

Successful Ageing for People with Autism Spectrum Disorders

Aspect Practice Annual Research Forum

Never Stand Still

Medicine

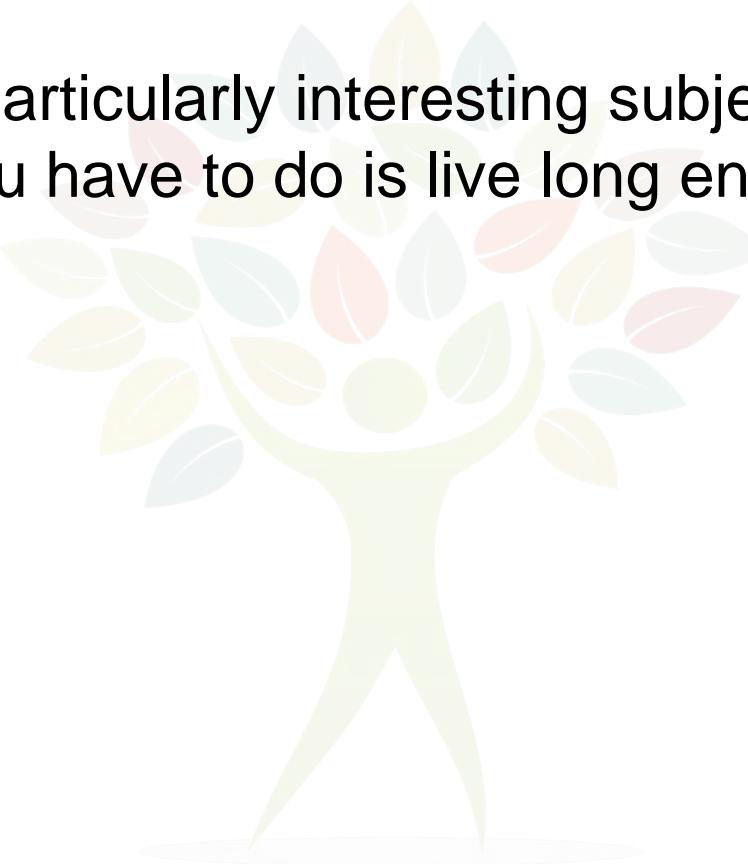
Department of Developmental Disability Neuropsychiatry

Julian Trollor, Kitty-Rose Foley & Jane Hwang
Chair of Intellectual Disability Mental Health
Head, 3DN <https://3dn.unsw.edu.au/>
School of Psychiatry, UNSW Australia
j.trollor@unsw.edu.au



Views on Age and Ageing

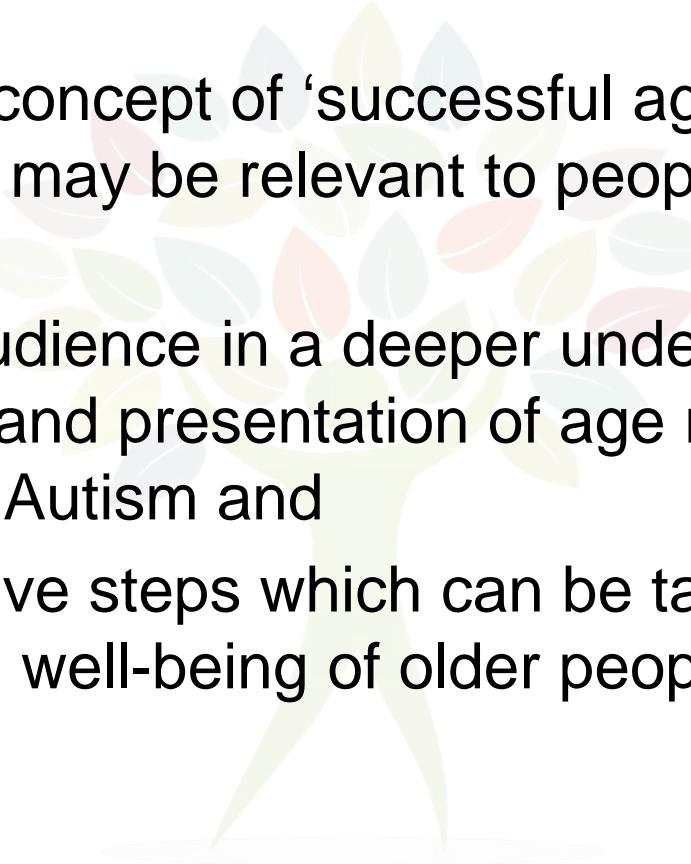
- Age is not a particularly interesting subject. Anyone can get old. All you have to do is live long enough.



