

Parent Stress Prior To An Autism Spectrum Disorder Diagnostic Evaluation: A DBPNet Study

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Autism and Parental Stress

- Parental stress is high in parents with children with ASD, even compared with parents of children with other developmental delays.
- Post-diagnostic parental stress is associated with:
 1. Impaired parenting skills
 2. Impaired family functioning & decreased family quality of life
 3. Disturbances in marital relationships
 4. Difficulties with child behavior
- Higher levels of social support, after the diagnosis of ASD, moderate parental stress.

What We Do Not Know

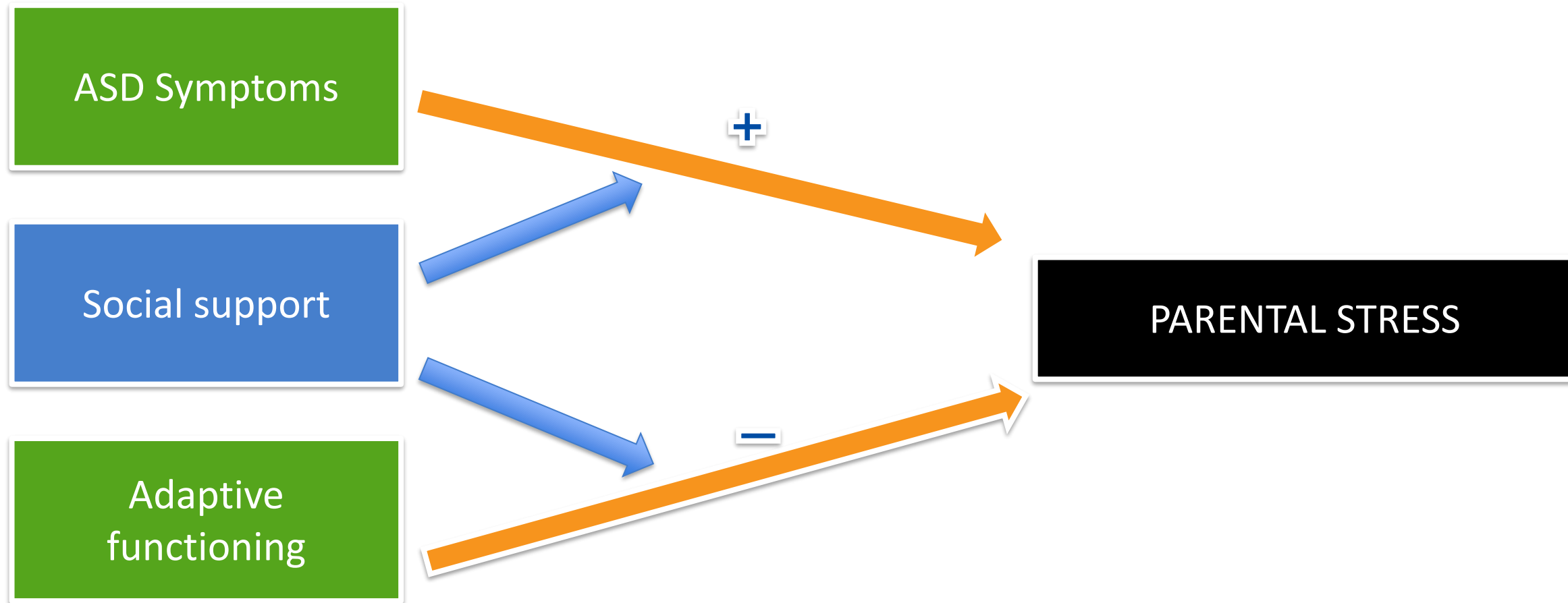
- Studies of stress in parents of children with ASD have been examined *after* diagnosis.
- No study to date, however, has examined the stress parents are experiencing *prior* to diagnosis.

