



# The SAge-ID Study

Summer 2017/2018 Newsletter

Dear Participants, Carers and Friends,

Welcome to latest edition of the Sage-ID newsletter! 2017 has been busy and exciting as we prepare to start the next round of the study and begin recruiting more new participants!

During this time we have welcomed Tanya to the team. We have also sadly said goodbye to Clancy and Adrian. We wish Adrian all the best for his future in medicine and Clancy with her Clinical Psychology Masters and PhD!

We hope you enjoy reading and as always, please don't hesitate to contact us if you have any questions or concerns.

Yours sincerely,

Prof Julian Trollor, Dr. Liz Evans, and the SAge-ID team.

## INSIDE THIS ISSUE

- 1 Welcome
- 1 Contact Details
- 2 Study Updates
- 3 Other News
- 4 Team Profiles

## POINTS OF INTEREST

- Thanks to new funding, SAge is continuing and expanding!  
Details on page 2.
- 3DN has a new Ambassador for Healthy Ageing, Mr. Michael Sullivan. See page 2.
- Resources for carers, page 3.

*Nature photography by our administration assistant, Daniel Pua.*



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# Study Updates



The SAge-ID study has now been running for over 5 years! Our first group of participants answered their first questionnaires way back in 2012. Many of these people continued being a part of the study two and a half years later.

Thanks to new government funding from the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC), SAge-ID is able to conduct a third round as well as recruit more participants! This means that we will be following up current participants in 2018, and recruiting a new cohort of participants Australia-wide .

## Introducing our Ambassador for Healthy Ageing

Michael Sullivan was appointed the Ambassador for Healthy Ageing for 3DN at UNSW. Mr. Sullivan has Down syndrome, and although retired, he maintains an active role as a vice-chair of the NSW Council for Intellectual Disability (CID).

Michael's role as Healthy Ageing Ambassador includes joint advocacy for improved services for older people with ID.

Michael recognises that studying dementia in people with ID is important because "we need to know what the early warning signs are for people with ID, to be able to pick the early warning signs as people age".

We are glad to have Michael's input into the study.



Michael Sullivan and  
Liz Evans

## Interesting study findings—Medication

Data from Wave 1 of the SAge-ID study found that 62.3% of older adults with an intellectual disability were taking at least one central nervous system medication, such as anticonvulsants, antipsychotics or antidepressants. Almost half of the sample was taking multiple medications affecting the central nervous system. Men in this sample were more likely to be prescribed multiple medications than were women.



These findings highlight the need for practitioners to continuously re-evaluate whether their patient's medications are still effective or whether they are no longer necessary. A paper about this has appeared in the *Australian & New Zealand Journal of Psychiatry*.

## Our work featured in *Voice*

The December edition of *Voice*, Down syndrome Australia's magazine, features our ambassador Michael Sullivan. He has written an article about his work in advocacy, including his work with 3DN. An article written by Liz Evans and Tanya Duckworth appears in the same edition.

# Other News

## An Opportunity to Have Your Say about Resources

The SAge-ID team are developing some resources about dementia and healthy ageing for people with intellectual disability and their family and carers. Earlier this year, Liz held a consultation with a group of older adults with intellectual disability about what sort of resources they would find helpful and what they would like to see in it. NSW CID were kind enough to lend us their boardroom and assist us in running that consultation, and we thank them for their terrific support.

We will also be holding a consultation process with family members who care for or support an older person with intellectual disability. Like the consultation for those with intellectual disability, it will occur in a small group (about 4 people). The first meeting will focus on what carers would find most helpful in a resource about dementia and healthy ageing in people with intellectual disability. At the second meeting, we will gather people's feedback about a draft resource.

If you would like to be involved in the consultation process, please contact us on (02) 9931 9160 or [SAge-ID@unsw.edu.au](mailto:SAge-ID@unsw.edu.au). We would love to have you involved!

## 'Get Healthy' Lifestyle Program

Our department will soon be starting a trial healthy lifestyle program for people with intellectual disability. The program is called '**Get Healthy!**' It has been designed to help people do exercise and eat well. The program will be held on Tuesdays and Thursdays at the University of New South Wales. A qualified dietitian and exercise physiologist will teach the program. If you are interested in learning more or think you may like to join, you can email the project officer Jessica Bellamy [j.bellamy@unsw.edu.au](mailto:j.bellamy@unsw.edu.au) or you can call (02) 9385 1344.

## e-Learning for carers about intellectual disability and mental health

Free online education is now available for carers of people with intellectual disability.



Topics include

- About intellectual disability • About mental health •
- Mental illness and intellectual disability •
- Detecting changes in mental health and wellbeing •

Signs and symptoms of mood disorders • Signs and symptoms of anxiety disorders

- Signs and symptoms of schizophrenia and other psychotic disorders •
- Signs and symptoms of dementia •

Each module is evidence-based, created with advice and input from carers and lets you learn about mental health and intellectual disability at your own pace. This resource is available for free to carers across Australia. To access the modules, visit [www.idhealtheducation.edu.au](http://www.idhealtheducation.edu.au) and register for your free account.

# Team Member Profiles

**Name:** Liz Evans

**Role:** Post-doctoral Research Fellow, Investigator

**What led you to this work?** When I studied psychology at university, we learned very little about intellectual disability. After finishing my degree, I worked as a research assistant in the area of mental health in people with ID. I was amazed to learn about how a group with high mental health needs can be so underserved. I became passionate about improving the health and mental health of people with intellectual disability. A few years on I started working with Professor Trollor. He suggested that ageing in people with ID was an important topic to research, to understand their changing needs. I agreed. The SAge-ID Study was born.



**What sort of impact do you hope this study will have in the future?** I hope that by documenting the health needs of adults with ID, we can begin to develop more tailored interventions to promote positive health as people age. Some of this is already being realised in our department's new work developing a healthy lifestyle intervention for people with ID. I also hope to see the results of the Sage-ID study helping to change in the way that health care, and particularly dementia care, is provided to ageing people with ID.

## Our Contact Details

If you have any questions, please contact us!

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