Groucho Marx



This brief talk aims to:

- 
1. Introduce the concept of 'successful ageing', and explore how it may be relevant to people with ASDs (Autism)
 2. Engage the audience in a deeper understanding of the epidemiology and presentation of age related disorders in people with Autism and
 3. Propose positive steps which can be taken to improve the health and well-being of older people with Autism.



Ageing: an Important Issue for People with Autism

- People with Autism are living into late life
- Ageing with Autism carries specific implications
 - Person, significant others, carers
 - For health, cognition, wellbeing and engagement in life
- A small decline in health, wellbeing or cognition can translate to a substantial change in function
- Ageing with Autism
 - Impacts the individual
 - Impacts carers
 - Has service and cost implications

What is Successful Ageing?

- ‘objective’- Rowe and Kahn’s (1987)
 - absence of disease
 - engagement in life
 - intact physical and cognitive functions
- ‘subjective’ (Diener et al., 1985)
 - well-being approach

*For some, the difference
between these 2 is
substantial*

Successful Ageing in the General Population

- ‘Objective’
 - large population based studies (Hank, 2011; McLaughlin et al., 2010)
 - 8.5% of people aged 50 years and over across 15 European countries were successfully ageing;
 - 11.9% in the USA.
- absence of disease
 - engagement in life
 - intact physical and cognitive functions
- ‘Subjective’
 - 50.3% of people aged 65-99 ‘ageing successfully’, only 18.8% met objective criteria (Strawbridge et al. 2002)
 - 92% of people aged 60+ ‘ageing successfully’, only 5% met objective criteria. (Montross et al. 2006)

What about successful ageing in people with Autism?



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Detecting ageing inequality in people with Autism

Disease Burden

Health outcomes

Mortality statistics

Subjective- impact on individual and carers

Intact Physical and Cognitive Function

Prevalence of mental and physical disorders

Subjective- impact on individual and carers

Successful Ageing in Autism

Participation

Statistical

Expectations of the person with Autism

Expectations of carers

Systems and Society

Access to health services

Inclusion of neurodiversity in models

Gaps in development & application of best practice



Successful Ageing for People with Autism

- Current situation
- Targets



Successful ageing for people with Autism: - *disease burden*

Current Situation

- Health conditions associated with Autism
 - Specific
 - Non-specific
- Health conditions as complications of treatment
- Health conditions arising from risks and misadventure associated with Autism

