

Tired of Spinning Plates: A Rapid Scoping Review of the Mental Health Needs and Mental Health Support of Carers of Adults with Learning Disabilities in the United Kingdom.

Plain English Summary

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Introduction

This paper is about the mental health of adult family carers of adults with learning disabilities. Research about being a family carer often highlights the joy that caring brings. Research also says that caring can be bad for family carers' mental health.

Not much of this research has included the mental health experiences of adult family carers of adults with learning disabilities. We worked with family carers, adults with learning disabilities, university researchers, and a charity to find out what has been written or shared about the mental health experiences of this specific group of family carers in the UK.

How We Did the Research

We searched for things that have been written about the mental health of adult family carers of adults with learning disabilities in the UK and since 2014 when the Care Act came into effect. We sorted through the evidence to make sure they specifically addressed the mental health of this group of family carers. We ended up with 18 items, which we then read to learn more about what this evidence says about being a family carer of an adult with learning disabilities. We organised what we found out into themes.

A Summary of the Main Findings

We found out that family carers worry a lot about the future and what will happen to the person that they love when they are no longer able to care for them. This worrying is reported by sibling and parent carers and adds to their experiences of stress and anxiety. Family carers find planning for the future difficult and the planning stressful. We found that the caring role can change throughout the life of a family carer. For example, a sibling carer might also become a carer for their parent(s) and/or become a parent themselves and need to juggle multiple responsibilities.

We found that family carers do not always have the support to do the things that would give them a break from caring and support their well-being. Even when family carers are able to take breaks they describe being "on call" all the time and are not able to "switch off". When services are not supportive or understanding of the caring that family carers do this can make family carers feel worse.

Family carers can face extra challenges with costs and earning money compared to other types of carers. This adds to their stress. Family carers might not experience a traditional

“retirement” chapter after a “working life” as they often care long after traditional retirement age.

We found that people with learning disabilities are not often included in research about the well-being of family carers of adults with learning disabilities. We think it is important to include and think about the points of view and the experiences of everybody being talked about in the research.

A Summary of the Main Implications of this Research

We did not find much evidence about the specific types of services or support that family carers of adults with learning disabilities find useful to support their mental health. This needs to be researched further. We also did not find any evidence detailing the use of medications or alternative therapy or how useful these things are for family carers of adults with learning disabilities.

More research is needed to address how better to support family carers of adults with learning disabilities with planning for the future. This planning needs to include the perspectives of adults with learning disabilities.

Attention needs to be paid and considered in relation to supporting the mental health of family carers through the ways in which caring changes over a person’s lifetime. The time and space available to family carers to engage with breaks or activities to support well-being must be considered together with family carers.

Kindness is needed in all these endeavours and in the services and support systems implicated in the lives of adults with learning disabilities and their families.

To find out more about the NIHR funded (135080) ***Tired of Spinning Plates*** project and the project team you can visit the project website at

<https://sites.google.com/sheffield.ac.uk/tired-of-spinning-plates/home>

You can also watch films about care, made by people with learning disabilities and family carers as part of this project, at <https://socialcaretalk.org/introduction/tired-of-spinning-plates-family-carers-of-adults-with-learning-disabilities/>.