

Early Intervention in Autism: What Matters Most?

Catherine Lord, Ph.D.

George Tarjan Distinguished Professor of Psychiatry and Education


Semel Institute of Neuroscience and Human Behavior

Conflict of interest

- I receive royalties from diagnostic instruments, including the ADOS, ADI-R, and SCQ.
- I have or have had research funding from NIH, DoD, HRSA, Roche, GW Pharmaceuticals, the Autism Science Foundation, Autism Speaks and the Simons Foundation.

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Outline of talk

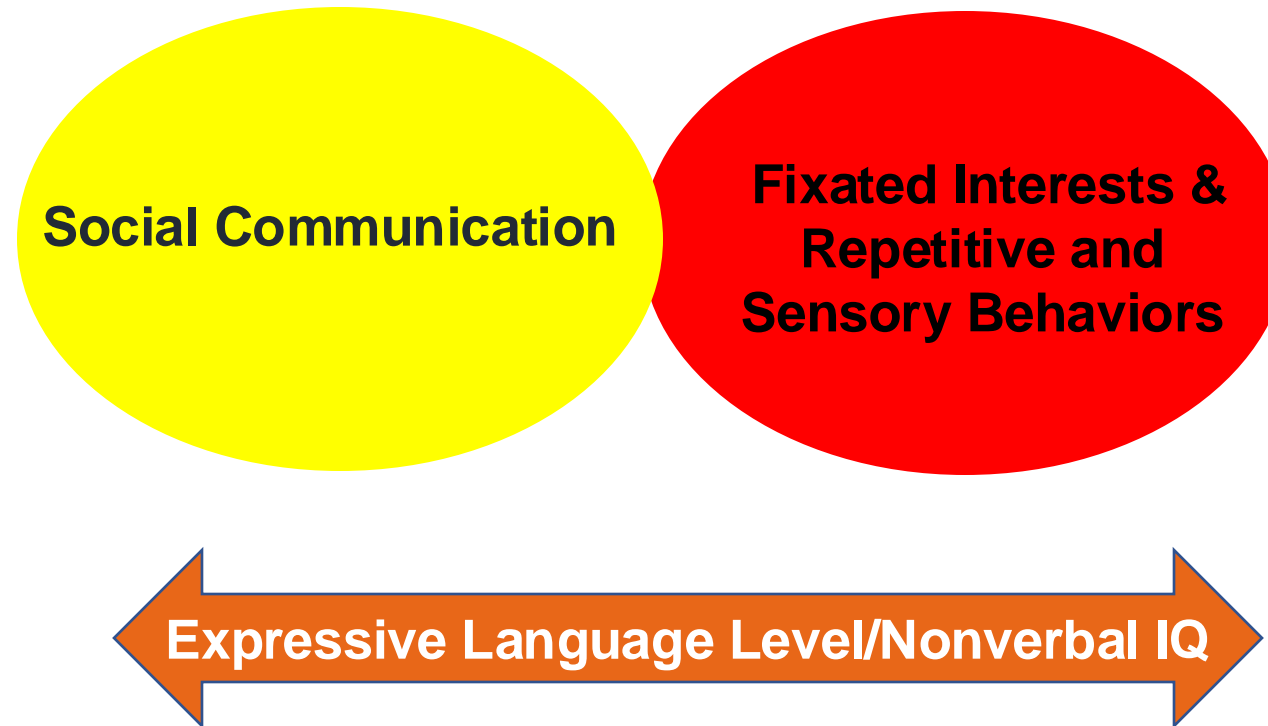
- Briefly talk about general issues in autism
 - Then talk about what we know about early development in autistic children
 - And how this should impact what we do in early intervention
 - Then talk about what we know about early intervention research
 - And then talk about how we can use this information
- 
- A series of four yellow curved dashes are located in the bottom right corner of the slide.

Autism as a neurobiological disorder of learning and processing

- A developmental disorder:
- Having ASD affects basic aspects of behavior (e.g., eye contact, vocalization) and attention (to certain kinds of stimuli) and maybe motivation
- Which in turn affect learning
- And opportunities for learning

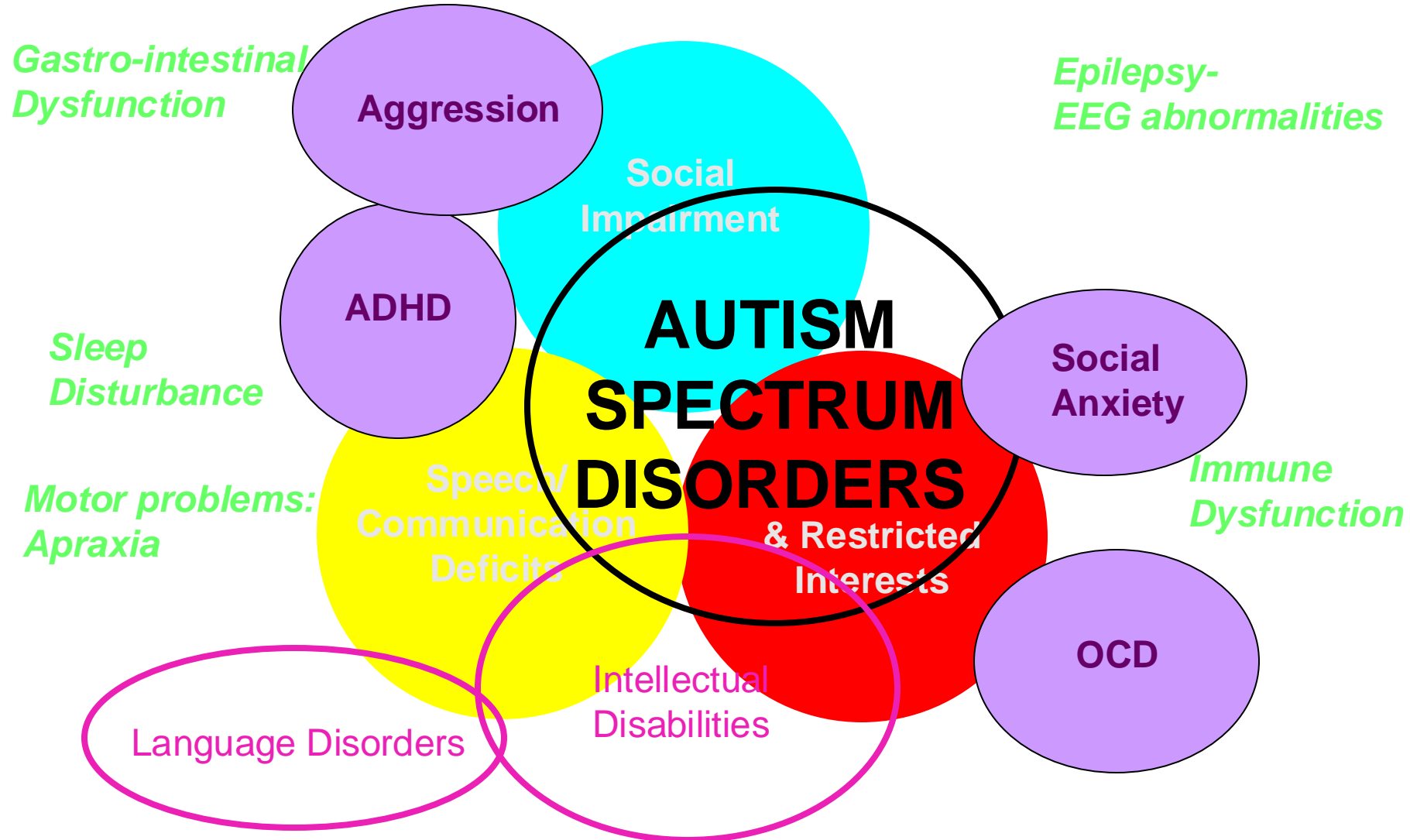


Domains in Autism Spectrum Disorders



Core Symptom Domains

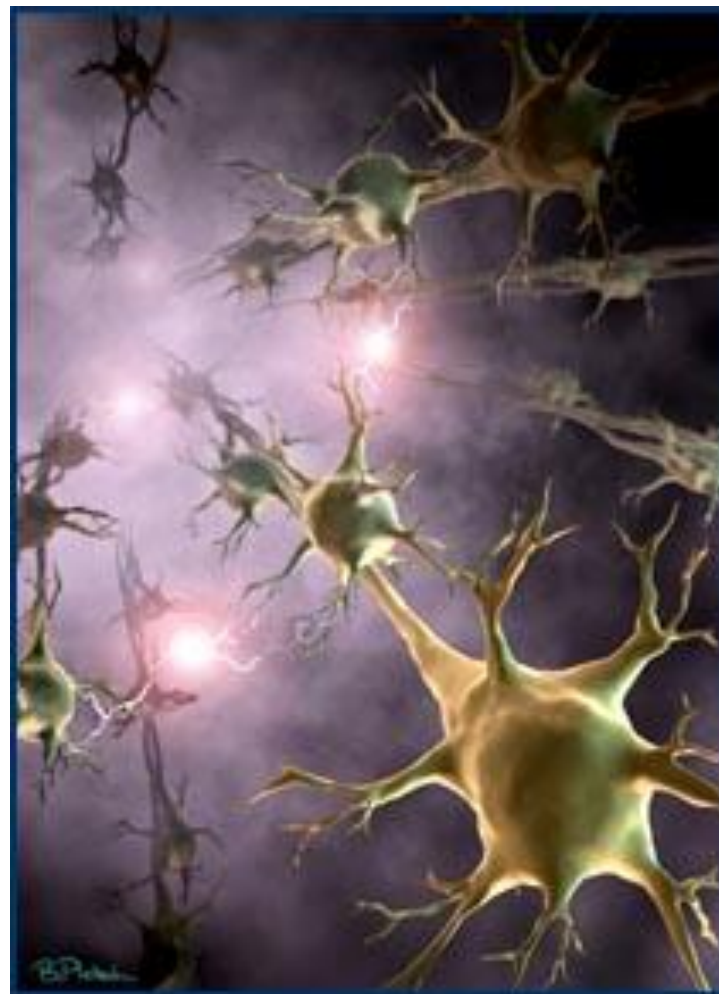
PLUS Associated Medical Features (this does not count strengths, which would add other circles)



Changing the social course of ASD...

Early core deficits may lead to a cascading effect on neurodevelopment that arises from impoverished social interaction.

