



Successful Ageing for People with Autism Spectrum Disorders

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry



Julian Trollor & Kitty-Rose Foley

3DN

School of Psychiatry, UNSW

j.trollor@unsw.edu.au

3dn.unsw.edu.au

 [3dn.unsw](https://www.facebook.com/3dn.unsw)

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



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This brief talk aims to:

1. engage the audience in a deeper understanding of the epidemiology and presentation of age related disorders including the dementias in people with an ASD (ASDs)
2. examine the application of the concept of 'successful ageing' in people with ASDs and
3. propose positive steps which can be taken to improve health and well-being in older people with an ASDs.



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Ageing: an Important Issue for People with ASDs

- For the first time, people with ASDs are living into late life
- Ageing with ASDs carries specific health implications
- A small decline in cognition can translate to a large decline in function
- Ageing with ASDs
 - Has an impact on carers
 - Has service and cost implications



Mental Health of Adults with ASDs



- People with an ASD experience:
 - an over-representation of mental disorders
 - very high lifetime rates of depression, anxiety disorders and developmental mental disorders (eg ADHD)
- People with ASDs + 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 ASDs, 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](#).



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High Functioning Individuals

- Study of 120 adults (16 to 60 years) with ASD 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](#)).



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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



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Cognitive Profile of Older People with ASDs

- Cognitive profile suggests relative weakness
 - 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 ASDs

- It is unknown how these cognitive impairments change throughout the ASD 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 ASDs?

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



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Could Dementia be less Common?

Brain Plasticity of Older People with ASDs

- “Hyperplasticity in Autism Spectrum Disorder confers protection from Alzheimer's disease”. Med Hypotheses. 2014 Jun 17. doi: 10.1016/j.mehy.2014.06.008. [Epub ahead of print]; Oberman LM, Pascual-Leone A
 - Hypothesize that people with ASDs may be protected
 - Cortical excitability experiments show divergence from usual ageing experience of reduced plasticity
- 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



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Could Dementia be more Common?

- Dementia prevalence elevated in people with ID
- Interaction between other health conditions and cognition
 - Eg epilepsy Turkey 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



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Dementia Assessment in ASD with ID

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



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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



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GOAL

The Highest Attainable Standard of Health and Wellbeing for Older Persons with an Intellectual or Developmental Disability



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Current Status: Services and Supports

Services and supports for people with ASDs are characterised by:

- Limited age-specific capacity in generic health and disability settings
- Limited availability of specialised ageing services
- Health and disability professionals with limited training in health and ageing in ASDs
- Lack of consensus about the preferred model, and
- A growing demand for age-related services



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Current Status: Health Status and Outcomes

Epidemiological Data

mental health

age-related disorders

physical health

Mortality Data



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)

- absence of disease
- engagement in life
- intact physical and cognitive functions



Successful Ageing in ASDs



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<input type="checkbox"/>	# ▲	Searches	Results
<input type="checkbox"/>	1	autism.mp. or *Autistic Disorder/	21593
<input type="checkbox"/>	2	successful ageing.mp.	154
<input type="checkbox"/>	3	successful aging.mp.	940
<input type="checkbox"/>	4	2 or 3	1090
<input type="checkbox"/>	5	1 and 4	0



Successful ageing in people with an ASDs: **- *absence of disease***

Current Situation

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

What it should look like

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

Successful ageing in people with an ASDs: **- *engagement in life***

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



Successful aging in people with an ASDs:

- intact physical and cognitive functions

Current Situation

- Some individuals have lifelong physical disability
- Cognitive dysfunction
- Higher 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 in people with an ASDs- how do we get there?



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Department of Developmental Disability Neuropsychiatry

