



Families in autism: Caregivers and siblings

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This is the
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Conflicts of Interest

- I receive royalties from Western Psychological Services for diagnostic and screening instruments. I am on scientific advisory boards of the Autism Science Foundation, Autism Speaks, the Child Mind Institute, and Kyo Learning Groups. I am working with GW Pharmaceuticals/Greenwich Biosciences/Signant, Yamo on particular projects. I have research funding from NICHD, NIMH, NIDCD, NIA, DoD and the Simons Foundation.

Autism is a heterogeneous condition (a “spectrum”)



- **Autism manifests differently *between* individuals**
 - Some autistic people can live independent lives; others need support every day throughout their lives; and many others fall in between
- **Autism also manifests differently *within* individuals across the lifespan**
 - It is a developmental condition
 - Autistic people will require different interventions and supports at different points in their lives
- **Valuing autism and neurodiversity benefits society as a whole**
- There are many evidence-based interventions related to autism which can make changes
- **But we hope their biggest value is in starting cascades of change**

Changes are gradual and usually small

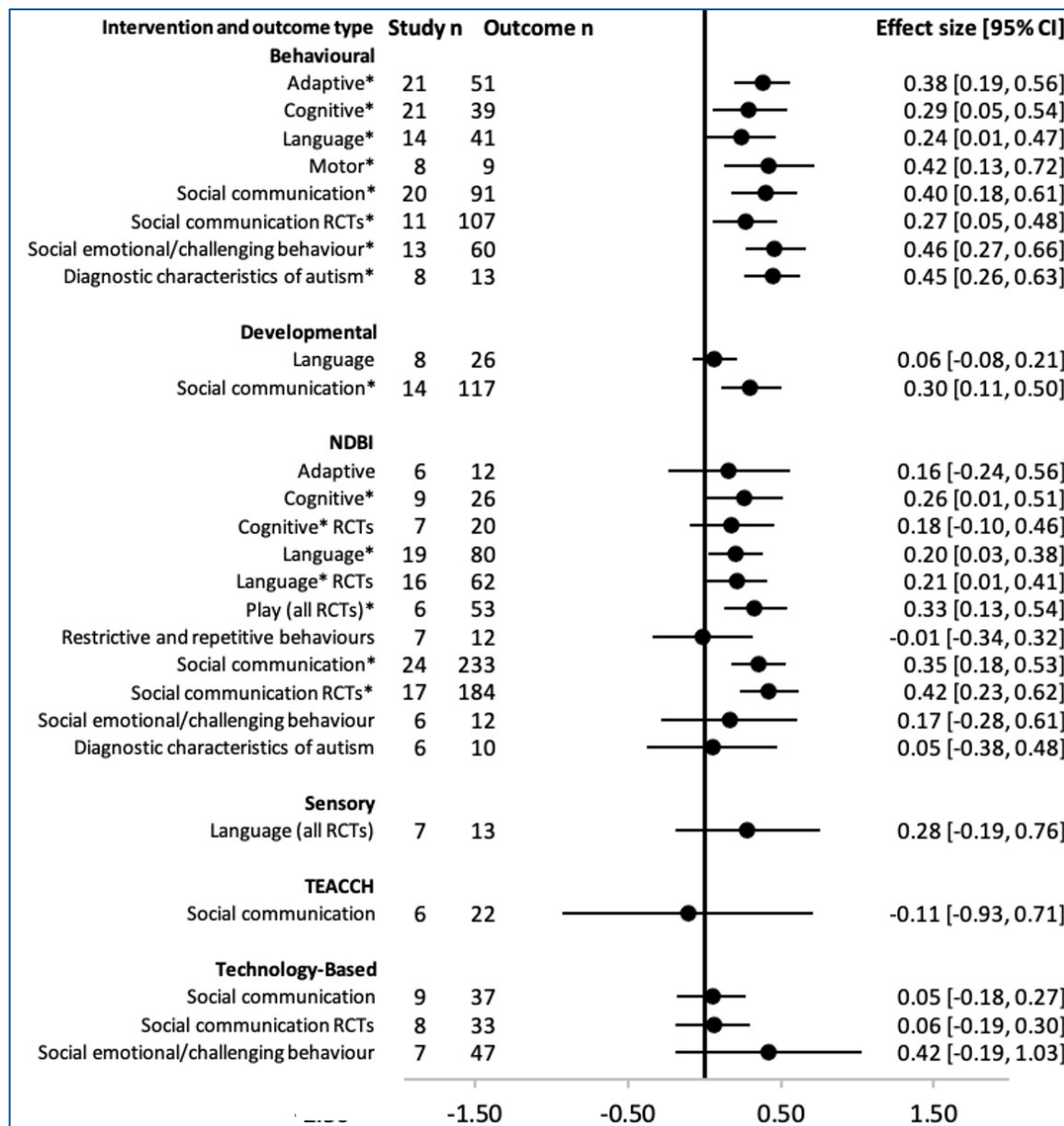
Changes in language level of 2 – 3 months more than expected in a year or two

Changes in cognitive ability of 10 – 15 points more than treatment as usual

Changes in estimates of social functioning



- Evidence-based psychosocial interventions exist for young, autistic children
- Naturalistic interventions to promote positive parent-child interactions have been successfully implemented in LMICs
- There is some general agreement about helpful intervention strategies (e.g., visual supports) even when lacking “traditional” empirical support
- Psychopharmacological treatments for co-occurring conditions become more common in later childhood or adolescence

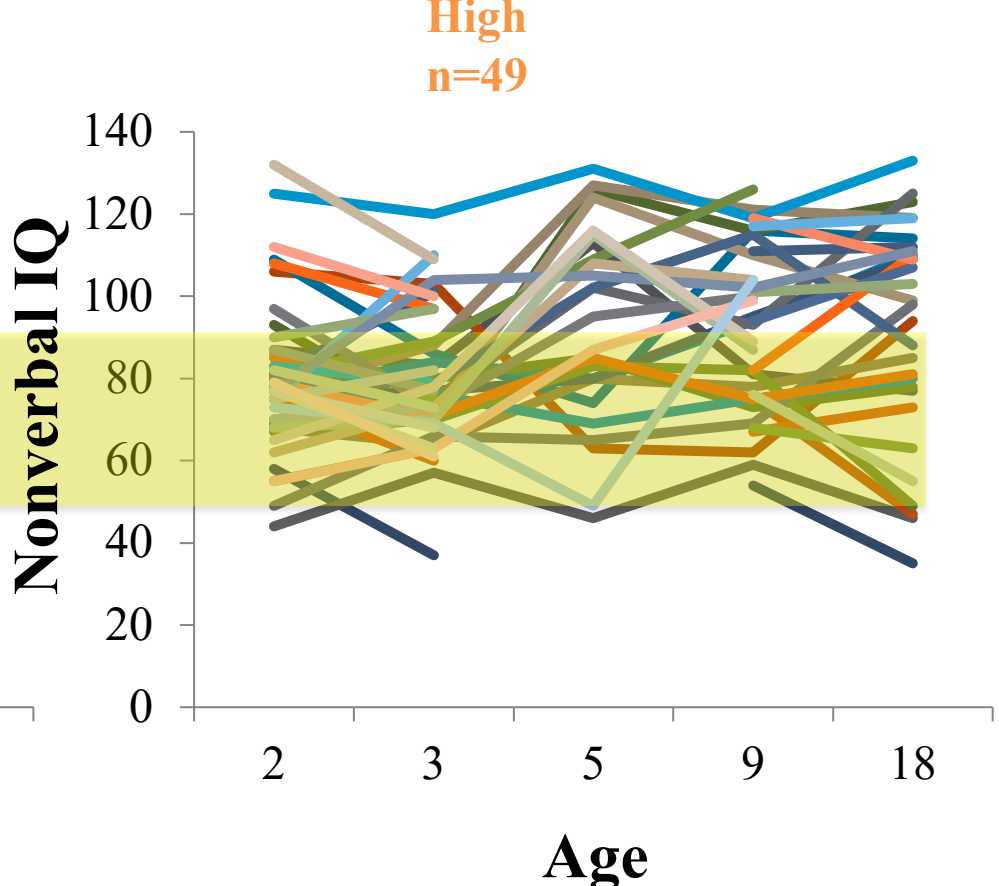
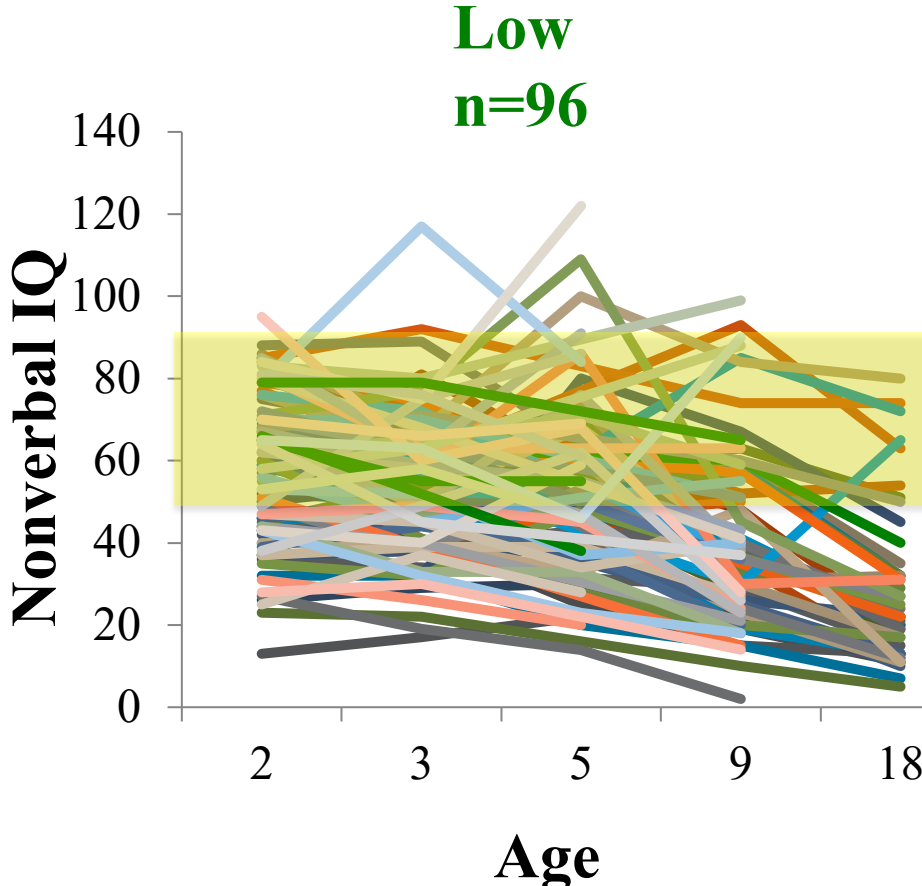