(Mundy & Burnette, 2005)



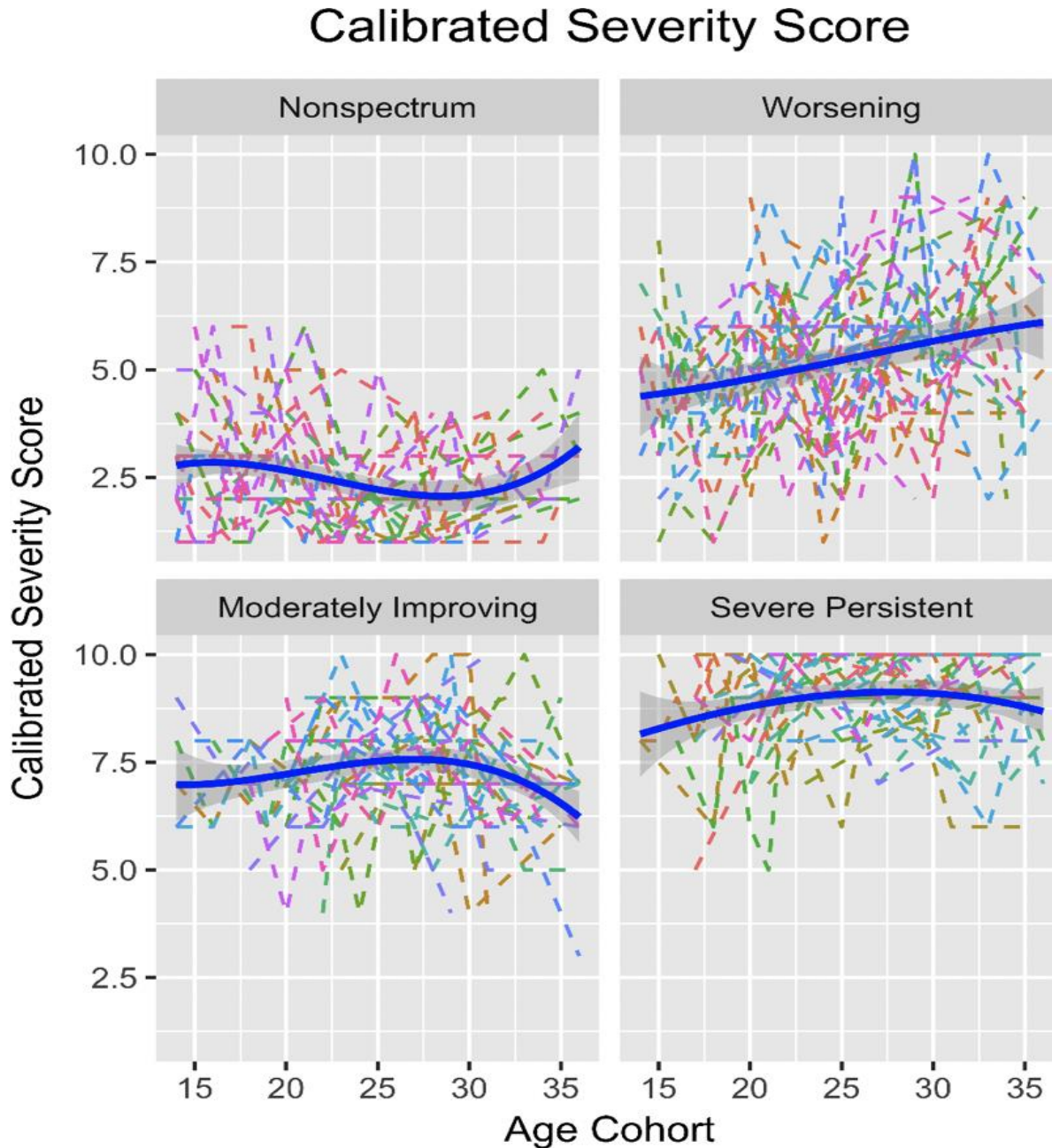
Underscores the importance of early interventions

Trajectory Classes from 1-3 years with frequent ADOS

Severe

Symptom severity

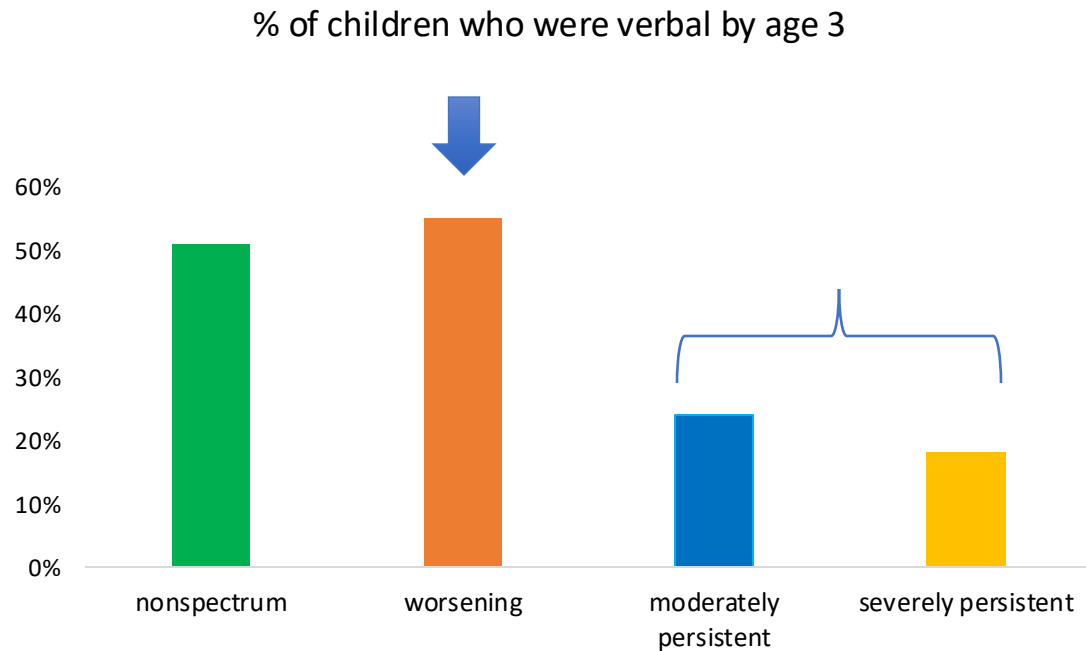
Mild



- 912 diagnostic observations
- 149 children followed 1-3 years
- Group—based growth modeling with CSS

Kim et al., 2018;
also Waizbard-Barber et al, 2021

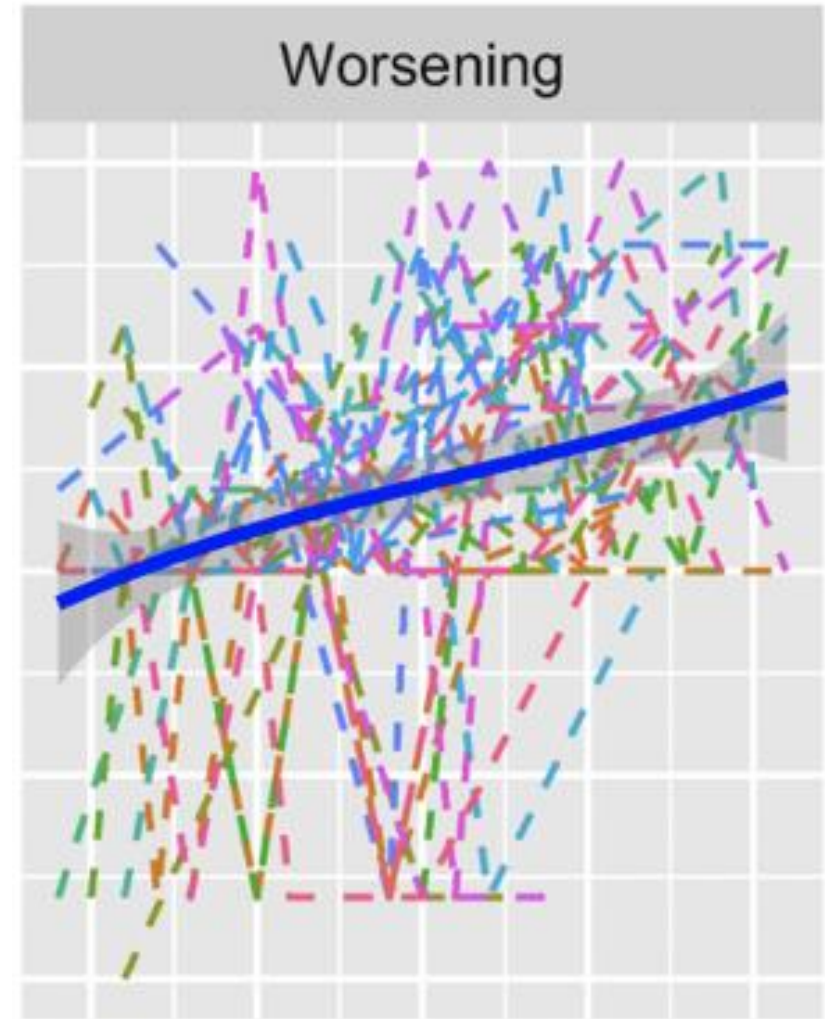
Worsening trajectory group (~20% ASD)