(02) 9931 9160

✉ ddd@unsw.edu.au

🌐 3dn.unsw.edu.au

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National Dementia and Intellectual Disabilities Action Plan		
Goal A: To better understand dementia and how it affects adults with an intellectual disability and their caregivers		
Number	Recommendation	Who could do it?
#1	Conduct nationwide epidemiologic studies or surveys of adults with intellectual disabilities that establish the prevalence and incidence of mild cognitive impairment and dementia.	Federal agencies and institutes (Administration on Developmental Disabilities, Administration on Aging, National Institute on Disability and Rehabilitation Research)
#2	Conduct studies to identify and scientifically establish the risk factors associated with the occurrence of dementia among adults with an intellectual disability.	Universities' academic and research centers
#9	Conduct studies on the impact of aging of family caregivers on the support and care of adults with intellectual disabilities residing in at-home settings.	Universities' academic and research centers
#11	Conduct nationwide medico-economic studies on the financial impact of dementia among people with intellectual disabilities in various service provision settings.	Universities' academic and research centers
Goal B: To institute effective screening and assessment of adults with an intellectual disability at-risk, or showing the early effects of, dementia		
#3	Develop guidelines and instructional packages for use by families and caregivers in periodically screening for signs and symptoms of dementia.	American Academy of Developmental Medicine and Dentistry
#4	Encourage provider agencies in the United States to implement screenings of their older-age clientele with an intellectual disability who are at-risk of or affected by dementia.	State developmental disabilities planning councils, State developmental disabilities authorities
#5	Examine the utility of adopting an instrument such as an adapted Dementia Screening Questionnaire for Individuals with Intellectual Disabilities for use annually in preparation for the annual wellness visit.	Universities, Providers, American Academy of Developmental Medicine and Dentistry
#6	Conduct an evaluation of a workable scoring scheme for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities that would help identify individuals in decline.	Universities' academic and research centers
#8	Promote the exchange of information among clinicians regarding technical aspects of existing assessment and diagnostic instruments for confirming presence of dementia in persons with an intellectual disability.	American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Developmental Disabilities Nurses Association
Goal C: To promote health and function among adults with an intellectual disability		
#15	Develop and disseminate a set of nutritional and dietary guidelines appropriate for persons with an intellectual disability affected by dementia.	American Academy of Developmental Medicine and Dentistry
#16	Develop and disseminate health practice guidelines to aid primary care physicians and related health practitioners address assessment and follow-up treatment of adults with an intellectual disability presenting with symptoms of dementia.	American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association
#17	Conduct studies on the nature and extent of health compromises, conditions, and diseases found among adults with an intellectual disability and affected by dementia.	Universities' academic and research centers
Goal D: To produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia		
#10	Enhance family support services to include efforts to help caregivers to identify and receive assistance for aiding adults with an intellectual disability affected by dementia.	State developmental disabilities authorities, State units on aging, Area agencies on aging, The Arc, National Down Syndrome Society
#12	Plan for and develop more specialized group homes for dementia care as well as develop support capacities for helping adults affected by dementia still living on their own or with their family.	State developmental disabilities authorities
#13	Plan and develop community-based dementia-capable supports to address the needs of those persons at-risk or affected by dementia.	State developmental disabilities authorities
#14	Develop and disseminate social care practice guidelines to community agencies and professionals that address assessment, service development and life planning for adults with an intellectual disability presenting with symptoms of dementia.	American Association on Intellectual and Developmental Disabilities
Goal E: To produce a capable workforce and produce education and training materials		
#7	Establish undergraduate, graduate, and continuing education programs, using various modalities, to enhance the diagnostic skills of community practitioners.	American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Council of Deans of Medical Schools and Allied Health Colleges
#18	Develop a universal curriculum, applicable nationwide, on dementia and an intellectual disability geared toward direct care staff, families, and other primary workers.	Administration on Developmental Disabilities, Universities, Developmental Disabilities Nurses Association
#19	Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families.	American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Developmental Disabilities Nurses Association, Universities' academic and research centers
#20	Develop and produce an education and information package for adults with an intellectual disability to help them better understand dementia.	American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association, Universities' academic and research centers

The following slides have been adapted from:
 National Task Group on Intellectual Disabilities and Dementia Practice. (2012). 'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports. Jan 2012. SBN 978-1-105-39437-9



Three Key Goals

- 1. To understand how ageing affects people with an ASD and their carers**
- 2. To develop and refine suitable models of care and support for people with ASDs and their carers as they age**
- 3. Disability and health professionals who provide quality services in the prevention, assessment & management of health conditions associated with ageing in people with an ASDs**



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Goal: To understand how ageing affects people with an ASD and their carers

What's needed?

- Large scale longitudinal studies of ageing adults with an ASD 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
 - reliability and validity of screening and assessment instruments
 - the impact of aging on family caregivers, service use
- With translational components which:
 - Develop national and state policy frameworks
 - develop prevention strategies
 - develop and support the implementation of screening in primary care and skilled assessment in specialist services
 - develop management guidelines
 - develop consumer and carer resources

Goal: To develop and refine suitable models of care and support for people with ASDs and their carers as they age

What's Needed?

- Development and evaluation of models of care, with appropriate consultation
- An understanding of the perspective of the person with ASDs and the family on the preferred service models, and workforce attributes
- Economic modelling:
 - cost/benefit associated with differing models of care
 - of supporting family carers
 - specific disorders incl MCI and dementia
 - Prevention, screening, and intervention.



Goal: Disability and health professionals who provide quality services in the prevention, assessment & management of health conditions associated with ageing in people with an ASDs

What's Needed?

- A focus on the health of adults with ASDs at an undergraduate level
- The availability of enhanced material for postgraduate studies in relevant fields and for professional associations
- A health and disability workforce strategy which includes a focus on ageing in ASDs (vocational training, competency frameworks)
- An enhanced focus on age-related conditions in health screening eg in the CHAP tool
- 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 ASDs (an opportunity) for:
 - disability workers
 - health professionals
 - carers and consumers

Summary

- A long way from “*The Highest Attainable Standard of Health and Wellbeing for Older Persons with an Intellectual or Developmental Disability*”
- Current status:
 - inequity in access to quality physical and mental health care
 - poor capacity in age-related health and disability care
- The concept of successful ageing may be useful
- Goals are identifiable
- There are multiple potential barriers
- Debate and prioritisation is needed



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Department of Developmental Disability Neuropsychiatry

(02) 9931 9160

✉ ddd@unsw.edu.au

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- Australian Government Department of Health and Ageing
- Australian Research Council (ARC)
- National Health and Medical Research Council (NHMRC)
- NSW Institute of Psychiatry
- Autism CRC