Purpose

To examine:

1. The relationships prior to diagnostic evaluation between:
 - parent-rated ASD symptoms and adaptive functioning in their child and
 - parental stress
2. Whether social support moderates these relationships

Hypothesis



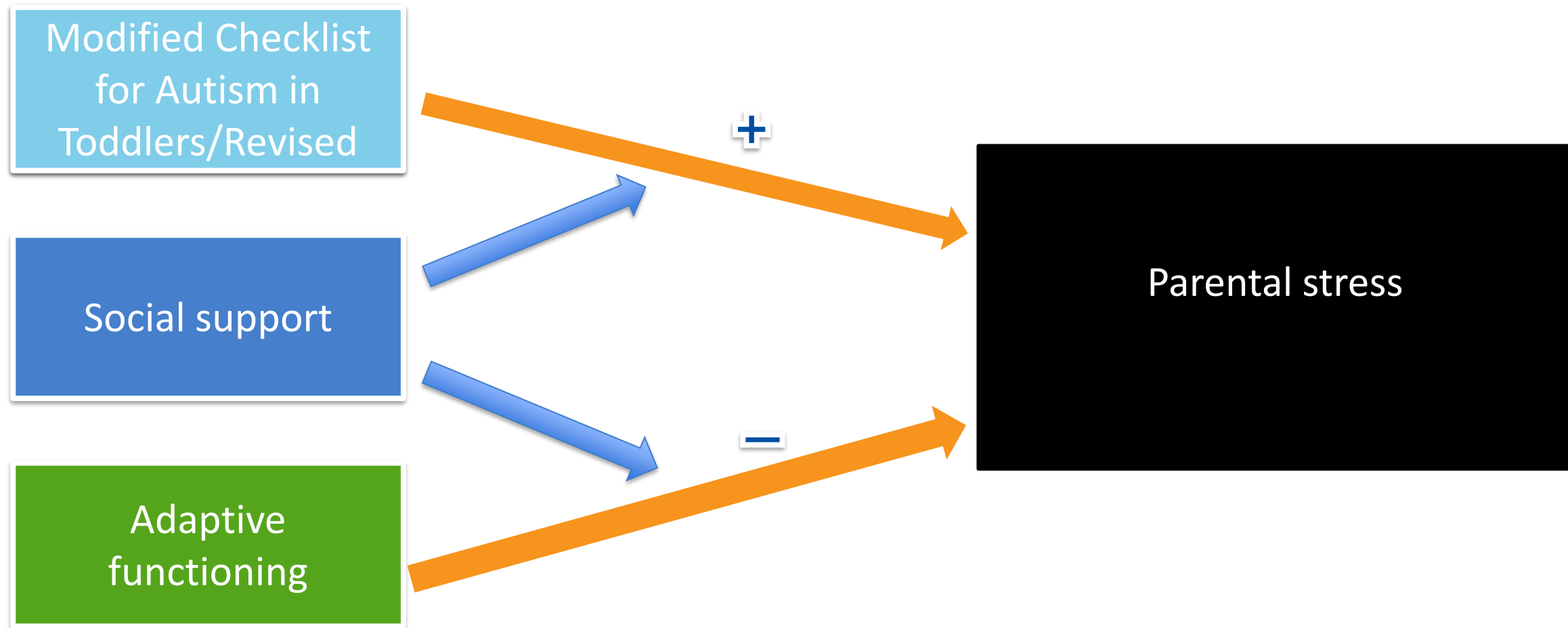
Overview – Project EARLY

- Multisite, randomized controlled trial.
- To test the effectiveness of a family navigator in reducing time to diagnosis and increasing access to treatment services in underserved, primarily minority children at risk of ASD, compared with care coordination only.
- 3 primary sites:
 - Boston Medical Center (6 pediatric primary care clinics)
 - Yale New Haven Hospital (2 pediatric primary care clinics)
 - Children’s Hospital of Philadelphia (2 pediatric primary care clinics)
- This study focused on baseline data

Inclusion criteria

- Children aged 15-27 months
- Screened positive for ASD at a primary care visit, or parent or clinician-identified concerns.
- No previous diagnosis of ASD