Severe

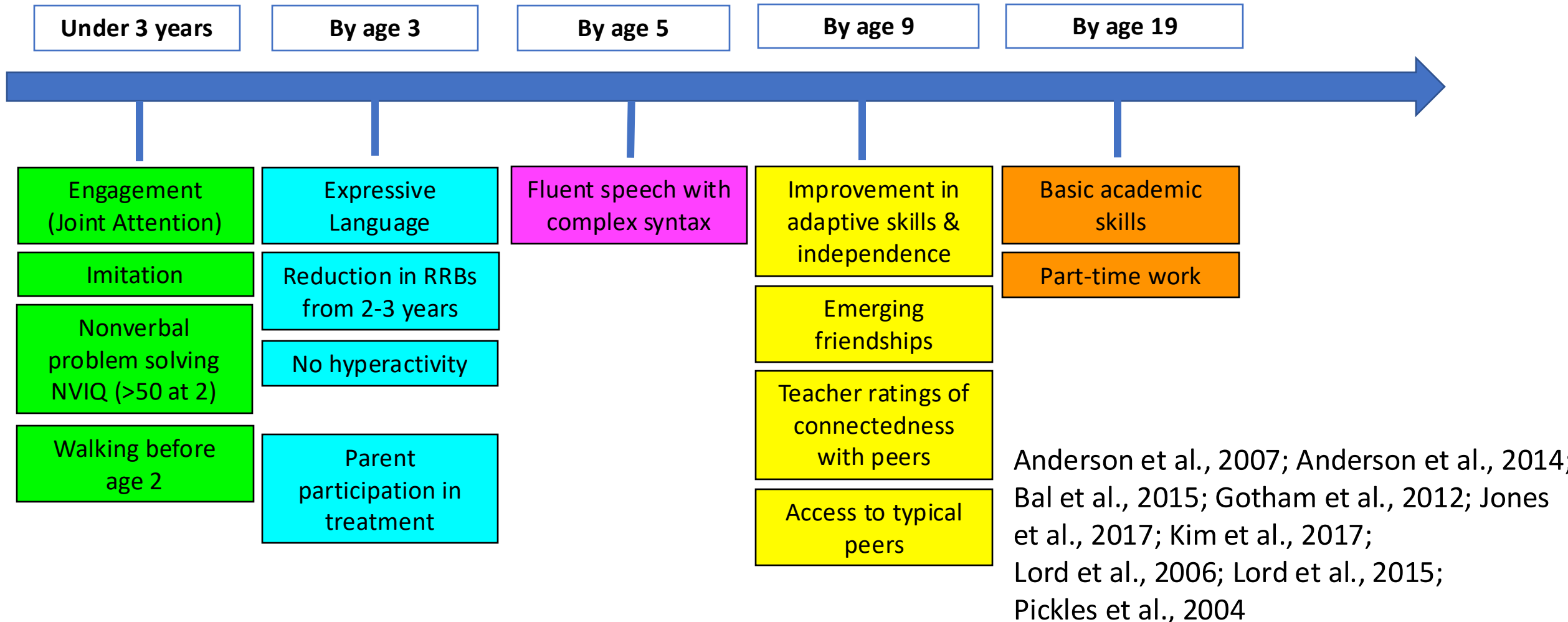
Symptom severity

Mild



Predictors of most positive outcomes

Necessary, but not sufficient



An 18 month old when we met him



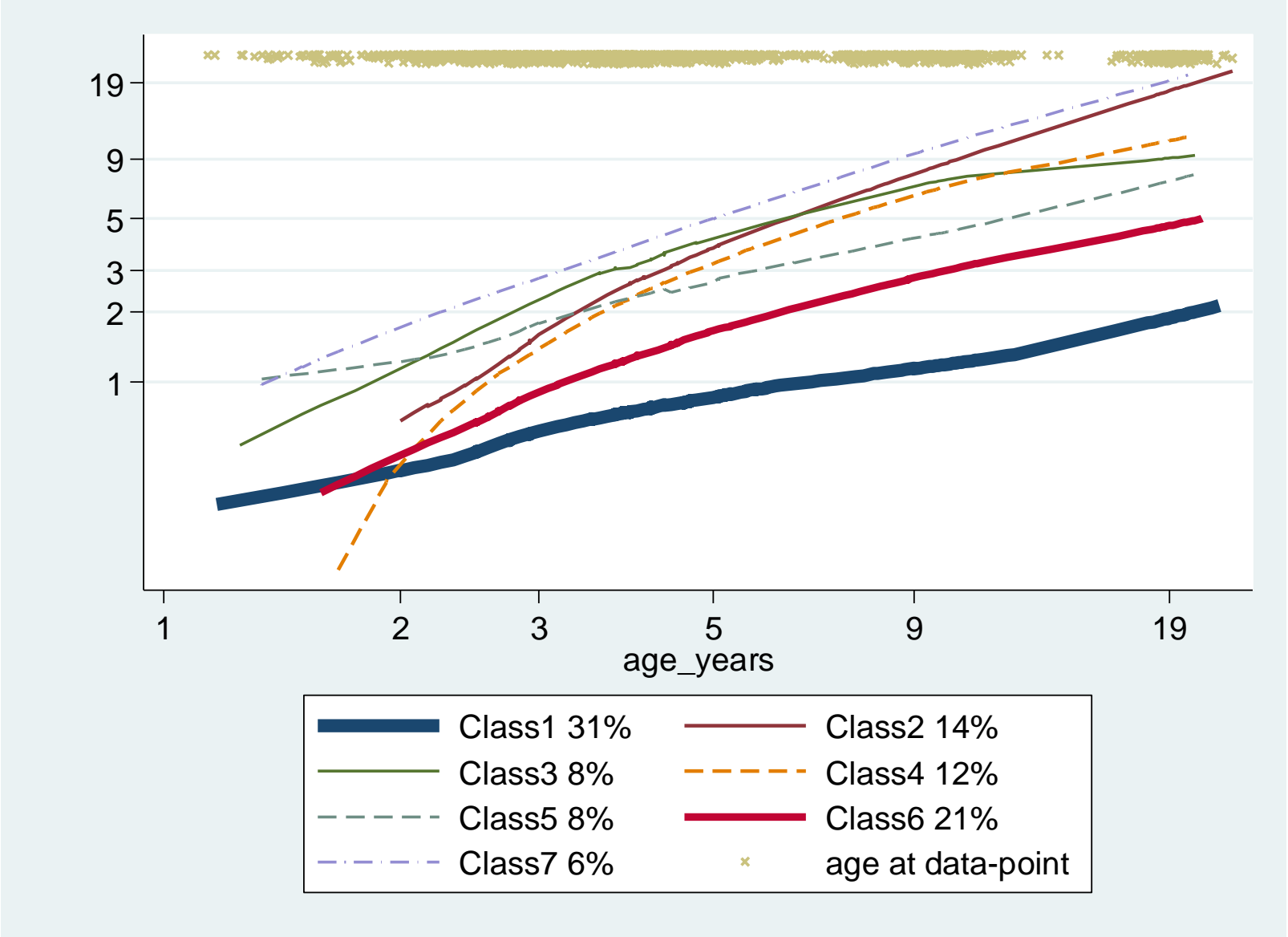
A 19 month old with a clever mother

More ideas

Tommy negotiates to take “Kercheville on Tuesday”
(not Wednesday)

On the way to school, just past Kercheville

Trajectories of Vineland Communication Ages



What Matters?

- Different things at different times with some “critical periods”
- Some things are internal to the child or adolescent
 - Language level
 - **Separate language comprehension**
 - Speech production
 - Any form of **intentional communication** (gestures, facial expressions, eye contact)
 - General delays (usually measured by **nonverbal cognitive level**)
 - **Ability to “engage” and “focus”**
 - Potential strengths: motor skills, social motivation, sense of humor

Each of these predicts more progress in response to interventions

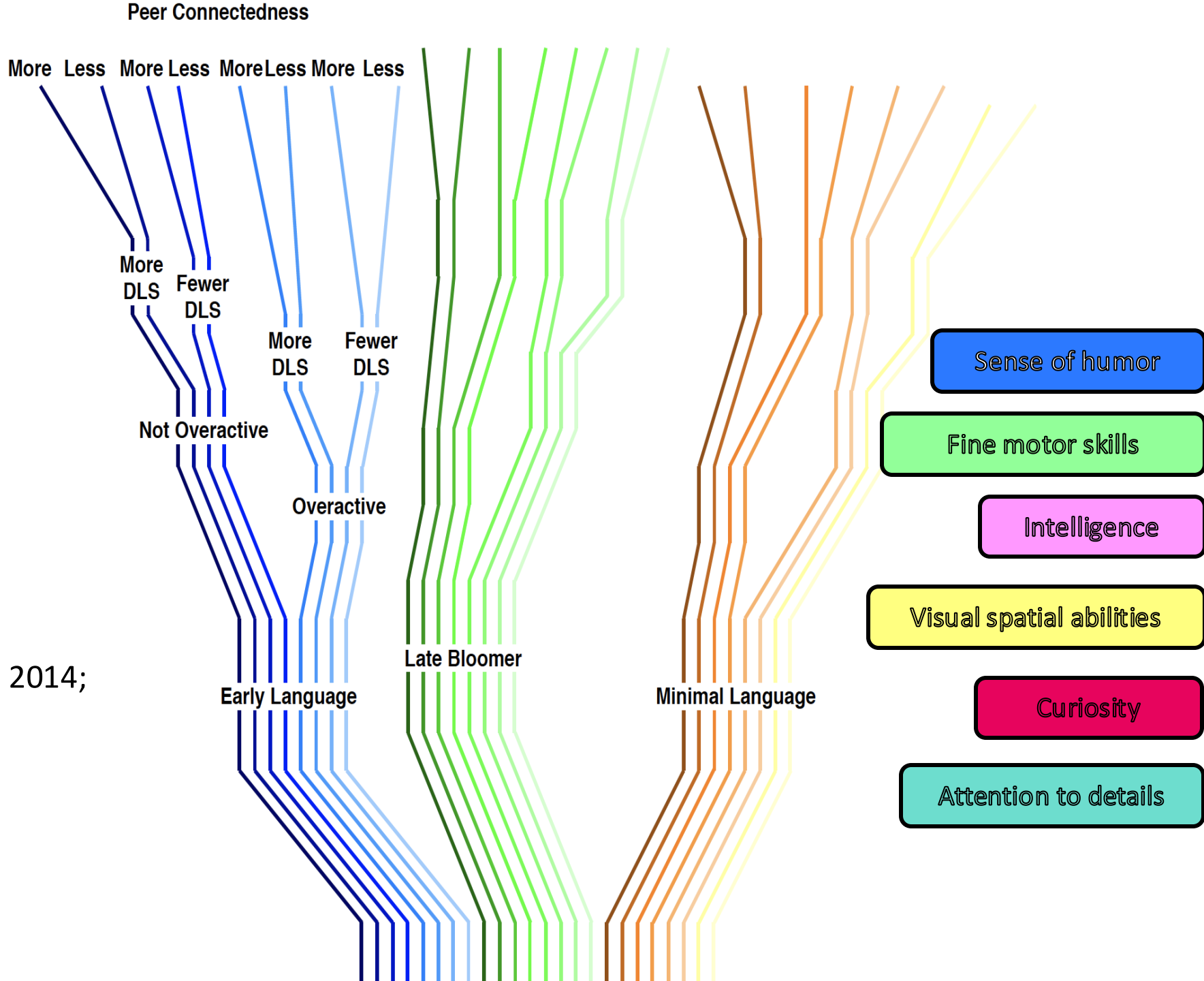
(Kasari et al, 2022; Pumpki et al, 2021; Sterrett et al, 2023; Vivanti et al, 2022)

Main points so far

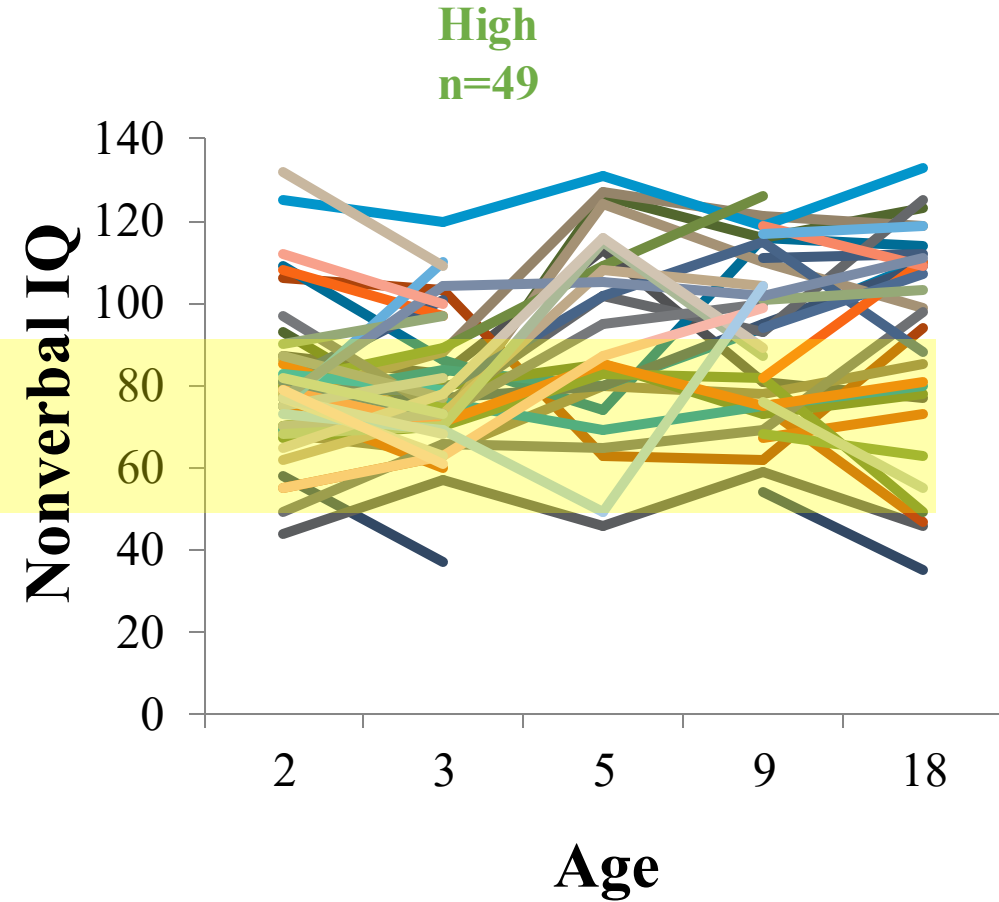
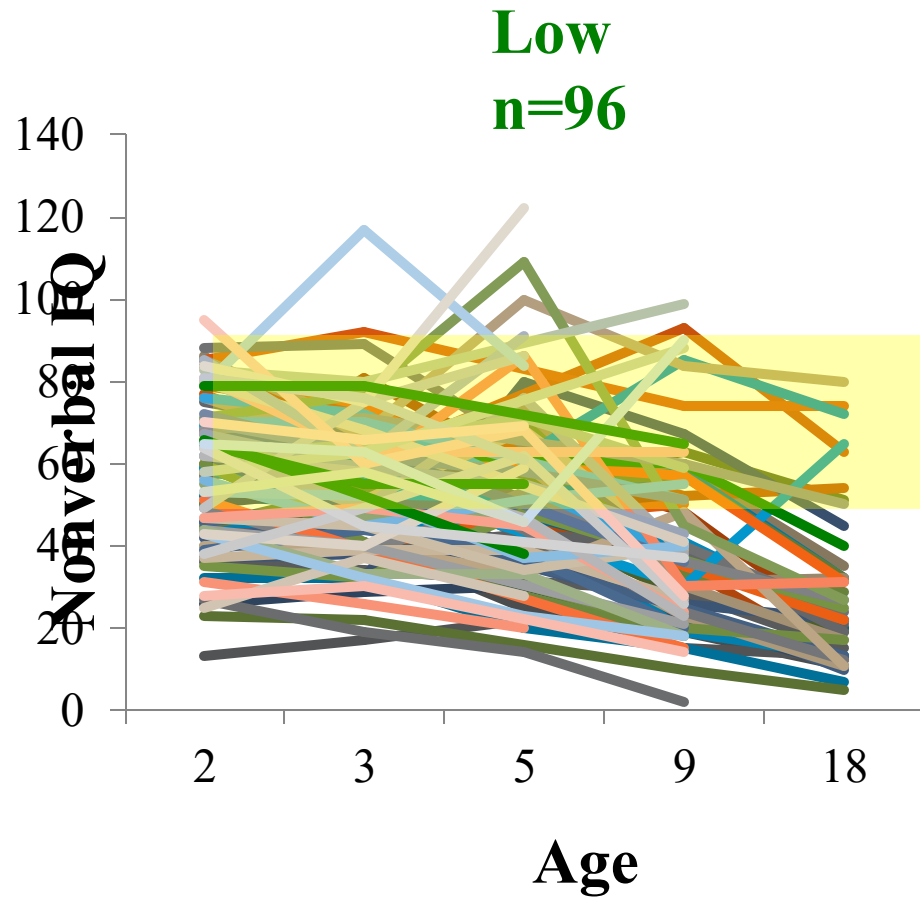
- Different aspects of development change at different rates
- We need to be aware of where a child is in these different areas
- So we can have reasonable expectations and goals
- And then get to work because we can help!

