

Health and Aging on the Autism Spectrum

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Dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases throughout the lifespan.



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ICTR

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Aging with Developmental Disabilities

- Deinstitutionalization
- Increased awareness and acceptance
- Access to care through Medicaid/Medicare
- Increased life expectancy



Population Approach

- Study people on the autism spectrum as a group
- Findings in a study may not be true to everyone
- Higher probability (risk) based on being in one group compared to another group
 - Autism vs. general population
 - Autism with intellectual disability vs. autism without intellectual disability



Autistic People Who Are Currently in Midlife and Old Age

- Donald Triplett: Kanner's Case 1:
 - 85 years old
 - Lives independently in Forest, Mississippi
- More health problems and earlier death compared to the general population
- Limited research on why and how these health problems develop limits prevention efforts



Health Disparities in Autism

Health differences that are avoidable, unnecessary, and unjust

- More health problems at all ages
- Sensory and communication differences
- Potential healthcare access challenges
- Potential discrimination from healthcare providers
- Overshadowing of health by autism/behavior problems

J Autism Dev Disord (2017) 47:3380–3391
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ORIGINAL PAPER

A Scoping Review of Health Disparities in Autism Spectrum Disorder

Lauren Bishop-Fitzpatrick^{1,2} · Amy J. H. Kind^{3,4}

COMMENTARY

A Matter of Time: The Necessity of Temporal Language in Research on Health Conditions that Present with Autism Spectrum Disorder

Eric Rubenstein  and Lauren Bishop-Fitzpatrick 



What I will discuss today:

- What are common health problems in midlife old age?
- Is intellectual disability driving health problems in autism?


For a later date: How do we help?



Study 1: Lifetime Health Problems, Evaluated at Death

RESEARCH ARTICLE

Using Machine Learning to Identify Patterns of Lifetime Health Problems in Decedents with Autism Spectrum Disorder

Lauren Bishop-Fitzpatrick , Arezoo Movaghar, Jan S. Greenberg, David Page, Leann S. DaWalt, Murray H. Brilliant, and Marsha R. Mailick



The Big Picture

- **Why?** No previous research on health problems in autism
- **Goals:** Identify health problems that distinguish people that have died with autism compared to a group of community members that have died:
 - Data-driven approach
 - Based on information in over the full lifetime electronic health records
- **Major Finding:** Autistic people have different patterns of health problems compared to matched community members



Data Source and Study

- Marshfield Clinic: a multi-specialty group practice
 - 97% of the population in northern, central, western WI
- Available electronic health records (EHRs) on people who have died: 91 with autism; 6,186 community members
- Question: Do patterns of diagnoses in EHRs distinguish those with autism from general community members?



Health Problems That Distinguish the Autism Group from the Community Group

<u>In Autism: Higher prevalence of:</u>	<u>In Autism: Lower prevalence of:</u>
Long-term medication use	Cancer diagnosis
Epilepsy	Cancer treatment
Developmental problems	
Skin conditions	
Ear problems	
Non-specific lab tests and encounters	
Urinary problems	
Respiratory problems	
Digestive problems	
Motor problems	
Cardiovascular problems	



Limitations

- Sample – small sample but large for autism research; people who died between 1979-2016; single region; lacks racial/ethnic diversity
- Replication
- No information about impact of intellectual disability



Study 2: Health of Middle Aged and Older Wisconsin Medicaid Beneficiaries

Bishop-Fitzpatrick, L. & Rubenstein, E. (in press). The physical and mental health of middle aged and older adults with autism spectrum disorder and the impact of intellectual disability.
Research in Autism Spectrum Disorders.



Why is intellectual disability important?

