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Pathways to Realizing the Vision
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Aging Adults with Autism Spectrum Disorders

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Knowledge Support Empowerment

What is Aging?

- Changes that are caused by processes within the individual which significantly decrease the probability of survival.
- The changes cannot be avoided or reversed; no one can escape the process of aging.
- Differs from disease, which may be avoided, managed, or cured, in some cases.

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Overview

General overview of aging and its diversity

Successful Aging

Life expectancy of individuals with ASD

Modifiable versus unmodifiable risks factors

Research challenges

What does the current literature tell us?

Optimizing the aging process

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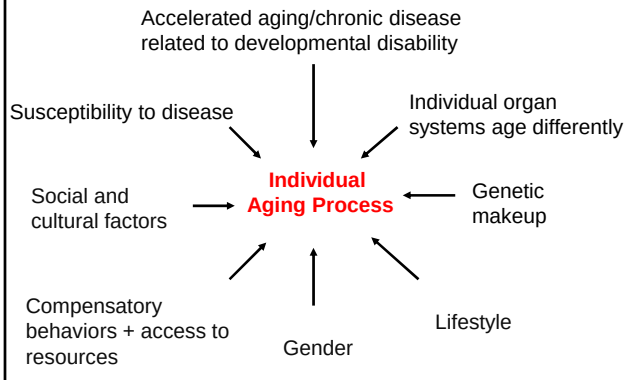
The Diversity of the Aging Process



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Types of Aging

- Primary Aging
  - Normal, disease free movement across adulthood
  - Changes are inevitable
- Secondary Aging
  - Changes related to disease and poor health practices
- Tertiary Aging
  - Rapid losses in function shortly before death

(Birren & Cunningham, 1985)

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Modifiable versus Unmodifiable Factors for Successful Aging

Unmodifiable

- Age
- Gender
- Genetics
- Ethnicity

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Successful Aging

Optimal Aging

"A kind of utopia, namely, aging under development enhancing and age-friendly environmental conditions" (Baltes & Baltes, 1990).

Successful Aging

Low risk of disease

Low risk of disease-related disability

Maintaining mental and physical function

Active engagement in life

(Rowe & Kahn,1987).

Modifiable versus Unmodifiable Factors for Successful Aging

Modifiable

- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Smoking (and secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

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Where are the older adults with ASD?

Empirical studies including samples aged 50+ are practically absent in the literature.

Who can we research - those with ASD dx known to formal support systems, those without formal ASD dx, but would meet researcher screening criteria for probable ASD.

Hidden population – never dx, and never accessed formal support system – positive (exemplars of fully inclusive life), negative (over-reliance on a primary caregiver – future planning absent).

The hidden population may give the most valuable insights to both the risk and protective factors to obtain an optimal quality of life and successful aging.

LIFE EXPECTANCY

Table 4

Life expectancies for persons with autism, with comparison to the general population (source: 1992 U.S. Life tables[9]). The mortality rates ages 10 and above were modeled using the data from Tables 2 and 3.

	males			females		
	mortality	life expectancy		mortality	life expectancy	
age	rate/1000	autism	u.s. males	rate/1000	autism	u.s. females
5	0.9	62.0	68.1	1.9	62.5	74.8
10	1.3	57.3	63.2	1.8	58.1	69.9
15	2.1	52.6	58.3	3.8	53.6	65.0
20	2.7	48.2	53.7	3.8	49.6	50.1
25	3.0	43.8	49.1	4.0	45.4	55.2
30	3.7	39.4	44.5	4.7	41.3	50.4
35	4.7	35.1	40.0	5.7	37.2	45.4
40	5.8	30.9	35.5	6.9	33.2	40.9
45	7.8	26.7	31.1	9.1	29.3	36.2
50	11.5	22.6	26.8	12.8	25.6	31.6
55	18.2	18.8	22.7	17.7	22.1	27.2
60	28.3	15.4	18.9	23.8	18.9	23.1
65	42.8	12.3	15.4	31.2	16.0	19.2
70	62.8	9.7	12.4	41.3	13.2	15.5
75	94.0	7.3	9.6	54.7	10.7	12.2
80	145.9	5.3	7.2	78.6	8.3	9.2
85	278.6	3.6	5.3	164.5	6.1	6.6

Shavelle, R. M., & Strauss, D. J. (1998). Comparative mortality of persons with Autism in California, 1980-1996. Journal of Insurance Medicine, 30, 220-225.