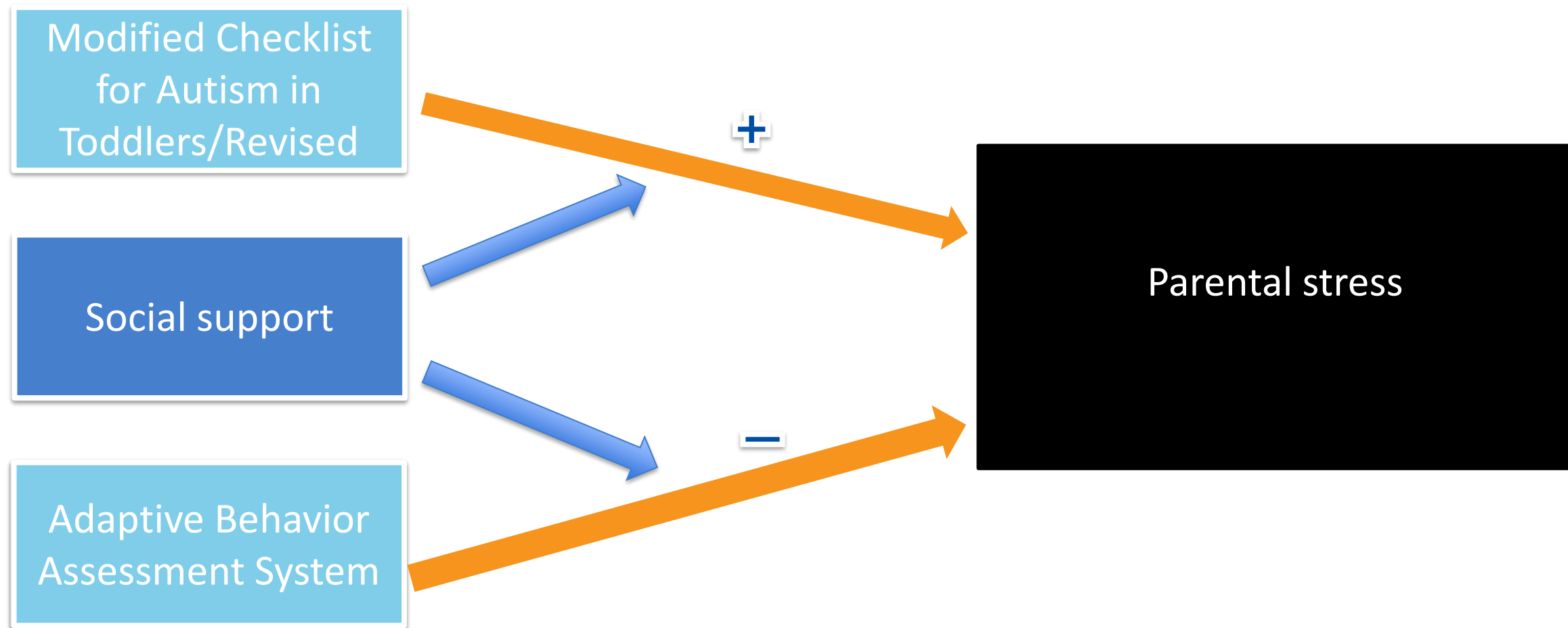
Measures



Modified Checklist for Autism in Toddlers/Revised : MCHAT-R

- Screening tool for autism with 20 questions.
- Score lower than 3 → no need of follow up
- Score equal or greater than 3 → administer MCHAT-R follow up interview and if score is greater than 2, represents a medium risk
- Score greater than 7 represents a high-risk for autism