Why are developmental pathways and trajectories important?

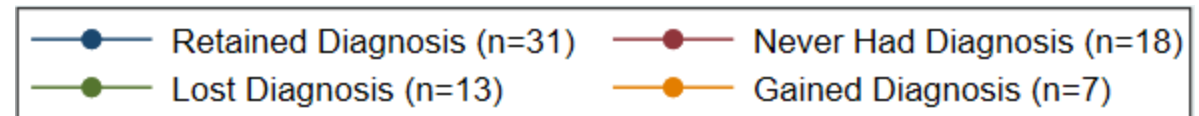
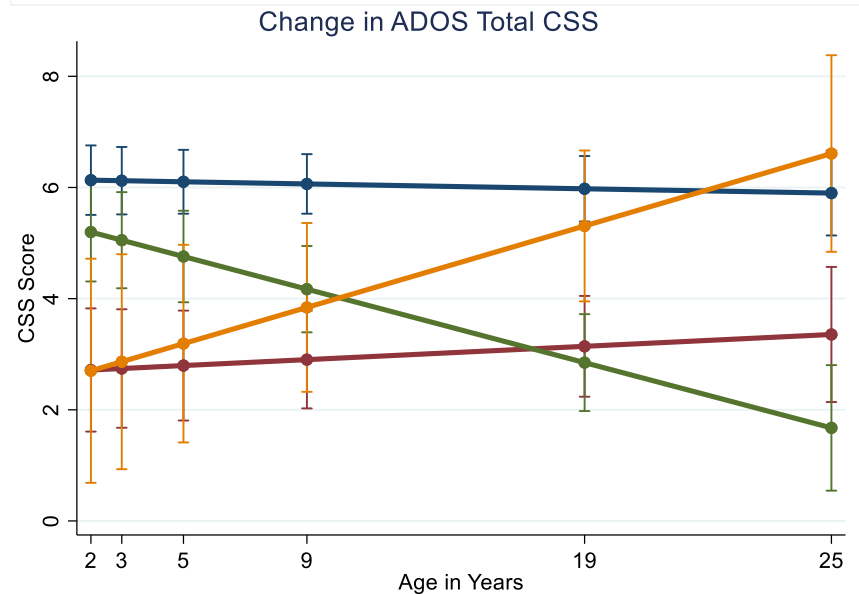
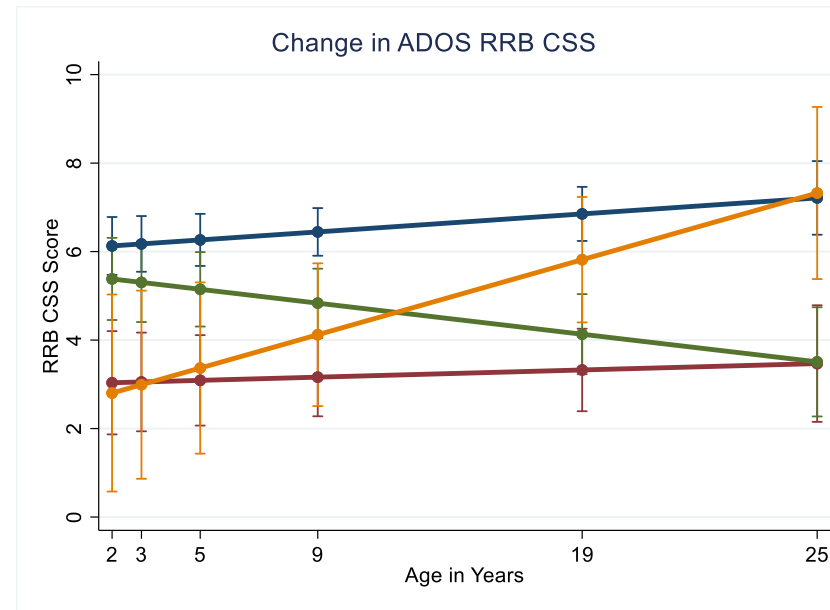
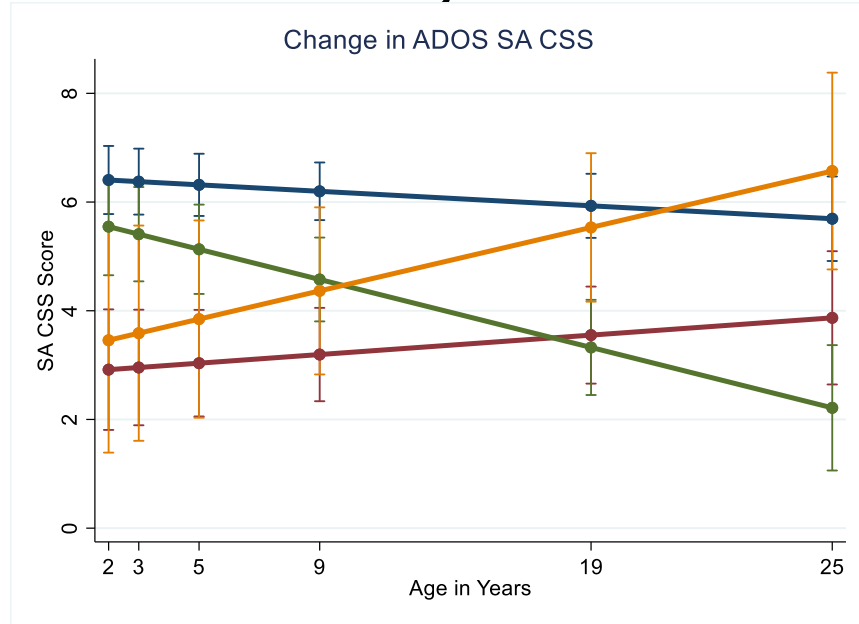
Anderson et al., 2007; Anderson et al., 2014;
Bal et al., 2015; Gotham et al., 2012;
Jones et al., 2017; Kim et al., 2017;
Lord et al., 2006; Lord et al., 2015;
Pickles et al., 2004

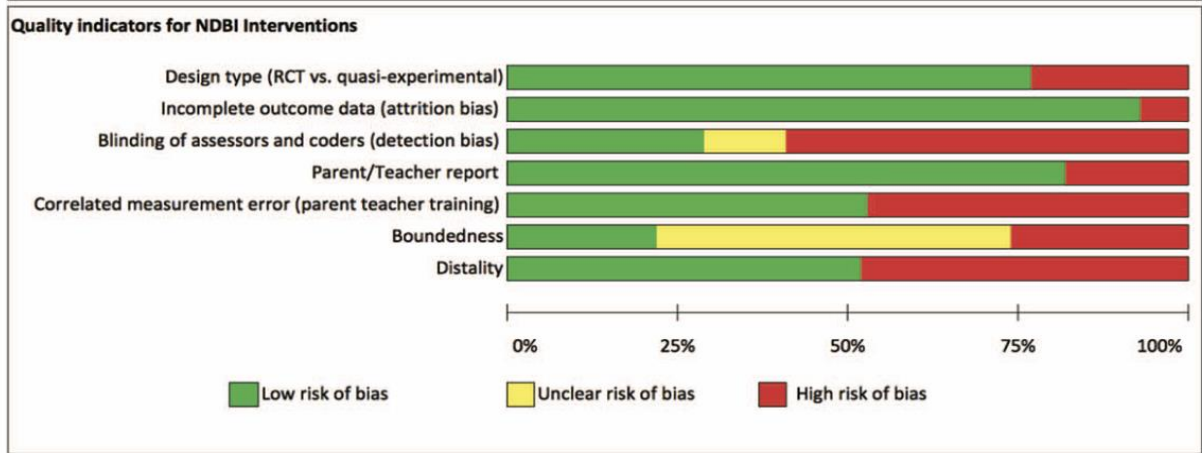
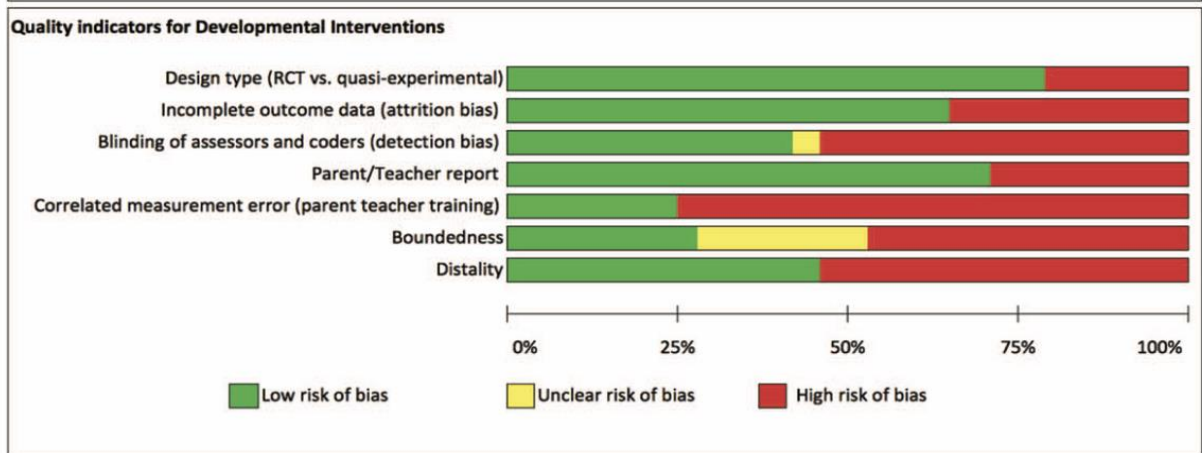
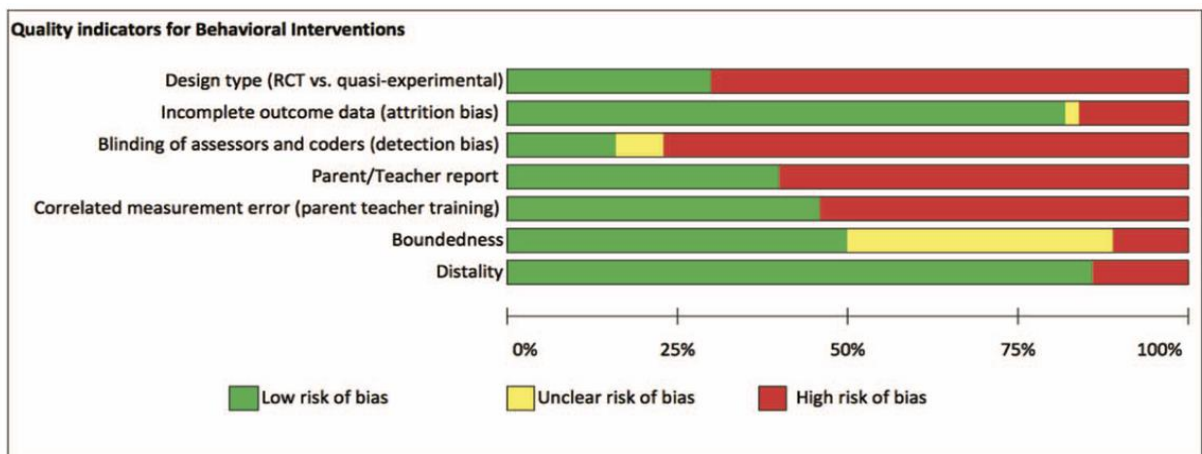


