Successful Ageing for People with Autism Spectrum Disorders

Aspect Practice Annual Research Forum

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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.

• ‘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?
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

High Functioning Individuals

• Study of 120 adults (16 to 60 years) with Autism who were relatively high function
  – ¼ 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.

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

  – Hypothesize that people with Autism may be protected
  – Cortical excitability experiments show divergence from usual ageing experience of reduced plasticity

  – 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
• 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
- Health outcomes
- Mortality statistics
- Subjective- impact on individual and carers

Intact Physical and Cognitive Function
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Successful Ageing in Autism

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Systems and Society
- Access to health services
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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
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 ≥ 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

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<th>Measure</th>
<th>Self-report version</th>
<th>Informant report version</th>
<th>Carer version</th>
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## Measures continued

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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.

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.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 managed, referral practices, prescribing practices
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)
  – NHMRC
  – Australian Government National Health and Medical Research Council
  – Australian Government Department of Health and Ageing
  – AutismCRC