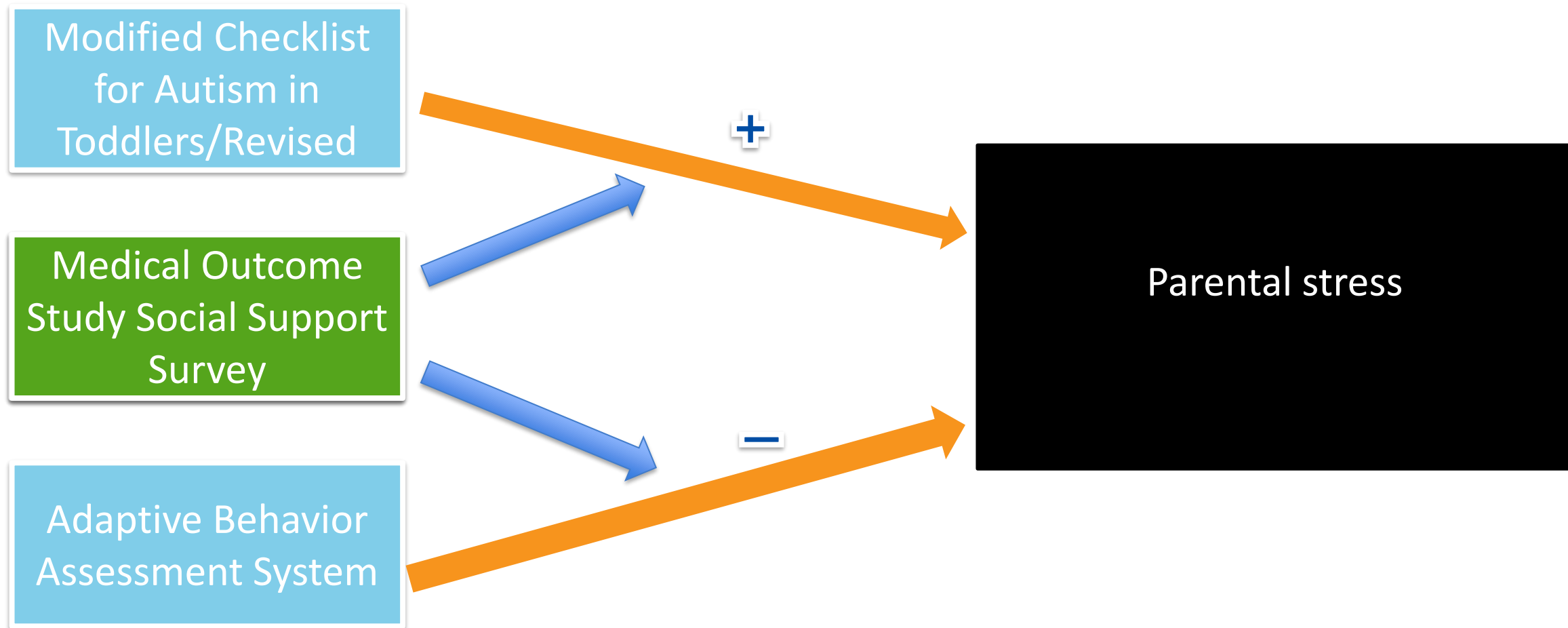
Measures



Adaptive Behavior Assessment System: ABAS-3

- Three subscales:
 1. Self-direction
 2. Social
 3. Communication
- Score lower than 7 considered below average.
- Score lower than 5 considered low.

