

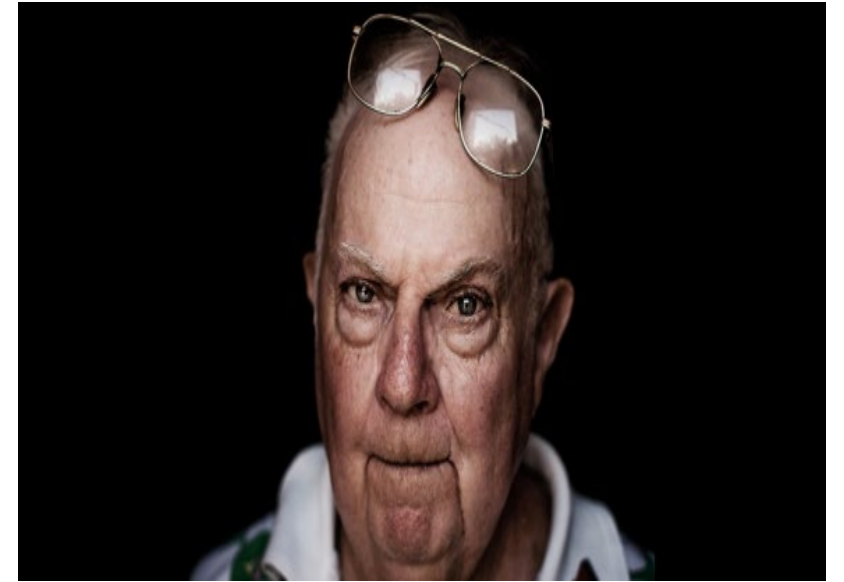
Autism into Midlife and Beyond

*Leann Smith DaWalt, PhD, Director, University Center for
Excellence in Developmental Disabilities*

Why Discuss Aging and Autism?

- To understand aging as a process, not a crisp age of onset
- To understand how to support healthy aging in autistic adults
- To inform clinical care, services, and public policy
- To address questions that autistic adults and families have about what they can expect about their own future

Story of Donald Triplett



<http://www.theatlantic.com/magazine/archive/2010/10/autism-8217-s-first-child/8227/>

[Donald Triplett, the 1st person diagnosed with autism, dies at 89 | PBS News](#)

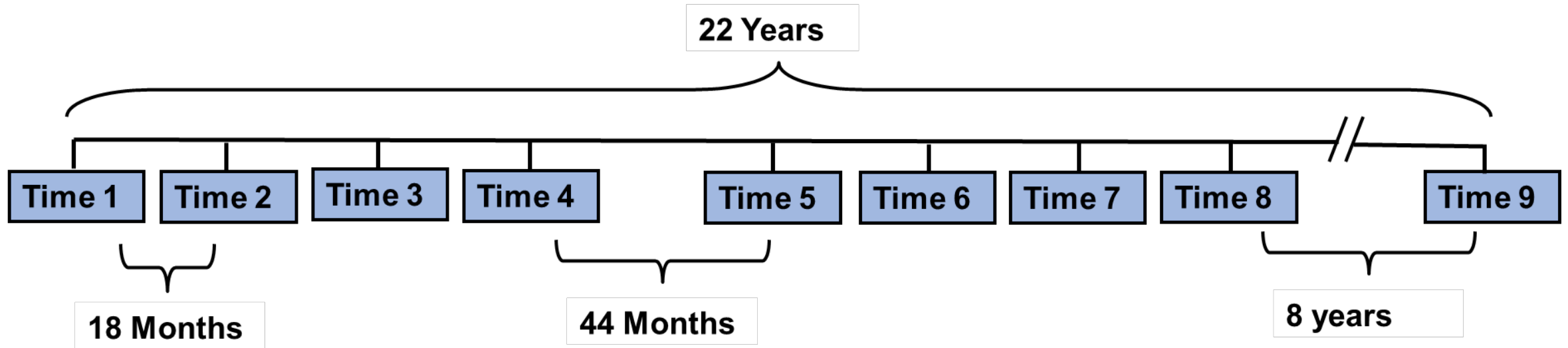
Goals for Today

- To share about aging and autism using data from our **20+ year longitudinal cohort study** (n=406)
 - Funded primarily by the National Institute of Aging (also NIMH and Autism Speaks)
- To consider how autistic adults, their families, and service providers can plan for the future to be responsive to changing needs during midlife and older age.
- It is important to recognize that future generations of autistic people might experience old age differently – due to early intervention, better services, etc.