The most consistent findings are that parent-mediated interventions have effects

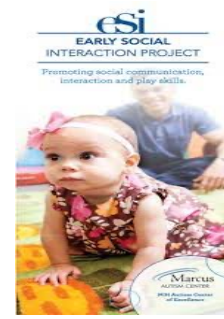
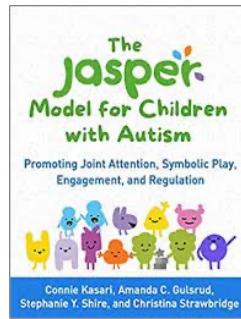
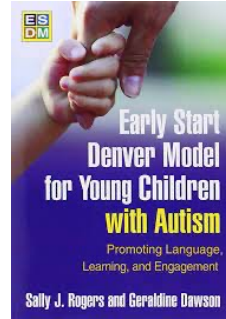
- This is most obviously true for preschool children BUT
- Also true for older kids, for example:
 - PEERS
 - BIACA
 - SELF-DETERMINATION



Group overlap in adaptive skills in mild-to-borderline range of cognitive impairment

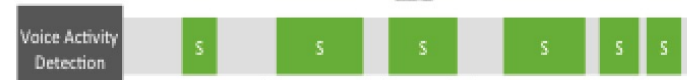
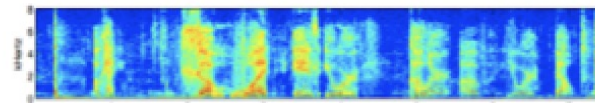


Unpacking Treatment Mechanisms: Combining Evidence from Three Early Intervention Models for ASD (5R01MH114925, PI: Kim)



Treatment month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
Videos for ESI	T1	T2	T3	T4	T5	T6	T7	T8	T9	T10															
ESI intervention	Starting with individual ESI (Treatment) n=42										Followed by group ESI (Control)														
	Strating with group ESI (Control) n=40										Followed by individual ESI (Treatment)														
Video for ESDM	T1	T2	T3	T4	T5	T6	T7	T8	T9	T10	T11	T12	T13												
ESDM Intervention	Treatment n=49													Control n=48											
Videos for JSAPER	T1		T2		T3																				
JASPER Treatment	Treatment n=59					Control n=48																			

Italicized time points are only available for michigan sample (n=24, 10 tx cases)



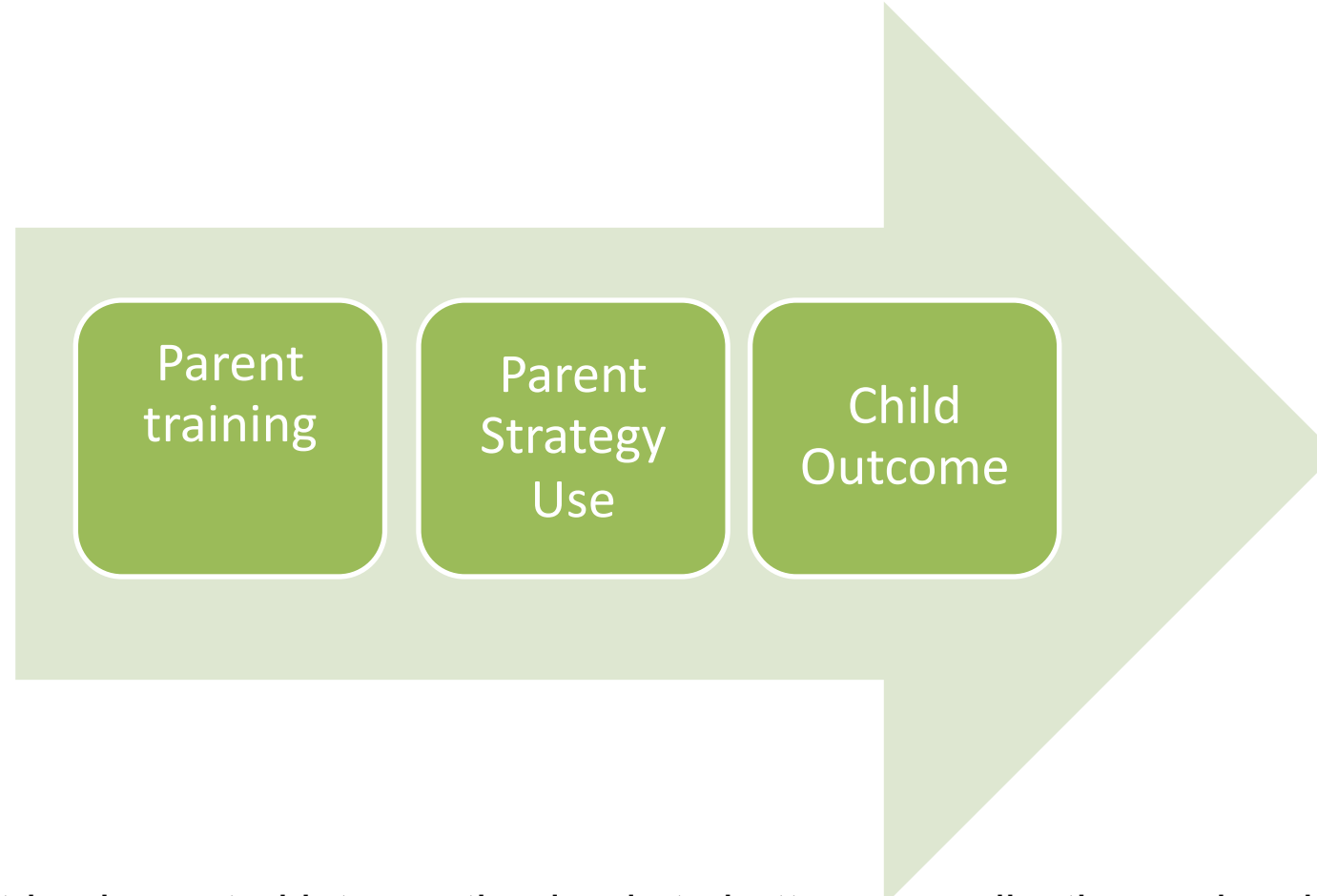
Detected Speech Regions



Speakers in the Vocal Interchanges

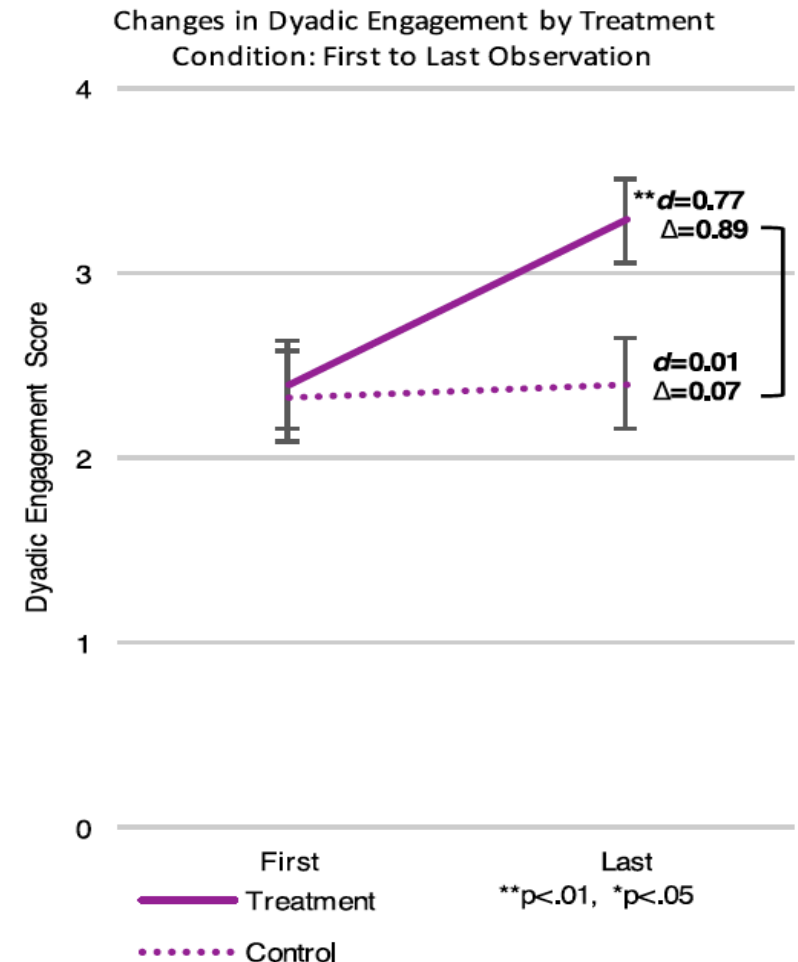
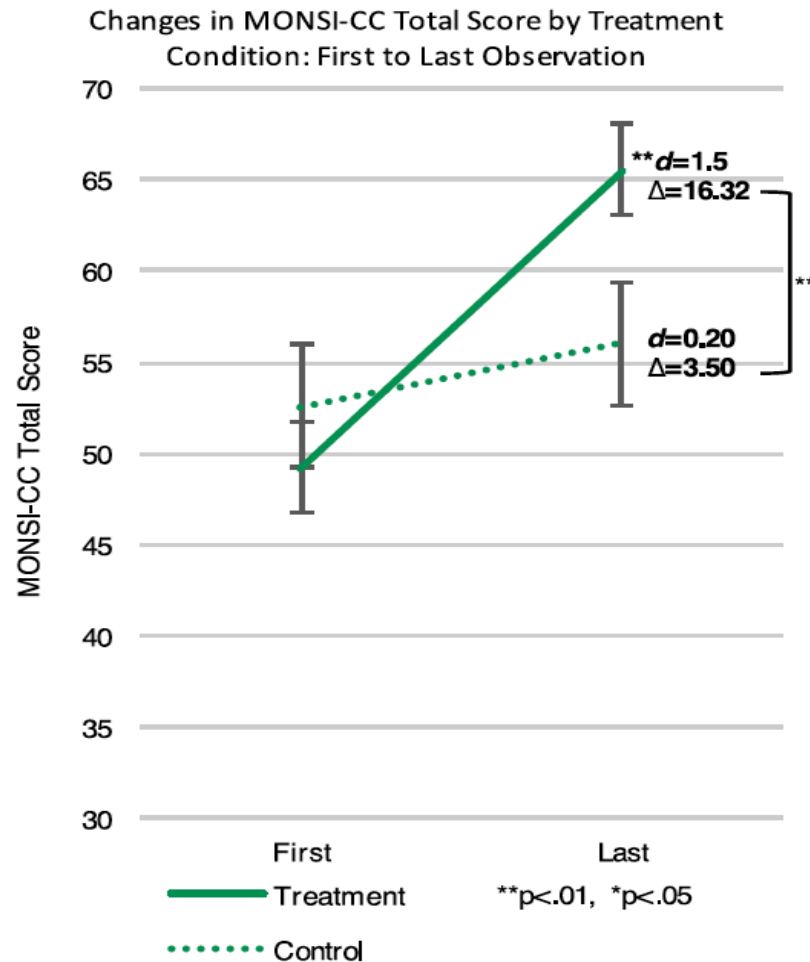