- Change in diagnostic criteria → cohort differences
- Well-established high prevalence of health problems in adults with intellectual disability
- Intellectual disability may be a marker of genetic subgroups
- Differences in level of support provided by parents and social service system for people with intellectual disability (historically and currently)



Medicaid Data for Autism Research

- **Medicaid** is a state-administered anti-poverty program that provides free or low-cost health and dental coverage to people with low income and/or disabilities
- Extremely important provider of health care for people with intellectual and developmental disabilities



The Big Picture

- **Why?** Test impact of intellectual disability on health in autistic adults who are lower income and/or racially diverse
 - Replication and specific test of intellectual disability
- **Study Goals**
 1. Describe the physical and mental health of middle aged and older Medicaid beneficiaries with autism spectrum disorder in Wisconsin
 2. Test differences in physical and mental health conditions between autistic adults with and without intellectual disability
- First step in describing the physical and mental health problems for which adults on the autism spectrum had Medicaid claims during the study period

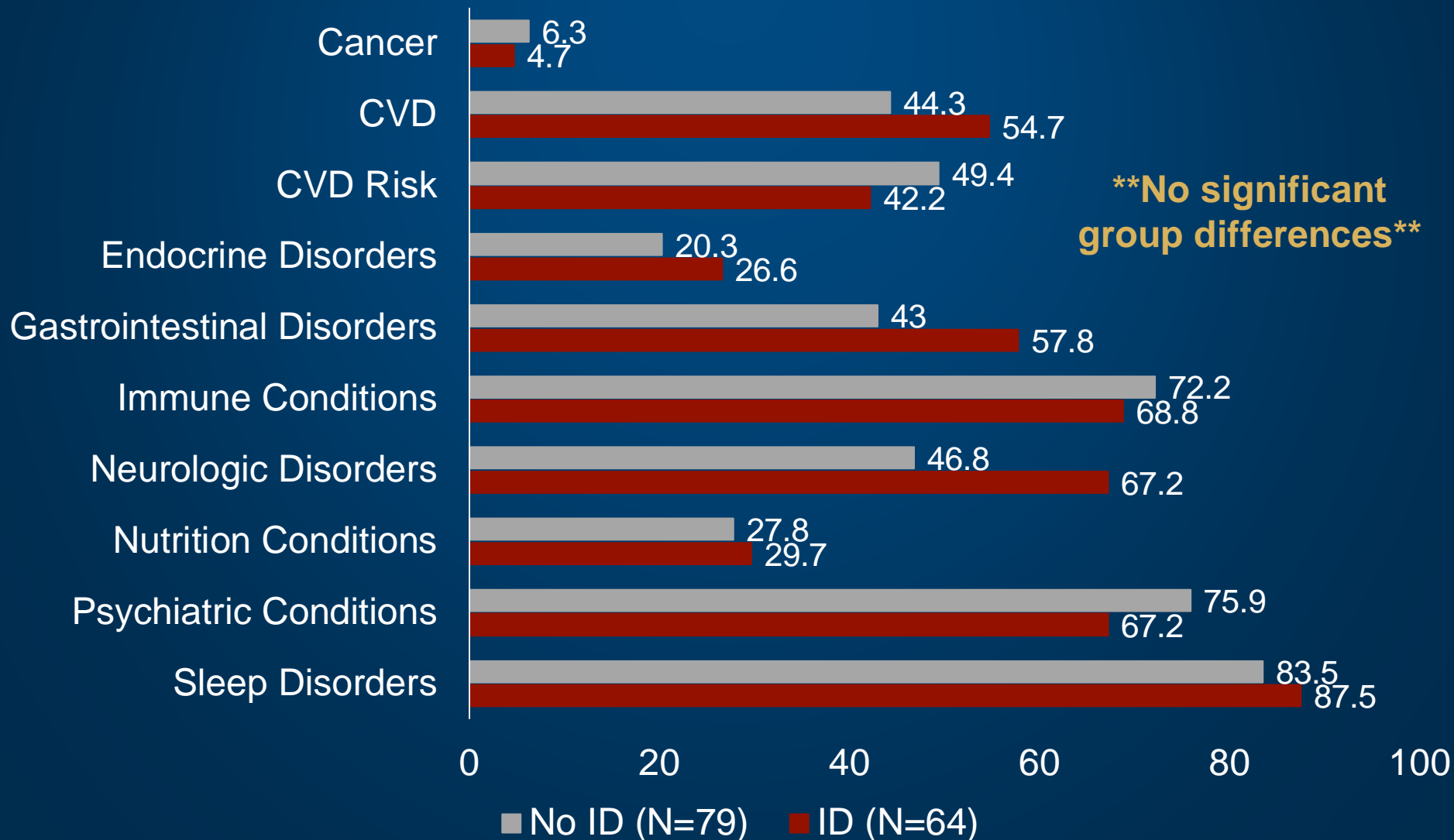


Characteristics of Sample

- All adults (N=143) with an autism spectrum disorder diagnostic code on two different days aged 40 and older who had Medicaid claims between 2012 and 2015
 - Mostly male (68.5%)
 - Mostly white (79.0%)
 - On average, in their mid-fifties (mean = 52.4; SD = 9.6)
 - Most enrolled in Medicaid for the entire four-year period
 - 44% (N=64) had a claim for intellectual disability



Diagnoses In Midlife And Old Age By Intellectual Disability (ID) Status



Health Research on Middle Aged and Older Adults on the Autism Spectrum

- More health problems that begin earlier autistic people compared to the general population
 - Could having autism be a health disparity in and of itself?
 - Poverty, discrimination, and structural bias may all affect autistic people
- Need to better understand **WHY**
 - Social and biological perspectives



(Preliminary)

Implications for Autistic Adults and Family Members

*Based on clinical experience and recommendations for