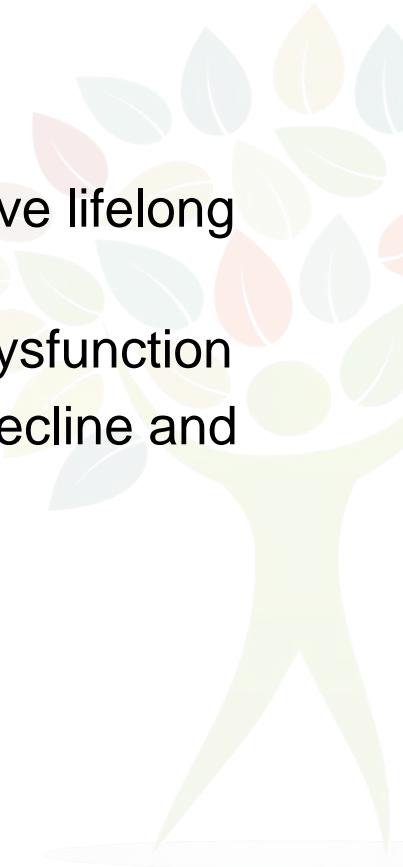
What it should look like

- Health conditions associated with Autism
 - optimally managed, disability minimised
- Minimal complications of treatment
- Mitigating risks and misadventure associated with Autism

Successful ageing for people with Autism: - *intact physical and cognitive functions*

Current Situation

- Some individuals have lifelong physical disability
- Baseline cognitive dysfunction
- ?rates of cognitive decline and dementia



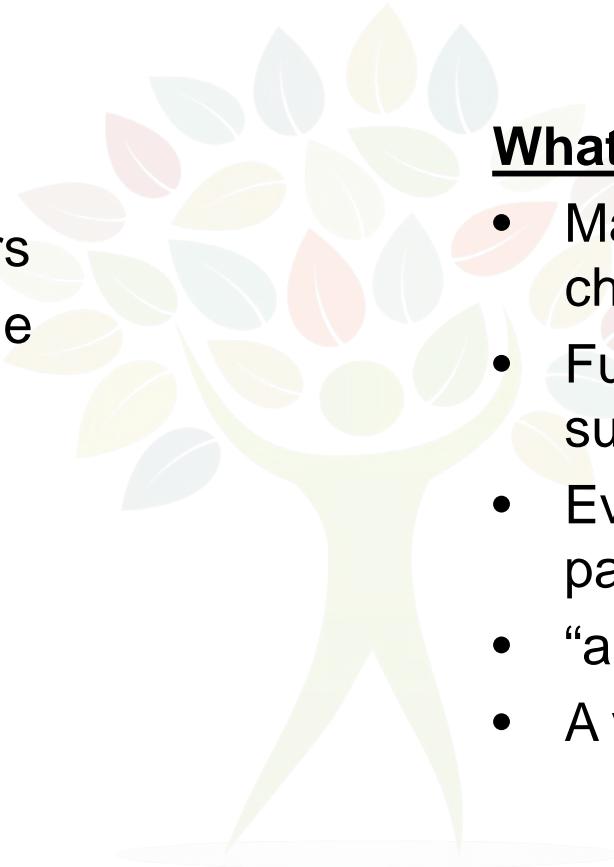
What it should look like

- Preventative health
- Mitigating the effect of age on exacerbation of long-term physical disability
- Addressing risks factors for cognitive dysfunction
- Screening for cognitive decline
- Access to skilled assessment and management in situations where cognition declines
- Cohesive array of supports

Successful ageing for people with Autism: - *engagement in life: Participation*

Current Situation

- Numerous barriers
- Magnified with age



What it should look like

- Maximised opportunity for choice
- Full access to appropriate supports
- Every possibility of participating in the community
- “a participating life”
- A valued elder

Mental Health of Adults with Autism

- People with Autism experience:
 - an over-representation of mental disorders
 - very high lifetime rates of depression, anxiety disorders and developmental mental disorders (eg ADHD)
- People with Autism and intellectual disability (ID):
 - Similar mental health burden as for people with ID- Autism
- Access to mental health supports and treatments is limited
- High impact for people with Autism, families and carers
- Multiple vulnerabilities

[Totsika et al 2010](#); [Tsakanikos et al., 2006](#); [Gillott & Standen, 2007](#); [Stewart et al 2006](#); [Mukaetova-Ladinska, et al 2012](#); [Stuart-Hamilton et al 2010](#) ; [Gillott & Standen, 2007](#).

