

Health of adults who have a learning disability

‘I’m sure we made it a better study...’

Public involvement experiences of adults with learning disabilities and parent carers

Researchers from St George’s, University of London, have recently completed a three-year project alongside people with learning disabilities and parent carers. Together they have worked on a number of studies related to the health of adults who have a learning disability. Results include six publications which are now available.

Sam Goold from INVOLVE met with contributors to ask about people’s experiences of involvement, their achievements and hopes for the research.



(Pictured from left) Elaine Fadden, Carole Beighton, Sue Hubbert, Tess Harris, Sam Goold (INVOLVE), Carole Mathurin, Sally Burns, Iain Carey

What was your experience of involvement?

“It was important to be asked and have our views listened to and acted upon in terms of influencing the project. As a long established carer group we have a wealth of knowledge regarding learning disabilities and health checks and although we are often telling our stories to professionals it is rare for them to action our suggestions.” **Sue Hubbert, Parent Carer**

“It was great to see family carers being actively involved in such valuable research. Too often we just see the end result!” **Sally Burns, Parent Carer**

“Personally, the research opened my eyes to the many issues faced by both people with a learning disability and their carers. My work normally involves analysing data without knowing the stories behind it.” **Iain Carey, Researcher**

“We felt throughout that our views and contributions were taken seriously - between us we had a wealth of experience, and could feed this into the work.” Sally Burns, Parent Carer

“It made me feel valued being involved and included.”

Nikki Mathurin,
Public Contributor

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What has the research achieved?

“Thanks to the Patient and Public Involvement (PPI) work in this study, we gained more insight into the key issues around health checks, and corroborated what the data was showing us.”

Iain Carey, Researcher

“We have been able to publish the results in journals and we hope to influence those who plan services including NHS health checks for those with learning disabilities.” **Tess Harris, Researcher**

Main achievements of the research

- Addressed knowledge gaps by describing the health characteristics of adults with learning disabilities compared to the general population.
- Showed that patients with learning disabilities are less likely to have long GP consultations or to see the same doctor.
- Utilised data linkage to describe hospital admission and mortality patterns for people with learning disabilities compared to the general population.
- Showed that adults with learning disability were almost 3 times as likely to have an emergency hospital admission, with 1-in-3 of these being potentially preventable.
- Showed that the introduction of health checks for adults with learning disabilities were associated with a reduction in potentially preventable hospital admissions.
- We found that health information recorded during health checks varied across practices.

What are your hopes for the research?

“I hope that the value of NHS health checks for people with learning disability is recognised more due to this positive evidence, and these continue to be provided and improved. I also hope that our papers highlight the increased health problems and inequalities faced by people with learning disability and that this will be more widely recognised.” **Tess Harris, Researcher**

“I hope the research is used to show how important it is to involve the people and families so that the data information is understood and interpreted appropriately, for example, with blood tests.”

Carole Mathurin, Parent Carer.

“I hope that professionals take note of the recommendations from our publications as the unique perspectives and personal insights from both groups has not only strengthened the quality of our findings but are important and relevant to them as users of both health and social care services.”

Carole Beighton, Researcher

“All in all an extremely positive experience - and we very much hope the success of this project will encourage other researchers to talk to the real experts!”

Sally Burns, Parent Carer

“I hope professionals take notice.”

Elaine Fadden, Public Contributor

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<https://njl-admin.nihr.ac.uk/document/download/2011006>

INVOLVE is part of the National Institute for Health Research and supports active public involvement in NHS, public health and social care research.

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