Adolescents and Adults with Autism (AAA) Study

- Ongoing longitudinal study started in 1998 (Mailick, PI)
- Large sample (n=406 families)
- Wide age range – the “child” was age 10 - 52 at the beginning of the study

Adolescents and Adults with Autism (AAA) Study



Caveats

- All diagnosed before the expansion of the autism spectrum (DSM-5)
- All were recruited via their families – a multi-generational aging study
- Little racial/ethnic diversity, but significant socioeconomic diversity (11.5% of families below the US poverty line when they enrolled)
- We are just at the beginning of the journey of learning about aging and autism – so all conclusions are tentative and warrant replication with autistic people born more recently.

RESEARCH

Open Access

Autism through midlife: trajectories of symptoms, behavioral functioning, and health

Jinkuk Hong^{1*}, Leann Smith DaWalt¹, Julie Lounds Taylor², Aasma Haider³ and Marsha Mailick¹



Research Questions

- What are the **trajectories** of behavioral functioning and health **over 22 years**
- Do trajectories differ by:
 - Intellectual disability versus no intellectual disability?
- We estimated a single long-term trajectory by combining multiple short-term trajectories from each person covering different ages → 60 year span



Jinkuk Hong, PhD

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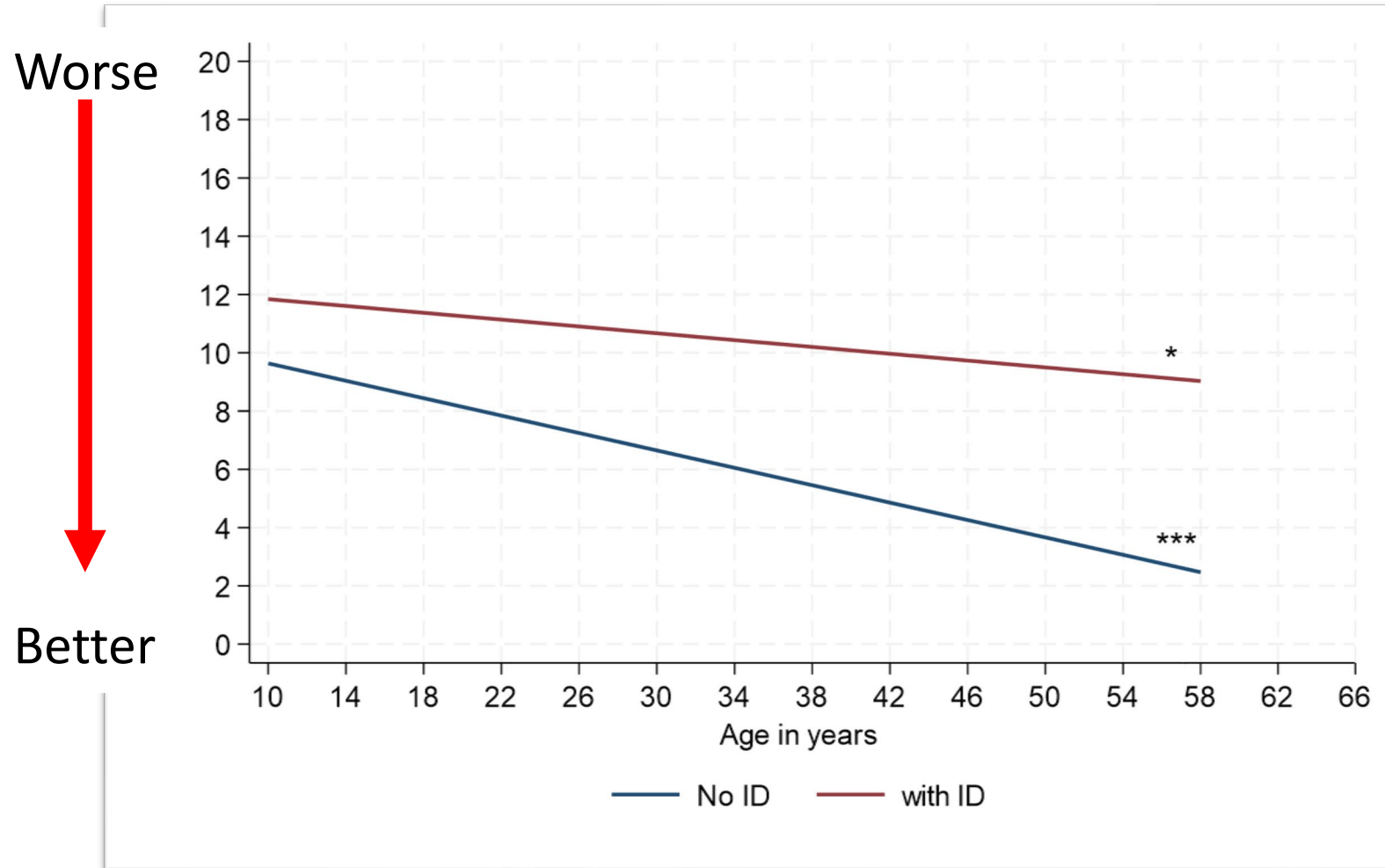
Trajectories of Adulthood

