MORE ABOUT ADULT OUTCOMES IN AUTISM SPECTRUM DISORDER

Catherine Lord, Ph.D
In collaboration with Andrew Pickles, Ph.D. from Kings College, London and James McCauley, Ph.D. from UCLA

Conflict of interest and funding

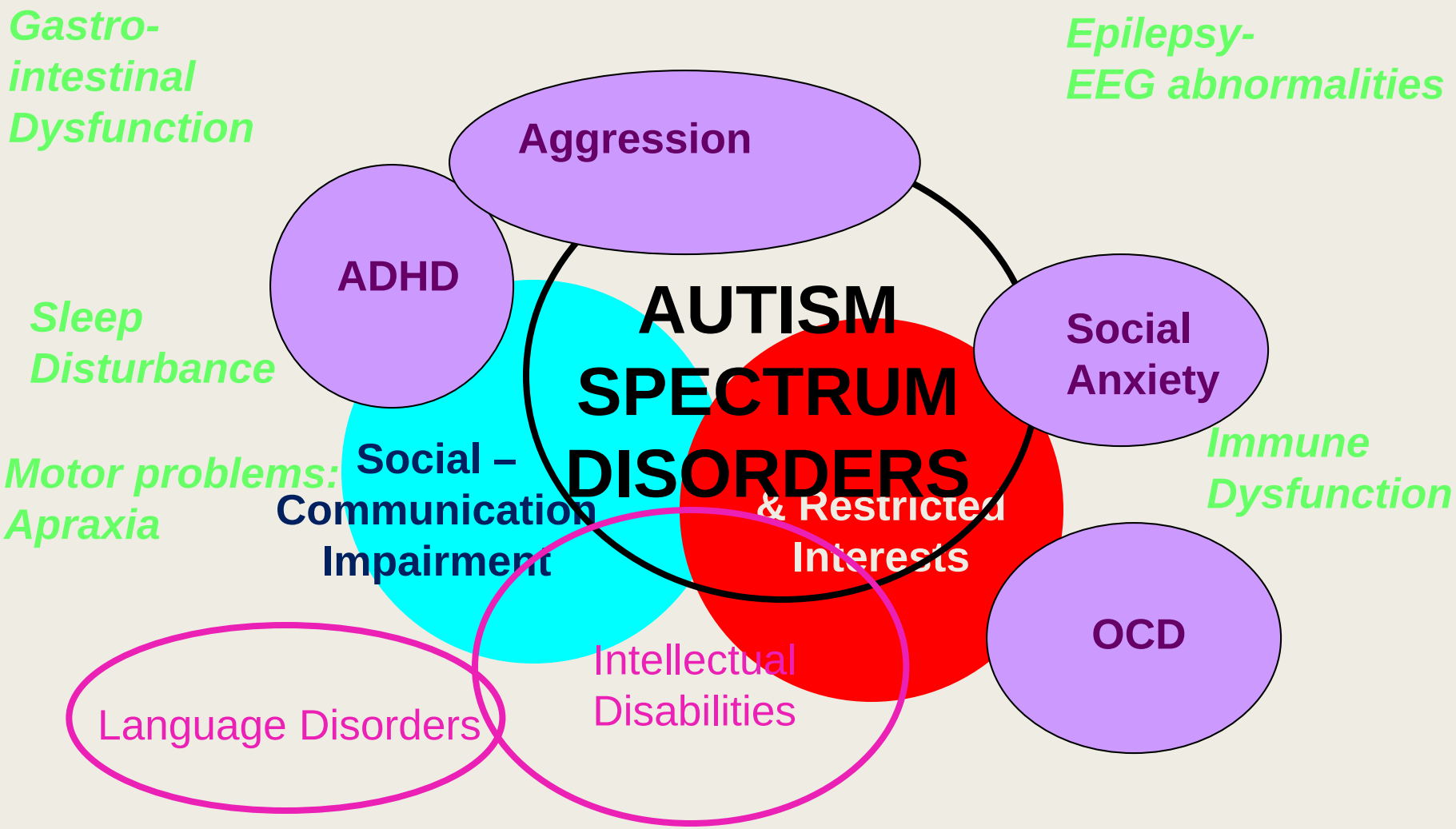
- I receive royalties from Western Psychological Services for the ADI-R, ADOS and SCQ. Proceeds from projects and clinics in which I am involved are donated to HAVE DREAMS in a wrap-around program in Chicago.

- I receive funding from NIMH, NICHD, DoD, HRSA, Autism Speaks and the Simons Foundation.

ASD as a Neurobiological Disorder of Learning and Processing

That changes with development and affects development in turn with opportunities to intervene and improve

Core Symptom Domains
PLUS Associated Medical Features



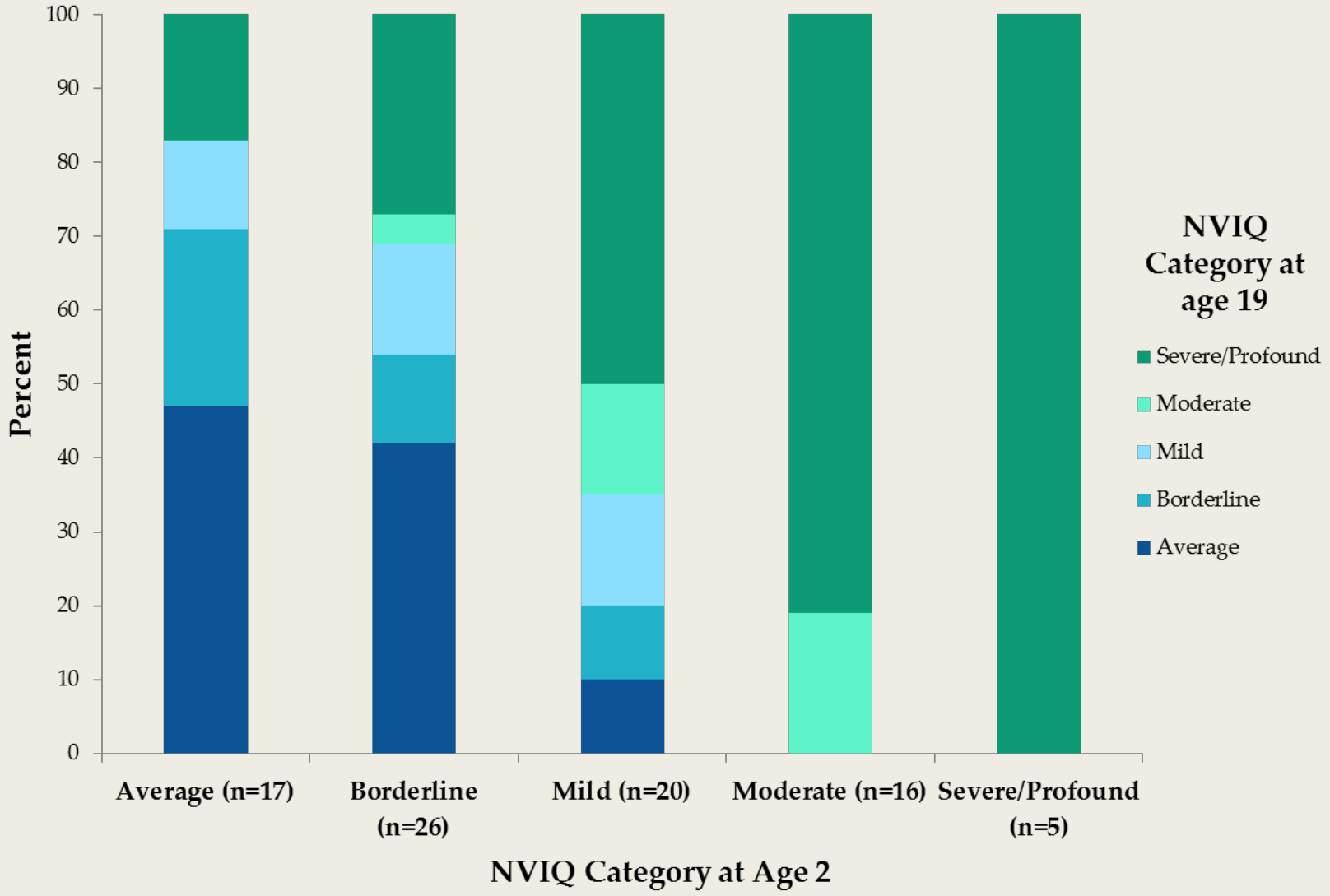
Can we diagnose autism in 2 year olds?