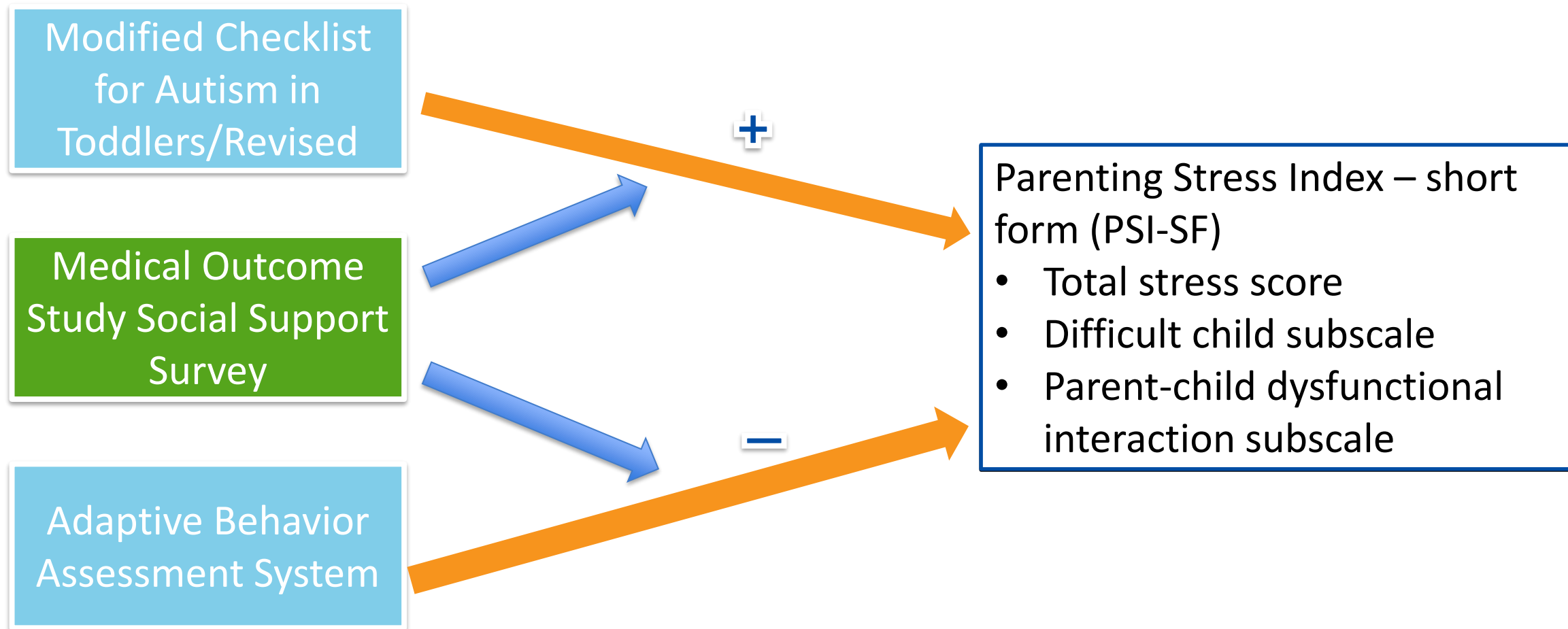
Measures



Medical Outcome Study Social Support Survey: MO-SSSS

- Comprised of 19 questions.
- Scored on a 1-5 scale, where 5 represents the greatest feeling of support.

Measures



Parental Stress Index- Short Form (PSI-SF)

- Total score and 2 subscales:
 1. Difficult child subscale
 2. Parent-child dysfunctional interaction subscale
- Stress is considered clinically significant for a score greater than the 85th percentile.

Covariates

- Demographics
 - Child age and gender
 - Parental age
 - Race
 - Ethnicity
 - Insurance status
 - Born in the United States
 - Marital status
 - Parental education
- Family resources
 - Enrollment in EI
 - WIC nutrition program
 - Food stamps
 - Subsidized housing
 - Cash assistance
- Psychosocial stressors
 - Domestic violence
 - Substance use

Data analysis – 1st hypothesis

To examine the relationship between parent-rated ASD symptoms and adaptive functioning in their child and parental stress:

1. Calculated unadjusted associations between the MCHAT and ABAS scores with PSI-SF, using Pearson correlation (r)
2. Adjusted Associations by :
 - Adding variables from the unadjusted associations at $p < 0.10$ to the model.
 - Performing multivariable linear regression, using stepwise selection with $p = 0.15$ for entry and remaining in the model.

Data analysis – 2nd hypothesis

To examine whether social support moderates these relationships:

1. We used the Interaction terms between social support and MCHAT-R, as well as social support and ABAS subscales in the same model, to assess effect modification.

Results

Baseline characteristics (N=317)

Child demographics	
Male	70%
Child age, mean (SD)	21.8 months (3.45)
Parent demographics	
Parent age, mean (SD)	31.8 years (7.3)
Black/African-American	57%
Hispanic	28%
Public insurance	82%
Born in the United States	62%
Married	55%
High school/GED or higher	82%

Results

Family Resources and Psychosocial Stressors








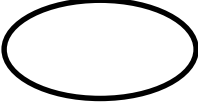












Variable	Percent reporting
Receiving EI	46%
Receiving WIC nutrition program	67%
Receiving food stamps	62%
Receiving subsidized housing	20%
Receiving cash assistance	22%
Domestic/sexual assault support	3%
Reported substance abuse	4%