- Communication
 - Verbal skills
- Social Reciprocity
 - Engagement in back and forth interactions
- Health
 - # of prescription medications
- Behavioral Health
 - Internalizing, externalizing, and asocial behavior
- Activities of Daily Living
 - Self-sufficiency in personal hygiene, meal preparation, financial management
- Social Participation
 - Time spent with friends or neighbors (several times per year to several times/week)

What We Have Learned

- Different patterns of change across adulthood depending on the outcome
 - Improvement
 - Worsening
 - Nonlinear change = improving during adolescence and young adulthood then worsening at midlife and beyond
- Lots of individual differences

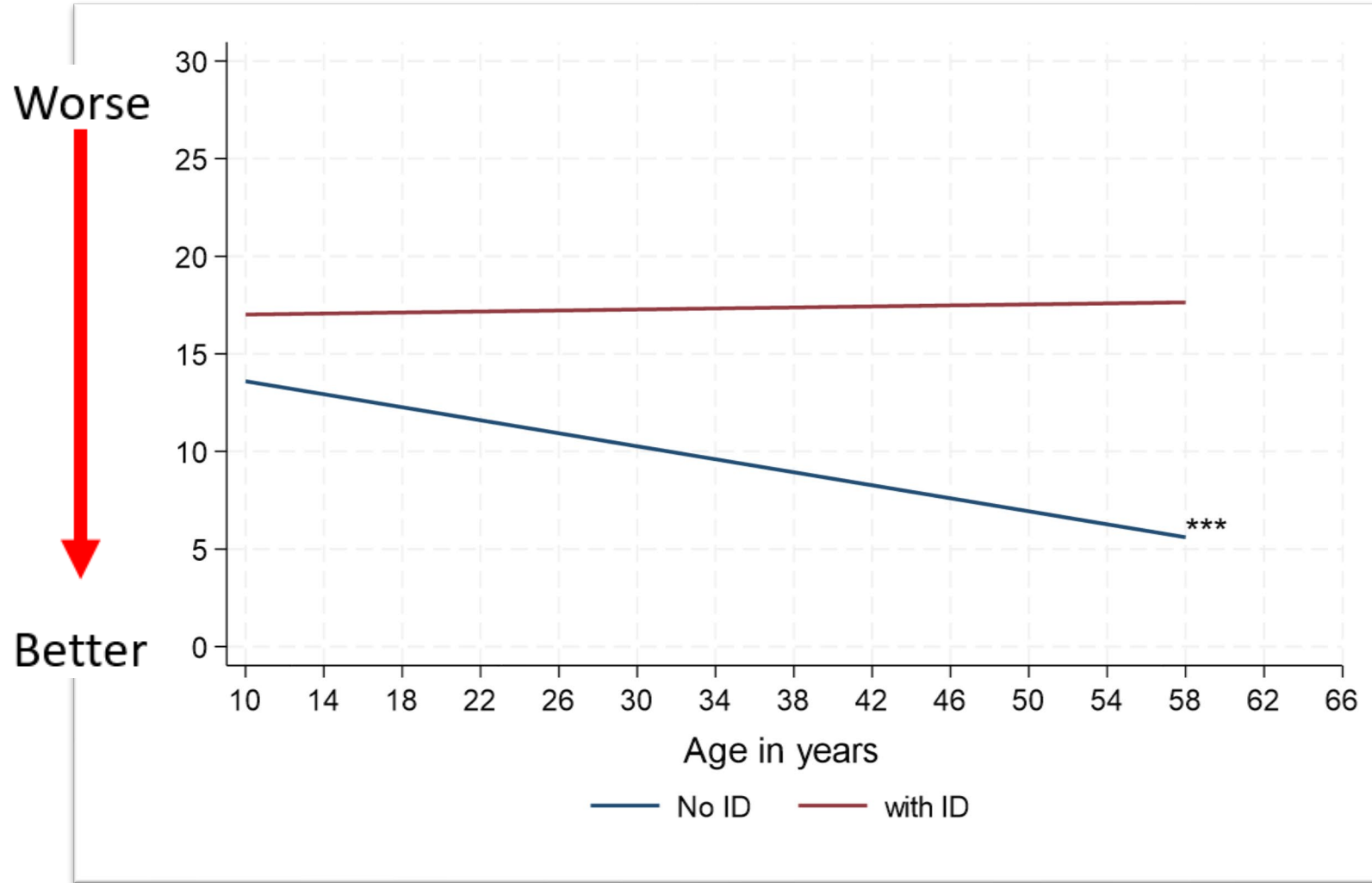
Improvement in Communication



Blue – average (+)
intellectual functioning
Red – intellectual
disability

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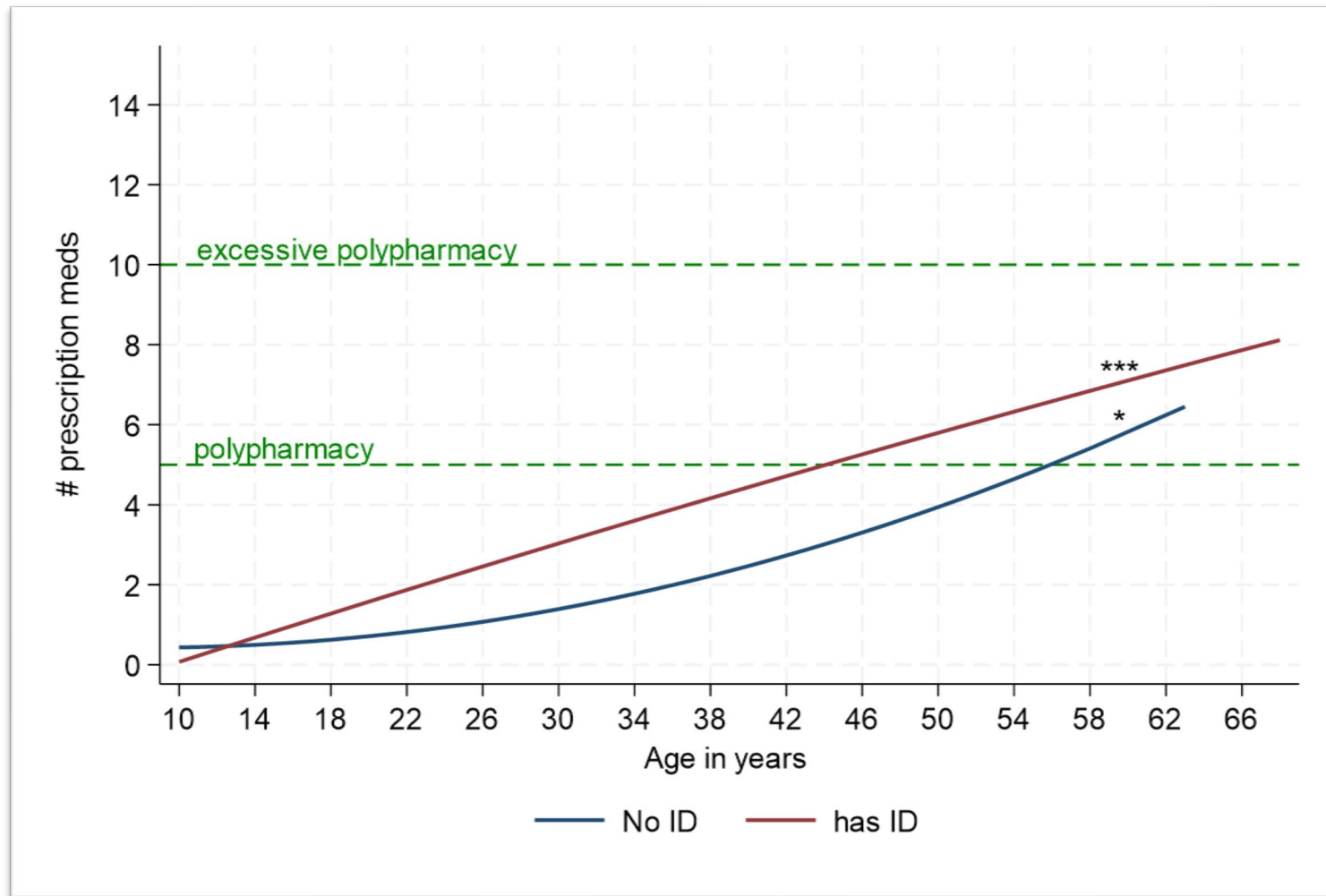
Changes in Social Reciprocity