- Multiple measures
- Two different cohorts: range of income, rural/urban, education levels; white and African American
- Parent reports and direct observations
- 192 consecutive referrals for ASD; 21 DD controls (no evid ASD);about 50 “new” recruits

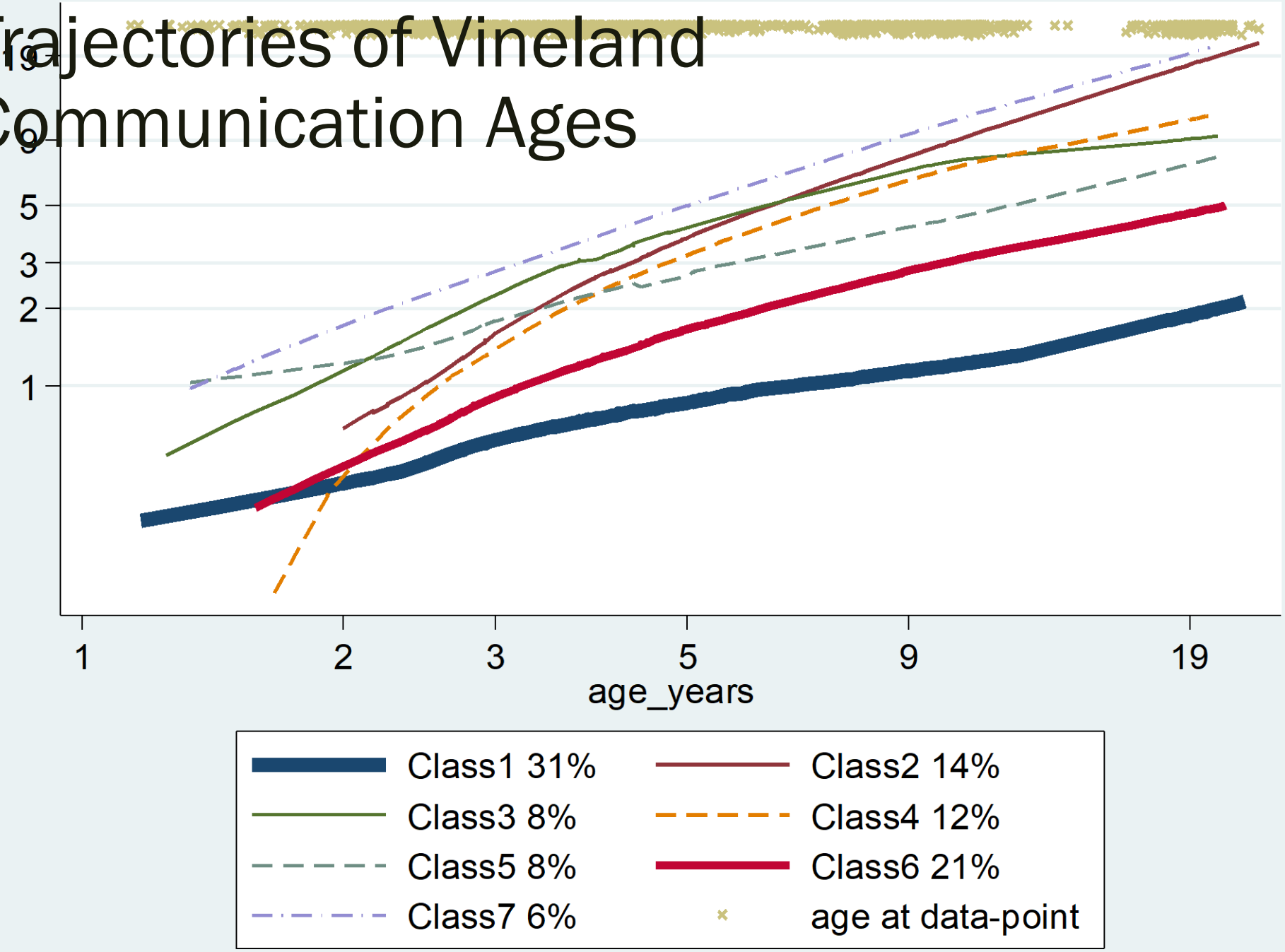
Watching “separate groups” become less distinguishable

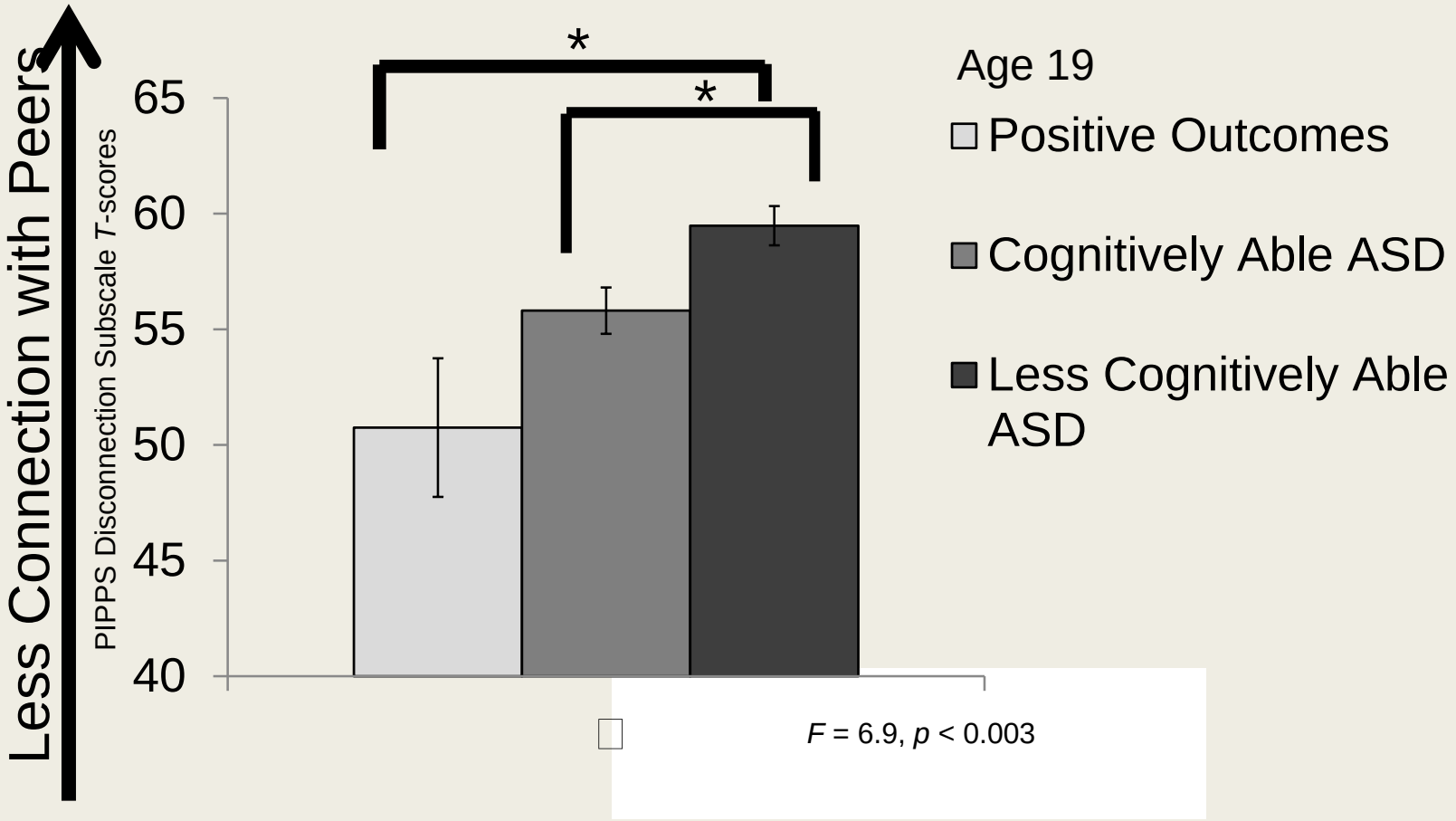
- In our longitudinal study: face to face at 2, 3, 4, 5, 9, 19, 26, 30 (long interview at 14)
- Some kids moved out of the spectrum – out of 192, one at 5, one more at 9, 8 at 19, 5 at 26
- Some moved into the spectrum, 2 at 3, 2 at 9, 2 at 19, 1 at 26
- Many of the outcomes of our “control” participants are not that different than the ASD participants with similar IQs