High Functioning Individuals

- Study of 120 adults (16 to 60 years) with Autism who were relatively high function
 - $\frac{1}{4}$ completed college or university
 - 43% employed or studying.
- High lifetime rates of mental disorders:
 - mood disorder 53%, anxiety 50%, ADHD 43%, dyslexia 14% and eating disorder 5% ([Hofvander et al., 2009](#)).

Mental Health and Ageing

- Lack of longitudinal studies
- Some cross sectional data suggests caseness may decline across age bands (eg [Totsika et al., 2010](#))
- Majority of studies show stable rates of mental disorder (eg [Totsika, Felce, Kerr, & Hastings, 2010](#); [Tsakanikos et al., 2006](#))
- Likely vulnerability persists

Cognitive Profile of Older People with Autism

- Cognitive profile suggests relative weakness in some areas:
 - episodic memory ([Lind & Bowler, 2010](#))
 - complex tasks involving multiple processes (attention, perception, memory and matching) such as face memory recognition ([O'Hearne, Schroer, Minshew, & Luna, 2010](#))
 - theory of mind, executive function
 - attention and everyday memory.

Cognitive Trajectory of Older People with Autism

- It is unknown how these cognitive impairments change throughout the Autism lifespan ([Mukaetova-Ladinska et al., 2012](#)).
- Cognitive Function with Age:
 - smaller impact on fluency in the high functioning autism (HFA) group than in the controls
 - a more profound effect on visual memory performance in the HFA group.

Hilde M. Geurts; Marlies E. Vissers; J Autism Dev Disord. May 2012; 42(5): 665–675

Is Dementia More or Less Common in People with Autism?

- Little research
 - ‘we haven’t seen anyone with Autism and dementia’
 - Under-representation of older people with both Autism and dementia on service system data base (Pascual Leone)
- Lack of coherence in the literature
 - Cognitive profile of people with Autism ‘already old’ might reduce the prospects of further cognitive decline in ageing individuals with Autism ([Mukaetova-Ladinska et al., 2012](#)).
 - Temporoparietal cortical thinning associated with Autism might confer extra vulnerability ([Greshwind & Miller, 2001](#); [Wallace, Dankner, Kenworthy, Giedd, & Martin, 2010](#); [Mukaetova-Ladinska et al., 2012](#)).

Could Dementia be less Common? Brain Plasticity of Older People with Autism

- “Hyperplasticity in Autism Spectrum Disorder confers protection from Alzheimer's disease”. Oberman LM, Pascual-Leone A, Med Hypotheses 2014
 - Hypothesize that people with Autism may be protected
 - Cortical excitability experiments show divergence from usual ageing experience of reduced plasticity
- **Cognitive Function with Age:** Hilde M. Geurts; Marlies E. Vissers; J Autism Dev Disord. May 2012; 42(5): 665–675
 - smaller impact on fluency in the high functioning autism (HFA) group than in the controls
 - a more profound effect on visual memory performance in the HFA group.

Could Dementia be more Common?

- Dementia prevalence elevated in people with ID
- Interaction between other health conditions and cognition
 - Eg epilepsy Turky A et al. Epilepsia. 52(7):1223-30, 2011 Jul.
- Lifestyle factors
 - Diet; exercise
 - Overweight and obesity
- Cognitive Reserve Hypothesis
 - Social interaction through the lifespan
 - Mental stimulation through the lifespan

Dementia Assessment in Autism with ID

- There is no gold standard
- Important things to consider are:
 - Measurement of severity of Autism
 - Establishing baseline functioning
 - Reliance on carer reports
 - Structured assessment of cognitive function, tailored to level of Autism
 - the ‘bounce’ phenomenon
 - Effect of medical and psychiatric comorbidities
 - Follow-up assessment

Dementia Assessment in People with High Functioning Autism

- Normative data lacking
- Best prospect is to have individual baseline
- Standardised tests useful
- Challenge of good ‘informant’ history
- Restricted range of interests need to be interpreted in context

Addressing ageing inequalities for people with Autism

Disease Burden

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Disease Burden

What's needed?