Causes of Death in People with ASD

Scant research on disease prevalence rates.

Causes of death that are higher in ASD population compared with general population include:

- Seizures (SUD)
- Accidental Death (drowning, suffocation)
- Heart Diseases
- Cancer
- Respiratory Disorders (mostly pneumonia)

(Shavelle et al., 2001; Mouridsen et al., 2008; Gillberg et al., 2010)

Trajectory of Autism Symptoms Across the Lifespan

With regard to symptoms of autism there are 3 possible lifespan outcomes (e.g. Seltzer et al., 2004, Shattuck et al., 2007).

- Some improve (abatement of symptoms)
- Some plateau
- Some lose skills (esp. associated with psychiatric disorders)

"Indeed, it is astonishing that as many as between 10 and 20% outgrow the diagnosis, as autism is arguably among the most severe and pervasive of the developmental disorders." (pg. 240, Seltzer et al., 2004)

"Behavior is not static, nor is how autism is in our lives static." (pg. 252, Bovee, 2000)

Aging Persons with Autism

Recent study (Esbensen et al., 2009) noted that restrictive repetitive behaviors, i.e.

- restricted interests
- stereotypical movements
- need for rituals/sameness
- compulsive behaviors
- self-injurious behaviors

were *less severe* and *more infrequent* with increasing age.

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Are Reduction in Behavioral Symptoms Related to Aging of the Sensory Systems?

- Sensory seeking and sensory defensiveness (i.e. high and low thresholds for response to sensory stimuli, oral, tactile, auditory, and visual)
- With increasing age – there are changes in threshold levels in both directions to levels usual in the general population (i.e. hypersensitivity decreases and hyposensitivity increases) (Kern et al., 2006).
- Therefore previous triggers to sensory defensiveness and sensory seeking behaviors are no longer as salient.

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Are Changes Related A Growing Sense of Self-Awareness and Social Mores?

Kanner reflected that the reason he believed that some of the individuals he worked with had more positive adult outcomes were that they were self-motivated to change their behaviors.

"Unlike most other autistic children, they became uneasily aware of their peculiarities and began to make a conscious effort to do something about them." (pg. 209, Kanner, 1973).

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Dual Diagnosis

A study of aged 50+ adults with ASD, reported 31% met criteria for psychiatric caseness *(Totsika et al., 2010).*

However, in contrast, studies in children and adults with ASD report 70-75% *(e.g. Ghaziuddin & Zafar, 2008; Simonoff et al.,2008).*

Most common issues generally noted Anxiety Disorders, Depression, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Tourette syndrome (e.g *Ghaziuddin & Zafar, 2008; Simonoff et al.,2008)*.

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Social and Vocational Outcomes

- Those with language skills, less impairment in social interaction, no ID, often fare better across lifespan in terms of education, employment, and social relationships, although still much lower rates of participation when compared to the general population (Howlin et al., 2004; Orsmond et al., 2004; Billstedt et al., 2005).
- Adults with ASD rely heavily upon their families in finding jobs, accommodations, and to utilize community facilities for social/recreational purposes (Howlin et al., 2004; Orsmond et al., 2004;)
- Emphasizes importance of lifelong learning, enriched environments, and community inclusion to optimize well-being over the lifespan.