Age 2 by age 19 NVIQ Categories



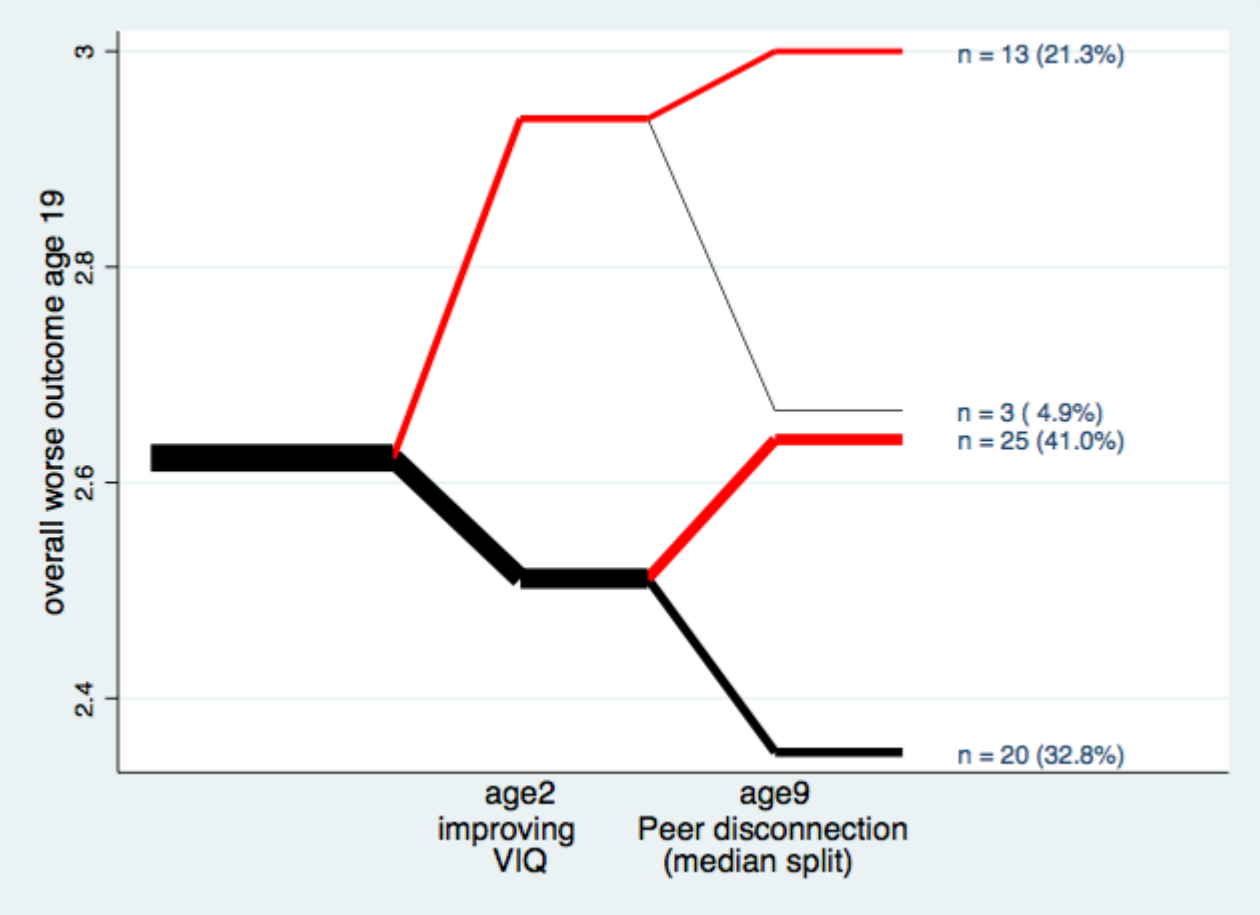
Trajectories of Vineland Communication Ages





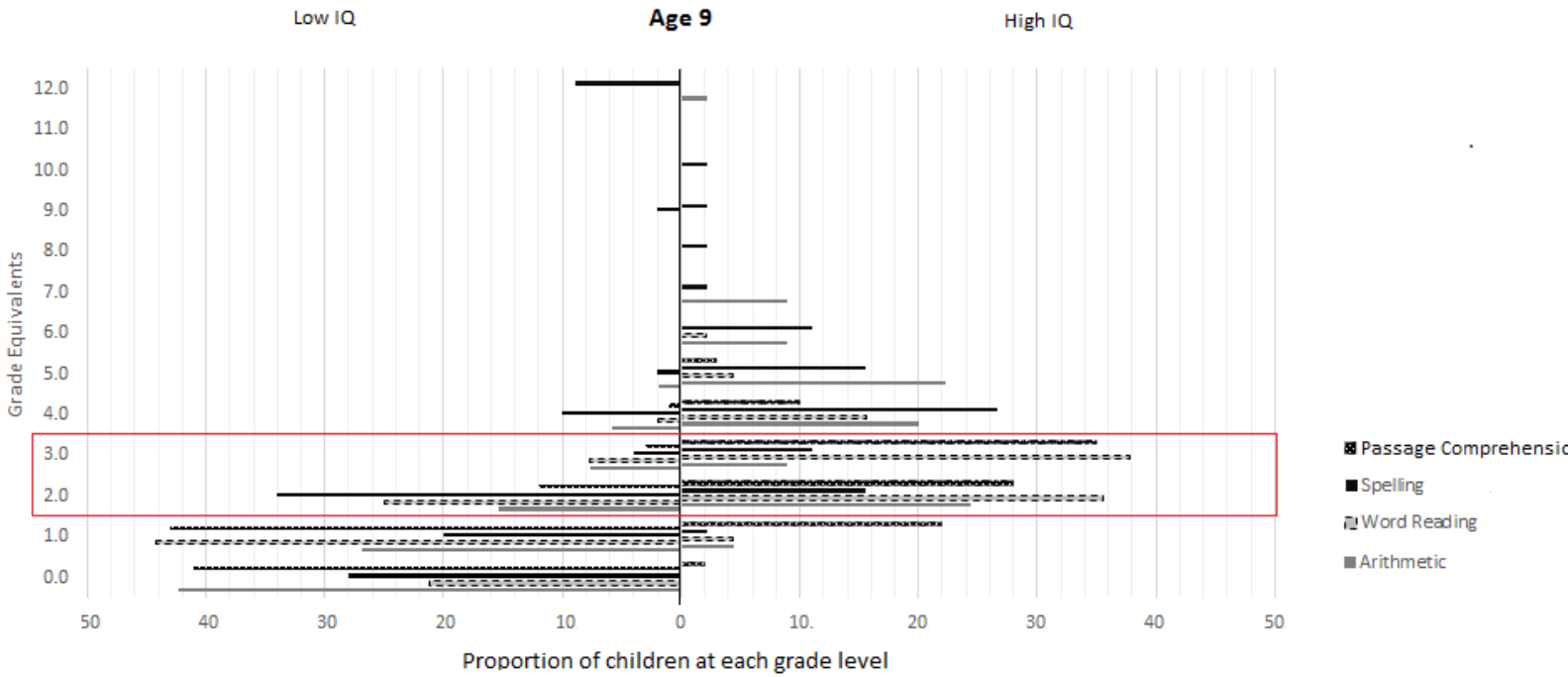
Quality of peer interactions during childhood (age 9)and early adolescence (age 14) predict autism outcomes

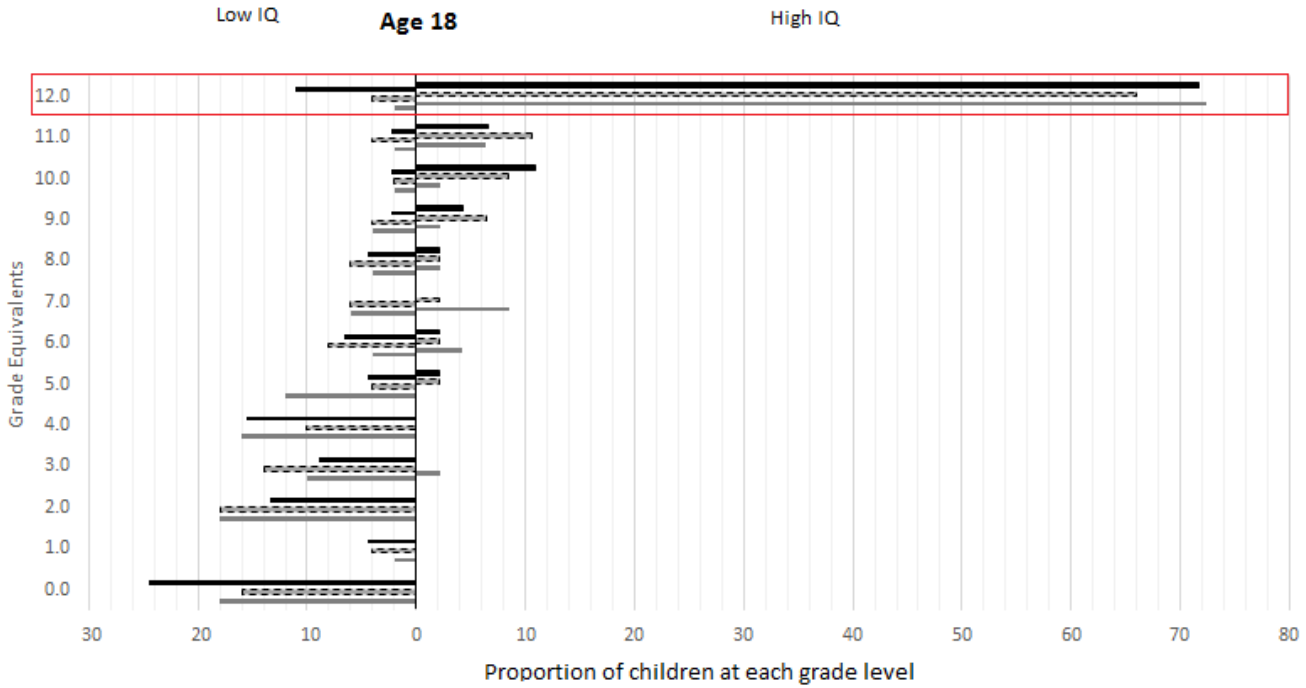
Jones et al., *2017*


overall worse outcome age 19
3
2.8
2.6
2.4
n = 13 (21.3%)
n = 3 (4.9%)
n = 25 (41.0%)
n = 20 (32.8%)
age2
improving
VIQ
age9
Peer disconnection
(median split)

