): The Health Impacts of Cold Homes and Fuel Poverty On: www.instituteofhealthequity.org/projects/the-health-impacts-of-cold-homes-and-fuel-poverty-full-report.pdf Accessed January 2019

Public Health England (2013): Excess winter mortality 2012-13 On: www.gov.uk/government/publications/excess-winter-mortality-2012-to-2013
This study is independent research funded by EAGA CT and the National Institute for Health Research CLAHRC Yorkshire and Humber. The views expressed are those of the author(s) and not necessarily those of the NIHR, the Department of Health and Social Care or EAGA Charitable Trust.