Parent implemented early intervention

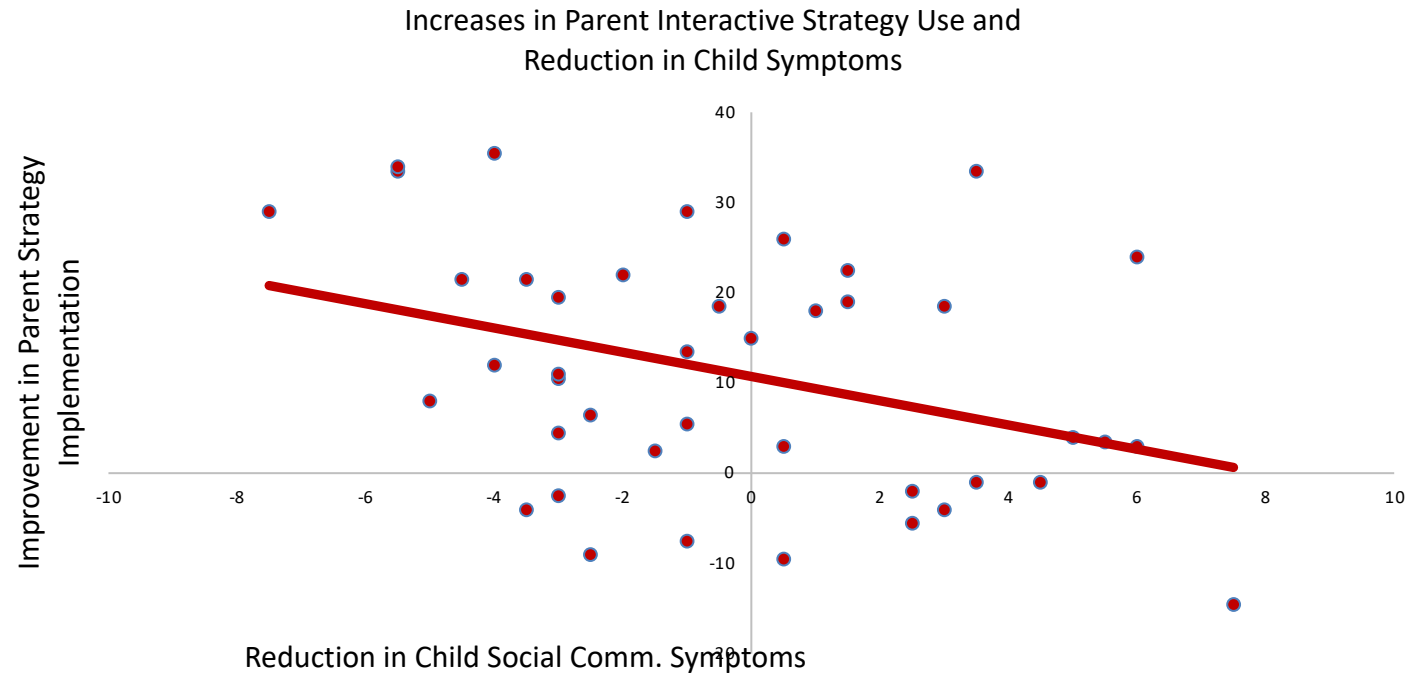


- Parent-implemented intervention leads to better generalization and maintenance of skills than therapist-implemented intervention (Koegel et al., 1982);

MONSI-CC captures changes in caregivers over the course of NDBIs

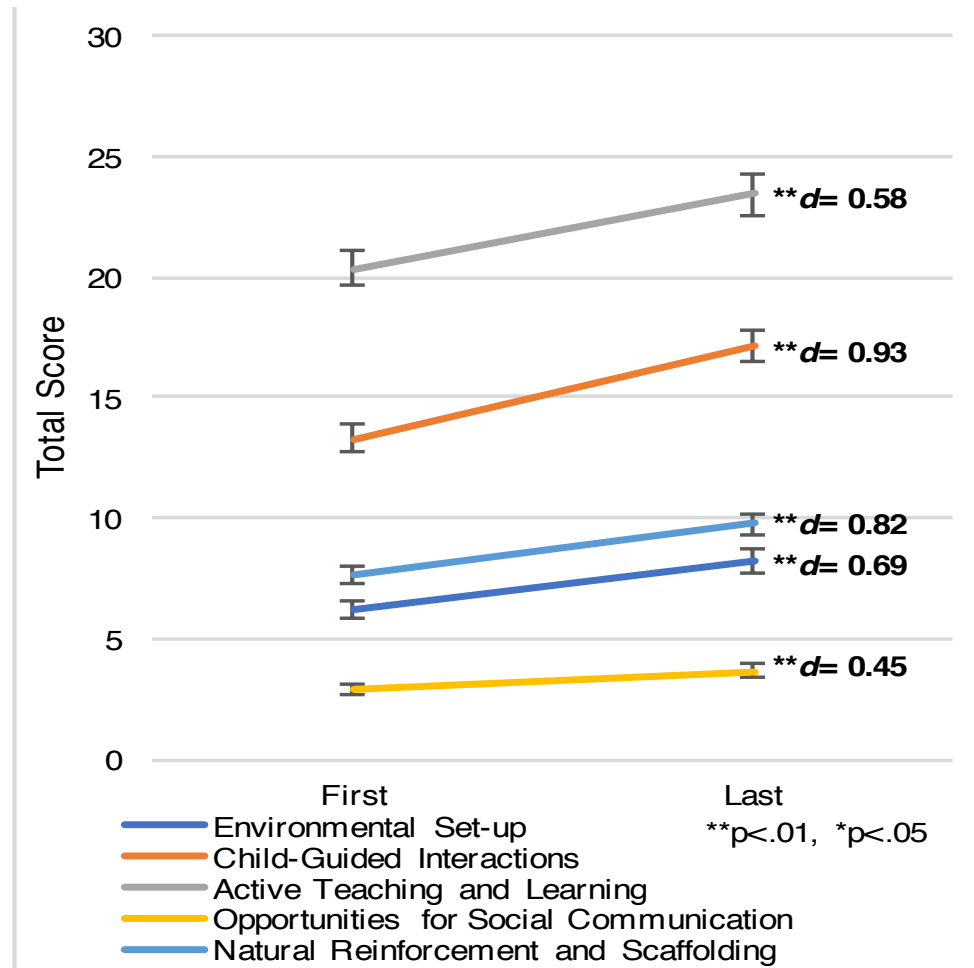


Improvements in parent strategies (MONSI-CC) were significantly correlated with reduction in child autism symptoms (BOSCC)



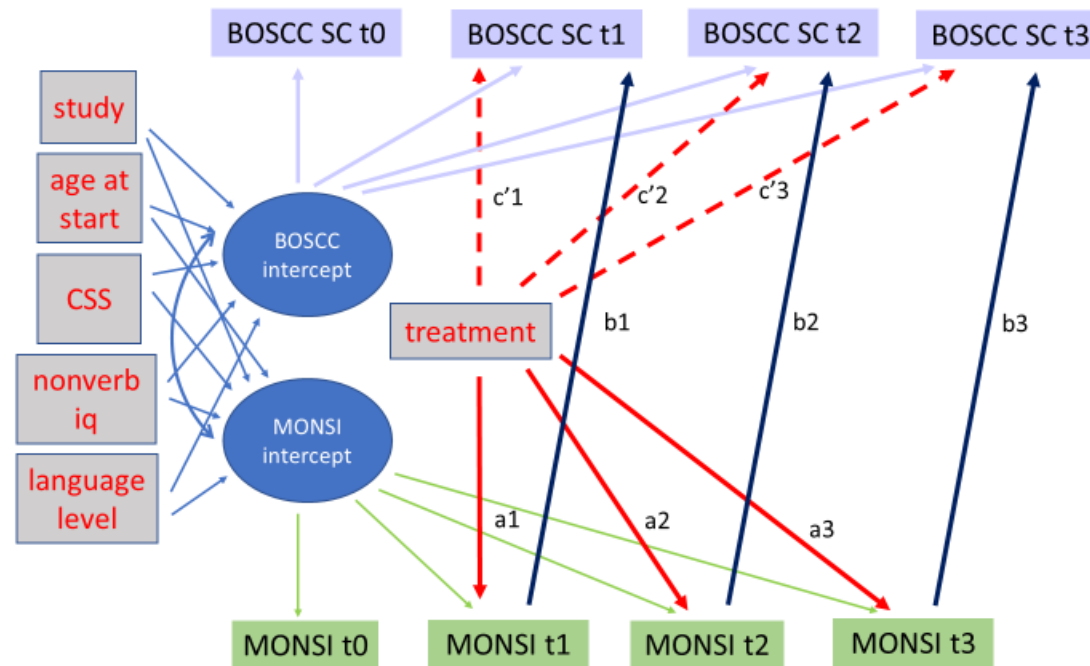
Vibert, Dufek, Klein, Winter, Lord & Kim, 2021, *JADD*

Using MONSI-CC, caregiver implementation of NDBI strategies improved over treatment



Vibert, Dufek, Klein, Winter, Lord & Kim, 2021, JADD

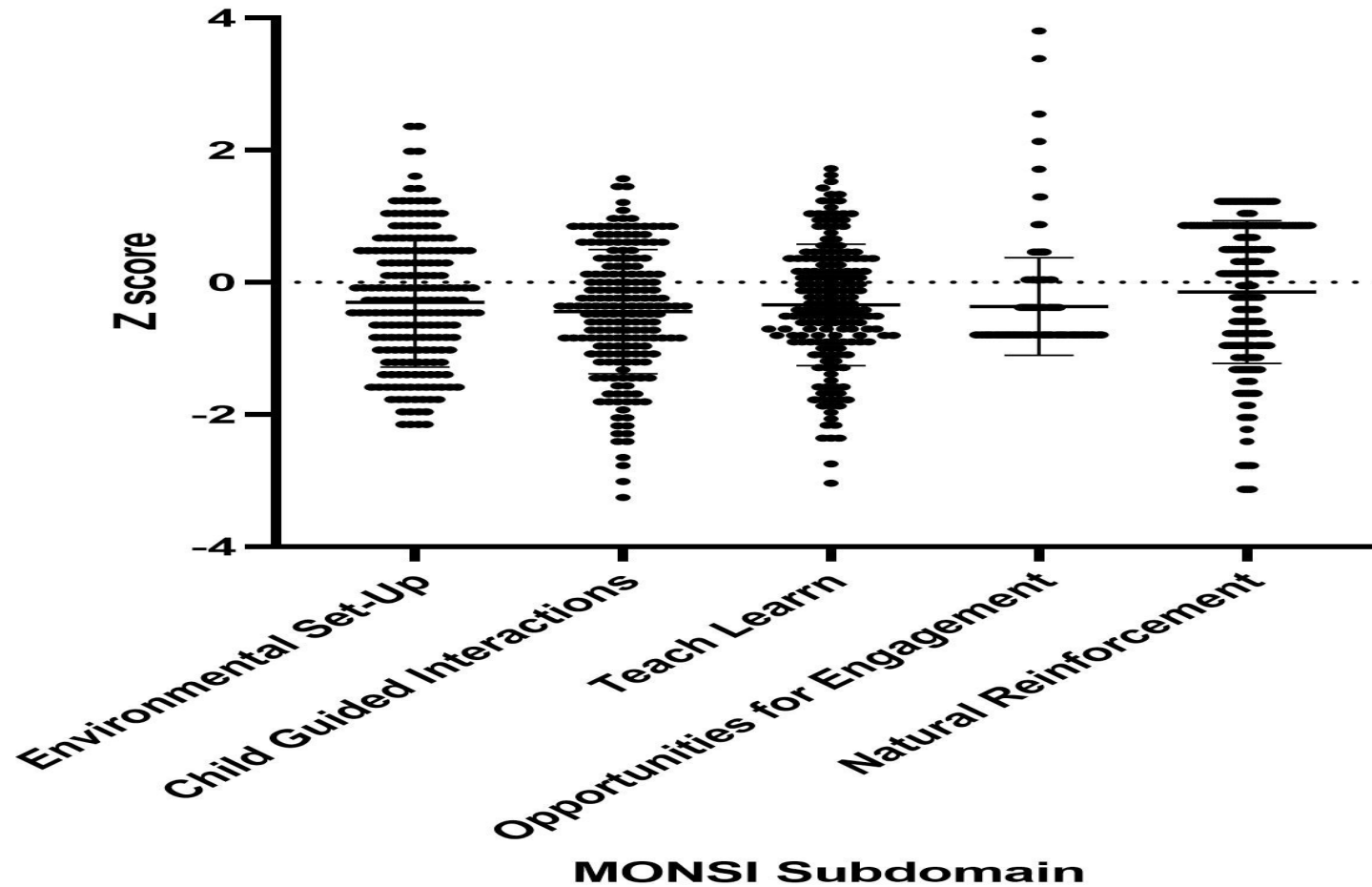
Treatment effects on children were significantly mediated by caregiver changes