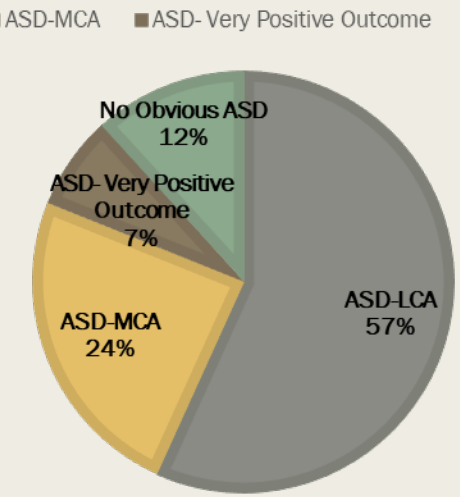
Variability in achievement levels at age 9 and 18 for low vs. high IQ groups

* Red boxes indicate the proportions of children in the grade level



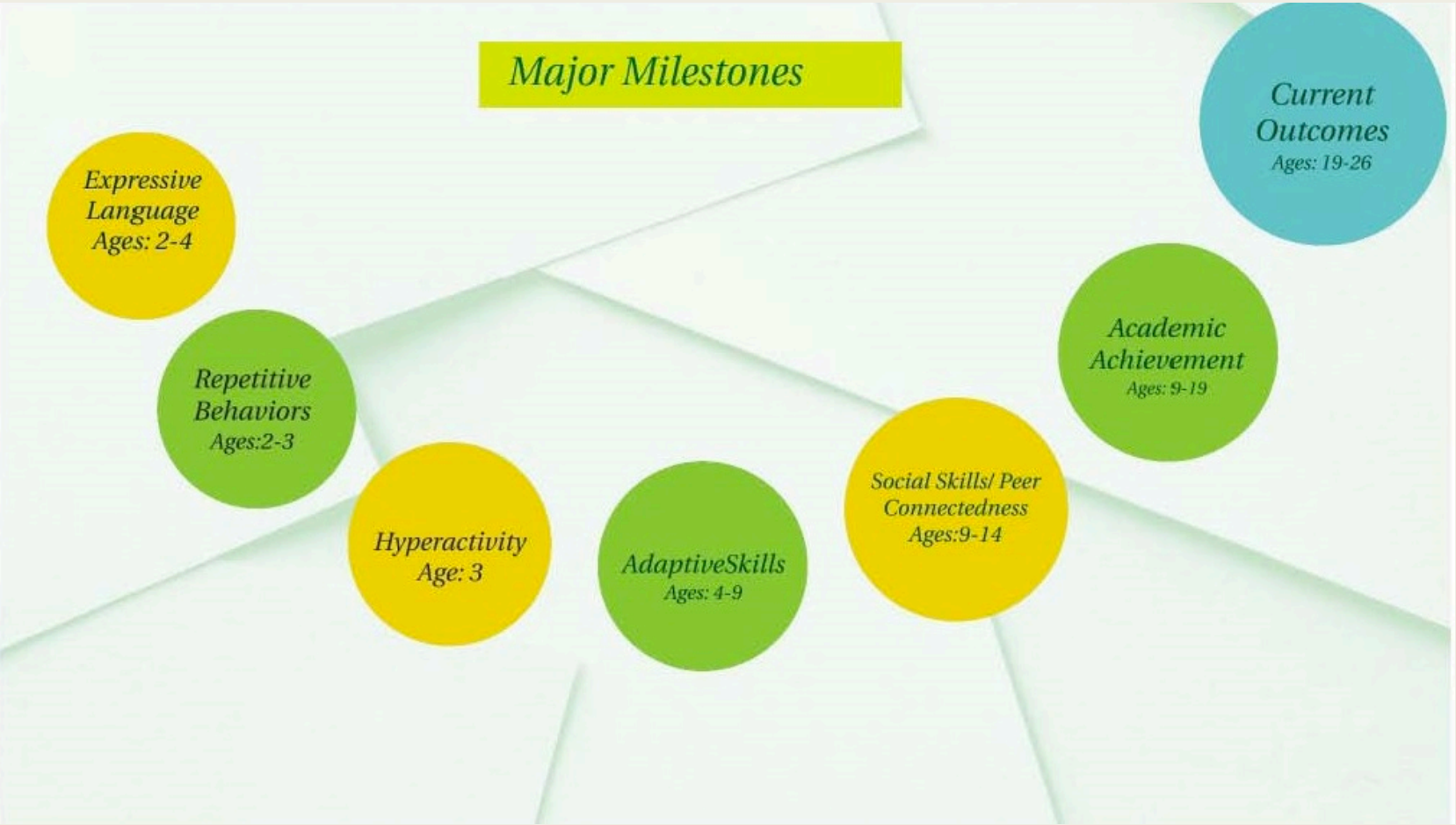


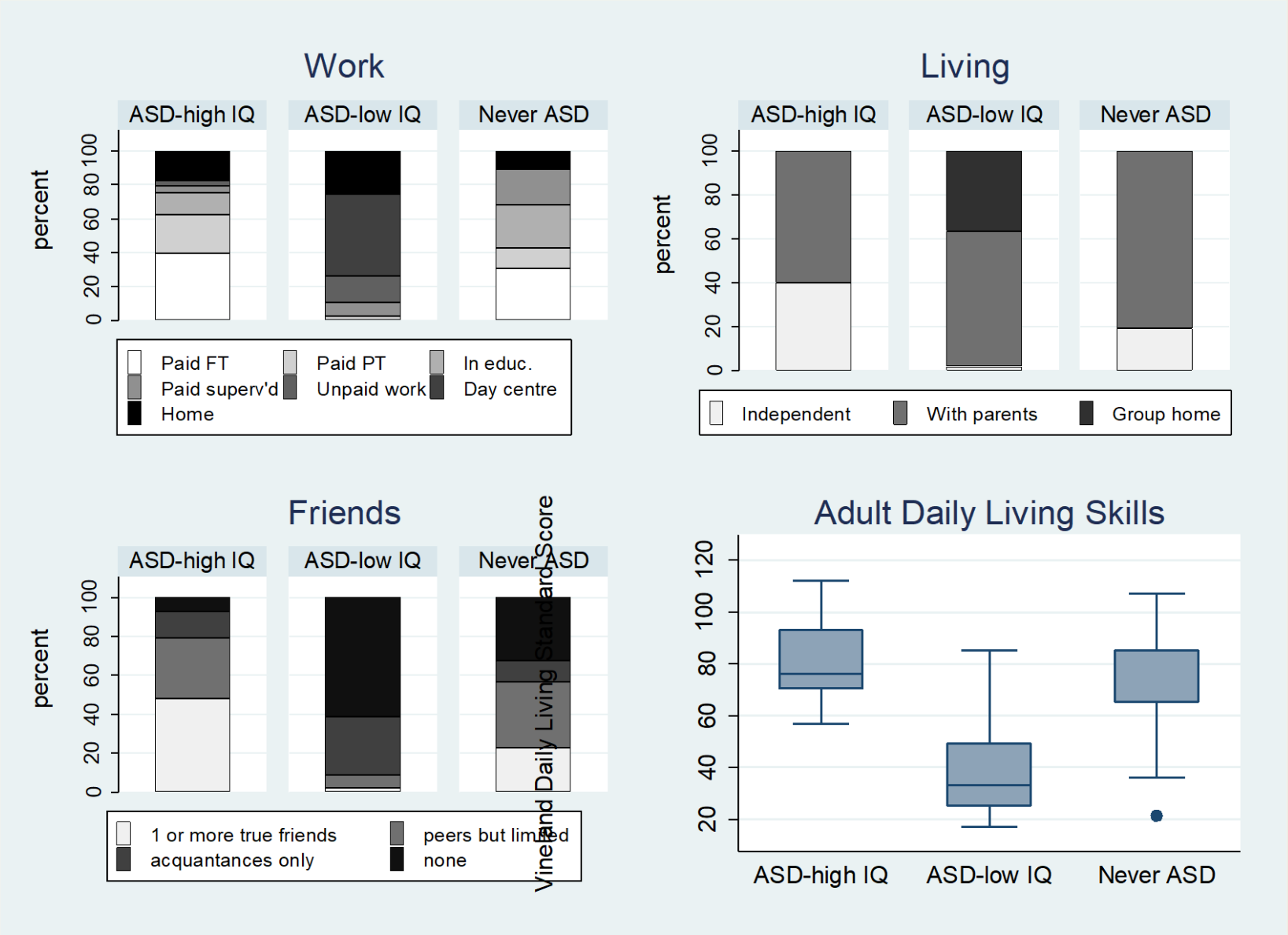
ADULT OUTCOMES BY ASD DIAGNOSIS, INTELLECTUAL DISABILITY AND INDEPENDENCE



Percent of Each of Four Groups, n=101

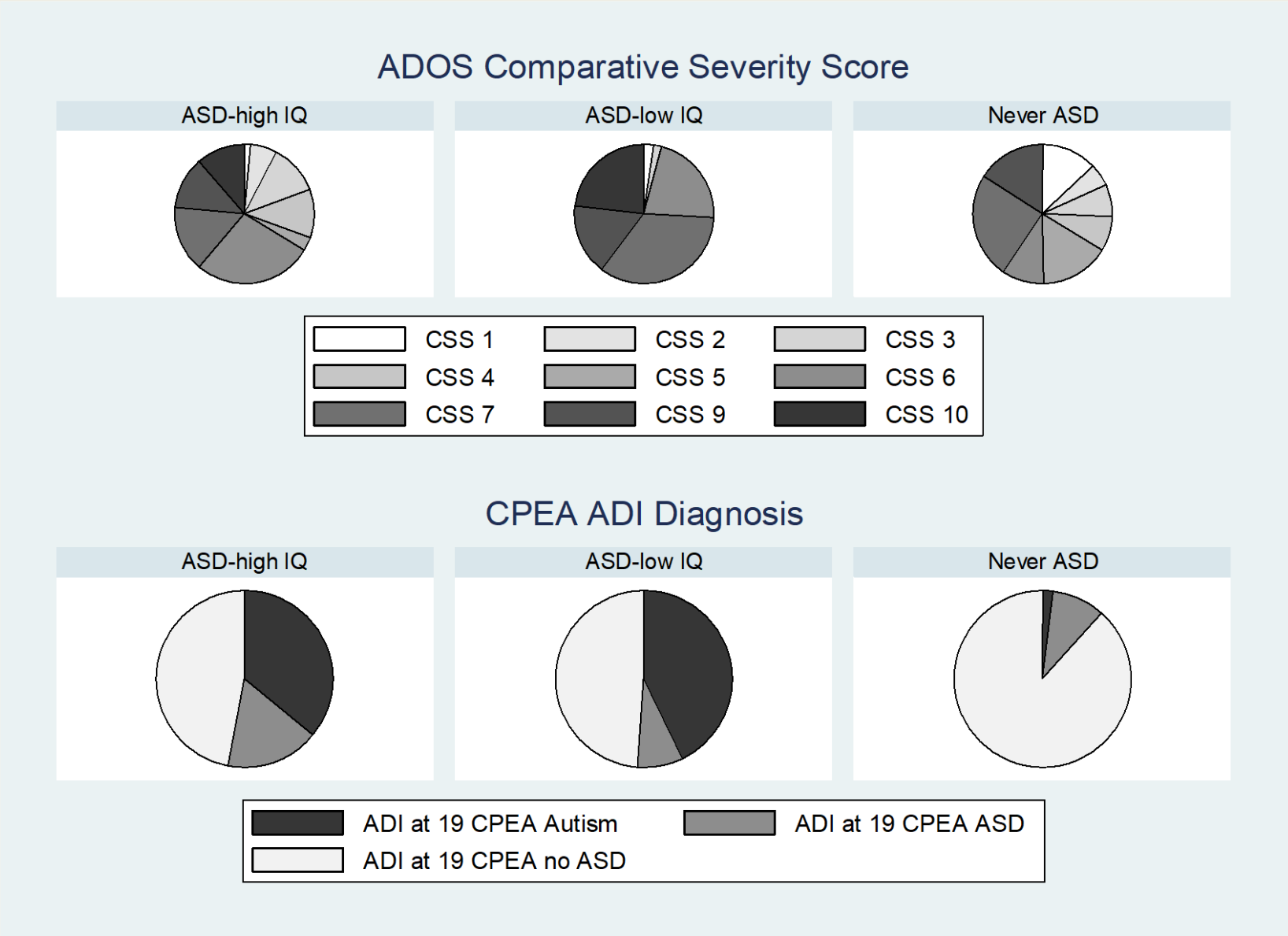
		Percent of participants with IQ >70, n=46
ASD-LCA	56.8	
ASD- MCA	24.3	56.2
ASD- VPO	7.2	16.7
No- ASD	11.7	27.1

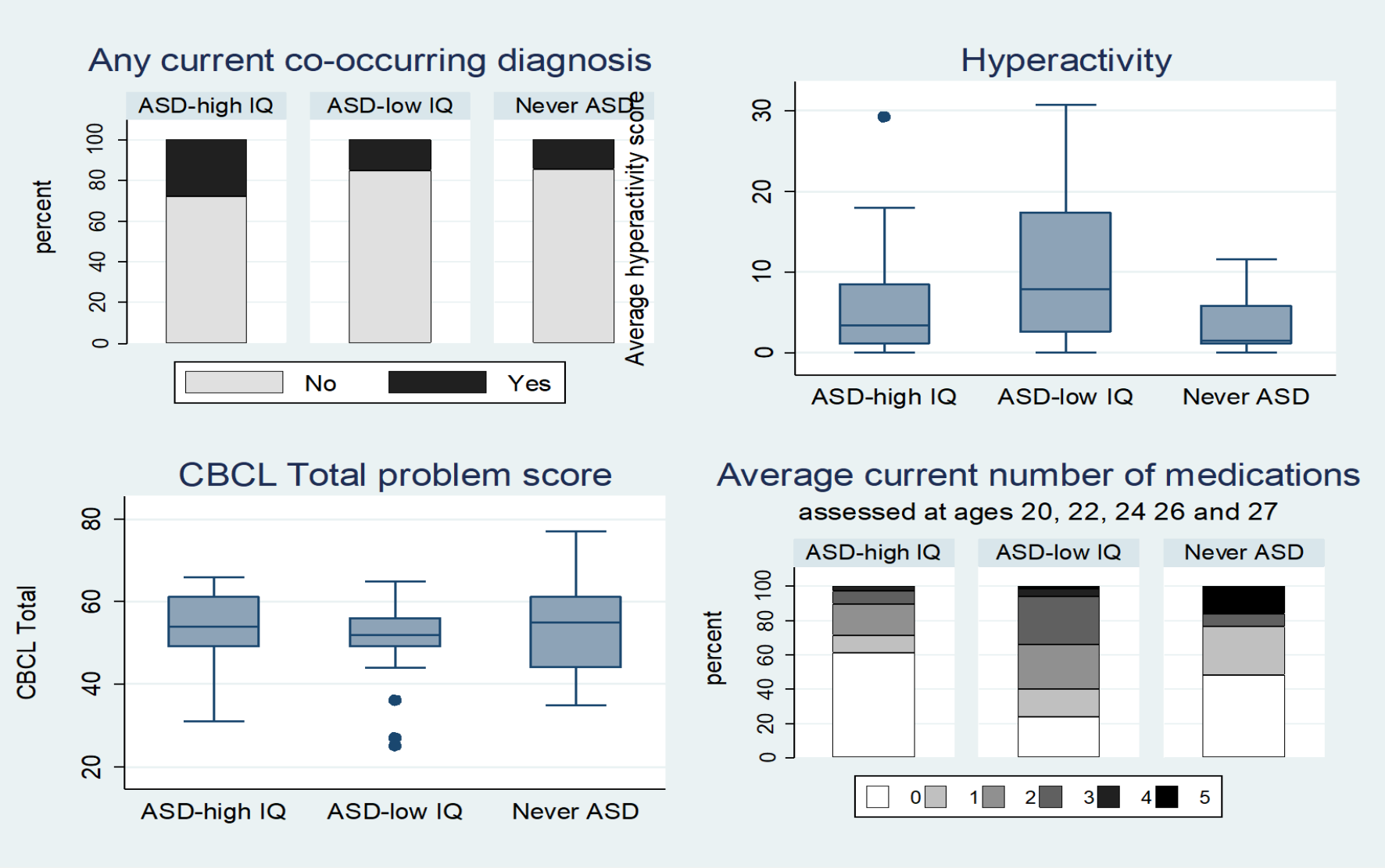

Major Milestones
Expressive Language Ages: 2-4
Repetitive Behaviors Ages:2-3
Hyperactivity Age: 3
AdaptiveSkills Ages: 4-9
Social Skills/ Peer Connectedness Ages:9-14
Academic Achievement Ages: 9-19
Current Outcomes Ages: 19-26


Work
ASD-high IQ
ASD-low IQ
Never ASD
percent
0 20 40 60 80 100
Paid FT
Paid PT
In educ.
Paid superv'd
Unpaid work
Day centre
Home
Living
ASD-high IQ
ASD-low IQ
Never ASD
percent
0 20 40 60 80 100
Independent
With parents
Group home
Friends
ASD-high IQ
ASD-low IQ
Never ASD
percent
0 20 40 60 80 100
1 or more true friends
peers but limited
acquantances only
none
Adult Daily Living Skills
Vineland Daily Living Standard Score
20 40 60 80 100 120
ASD-high IQ
ASD-low IQ
Never ASD