Blue – average (+)
intellectual functioning
Red – intellectual
disability

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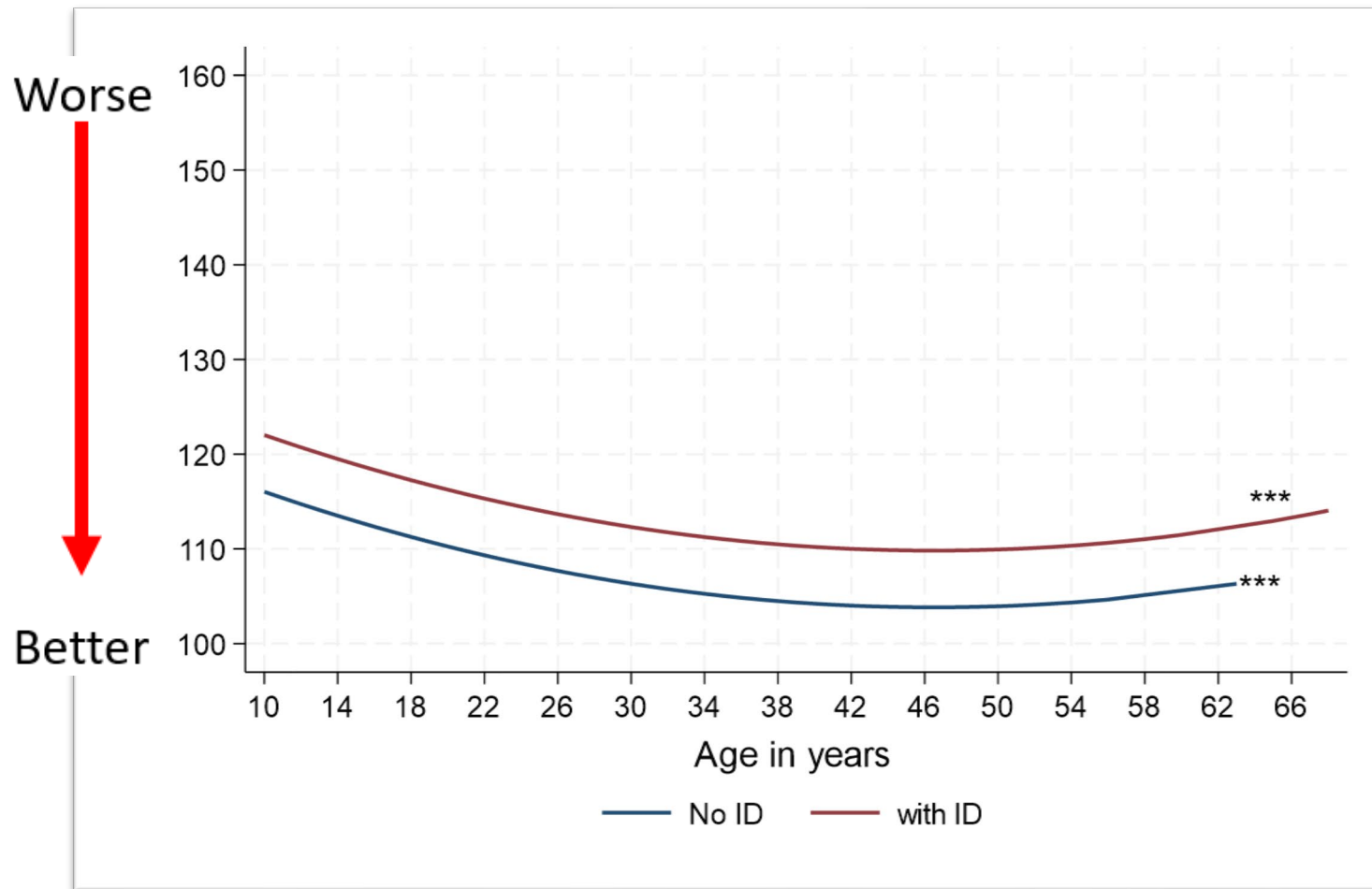
Increases in Total Number of Prescription Medications