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Two Notable Examples of Older Adults with Autism Aging Successfully

Temple Grandin., PhD
Age 64

Donald Gray Triplett
Age 77

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Vulnerability of Hidden Older Adults

64 year old with suspected Asperger's Syndrome, lived independently, drove, and worked in a mail room of a department store for 20 years. Mother died (aged 101), he relocated to Florida to be near his siblings. Living in an ALF, developed late onset epilepsy and is no longer able to drive..... In a period of 12 months, he retired, lost his mother, his home, and driving license....

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Optimizing Successful Aging for Older Adults with ASD

- ✓Health promotion/health prevention -Wellness screenings (e.g. cancer screenings, dental checkups, mammograms).
- ✓Psychological well-being - advocate to ensure availability of optimal treatments/medications for those with dual diagnosis (e.g. anxiety, depression).
- ✓Effective epilepsy management.
- ✓Polypharmacy (careful monitoring with increasing age).

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Optimizing Successful Aging for Older Adults with ASD

- ✓ Essential to promote lifelong learning, education, employment (retirement) and socialization opportunities – with increasing age.
- ✓ Important to offer a range of new activities, that may result in continuing personal development and skill building.
- ✓ Fiscal management – essential to plan for financial security and how this will be achieved into the retirement years.

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Broader Questions and Next Steps...

- Where are the aging people with ASD?
- Where are they living and with whom?
- What are they doing?
- Who are they doing it with?

Final thoughts..... Because there may be an uptake of new skills and interests, older adulthood may potentially be a very rewarding period of life for adults with ASD (with appropriate support).

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References

Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M. M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences* (pp. 1–34). New York: Cambridge University Press.

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13 to 22 year follow up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35,* 351-360.

Birren, J. E., & Cunningham, W. R. (1985). Research on the psychology of aging: Principles, concepts and theory. In J. E. Birren & K. W. Schaie (Eds.), *Handbook of the psychology of aging* (2nd ed.). New York: Van Nostrand Reinhold.

Bovee, J. P. (2000). A right to our own life, our own way. *Focus On Autism and Other Developmental Disabilities, 15,* 250-252.

Esbensen, A. J., Seltzer, M. M., Lam, K. S. L., & Bodfish, J. W. (2009). Age-related differences in restricted repetitive behaviors in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39,* 57-66.

Ghazziuddin, M., & Zafar, S. (2008). Psychiatric comorbidity of adults with autism spectrum disorders. *Clinical Neuropsychiatry, 5,* 9-12.

Gillberg, C., Billstedt, E., Sundh, V., & Gillberg, I. C. (2010). Mortality in autism: a prospective longitudinal community-based study. Journal of Autism & Developmental Disorders, 40, 352-357.

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References

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45,* 212-229.

Janicki, M. P. (1996). Longevity increasing among older adults with an intellectual disability. *Aging, Health, and Society,2, 2.*

Kanner, L. (1973). *Childhood psychosis: initial studies and new insights.* Washington: V. H. Winston.

Kern J. K., Trivedi, M. H., Garver, C. R., Grannemann, B, D., Andrews, A. A., Savla, J. S., Johnson, D. G., Mehta, J. A., & Schroeder, J. L. (2006). The pattern of sensory processing abnormalities in autism. *Autism, 10,* 480-494.

Mouridsen, S. E., Brønnum-Hansen, H., Rich, B., & Isager, T. (2008). Mortality and causes of death in autism spectrum disorders: an update. *Autism, 12,* 403-414.

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34,* 245-256.

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10,* 234-247.

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References

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37,* 1735-1747.

Shavelle, R. M., & Strauss, D. J. (1998). Comparative mortality of persons with Autism in California, 1980-1996. *Journal of Insurance Medicine, 30*, 220-225.

Shavelle, R. M., Strauss, D. J., & Pickett, J. (*2001*). Causes of death in autism. *Journal of Autism and Developmental Disorders*, *31*, 569-576.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47,* 921-929.

Totsika, V., Felce, D., Kerr, M., & Hastings, R. P. (2010). Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without Autism. *Journal of Autism and Developmental Disorders, 40,* 1171-1178.

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