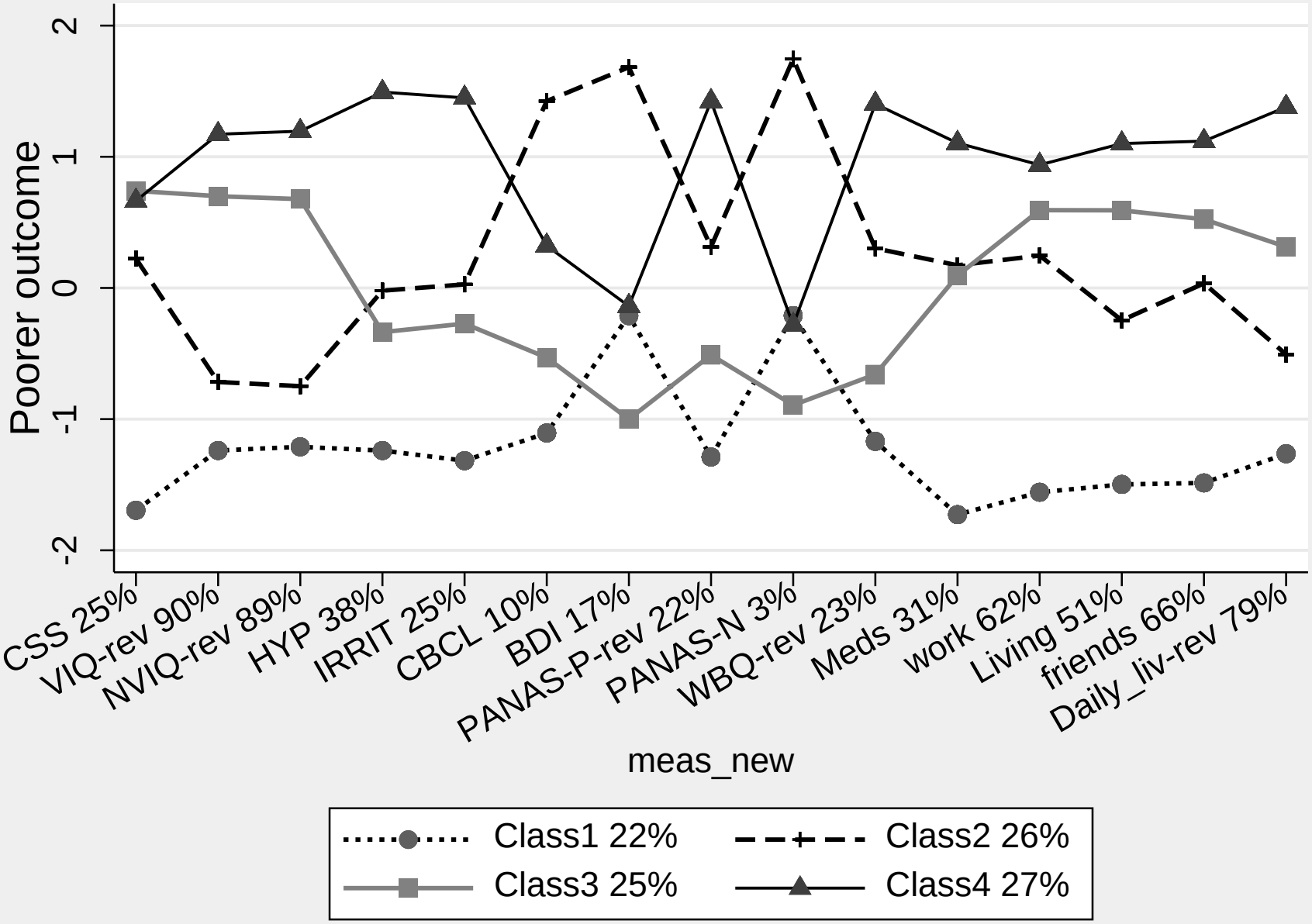
#AutismDay2018 #Medbiotech

Different Not Less


ADOS Comparative Severity Score
ASD-high IQ
ASD-low IQ
Never ASD
CSS 1
CSS 2
CSS 3
CSS 4
CSS 5
CSS 6
CSS 7
CSS 9
CSS 10
CPEA ADI Diagnosis
ASD-high IQ
ASD-low IQ
Never ASD
ADI at 19 CPEA Autism
ADI at 19 CPEA ASD
ADI at 19 CPEA no ASD


Any current co-occurring diagnosis
ASD-high IQ
ASD-low IQ
Never ASD
percent
0
20
40
60
80
100
No
Yes
Hyperactivity
Average hyperactivity score
0
10
20
30
ASD-high IQ
ASD-low IQ
Never ASD
CBCL Total problem score
CBCL Total
20
40
60
80
ASD-high IQ
ASD-low IQ
Never ASD
Average current number of medications
assessed at ages 20, 22, 24 26 and 27
ASD-high IQ
ASD-low IQ
Never ASD
percent
0
20
40
60
80
100
0
1
2
3
4
5

Class 1 Best outcome
Class 2 High IQ Autism
Class 3 Low IQ Autism w/o behavioural prob
Class 4 Low IQ Autism with behavioural prob



Incremental Prediction of adult Outcome classes:

Class 1 Best outcome
Class 2 High IQ Autism
Class 3 Low IQ Autism w/o behavioural prob
Class 4 Low IQ Autism with behavioural prob

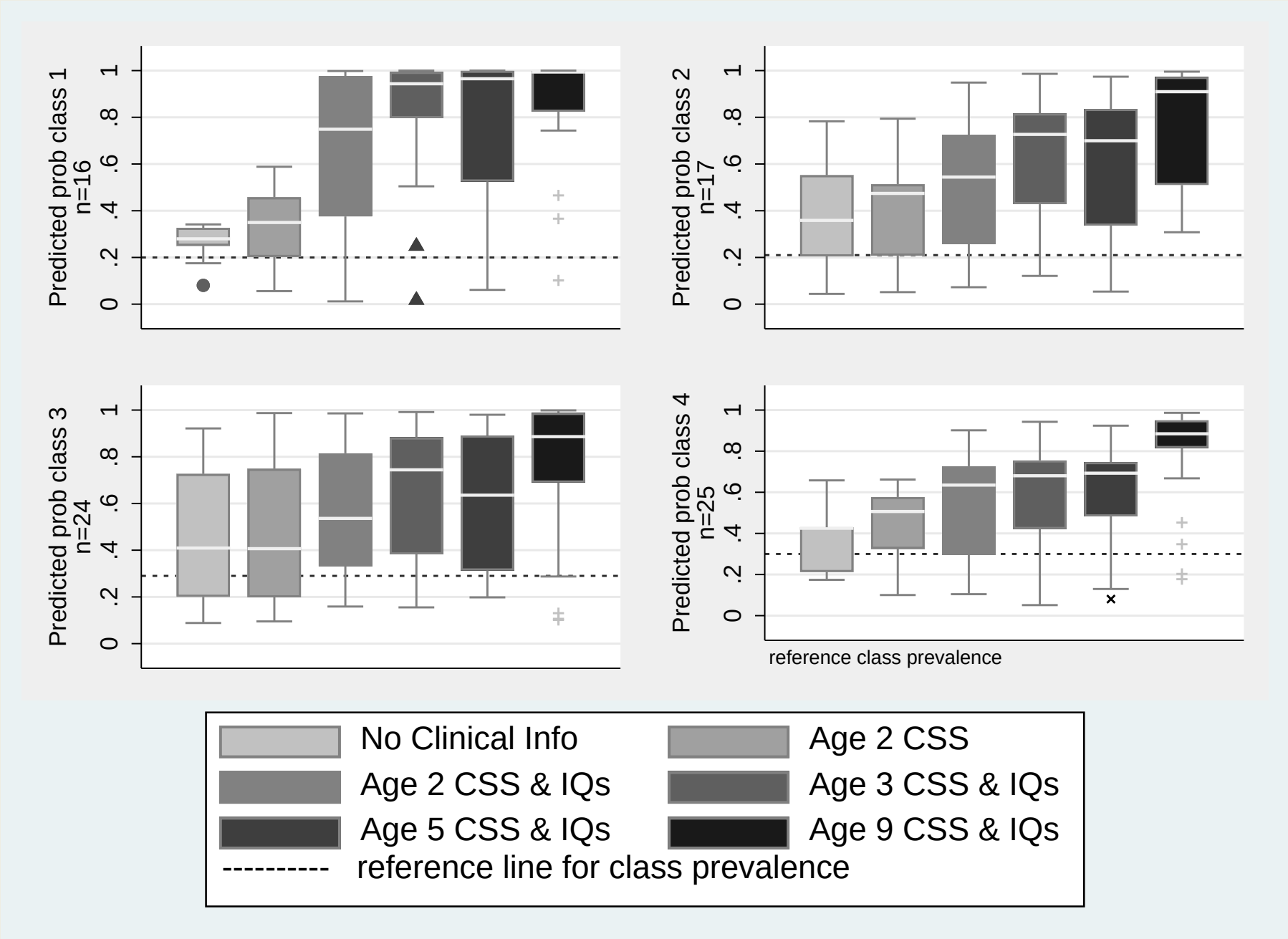


Figure S1 4-class adult outcome latent profile omitting adult verbal and non-verbal IQ