Results

Key variables

Variable	Mean (SD)
MCHAT-R score	8.6 (3.0)
ABAS	
• Communication	4.7 (2.4)
• Social	5.2 (2.5)
• Self-direction	5.2 (3.0)
MO-SSSS	3.8 (1.0)
PSI-SF	
• Total stress	88.6 (25.4)
• Parent/child dysfunction	27.7 (8.4)
• Difficult child	31.3 (10.5)

Hypothesis 1

Variable	Unadjusted ¹			Adjusted Model		
MCHAT-R score						
ABAS						
- Self-Direction						
- Social						
- Communication						
MO-SSSS						

¹Pearson correlation for continuous predictor
 *p<0.05, **p<0.01, ***p<0.001

Hypothesis 2

- Social support did not moderate the association between parent-rated ASD symptoms and adaptive functioning and parental stress.

Conclusions

First hypothesis

- After adjusting for multiple variables, parent-rated ASD symptoms were shown to have a positive association with parental stress level before a diagnostic evaluation was completed.
- Only one subscale of the adaptive function measure, the self-direction subscale, had a negative association with parental stress.

Second hypothesis

- While higher social support negatively correlates with parental stress, it does not moderate the effect of symptoms or adaptive functioning on parental stress.

Clinical implications

- Our study is the first to assess parental stress before an evaluation is completed in children at risk for ASD.
- This study provides a glimpse into the parental minds at this critical time, and offer us data regarding the various variables that can affect parental stress in this period.
- The importance of social support is yet again demonstrated as an essential instrument to alleviate parental stress
- Due to the well-studied effect of stress on family-life in general and child development specifically, clinicians may consider assessing for stress in parents of children at risk of ASD even before they have been evaluated.

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 - Ada Fenick
 - John M. Leventhal
 - Abha R. Gupta
 - Veronika Shabanova
 - Marisol Credle
 - Jenny Acevedo
 - Cynthia Guillen
- **All the families who participated in the study**

Variable	N (%)	Mean (SD)	Unadjusted ¹			Adjusted Model ¹		
			Total Stress Score	Parent-Child Dysfunction Subscale	Difficult Child Subscale	Total Stress Score F-Value	Parent-Child Dysfunction Subscale F-value	Difficult Child Subscale F-value
MCHAT score	317	8.65(3.0)	0.14*	0.17**	0.19***	6.25**	5.20*	3.83*
ABAS Self-Direction Scale Score	315	5.21(3.0)	-0.19***	-0.16**	-0.23***		4.35*	8.81***
ABAS Social Scale Score	312	5.23(2.6)	-0.11*	-0.13*	-0.14*			
ABAS Communication Score	312	4.70(2.4)	-0.06	-0.08	-0.07			
Social support	314	3.77(0.97)	-0.38***	-0.32***	-0.25***	43.53***	33.53***	20.26***
Marital Status								
Married or living with partner	174 (55.1)		84.9 (24.5)	26.7(8.1)	30.0 (9.8)			
Single/Separated/Divorced	142 (44.9)		92.9(26.1) **	28.8(8.7) *	32.8(10.1) **			
Parent born in US								4.89*
Yes	197 (62.1)		90.0 (26.2)	27.8 (8.8)	32.6 (10.6)			
No	120 (37.9)		86.1 (23.9)	27.4 (7.8)	29.3(8.8) **			
Receipt of cash Assistance						7.67**	4.06*	9.20***
Yes	69 (21.8)		98.9(26.2)	30.4(8.5)	35.8 (10.6)			
No	248 (78.2)		85.7(24.5) ***	26.9(8.3) **	30.1(9.5) ***			
Receipt of food stamps								
Yes	196 (61.8)		91.1(25.2)	28.3 (8.5)	32.6(10.3)			
No	121 (38.2)		84.4(25.3)	26.7 (8.3)	29.3(9.3) **			

¹ Pearson Correlation for Continuous Predictor, Means (Standard Deviation) for Categorical Predictors

*p<0.05, **p< 0.01, *** p<0.001