

## THE HEALTHY AGEING IN ID STUDY: FACT SHEET FOR LOCAL SERVICES

The life expectancy for people with Intellectual Disability (ID) is increasing dramatically, ensuring a rapidly expanding group of elders with ID. Yet little is known about the physical and mental health problems for this group, or about the needs of their carers. Furthermore, in this group, both current levels of health service use, and their unmet needs, remain unclear. Therefore, future service requirements cannot be predicted with any accuracy.

The longitudinal study of a large cohort of ageing Australians with intellectual disability would allow a comprehensive evaluation of the predictors and correlates of cognitive decline, the needs and unmet needs of this population, the service use and the carer burden associated with ageing. Overseas, research regarding older people with ID has been critical in highlighting the needs of this population: e.g., the UK National Dementia Strategy resulted in changes to service provision for people with ID to ensure inclusive pathways of care). This will be the first comprehensive study of its kind in Australia. The cohort will be of international interest as there are only a small number of studies in this area worldwide, and none as comprehensive in approach as the proposed study.

We will study a group of people with ID over time. We will evaluate their cognitive, physical and psychiatric status at baseline and determine the how many of them show age-related cognitive decline; we will also determine those factors relating to the person's health and supports that increase or decrease the chances of cognitive decline.

### **Suitable participants would:**

- **Be aged 40 years or older, and**
- **Have an intellectual disability (ranging from mild through to profound), and**
- **Live in either the Randwick, Botany or Rockdale Local Government Areas in NSW, or within the Hume or Loddon-Mallee Local Government Areas in Victoria.**

### **PARTICIPATION IN THE STUDY INVOLVES:**

#### **For all participants:**

**CARER AND FAMILY MEMBER QUESTIONNAIRES:** These will take up to 1.5 hours to complete and cover such topics as indicators of cognitive and functional decline, behaviours and mental health, and lifestyle factors, such as sleep, exercise, nutrition, and social networks.

#### **For a subsample of participants:**

**A FACE-TO-FACE ASSESSMENT OF THE PERSON WITH INTELLECTUAL DISABILITY:** This involves comprehensive assessments of the person's cognitive abilities, memory and language skills; a detailed health assessment, including standing and sitting blood pressure, posture, height and weight, vision and hearing, and arterial stiffness, to be undertaken either at our study centre or in the participant's home.

**A BLOOD TEST (IF POSSIBLE):** Taking of blood samples can be conducted at the SEALS pathology laboratory at Prince of Wales Hospital, or another local pathology laboratory. Basic biochemistry, thyroid function, nutritional status, inflammatory markers and vitamin and folate levels will be tested, and DNA will be stored for later analysis of genes known to influence the ageing process.

**AN OPTIONAL BRAIN MRI SCAN:** This test will be offered to a small number of people with mild ID.

**A DETAILED CARER INTERVIEW:** This will take around 40 minutes and provides information on signs of dementia in people with ID.

**We plan a longitudinal study, with follow-up questionnaires at 12 months, and repeated assessments at 24 months.**