Group overlap in adaptive skills



ADOS Trajectories by Diagnosis Group (MA; $n=69$)





Switching gears to
early intervention:

Quality of studies of
the effectiveness of
early intervention

Sandbank et al. 2020

Switching gears: What do we know about what early intervention can do?

- Intensive ABA/ESDM: **increases IQ and language scores of 10 – 20 points.**
- Brief parent-oriented and direct interventions for joint attention: **changes in parent behavior; changes in child language, attention.**
- Specific interventions (e.g, behavior plans, pausing, schedules, TEACCH, joint attention) result in **specific improvements.**
- **Mostly you get what you see**
- Specific objectives results in specific changes, but with slightly messier treatment you might get more generalizable changes



Aspects of children that predict better response to different interventions

- A variety of interventions (JASPER, ESDM group, parent coaching, inclusive groups, speech-generating devices)

All work better for children with stronger

Receptive language

Nonverbal cognitive skills

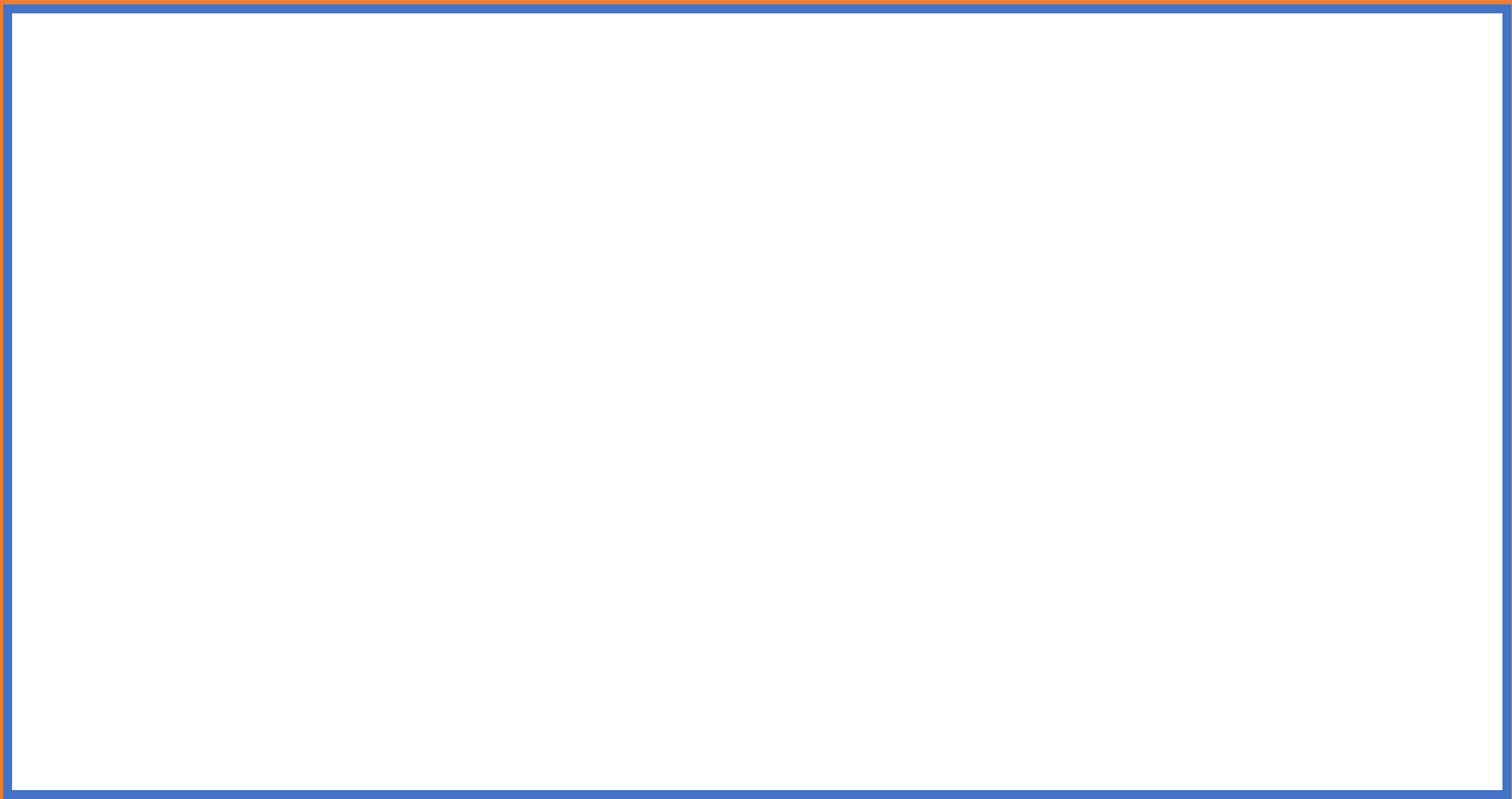
Attention (initiation and sustained)

Social motivation



AB

AGE: 2



More recently

- **Earlier intervention** may have larger effects (though again may depend on caregiver involvement)
- **Intensity** --at least the difference between 15 and 25 hours, makes less difference than other things but may be differences in 1 hour vs 3 hours vs 15-20 hours a week
- Some hints that more behavioral approaches may help older preschool children who are more behind (but not clear yet)



Treatment effects from our longitudinal study from 2 to 22

- Between 2 and 3 years:
- Working with a professional for 6 months during preschool years was associated with higher verbal, adaptive and social skills in all children from age 5 on to adulthood.
- Therapy of any sort with a stable relationship between a caregiver and a professional from 2 to 3 was associated with more positive outcomes in more able young adults.



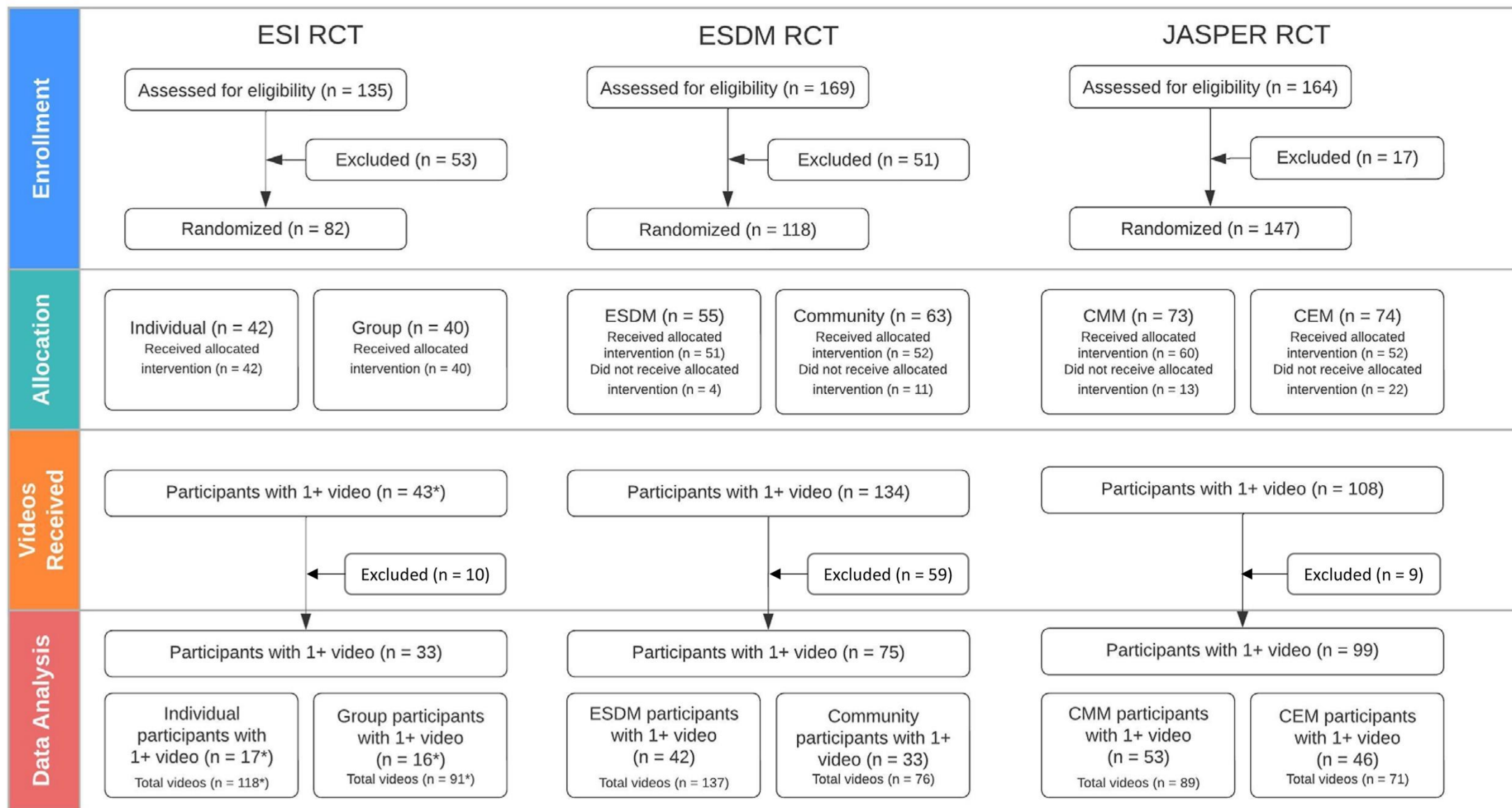


Figure 1. Adapted Consolidated Standards of Reporting Trials (CONSORT) Diagram (Swain et al. 2024).