Blue – average (+)
intellectual functioning
Red – intellectual
disability

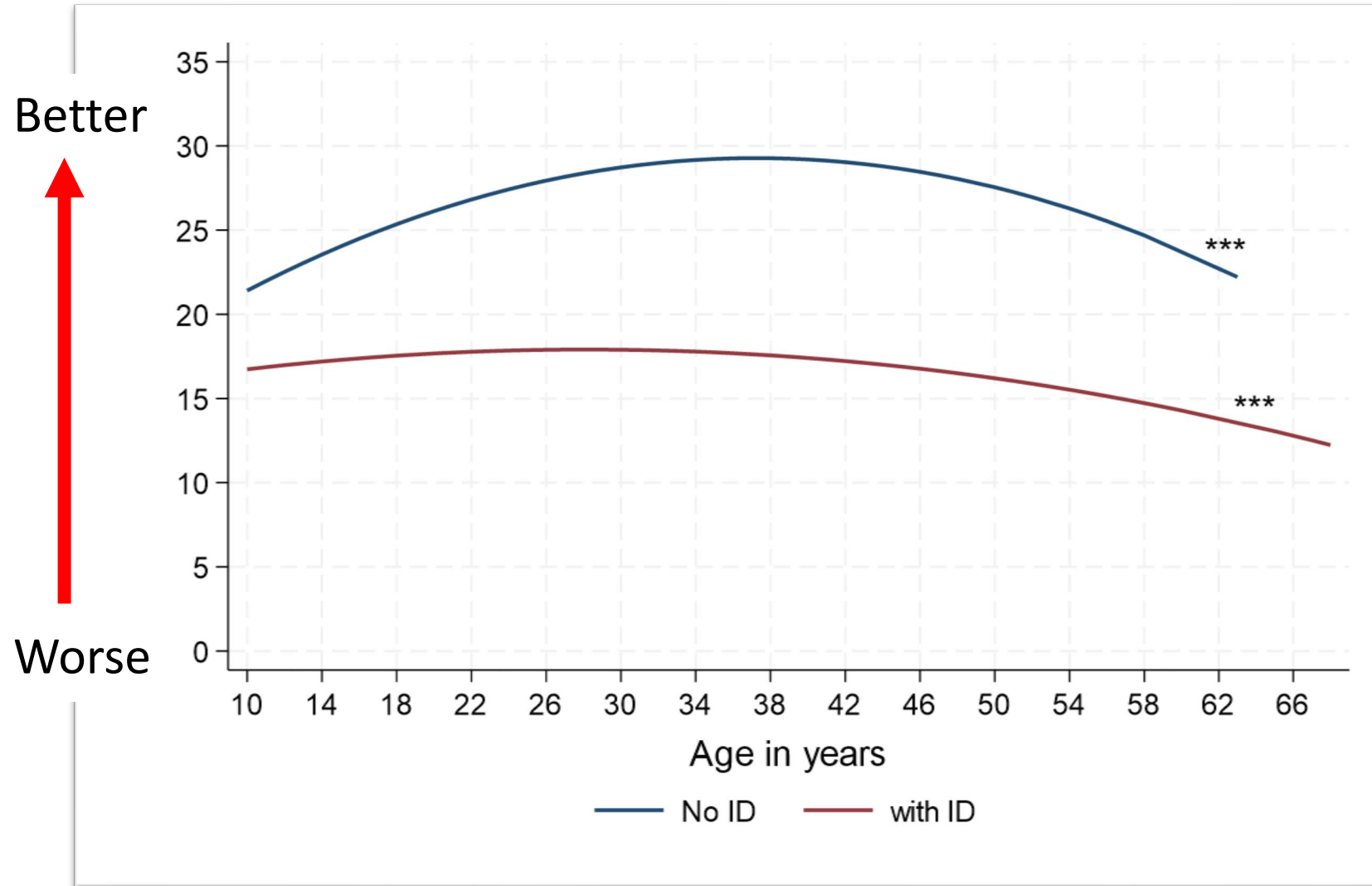
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Improvement then Worsening in Behavioral Health



