



Care

Bolstering support for people with intellectual disability living with dementia

What is the focus of the research?

Conducting critical research that improves our understanding of how to support people with intellectual disability living with dementia.

Why is this important?

People with intellectual disability are more likely to develop dementia, often at a younger age, than people without intellectual disability.

By the age of 40, almost all people with Down syndrome will have brain changes associated with Alzheimer's disease. People with intellectual disability who don't have Down syndrome develop dementia about 10 years earlier than people without.

People with intellectual disability and dementia often require specialised support and services. Despite this

understanding, research on their health and mental health needs is lacking. Similarly, little research has focused on how to support people when they experience changed behaviours related to dementia.

In this project, Dr Cvejic will advance the research field's knowledge of this important but overlooked issue. In collaboration with people with intellectual disability, people living with dementia, their supporters and health professionals, she will design easy-to-read resources about changed behaviours and dementia for people with intellectual disability.

Her work will inform policy and service delivery, and lead to the development of evidence-based strategies to better meet the needs of people with intellectual disability living with dementia.



How will it happen?

Stage 1: use linked health data to determine the prevalence of dementia in people with intellectual disability in New South Wales and describe their health outcomes.

Stage 2: examine changed behaviours related to dementia in people who have used Dementia Services Australia programs.

Stage 3: interview and survey people with intellectual disability living with dementia, their supporters and health professionals, to understand how to best support people with intellectual disability experiencing changed behaviours related to dementia.

Stage 4: work with people with lived experience of intellectual disability and dementia to co-create accessible resources about changed behaviours related to dementia.



What will it mean for people with intellectual disability?

- A greater understanding of their dementia-related health and mental health needs.
- Evidence-based strategies to support people experiencing changed behaviours related to dementia.



Who's undertaking the research?

Dr Rachael Cvejic, UNSW Sydney

Dr Cvejic is a registered psychologist and Senior Research Fellow at the Department of Developmental Disability Neuropsychiatry, Faculty of Medicine & Health, UNSW Sydney. Her clinical and research experience includes working with people with complex support needs, including people with intellectual disability, people living with dementia and other neurological conditions, and people with serious mental illness.

Dr Cvejic uses a range of research methods to investigate health outcomes and health service use of different population groups. She routinely partners with people with lived experience and values their input into her work.

The title of Dr Cvejic's project is *Understanding responsive behaviours among people with intellectual disability living with dementia*.

Dr Cvejic and Dementia Australia Research Foundation would like to acknowledge Dr Stuart and Bonnie Bartle for making this research possible.