Differences in mothers in use of NDBI strategies

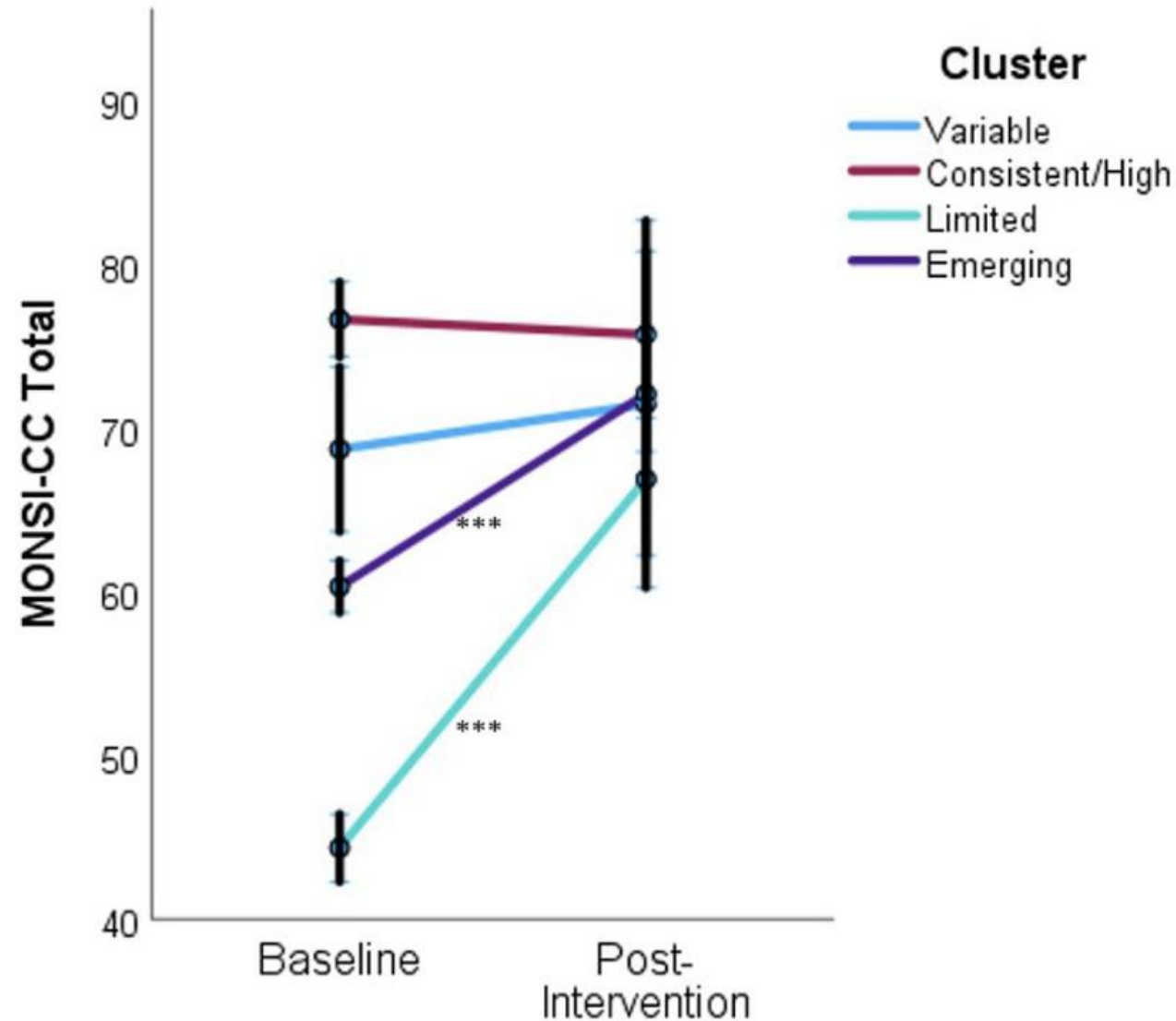
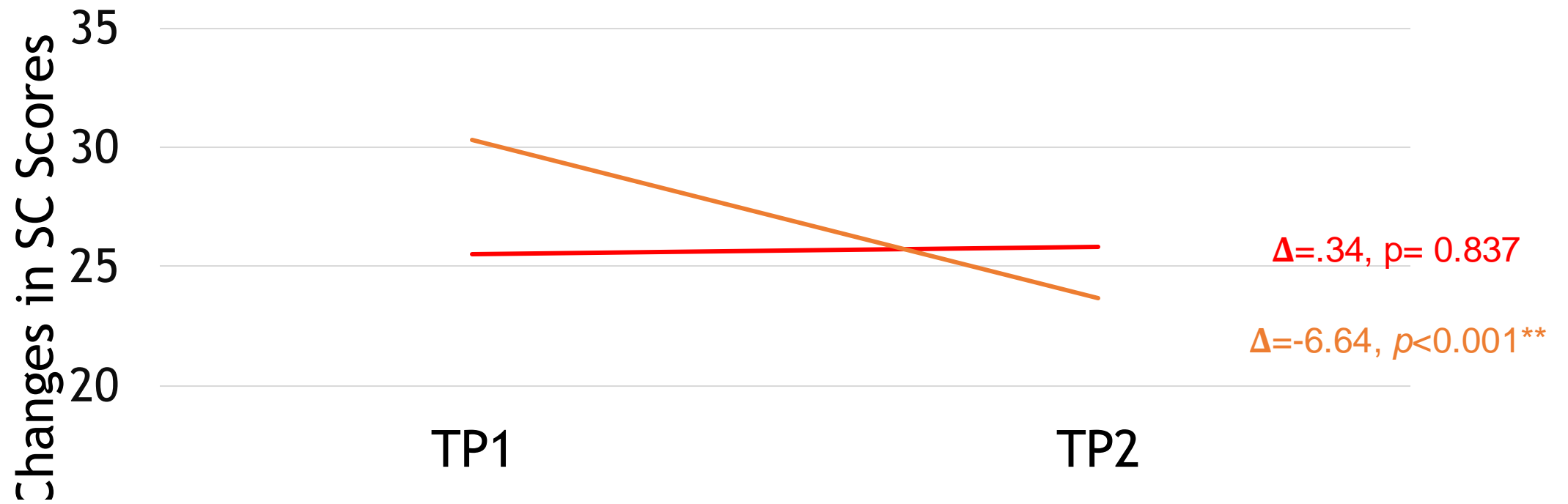


Figure 4. Interaction effect of caregiver strategy cluster by time on MONSI-CC total score.

Note. Significant change scores are marked based on follow-up t-tests. MONSI-CC, Measure of NDBI Strategy Implementation: Caregiver Change. *** $p < .001$.

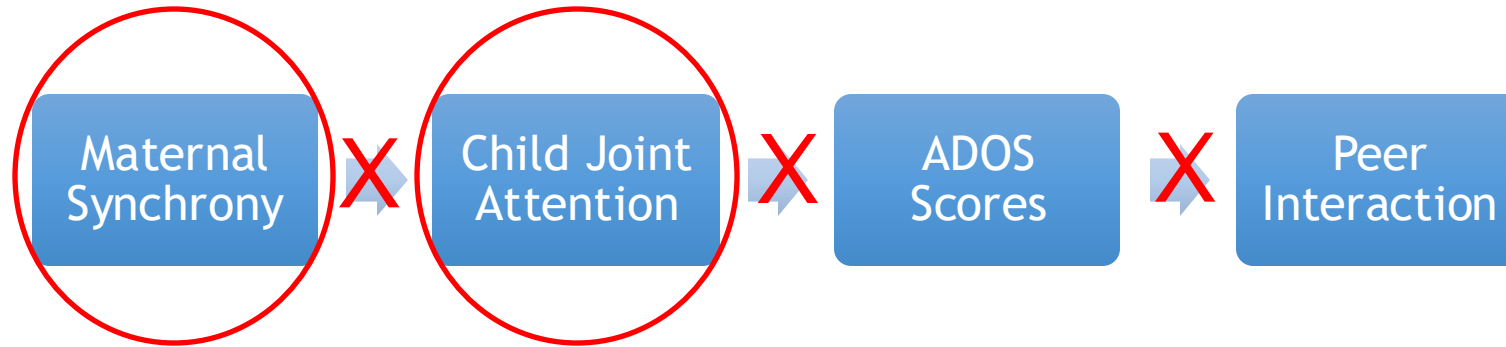
Brown et al. 2024

Changes in Children's Social Communication for Lower and Higher Parent Strategy Use Groups

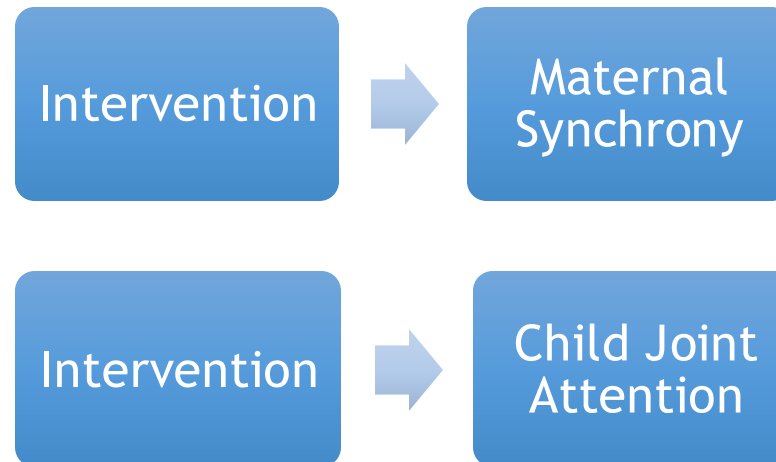


Parental Intervention

PREDICTED



RESULTS



Green et al., (2010).
Lancet.