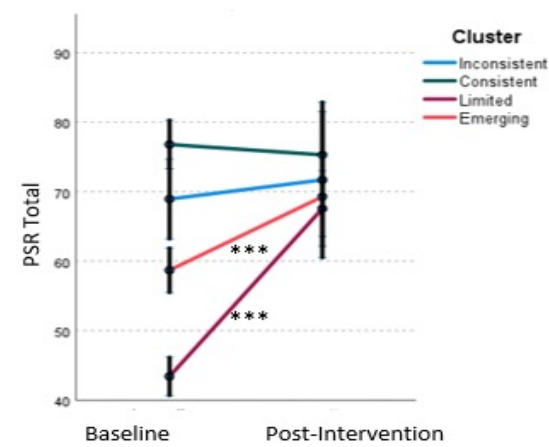
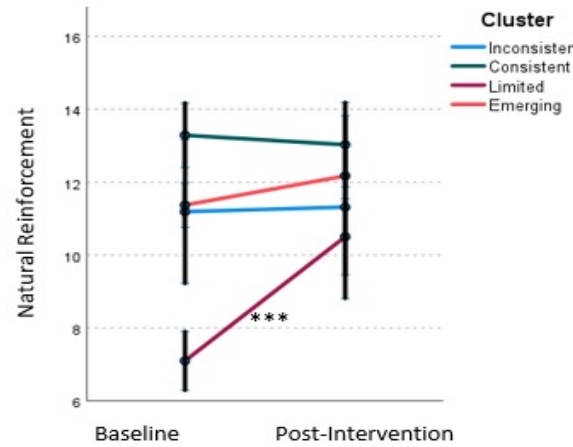
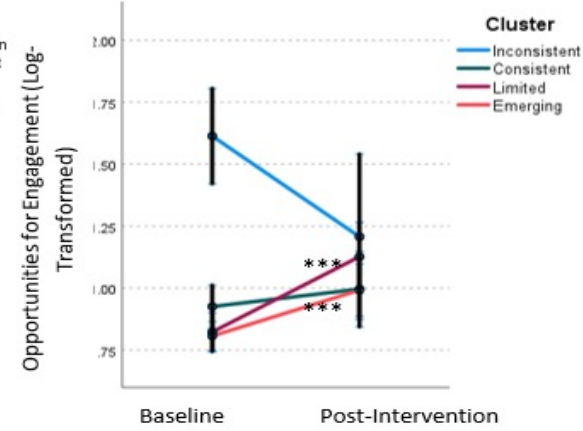
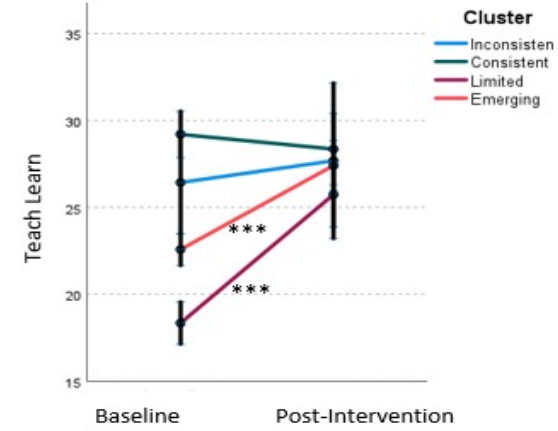
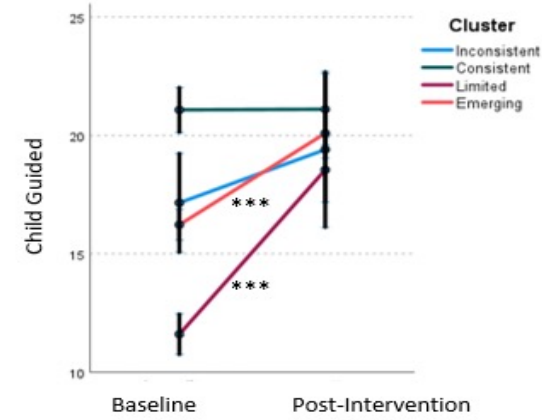
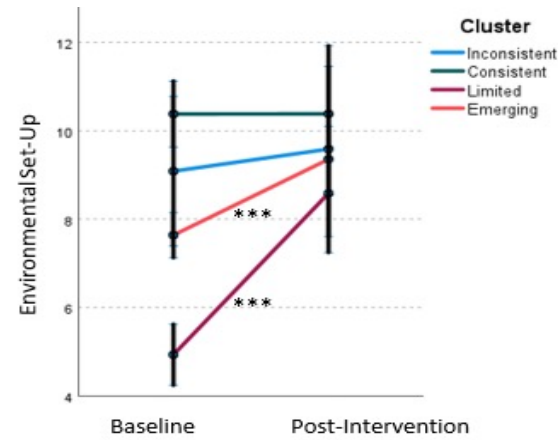


This means we need to think about families and long-term sources of support and meaning as well as our usual assessments and treatments.

Variability across caregivers at treatment entry among 5 MONSI domains; n=191



Most caregivers gain or maintain their skills but caregivers who start low change the most!



Findings from our longitudinal study

- Following the same themes:
- Families who had 6 - 12 months involvement with one provider whom they worked with from years 2 to 3 had children and adolescents with:
 - Better adaptive skills
 - Better achievement skills
 - Higher cognitive scores (about 10 points)
 - into adolescence and young adulthood
- This may well be the parents, not the providers
- We need to know more about what helps families when and how





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North Carolina/Chicago/Michigan Early Diagnosis Study



- Multiple measures
- Parent reports and direct observations
- 192 consecutive referrals for ASD; 21 DD controls; 54 additional from Michigan; 75% boys; 75% Caucasian; Rural, urban, suburban

Where did our data come from?

We have a special sample of families who sought help for a 2 year-old with possible autism 30 years ago.

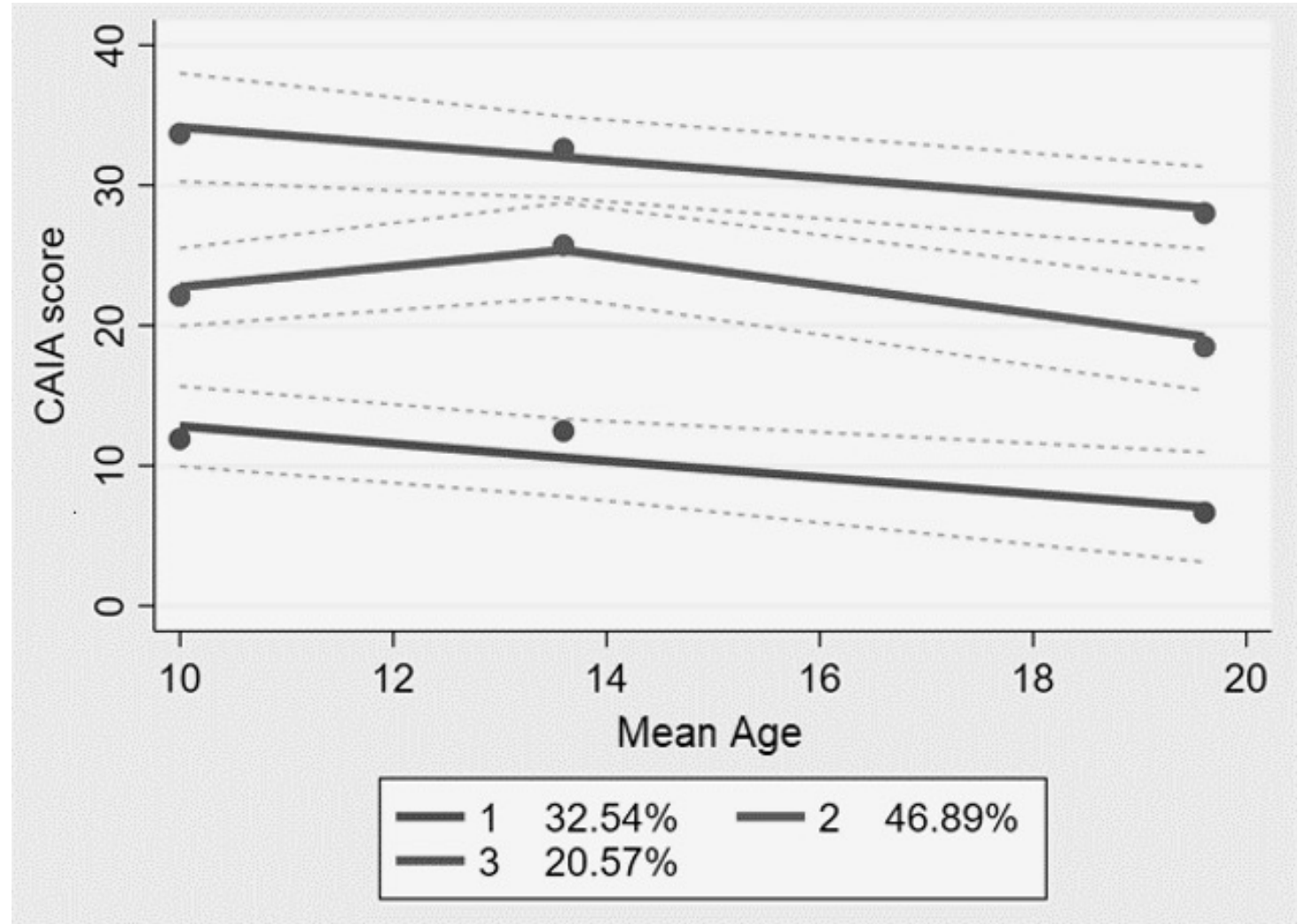
- **These families were not in poverty but not wealthy or very well-educated and reflected both Black and White working class families.**
-

What factors affect caregivers' well-being and perceptions of their lives?



THE CAIA

- Families described perceived negative (and positive impact) of having a child with autism or an NDD.
- The primary positive factor was joint family support (with husbands mostly)



Parents' reports of difficulties go down; what else?