Blue – average (+)
intellectual functioning
Red – intellectual
disability

Increases then Decreases in Daily Living Skills

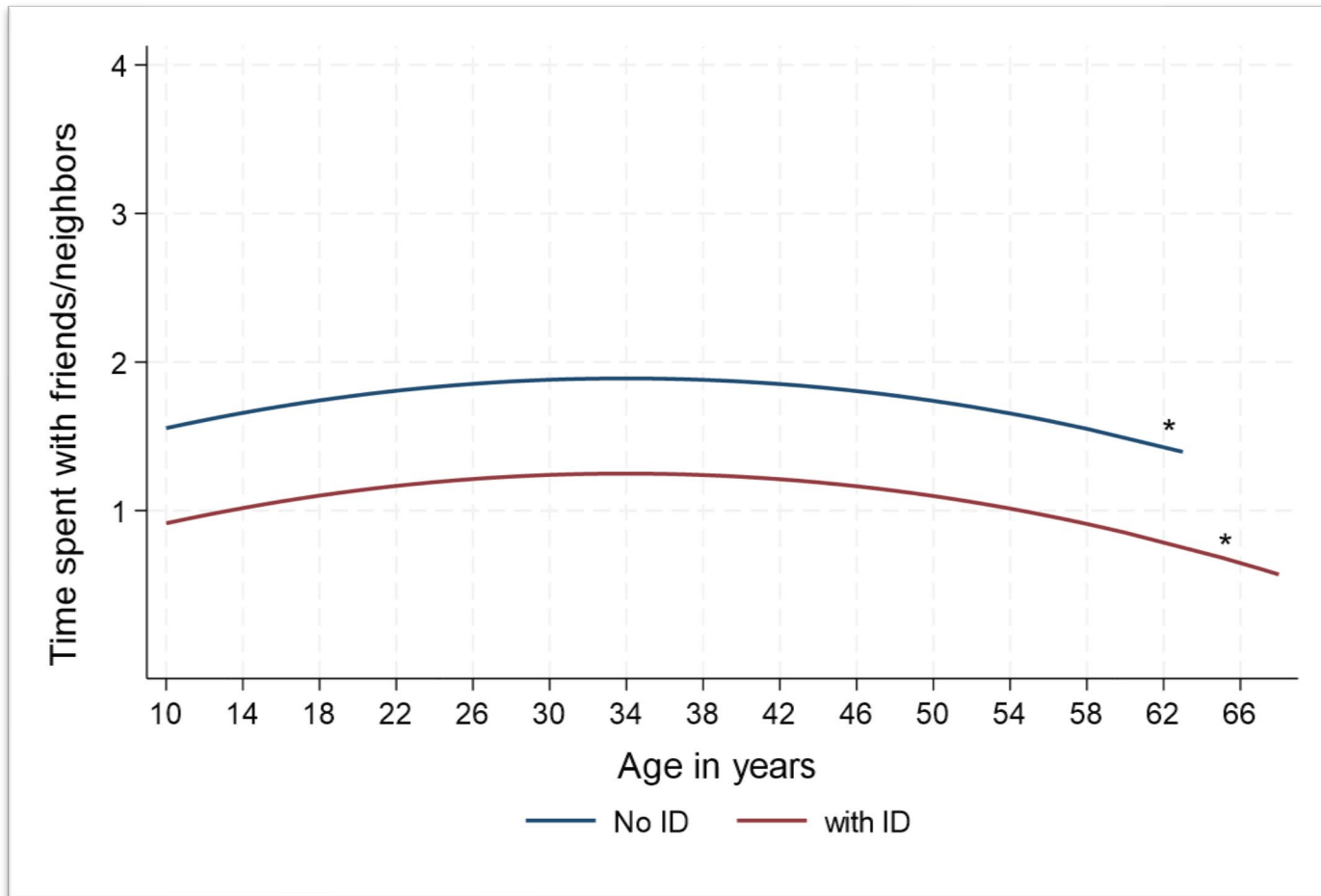


Blue – average (+)
intellectual functioning
Red – intellectual
disability

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Increases then Decreases in Time Spent with Friends and Neighbors

(1=several times per year to 4=several times per week)



Blue – average (+)
intellectual functioning
Red – intellectual
disability

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Is Midlife a Turning Point for Autistic Adults?

- Behavioral health worsens after midlife
- Self-sufficiency declines after midlife
- Time spent with friends and neighbors declines after midlife
- Increasing, accelerating polypharmacy after midlife (risks: drug interactions, side effects)

What about Work?

Employment Patterns over 20 Years

- More than 15% of the sample had **no consistent pattern** of work over 20 years – moving in and out of multiple work categories, including not working.
- Almost 40% of autistic adults with average intellectual functioning had **sustained competitive employment** whereas about 20% were **consistently unemployed**.
- Adults with ID often had an **employment safety net**, including agency-based and supported community employment (75%). About 10% had no engagement in work activities – half the percentage of those without ID.
- We know very little about **retirement** of autistic adults – priority for future research.

Overall Conclusions

- Adulthood is not a static stage of life for autistic individuals.
- Adolescence and young adulthood is a period marked by some key gains.
- Midlife is a pivotal period, with increasing risk. For many indicators, accelerated aging begins in the 30s and 40s.
- In older age: reduced self-sufficiency, increased medication use, worsening behavioral health, and reduced social engagement

What Can We Do to Enhance Aging?

Midlife is a time for an additional “early intervention”

- Consider personal priorities for quality of life – what matters most now and for the future?
- Engage siblings, other family members
- Focus on maintaining independent skills and social engagement
- Financial planning – review and update wills, trusts, etc.
- Health “audit” – are all medications currently needed? Check for drug interactions, encourage regular health screening and monitoring
- Think about the broader context – family members living nearby, access to health care, safety, accessibility, other important neighborhood factors

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- Julie Lounds Taylor, PhD

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<https://family.waisman.wisc.edu/autism/>