Ways that caregivers have effects

- Caregivers' understanding of their child
- Caregivers' direct effects
- Caregivers' choices about tx options
 - Choices among different tx's
 - Social-behavioral
 - Kind of childcare
 - Medical
 - Alternative
- Effect on family function and caregivers' own health and daily life



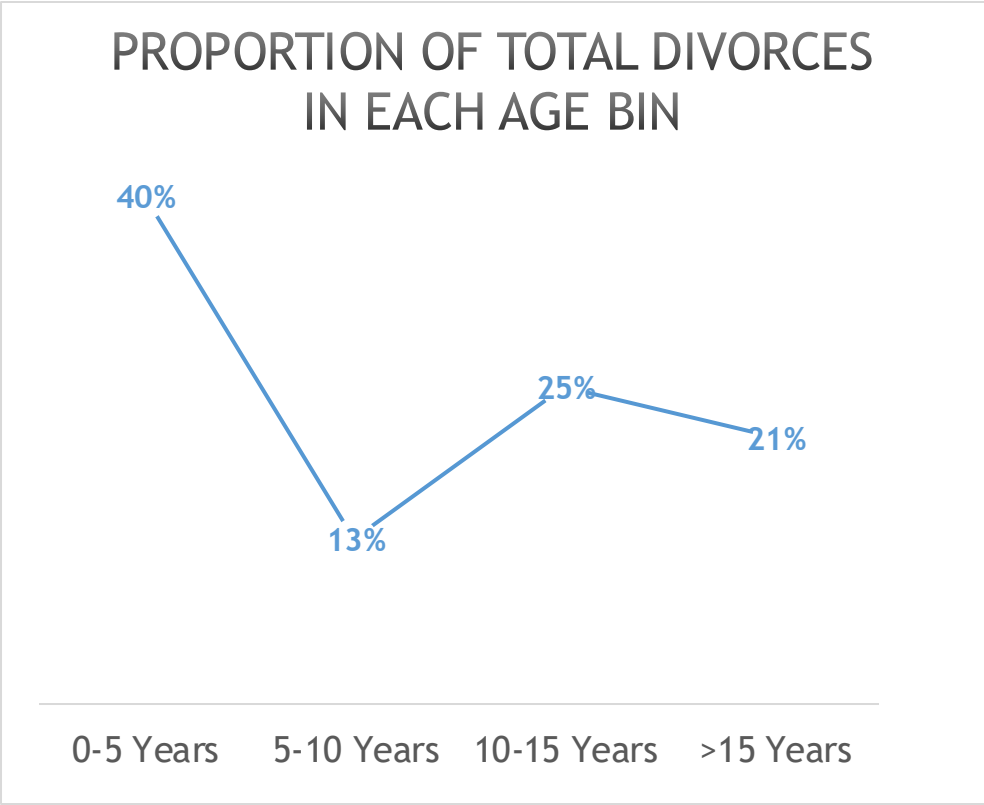
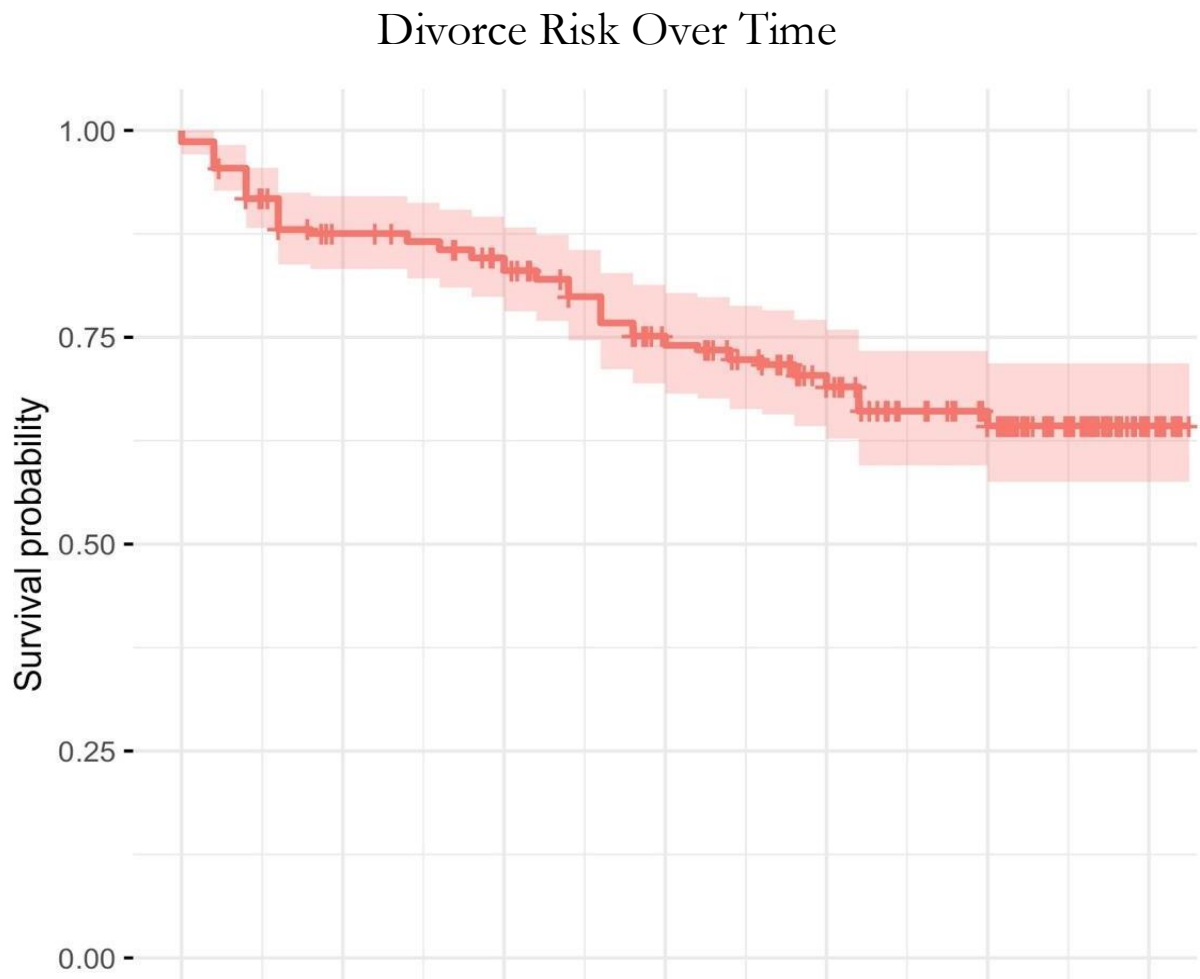
Caregivers as most important at young ages directly and even later for direct and indirect support

- What do parents/caregivers want to do
- Understanding their options
- Strategies for communication and engagement
- Helping families give their children opportunities to initiate activities
- Address difficult behaviors
- Support families mental health



Marital Status over 28 Years of Parents of Individuals with Autism and Other Developmental Disabilities

Niki Bahri, Kyle Sterrett, PhD, & Catherine Lord, PhD



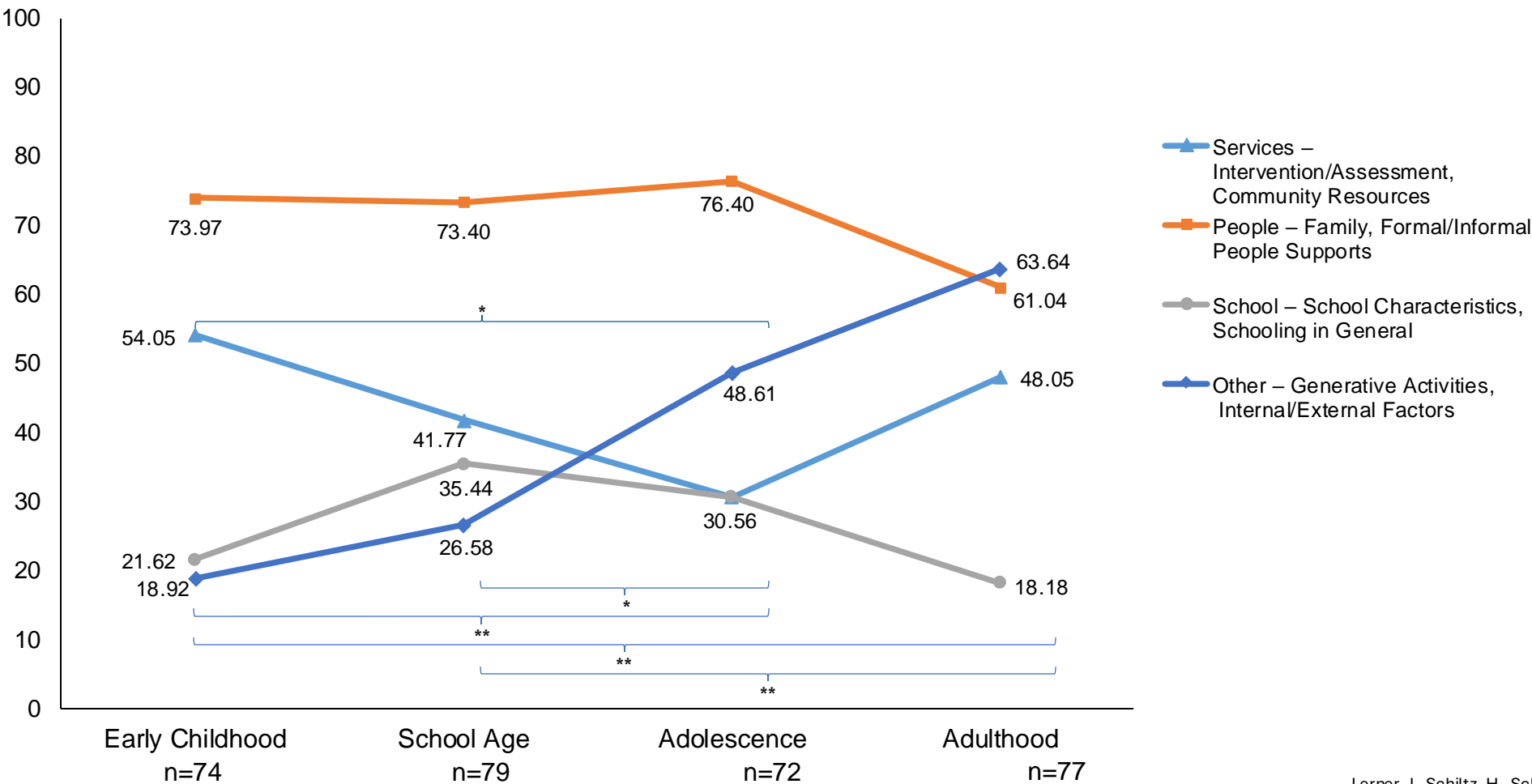
Bahri, N., Sterrett, K., & Lord, C. (2023). Marital status over 28 years of parents of individuals with autism and other developmental disabilities. *Journal of family psychology: JFP : journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, 37(6), 920–931.

Identifying the Most Helpful Factors Experienced Across Development According to Autistic Adults and Their Caregivers

Juliette Lerner, BA, Noa Schisterman, BA, Sonya Ziegler, & Catherine Lord, PhD



Caregiver Endorsement of Promotive Factors Reflecting Across Developmental Stage (%)