There are considerable differences between reports of more educated parents of any race and particularly African American parents with less education

- Who report less negative impact
- Which may be related to the number of other challenges these families face
- Note: we think we're seeing more education and race effects as our adults grow older (and are farther from easier access to services through schools)

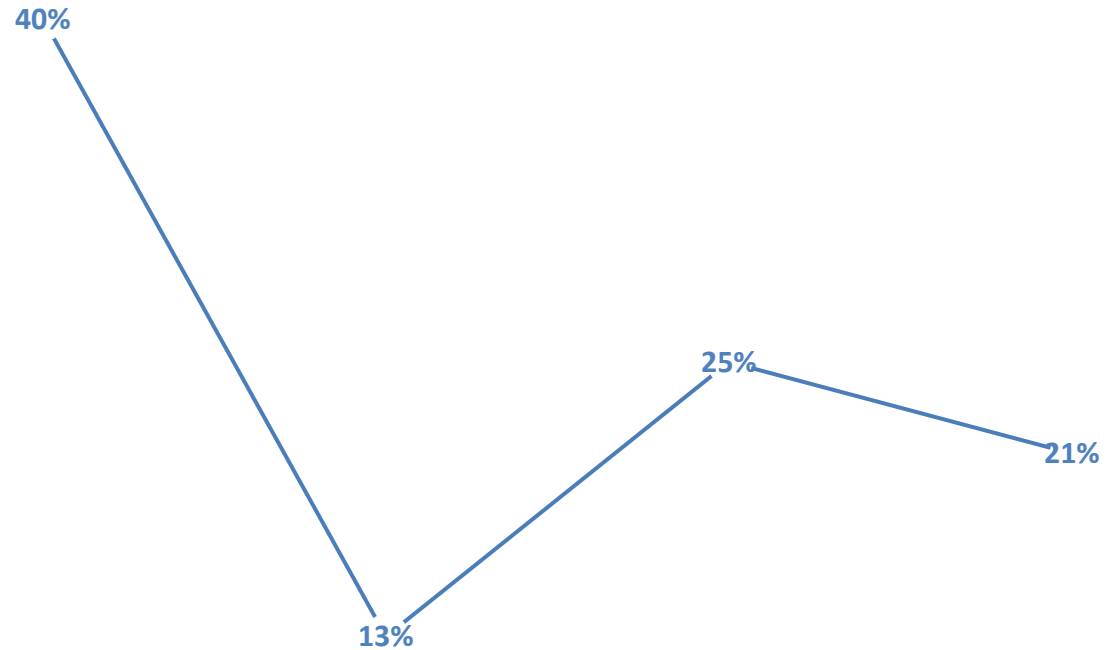
Parent reports of negative impacts on the family ARE NOT related to autism severity in general or intellectual disability but to behavior problems (**aggression, irritability**) and to **repetitive behaviors**

And social support protects!

Divorce Risk Over Time

Individuals who experienced a divorce after age 15 had significantly higher daily living skills and non-verbal IQ scores than others

PROPORTION OF TOTAL DIVORCES IN EACH AGE BIN



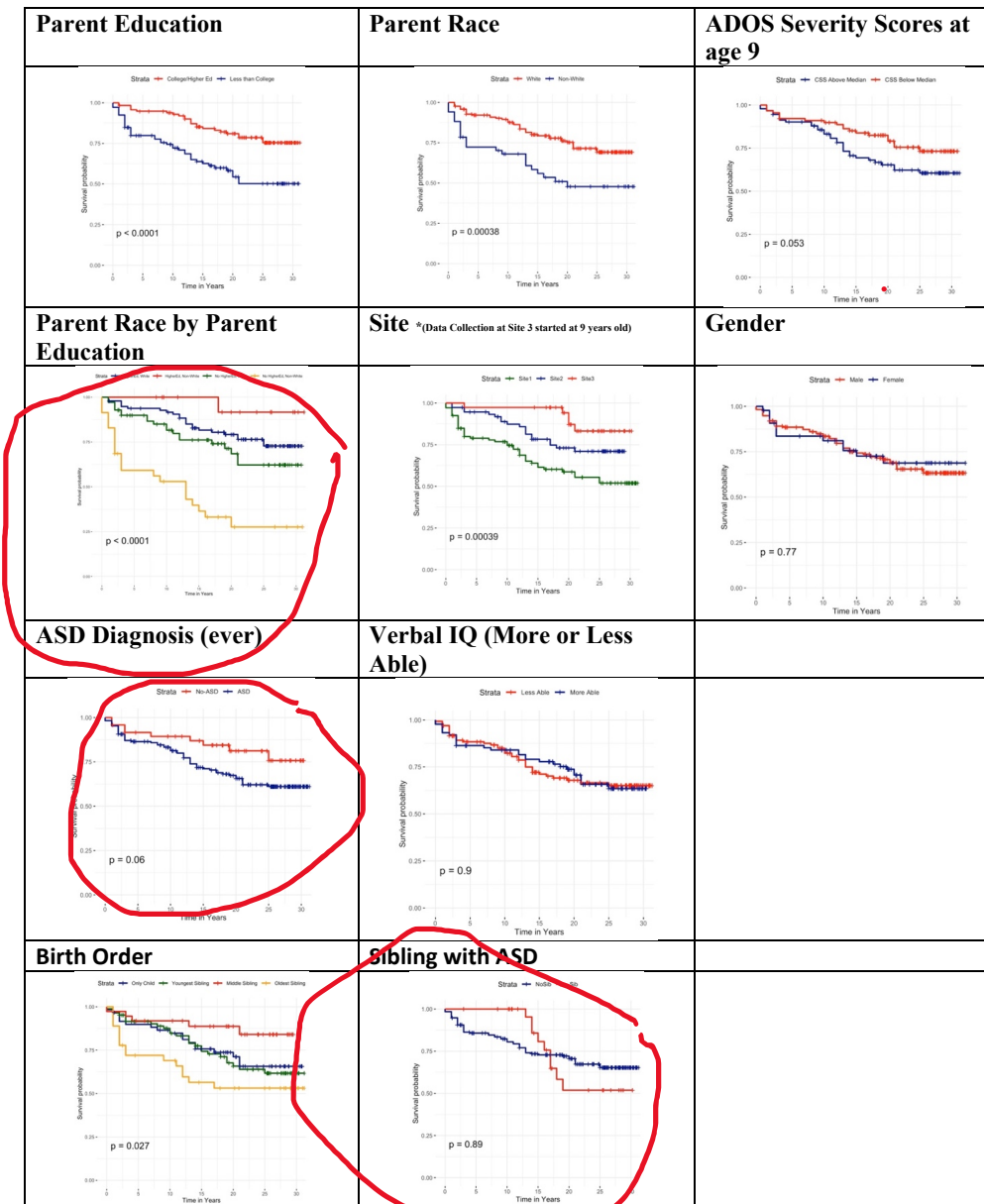
	Best NVIQ, M (SD)	VABS Daily Living, M (SD)
Divorce between 0-5 (<i>n</i> = 27)	64.52 (29.84)	63.92 (14.37)
Divorce between 5-10 (<i>n</i> = 9)	49.78 (27.84)	54.00 (10.25)
Divorce between 10-15 (<i>n</i> = 17)	57.47 (34.64)	54.29 (14.95)
Divorce between 15-30 (<i>n</i> = 14)	87.46 (29.58)	68.58 (15.49)

Factors that affect risk for divorce

Variable	Hazard Ratio	Slope 95% CI	p-value
Rac.	0.2	[0.03, 2.03]	0.20
Mother's Education	1.41	[0.70, 2.83]	0.02
Race*Education	9.08	[1.09, 75.38]	0.04
Mother's Age	0.95	[0.90, 0.99]	0.01
ASD Ever	1.95	[0.88, 4.29]	0.09
Birth Order			
Youngest Child	0.71	[0.36, 1.41]	0.31
Middle Child	0.42	[0.18, 0.94]	0.06
Oldest Child	0.55	[0.23, 1.29]	0.36
Site			
Chicago	0.53	[0.28, 0.99]	0.05
North Carolina	0.23	[0.05, 1.05]	0.06

Figure 2

Survival Curves Split by Clinical and Socio-Demographic Factors



Note. ADOS= Autism Diagnostic Observation Schedule, ASD= autism spectrum disorder, IQ= intelligence quotient.

What underlies these findings?

- Again – mostly NOT AUTISM or intellectual disability
- The clearest child factor was **aggression, irritability, externalizing**
- Black, less well educated families had the highest early divorce rates
- Younger mothers were more likely to get divorced
- No effect of having siblings except that families with two autistic children were less likely to get divorced in early years
- Divorces when our participants were 10-15 and older than 15 were more likely to occur when participants had **HIGHER IQs**

What might make these situations easier or harder?

- Beyond "child" characteristics
- How do these change over time?
- Sources of support
- Mothers' coping strategies



Quantitative
Analyses:
*Trajectories of
Family Support
& Predictors*
(Schiltz et al,
2023)

Family
Support

Helpfulness
→ No change

Use
→ Decline
→ Autism Sx

Value
→ No change

Other
Informal
Support

Helpfulness
→ Decline

Use
→ No change
→ Autism Dx

Value
→ No change

Formal
Support

Helpfulness
→ Decline

Use
→ Decline
→ Verbal IQ

Value
→ Decline
→ Verbal IQ

TYPES of COPING

Brief-COPE (Carver et al., 1989)

- 28 items
- 4-pt Likert scale

Active Avoidance

- To “avoid” the stressor/ its effects.
- Items of substance use, behavioral disengagement, self-blame, venting of emotions, and one item from the distraction scale.

Problem-focused

- To directly confront stressor to modify or eliminate the stress.
- Items on planning, active coping, instrumental support, one item from seeking emotional support.

Positive

- To mentally reframe stressor in positive light.
- Items on humor, positive reframing, acceptance, and one from emotional social support.

Religious

- To seek comfort in religion or spirituality.
- Two items on prayer/ meditation and spiritual beliefs.

Denial

- Ignoring reality of situation to quell anxiety.
- Two items on denial.

Differences in coping styles across time related to parental well-being

Clearest effects of religious coping and problem-focused coping

High religious coping was related to good parental well-being **early but well-being declined** as children reached adolescents

Problem-focused coping and positive coping was related to parental well-being, particularly for parents of children **with externalizing or aggressive behavior** and, separately, **for African American families**

WHAT ABOUT SIBLINGS?