- Large scale longitudinal studies of ageing adults with Autism and their carers which establish:
 - the prevalence of psychiatric disorders, cognitive disorders (including mild cognitive impairment & dementia) and physical disorders
 - change in psychiatric, cognitive and physical health status over time
 - modifiable risk factors for cognitive and physical decline
 - the impact of ageing on the person, family caregivers, service use
- Development and evaluation of models of care
- Economic modelling:
 - cost/benefit associated with differing models of care, components of care
- Translational work which:
 - develops national and state policy frameworks
 - develops prevention strategies
 - develops and supports the implementation of screening in primary care and skilled assessment in specialist services
 - develops management guidelines
 - develops consumer and carer resources



Intact Physical and Cognitive Functioning

What's needed?

- Collection of and interrogation of large representative datasets
 - Prevalence of physical disabilities
 - Prevalence, correlates and predictors of age-associated cognitive disorder
 - Change in disability with time
 - the impact of ageing on the person, family caregivers, service use
- Development of reliable and valid screening and assessment instruments
- Opportunities:
 - NDIS datasets
 - Linkage to PCEHR
 - Large voluntary register for representative sampling

Participation

What's Needed?

- Large scale evaluation of participation and engagement with life
- Qualitative studies to capture the experience and expectations of people with Autism and carers

→ Identification of age-specific barriers and enablers

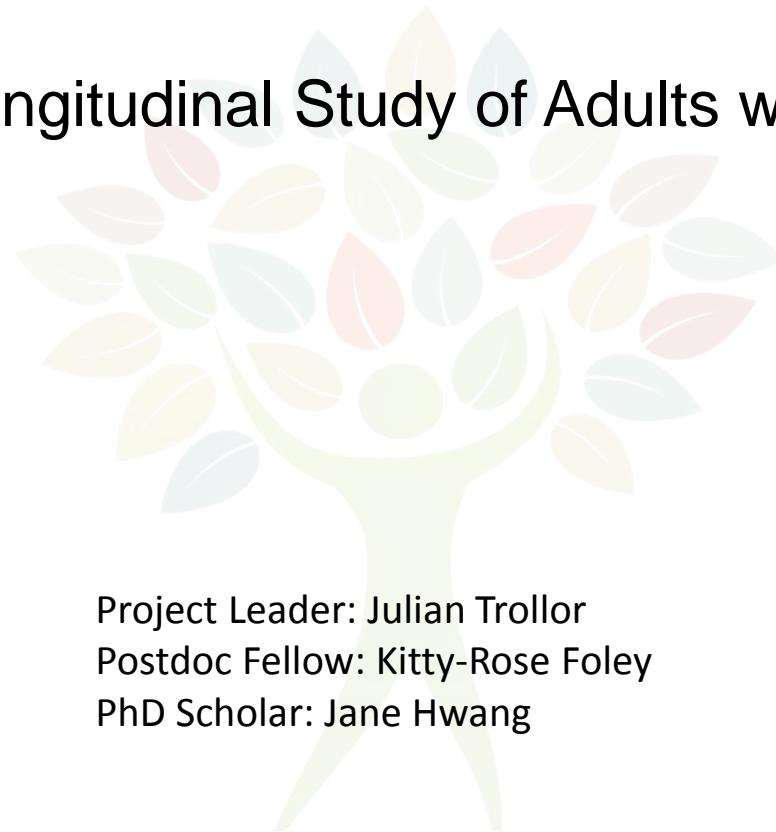
→ Design of age-specific tools

Systems and Society

What's Needed?