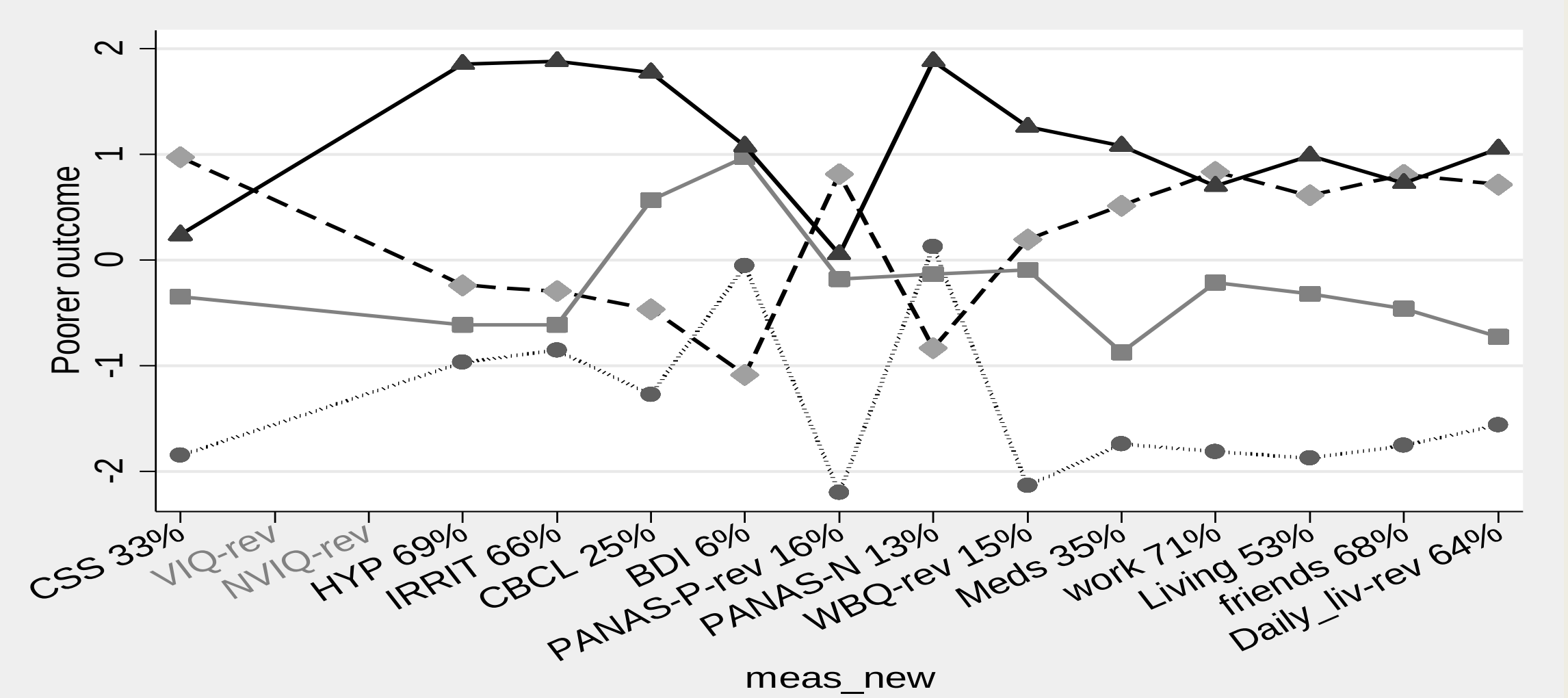
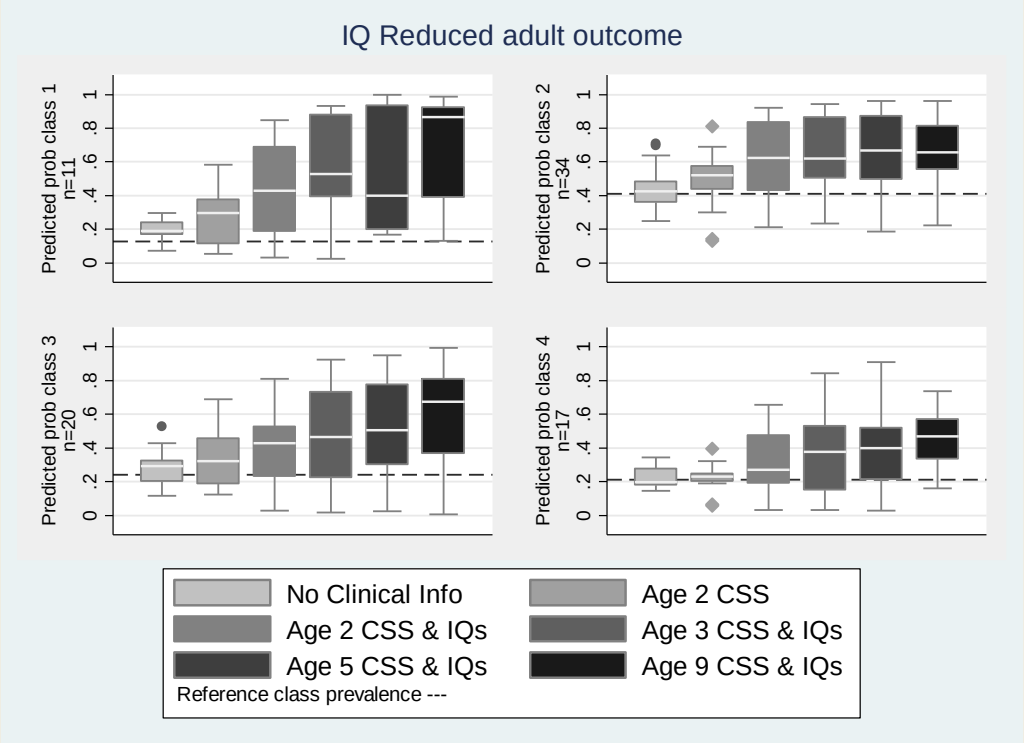
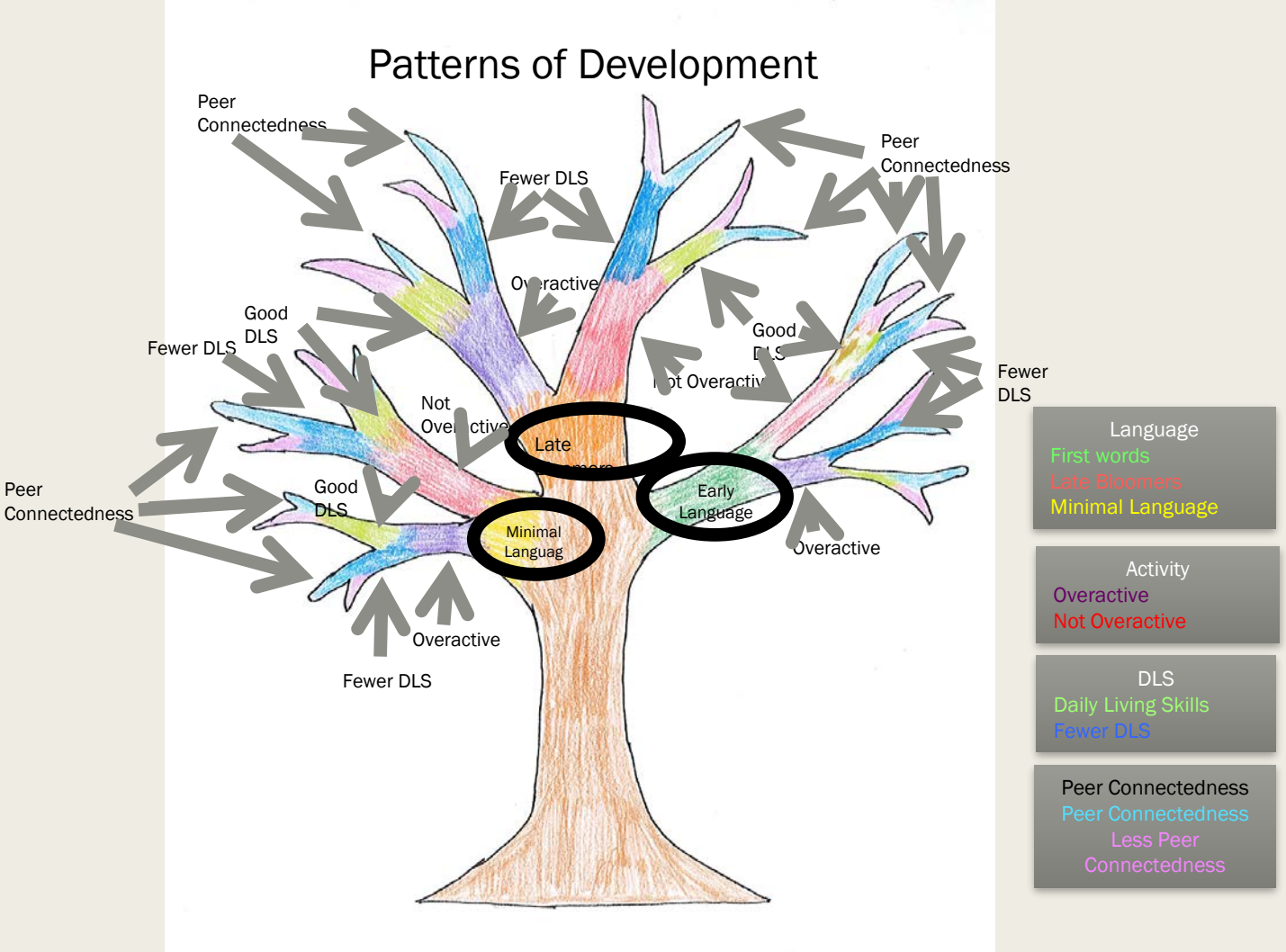