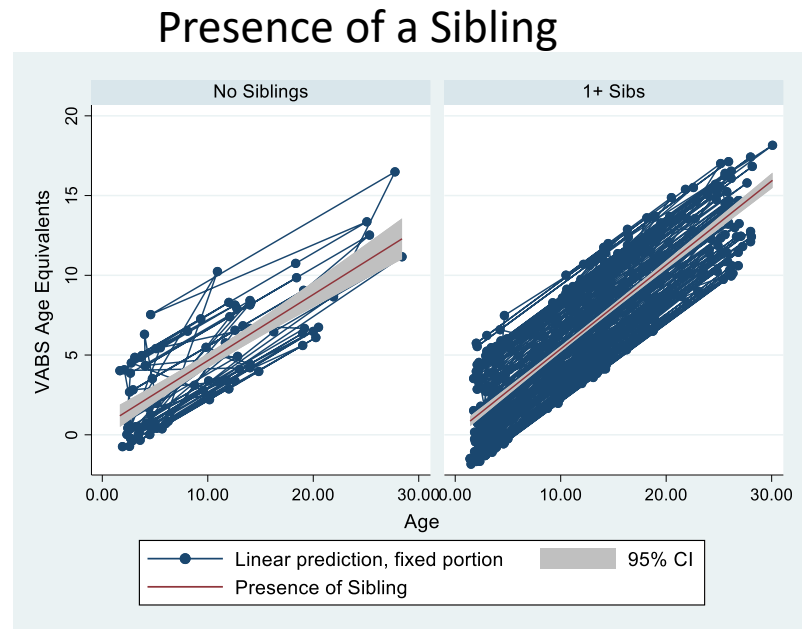


Influence of Siblings on Adaptive Behavior Trajectories in Autism Spectrum Disorder

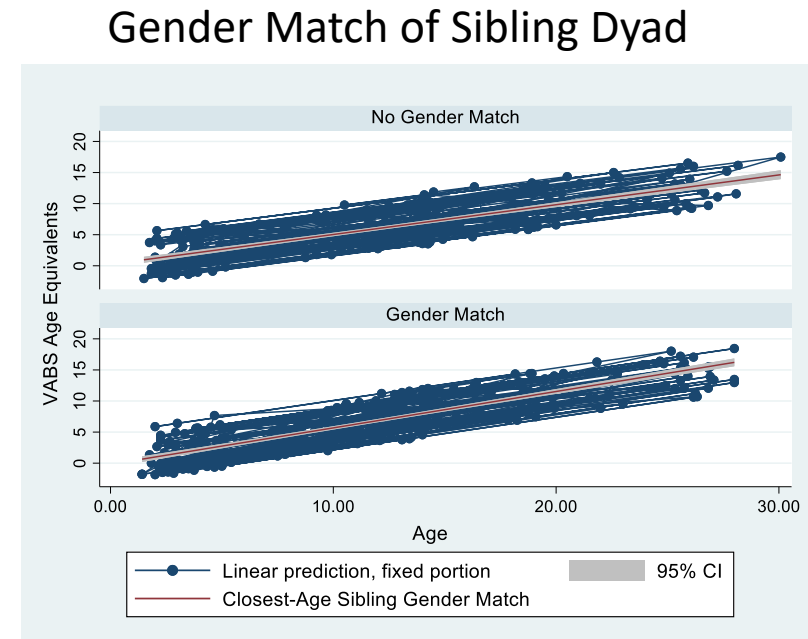
Nicole Rosen, MA, James McCauley, PhD, & Catherine Lord, PhD



Rosen, N. E., McCauley, J. B., & Lord, C. (2022). Influence of siblings on adaptive behavior trajectories in autism spectrum disorder. *Autism*, 26(1), 135–145. doi:10.1177/13623613211024096



Participants with siblings presented with **higher** VABS-AEs across all times and experienced significantly **steeper** VABS-AE growth trajectories through adulthood compared to those with no siblings.



Participants with a gender-matched sibling demonstrated significantly **steeper** VABS-AE growth trajectories than participants with a non-gender-matched sibling.

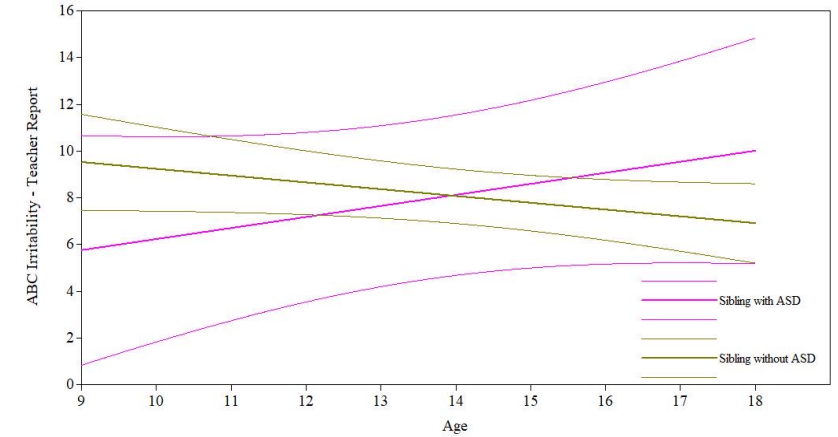
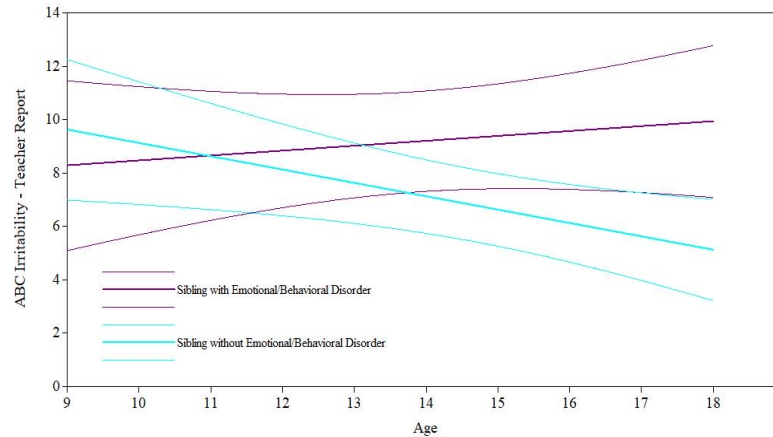
Sibling Influences on Teacher-Reported Trajectories of Maladaptive Behaviors in Autism



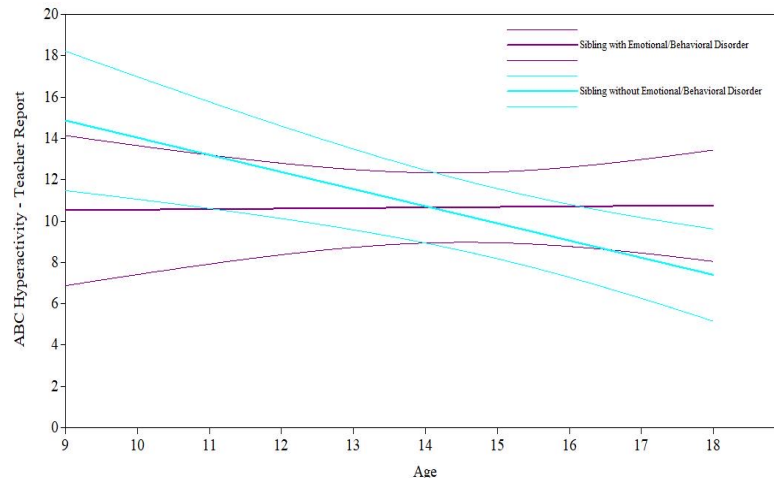
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Rosen, N. E., Schiltz, H. K., & Lord, C. (2022). Sibling influences on trajectories of maladaptive behaviors in autism. *Journal of Clinical Medicine*, 11(18), 5349. doi: 10.3390/jcm11185349

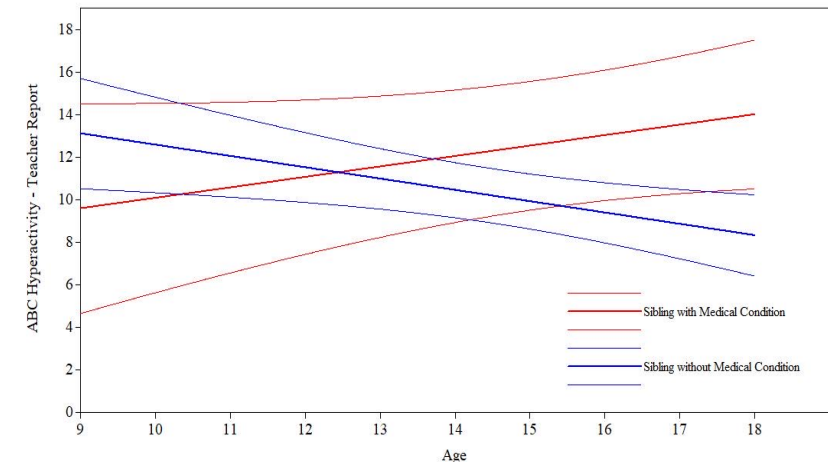
Participants with siblings with emotional/behavioral disorders and/or ASD experienced an **increase** in irritability over time compared to a **decrease** among participants with siblings without these diagnoses.



Participants with siblings with emotional/behavioral disorders experienced **less improvement** in hyperactivity over time than participants with siblings without these conditions.



Participants with siblings with a medical condition experienced an **increase** in hyperactivity over time compared to a **decrease** among participants with siblings without a medical condition.



A stepped care, personalised health model for autism

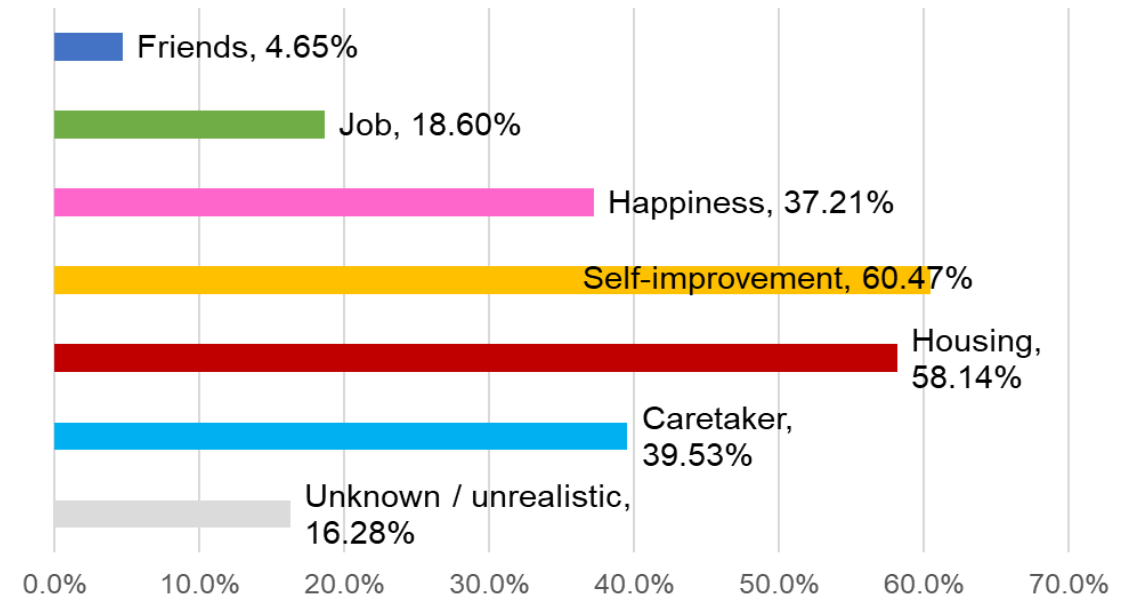


- We propose to shift the traditional stepped care perspective and propose steps that take into account the costs, burden and preferences of individuals or families (rather than just to the health system) and personalization on the basis of the autistic individual and families' needs, strengths and challenges.
- This means that information needs to be gathered about the skills and needs of each autistic person and their family, beyond a diagnosis to include other factors and preferences....
- This is more than “person-centered.”
- And updated as needed because it will change as children become adults and as adults grow older.