- Neurodiversity inclusiveness in ageing policy and practice
- Focus on developmental disability in health and ageing policy
- An equipped health workforce
- The development of specialist models of practice in health and disability fields with a focus on age-related conditions (geriatricians, psychiatry of old age, behaviour support specialists).
- Education and training in age-related health conditions in Autism (an opportunity) for:
 - disability workers
 - health professionals
 - carers and consumers

- Australian Longitudinal Study of Adults with Autism (ALSAA)

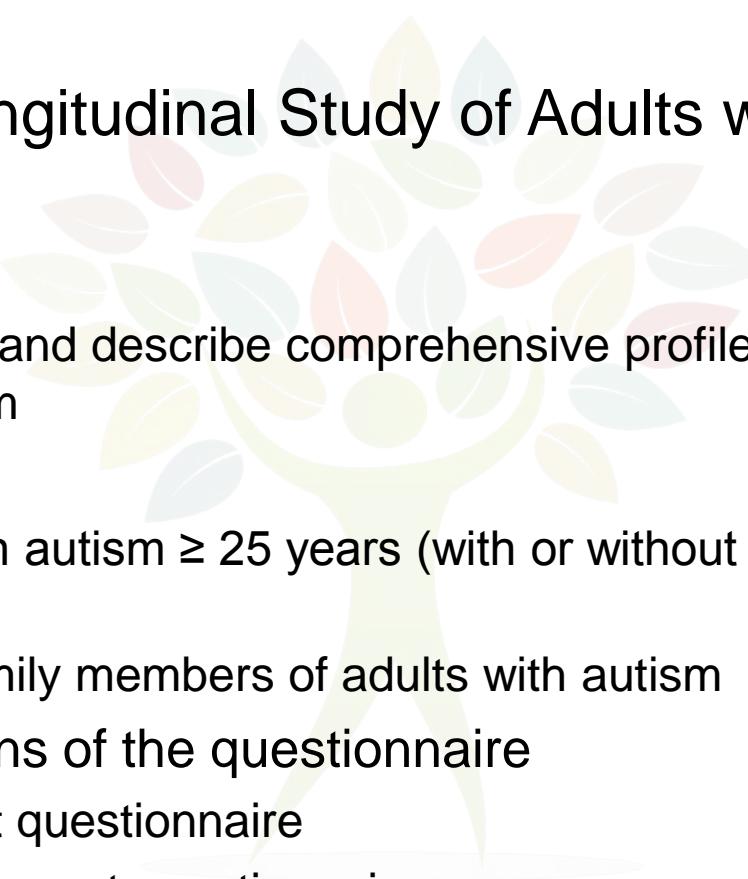


Project Leader: Julian Trollor
Postdoc Fellow: Kitty-Rose Foley
PhD Scholar: Jane Hwang



Australian Longitudinal Study of Adults with Autism (ALSAA)

- Australian Longitudinal Study of Adults with Autism (ALSAA)
 - Aim
 - to identify and describe comprehensive profiles of Australian adults with autism
 - Participants
 - Adults with autism \geq 25 years (with or without comorbid intellectual disability)
 - Carers/family members of adults with autism
 - Three versions of the questionnaire
 - Self-report questionnaire
 - Informant report questionnaire
 - Carer/family member questionnaire



Measures

Measure	Self-report version	Informant report version	Carer version	L1 or L2 Study
Background Questionnaire	✓	✓	✓	L1 & L2
The Autism Quotient (AQ)	✓	✓	✓	L1 & L2
Communication Checklist – Adult	✓	✓		L1 & L2
Repetitive Behaviours Questionnaire-2	✓	✓		L1 & L2
Developmental Behaviour Checklist-Adolescent/Adult version		✓		L1 & L2
The Glasgow Sensory Questionnaire	✓	✓	✓	L1 & L2
Waisman Activities of Daily Living Scale	✓	✓		L1 & L2
WHO-DAS 2.0	✓	✓	✓	L2
Sternberg's Behaviour Check List	✓	✓		L1
Pittsburgh Sleep Quality Index	✓			L1 & L2
Flinders Fatigue Scale	✓		✓	L1 & L2
DSM-5 Dimensional Anxiety Scales: Generalized Anxiety	✓		✓	L1 & L2
DSM-5 Dimensional Anxiety Scales: Social Phobia	✓		✓	L1 & L2
The Patient Health Questionnaire-9	✓		✓	L1 & L2
The Patient Health Questionnaire-15	✓	✓	✓	L2
SF-12	✓		✓	L2
Hospital Anxiety and Depression Scale	✓			L1