Different aspects or different treatments have overlapping but different effects

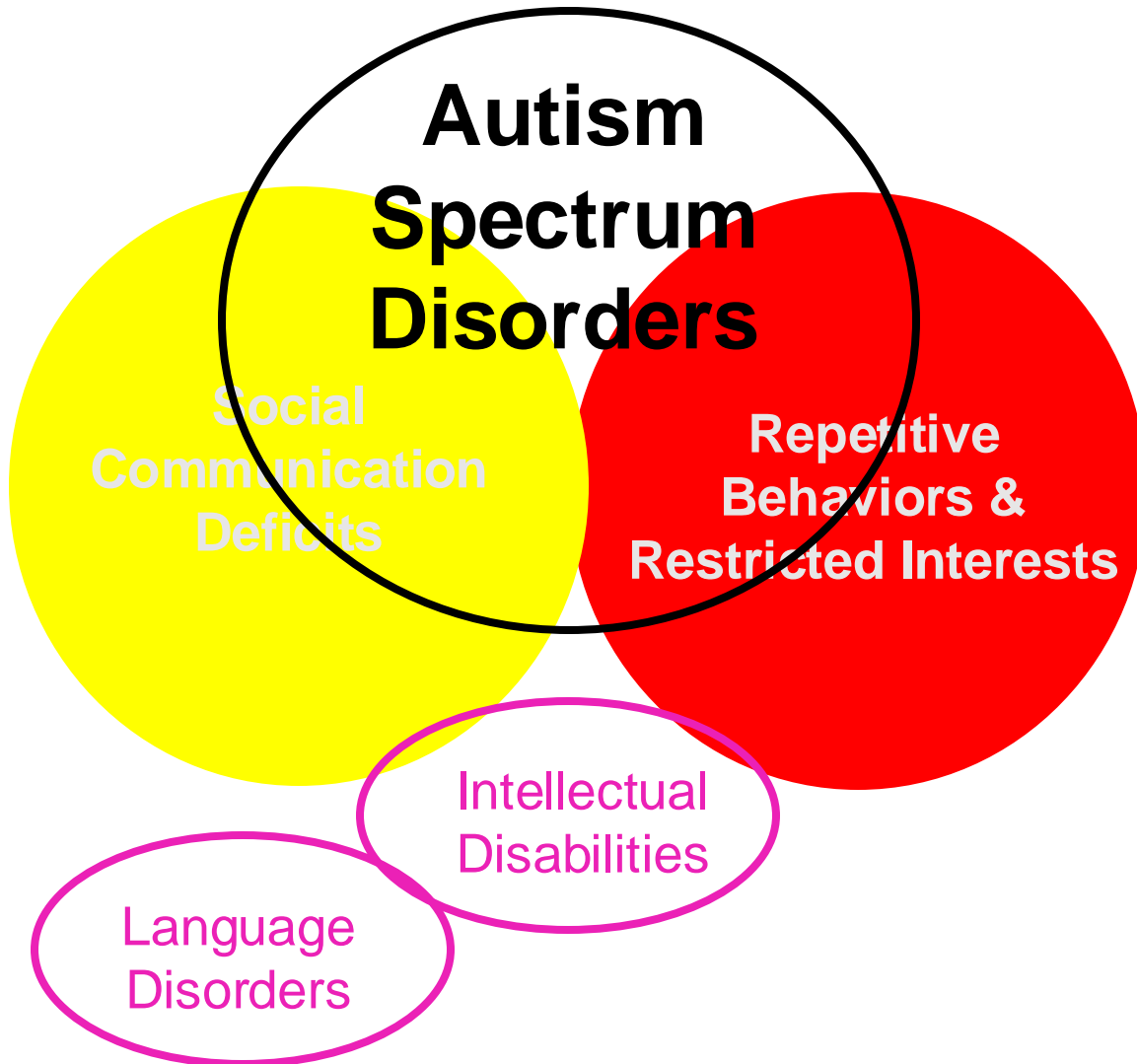
Caregiver factors

- Shift expectations to possible behaviors
- Relationship with the child
- Confidence and empowerment
- Dealing with behavior
- Communication
- Dealing with own fears and feelings

Child factors

- Understanding what is happening and expected
- Ability to pay attention
- Learning of specific skills
- **Communication behaviors**
- People as positive; joy together
- Activity “tools”
- Tolerance of frustration/intrusion

Autism Spectrum Disorders



Sense of humor

Fine motor skills

Predictability

Intelligence

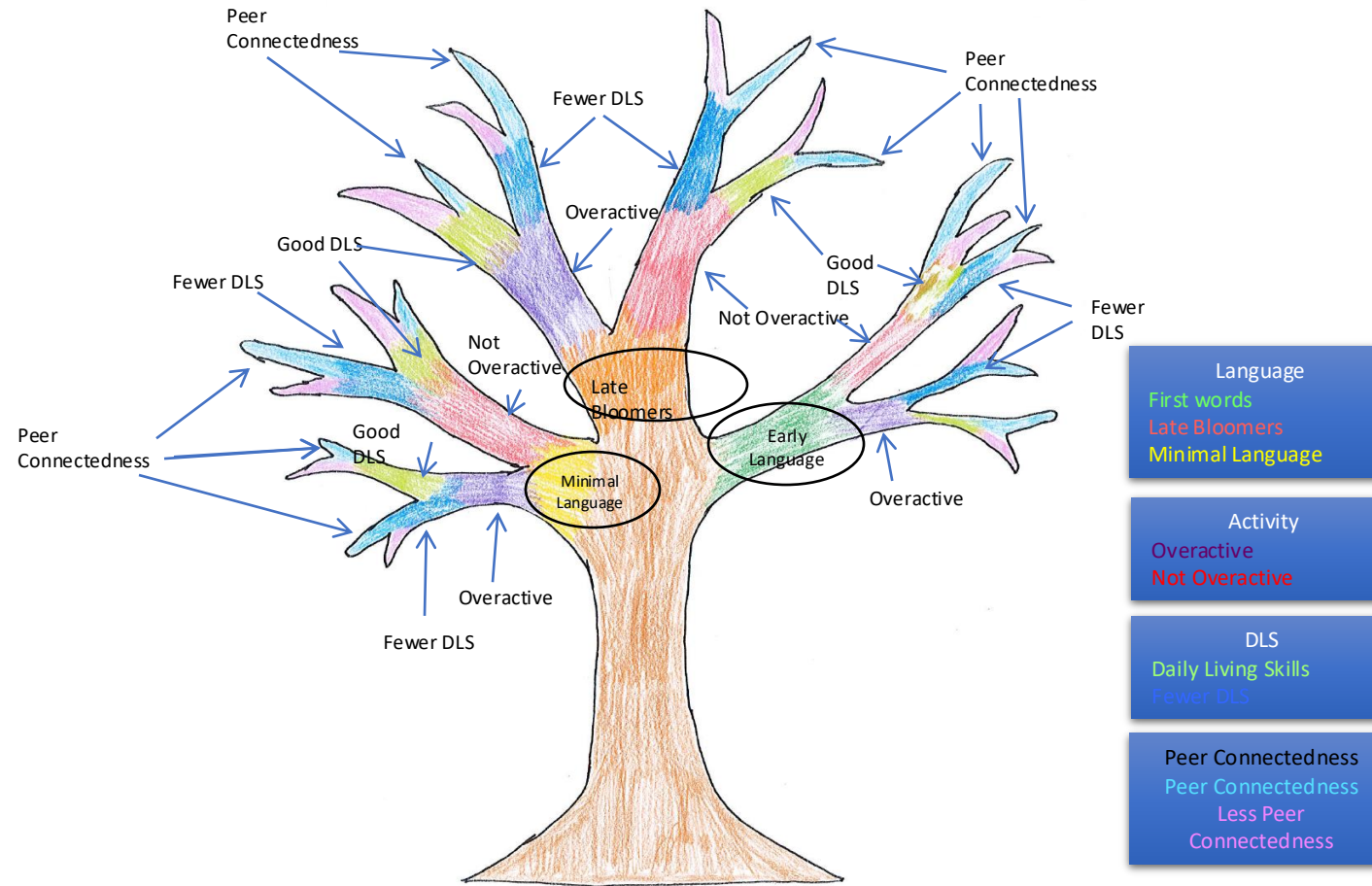
Visual-spatial skills

Curiosity

Attention to detail

Honesty

Patterns of Development



Autism is more than the sum of its parts

- ▣ Autism is just the beginning in terms of defining the difficulties faced by children and adults and their families with this condition.
- ▣ Strengths also make a difference - in the person with ASD and the family.



**Thank you for listening and thanks to all the patients
and parents and clinicians who allowed us to work
with them and show you these examples.**



Collaborators

■ **Somer Bishop**

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■ **Pamela C. DiLavore**

■ **Glenna Fields**

■ **Amy Esler**

■ **Kaite Gotham**

■ **Audrey Thurm**

■ **Shanping Qiu**

■ **Amy Wetherby**

■ **Susan Risi**

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- **Vanessa Hus Bal**
- **Whitney Guthrie**
- **Juliette Lerner**
- **Cory Shulman**
- **Rebecca Grzadzinski**
- **Maira Tafolla**
- **Nicole Rosen**
- **Marisela Huerta**
- **Children and families with ASD**
- **NIMH, NICHD, DOE, NINDS, HRSA, Simons Foundation, Autism Speaks**



Charlie D.

Age 7

Climbing a mountain to get a diagnosis .

- I would love to say it was easy to get him properly diagnosed but of course nothing comes easy.
- Constantly asked pediatrician if there was something more than his delayed speech. This conversation started at 18 months.
- Regional center gave him a diagnosis of global development delay at age 2 years, 8 months (covid/zoom).
- CAN Clinic at UCLA diagnosed him with autism spectrum disorder age 3 years, 6 months (in person).

Many interventions, many outcomes.

- Speech Therapy
 - Three different places that weren't a good fit.
 - One pre-covid and pre-diagnosis. Would have been adequate for neurotypical child.
 - Post diagnosis and during covid. Only on zoom to begin with (you can imagine how that went).
 - Covid but in person. 20 minute only sessions. That limited amount of time actually working on signs language and sounds.
 - **Game Changer - in home SLP!**
 - Charlie needed to not have to transition to an office in order to be regulated to even begin to think of interacting with a new person. Some kids do better in a clinic setting. It's all about what works and fitting it to the child.
 - Our SLP came into our house and became part of the family. She told me the science behind ABA therapy. She reached out to other clients to find an appropriate setting for Charlie. She saw the potential in Charlie. We are surrounded by limits regarding our kids and she didn't abide by that thinking. She also kept us on our toes and kept pushing us up hill when we couldn't do it anymore. For you it maybe a OT, a floor time person etc. Find the game changer.

Breaking up with a therapist is hard... but ok.

- Half of my job is what I call “autism matchmaking”. I have searched high and low for people that Charlie responds too.
- Many hiccups on the path that we are on now
 - Floortime therapy - One nightmare experience and one great one with sadly really no impact.
 - ABA therapy - Scary to most but beneficial to my son. I read and was told that it would be child abuse to submit my child to ABA therapy. I went down the REDDIT rabbit hole. Discrete Trial Therapy has been a what propelled him forward along with his brilliant SLP.

Center based ABA therapy

- This is just what has worked for Charlie.
- He started to attend a center based ABA program in July 2022 (almost 4 years).
- With SLP/ABA we started to use PECS and moved to an ACC device.
- Words started to come - used highly motivating words such as tickle and bologna.
- Was able to be potty trained and dressed himself.
- Currently he is able to communicate most of his wants and needs. Check in on other peoples emotions. Sleeps thru the night. Cook and Bake. Important everyday activities.

How we got here.

- I have never been afraid to admit that I don't know how to parent my child. I have no ego attached to his development.
- I've only ever wanted a happy child. A couple years of his life Charlie was frustrated and angry. I had two black eyes to show for it. It has been really rough and isolating (more on that).
- Charlie needed to communicate his needs in order to be happy and I knew that was the main focus for us to work on as a family.
- Communicate doesn't mean talk.
- Work on as a family - it's the family and the people that surround the child that need to really do the work. It's not a on a professional who only sees a kid for a sliver of time to do the work. We call ours "the Sara program (slp's name)"
- I sit on sessions as much as allowed and always in home sessions so that I and my family can be "trained". My younger daughter has been an awesome teacher with Charlie and loves the "Sara program".

Be relentless and open.

- Our kids are capable. I say Charlie can do everything until proven otherwise. Make sure you find therapists that also see this in your child. Most people would have been afraid to let a kid crack an egg or fry up sausage .
- Don't isolate yourself. By not telling people that your kid is autistic you may miss out recommendations from others. I always say to people "at least we know our kids won't be peer influenced brats". I have gained more resources by talking than staying silent.
- When times are dark focus on one thing that will make you laugh or love the uniqueness. Charlie throws out really inappropriate movie quotes. When he's being really rigid I can call up these moments for laugh.