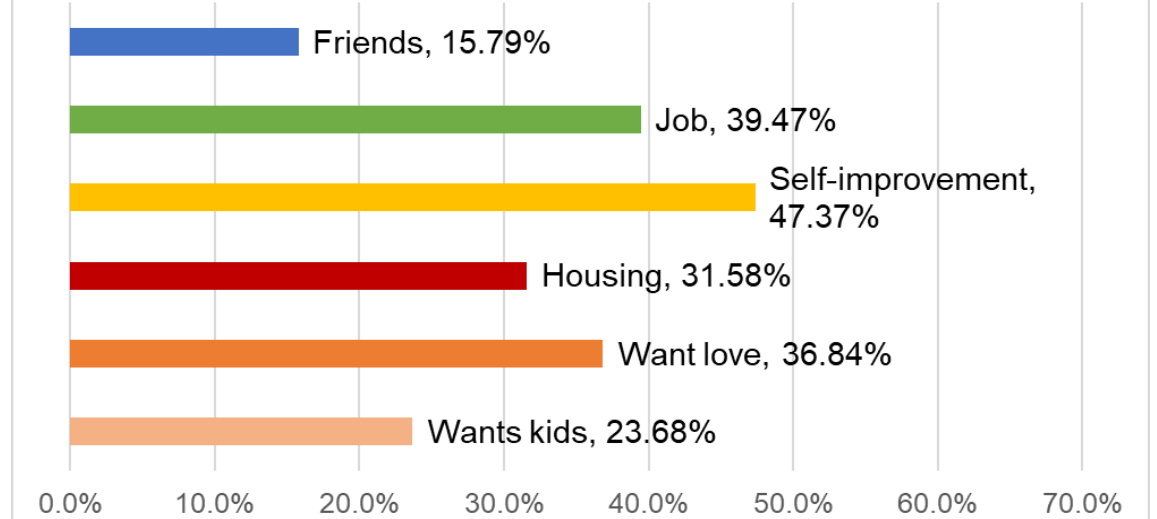
Hopes and Goals for Future: Key

- Community / Friendship
- Job/Career/Financial stability
- Happiness / Well-being / To be loved
- Self-improvement (develop life skills, pursue interests, gain autonomy)
- Living situation or services (find group home, move out, etc.)
- Sibling or caretaker to take over care
- Doesn't know or unrealistic wishes (e.g. "wanting a miracle")
- Find love and/or start family
- Want kids