Measures continued

Measure	Self-report version	Informant report version	Carer version	L1 or L2 Study
Obsessive-Compulsive Inventory – Revised	✓	✓		L1
The Composite Autonomic Symptom Score	✓	✓	✓	L1 & L2
The Warwick Edinburgh Mental Well-being Scale	✓		✓	L1 & L2
Leisure Satisfaction Scale	✓			L2
The Adult Temperament Questionnaire	✓	✓	✓	L1
WHOQOL-BREF	✓		✓	L1 & L2
The Emotion Regulation Questionnaire	✓	✓	✓	L1 & L2
The Intolerance of Uncertainty Scale-12	✓		✓	L1 & L2
The Brief COPE	✓		✓	L1 & L2
Memory Complaint Questionnaire	✓		✓	L2
University of California Los Angeles Loneliness Scale	✓			L1 & L2
The Social Support Questionnaire-6	✓	✓		L1 & L2
Client Service Receipt Inventory	✓	✓		L2
Positive Affect Index			✓	L1 & L2
Caregiver Activity Survey (CAS-ID)			✓	L1 & L2
Zarit Burden Interview			✓	L2



AutismCRC



UNSW
AUSTRALIA

Online Questionnaire Study for Adults with Autism/Asperger's syndrome

Researchers at UNSW Australia and Autism CRC are seeking volunteer research participants to learn about life in adulthood for people with Autism/Asperger's syndrome.

Press release:

<https://newsroom.unsw.edu.au/news/health/what-does-life-lived-autism-spectrum-look>

Would the research project be a good fit for me?

The study might be a good fit for you if:

- You are an adult and you have Autism/Asperger's syndrome
- You are a carer or family member of an adult with Autism/Asperger's syndrome

What would happen if I took part in the research project?

If you decide to take part you would:

- Complete a questionnaire either online or via a paper copy.
- The questions will be about many aspects of life including mental and physical health, employment and other day occupations, behaviour, emotions, coping, memory, friendships and health service utilisation.
- It might take 2 to 3 hours or more, to finish, but you don't have to do it all at once.
- Complete a second questionnaire about two years later if you want to.

Will I be paid to take part in the research project?

There are no additional costs associated with participation in this research project, nor will you or the participant be paid.

Who do I contact if I want more information or want to take part in the study?

If you would like more information or are interested in being part of the study please contact:

Kitty Foley
e: autismcrc@unsw.edu.au
p: (02) 9385 0620
www.autismcrc.com.au/adult-study
www.3dn.unsw.edu.au

Autism CRC is the world's first cooperative research effort focused on autism across the lifespan.



Health and wellbeing of people with disabilities in the NSW service systems: data linkage

- Life expectancy, mortality, cause of death, potentially avoidable deaths
- Health and disease profiles: physical health; mental health
- Health service use: emergency, inpatient
- Health service costings

Primary Health Care for people with Autism

- BEACH data set
- Characteristics of patients and GPs where Autism is managed
- Problems manages, referral practices, prescribing practices

3DN Core Staff June 2015



Funding Sources

Funding: Core

- Ageing Disability and Home Care | Family and Community Services NSW
- UNSW Medicine

Funding: Research and Projects

- NSW Ministry of Health & Related Organisations
 - MHDAO, MH Kids, HETI, ACI ID Network
- Australian Government Department of Health and Ageing
- Australian Research Council (ARC)
- National Health and Medical Research Council (NHMRC)



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