Figure S2 Prediction of adult outcome classes for profile omitting adult verbal and non-verbal IQ

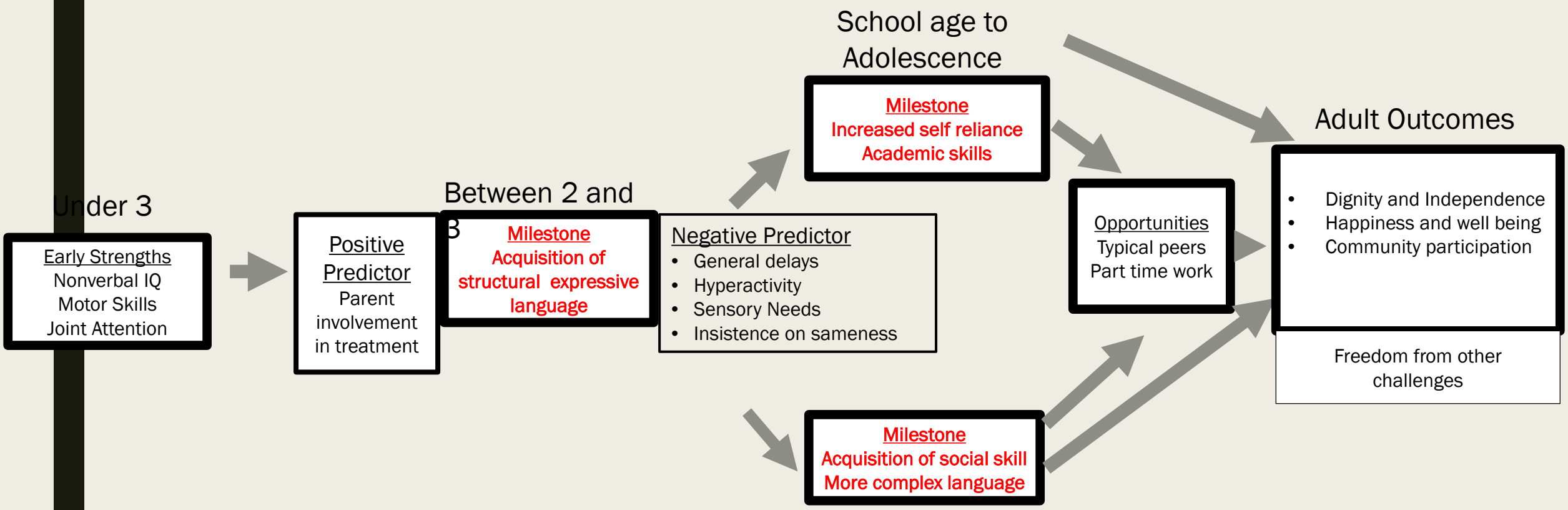


Key messages so far

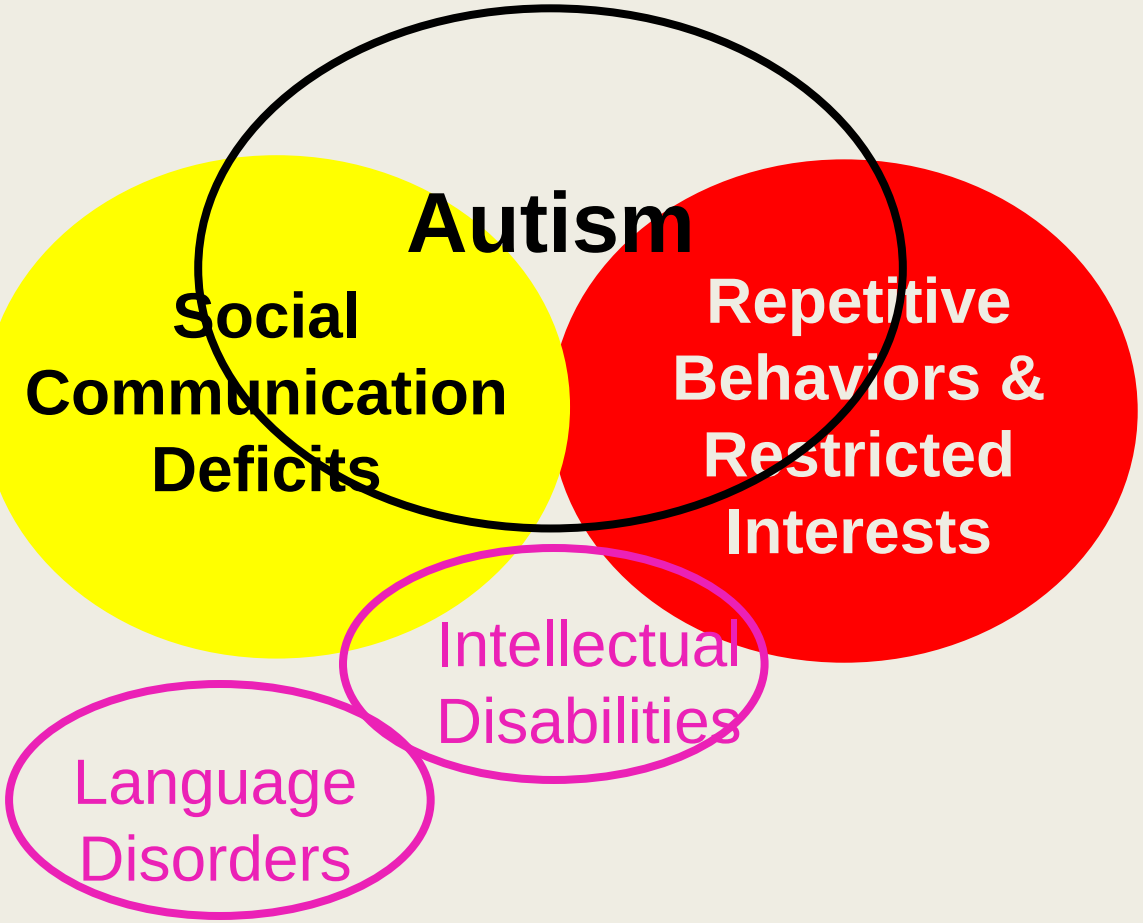
- Subjective and objective measures of adult outcome are not the same
- We struggle with how to measure subjective outcome
- ASD outcomes are not that different than those of children referred at 2 or at 10 for possible autism
- Can’t deny or underestimate the effects of intellectual disability, which are not that apparent at age 2, but become clearer by 3
- We can’t underestimate the importance of trajectories of language, adaptive and social development
- We can measure milestones such as peer connectivity, academic progress, decreases in repetitive behavior but we don’t really no directions of causality
- Remember role of parents and probably nonspecific aspects of the environment


Patterns of Development
Peer Connectedness
Fewer DLS
Peer Connectedness
Good DLS
Fewer DLS
Fewer DLS
Not Overactive
Late
Peer Connectedness
Good DLS
Early Language
Minimal Languag
Overactive
Overactive
Fewer DLS
Language
First words
Late Bloomers
Minimal Language
Activity
Overactive
Not Overactive
DLS
Daily Living Skills
Fewer DLS
Peer Connectedness
Peer Connectedness
Less Peer Connectedness

Milestones


Under 3
Early Strengths
Nonverbal IQ
Motor Skills
Joint Attention
Positive Predictor
Parent involvement in treatment
Between 2 and 3
Milestone
Acquisition of structural expressive language
Negative Predictor
General delays
Hyperactivity
Sensory Needs
Insistence on sameness
School age to Adolescence
Milestone
Increased self reliance
Academic skills
Milestone
Acquisition of social skill
More complex language
Opportunities
Typical peers
Part time work
Adult Outcomes
Dignity and Independence
Happiness and well being
Community participation
Freedom from other challenges

Pervasive Developmental Disorders



Sense of humor

Fine motor skills

Predictability

Intelligence

Visual-spatial skills

Curiosity

Attention to detail

Honesty

Thanks to you

And the families and all the people who worked on this research, Andrew and Jamie

Catherine Lord