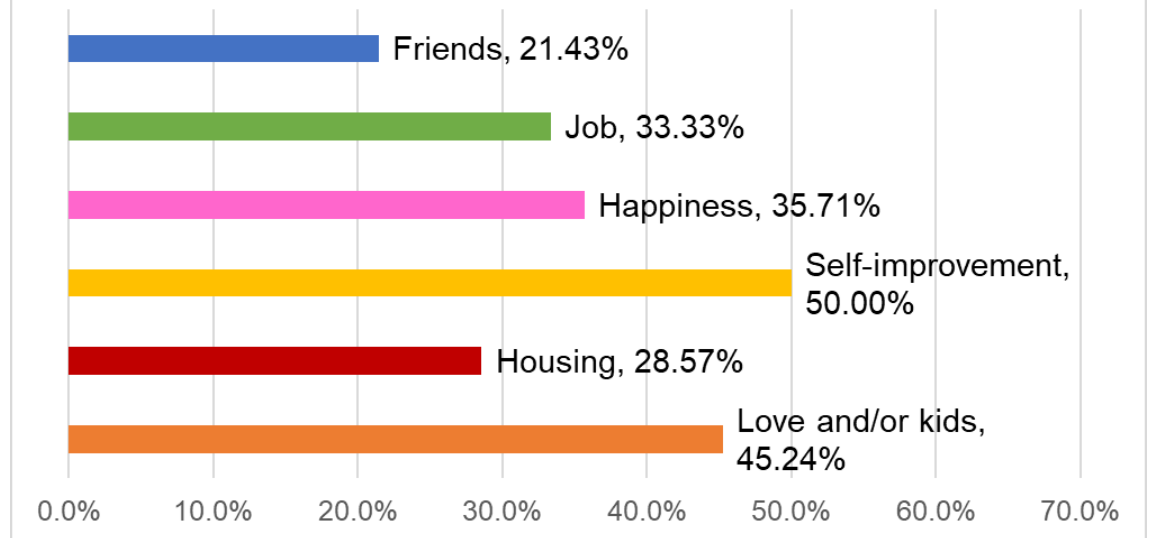
Parent on Child with ID

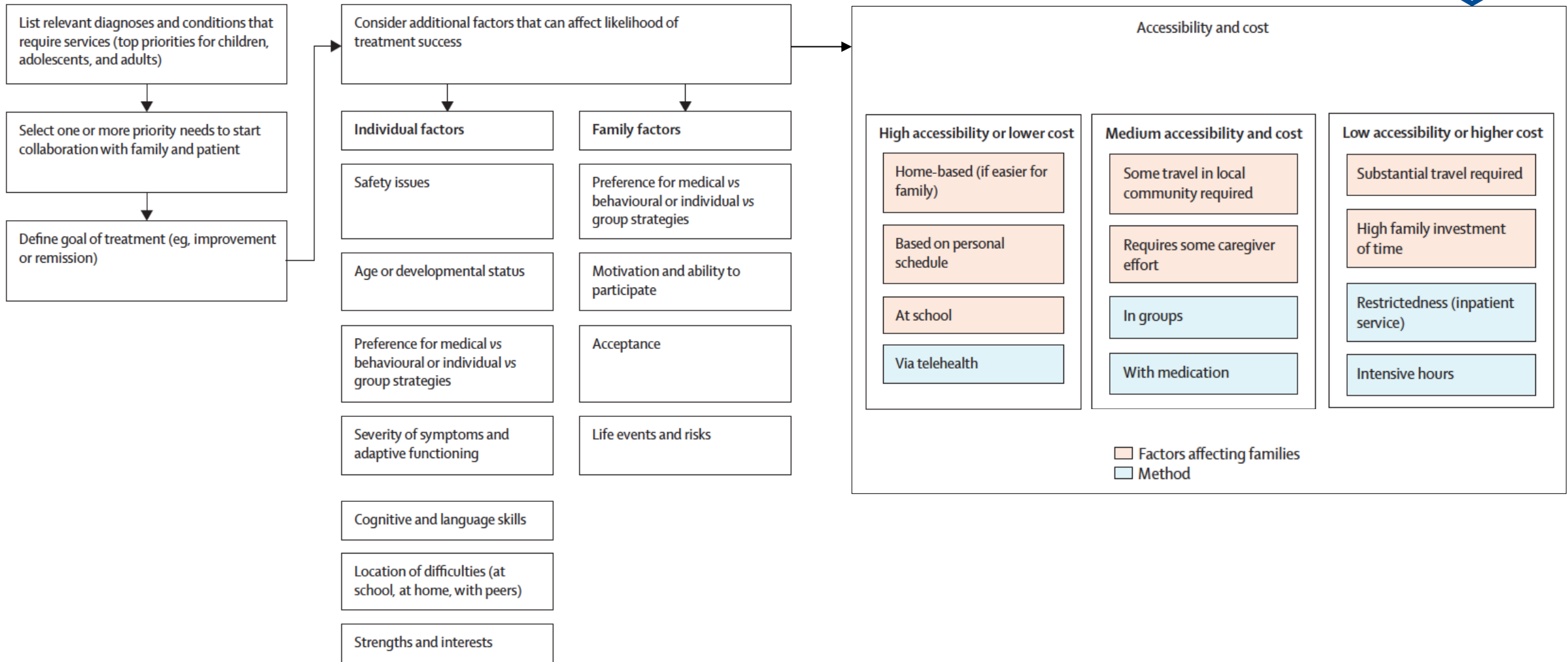


Adult without ID on Self

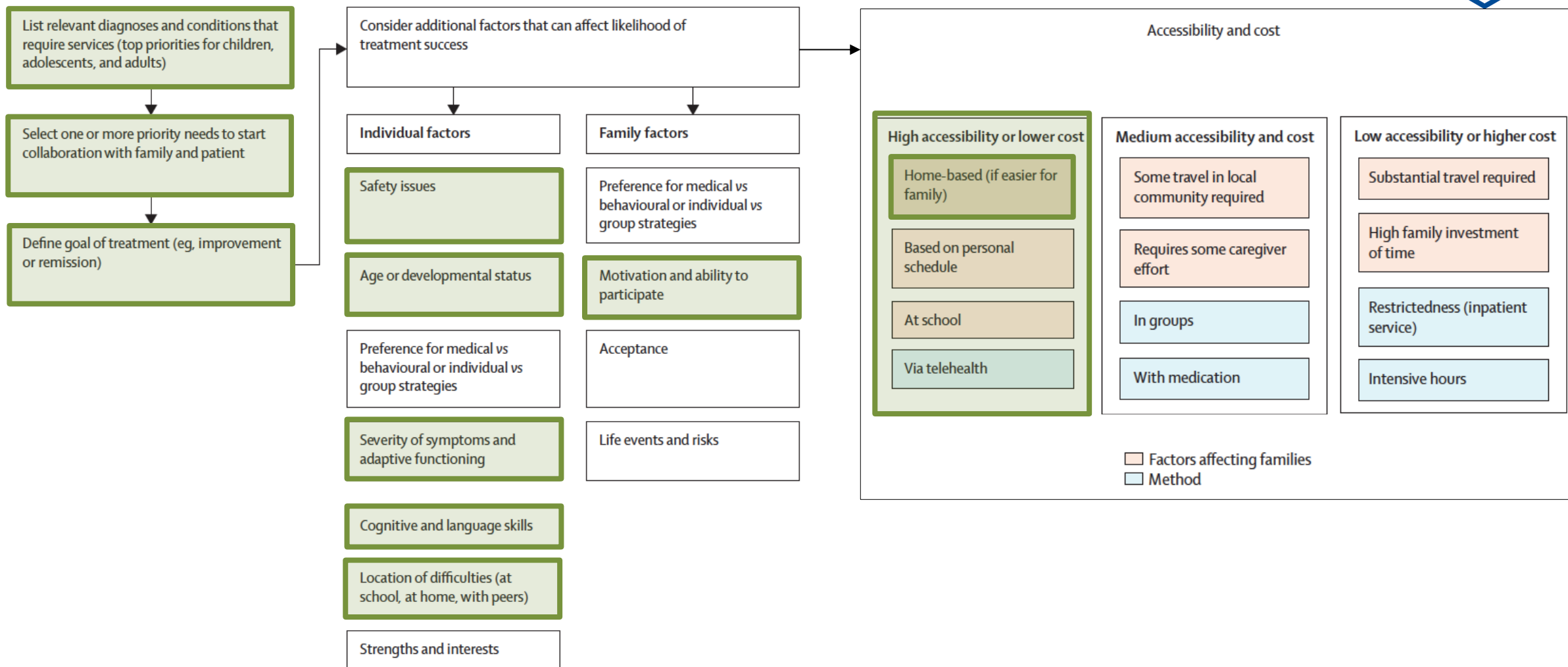


Parent on Child without ID

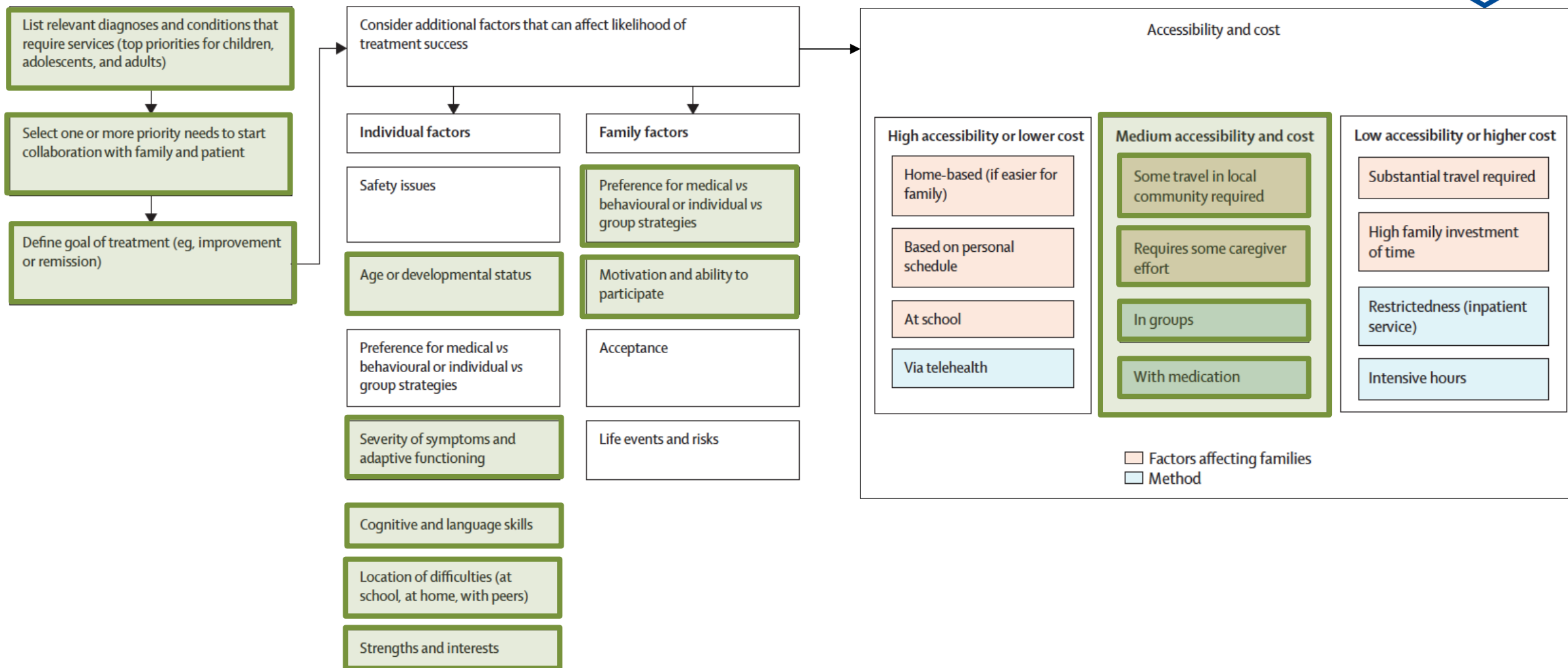




Stepped care example – minimally verbal 5 year old in LMIC



Stepped care example – 15 year old with social anxiety in HIC



Child has own ideas about what we want



#AutismDay2018

#Medbiotech



Different Not Less



What can we take from all of this?

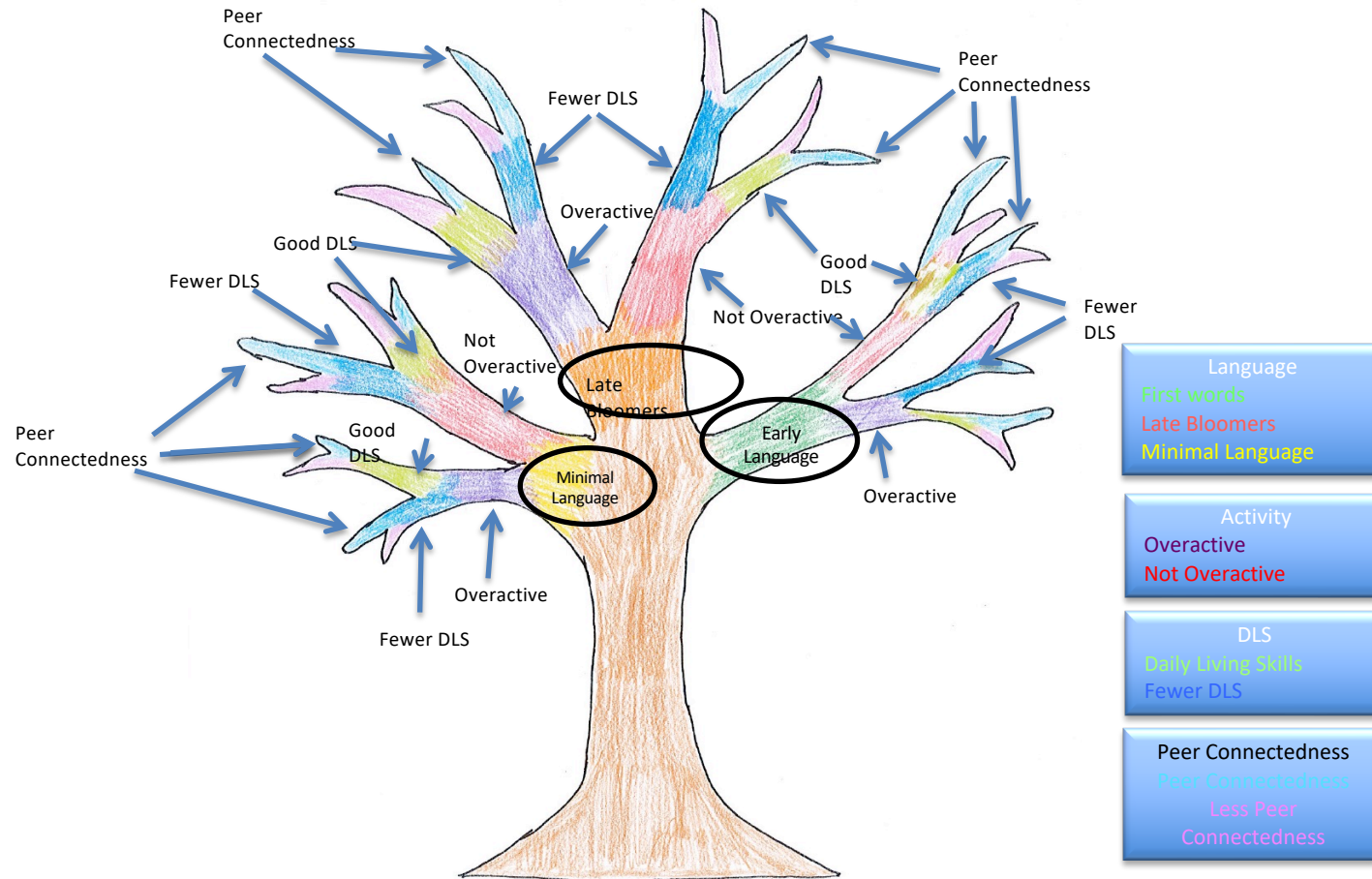
- Families matter and often we don't pay enough attention to them
- This can be very difficult to do during an assessment
- And also treatment when the focus is on the child or adolescent
- But... Siblings tell us how neglected they often feel
- Siblings can make a difference both positive and negative
- In our NY clinic, we started expecting to meet siblings before any child enrolled in our early intervention programs, which really helped— more to come from Nicole Rosen
- Also factors that affect parents are not necessarily autistic diagnoses: child irritability, externalizing behaviors and early on RRBs had much greater effects than social communication or intellectual ability on parents' wellbeing
- Different parent coping styles worked better at different times, in part probably related to other support available
- Relationships between “perceived impact” and stress are not necessarily as expected
- And we were struck by the increased divorce rate of parents of verbal, more skilled adolescents



- Existing service systems may not be designed to meet the specific needs of autistic individuals or are underfunded
 - Service deserts exist for many groups, especially those living in LMICs or impoverished neighborhoods in HICs
- Service user is a lifelong social role for many autistic individuals

95% of children
under age 5 with
developmental
disabilities live in
LMICs

Patterns of Development



A message of hope and potential for change

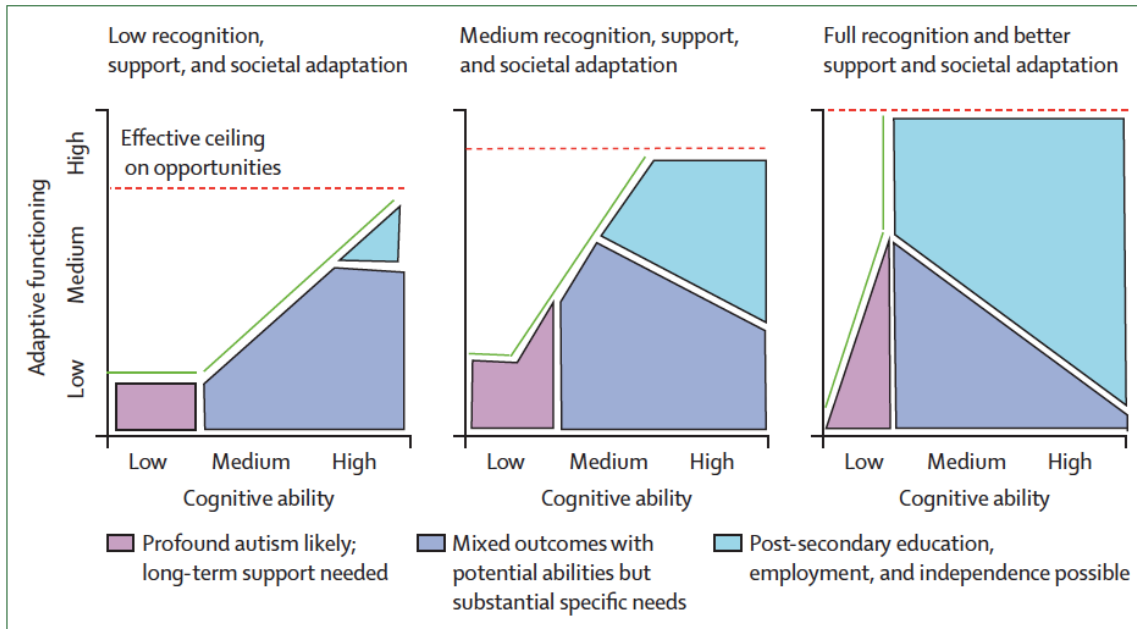


Figure 4: Societal response and services can optimise outcomes for all people with autism
The green line indicates the hypothetical degree to which the environment supports the adaptive potential of autistic people with different cognitive abilities.

- In the end, this is a message of hope.
- We know much about what autism is, how it differs across individuals and how we can support development in autistic people – though we have not put this information to practice as much as we need to.
- We know about the potential for change and ways to make this happen.
- We can also extend much of what we have learned and will learn to other developmental disorders and mental health conditions.
- Let's work together and do this now.

Thanks to the families and the participants in our research and to all our lab and collaborators





The Gilbert Family

The Gilbert Family