people in the general population*



Services & Supports Can Help Encourage Healthy Aging



Social: Inclusion in social, recreation, and leisure activities



Family: Supporting families in care transitions as parents age



Housing: Independent living, family living, and nursing home care



Health: Preventive and routine health care



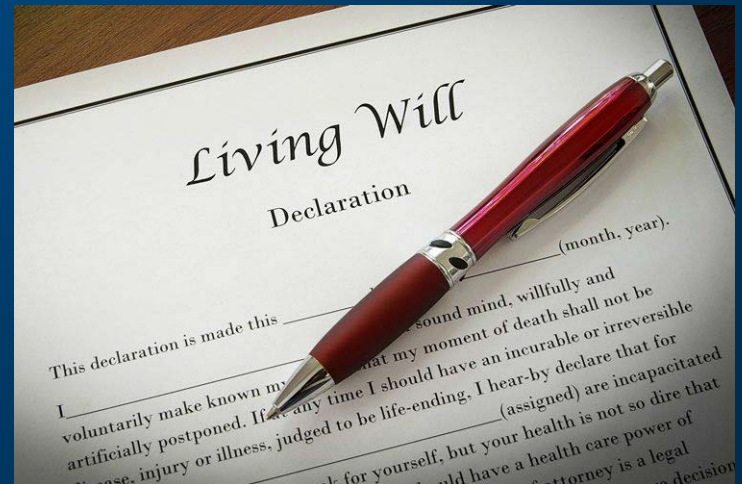
Activity: Aging autistic adults need to be active like all adults



Special Care: Disability-specific risks and accelerated aging may necessitate early screening

Establish Correct Permissions/Legal Documents

- Medical power of attorney
- Mental health power of attorney (if applicable)
- Advanced directive/living will
- Permissions on file with doctor to allow trusted people to access medical records



Advocate...while we work on changing physician behavior

- Know what preventive care you should receive and ask for it
- Request sensory and communicative accommodations
- Be aware that autistic people may experience pain differently
- Insist that providers see more than the autism diagnosis
 - “Behavioritis” (Sara Luterman) – inappropriately placing importance on a person’s behavior and not their health or medical problems
 - Changes in behavior or mood may indicate a medical problem

Thanks to #ActuallyAutistic advocates @slooterman, @autismage, @A4AOntario, @TuffRings, @RoaDemille, & @AutisticDoctor for advice on tips based on autistic lived experience





**“You have to learn about thousands of diseases, but
I only have to focus on fixing what’s wrong with ME!
Now which one of us do you think is the expert?”**



What's Next?

- Using Medicaid and Medicare data to delineate patterns of health problems, as well as predictors of health outcomes, at the population level in autism
 - Expanded Medicaid sample includes all adults with autism; intellectual disability/Down syndrome comparison groups
 - Using national Medicare data (51,132 autistic people)
- Beginning mixed methods data collection on health and health service utilization in middle aged adults on the autism spectrum this spring
- Patient navigation intervention
- Training healthcare providers to work with autistic adults



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Questions?

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