

# Linking Therapy to Outcomes: Potential Successes and Areas of Need for Children with ASD

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# Goals

- Give a broad background on longitudinal outcome studies on persons with ASD.
- Acknowledge the role of researching and understanding the critical components of change.
- Identify the relationship of general services to change.
- Consider, for practical purposes, the need for a few broad changes to service provision for preschool and school aged children with ASD that might really make a big difference!

# The Outcome Pyramid

Long Range Broad Construct Outcomes

Shorter Range Broad Construct Outcomes

Shorter Range Targeted Construct

Critical Elements & Intervention

Community  
Therapy  
Impacts



# Broad Construct Outcomes

- Intelligence (IQ)
- Academics/Graduation Rates
- Language
- “Autism Symptoms” or Behaviors
  - Repetitive and Restrictive Behaviors
  - Social Communication/Social Development
- Adaptive Skills/Employment
- Comorbidity
- Medical

**What will my child be like when they are older?**

# Large-Scale Longitudinal Studies – Historically (1970s & 80s)

- Vast majority of individuals with ASD meet criteria for the disorder across the lifespan
- Overall symptom severity tends to decrease with age
- IQ is the strongest predictor of outcome in these studies. Some early studies attribute phrase speech before age 6 as predictive.
- Few adults marry or develop reciprocal/true friendships in spite of developing interests
- Psychiatric and medical comorbidities are concerning

# Recent Longitudinal Studies (90s & 00s)

- Improved in autism symptoms
- Improved or remained stable in behavior problems (Mailick Seltzer et al,)
  - Improvements in both areas related to IQ and maternal praise
- Slowing of improvement after high school (Taylor & Mailick Seltzer, *JADD*, 2010)
- Employment post-high school was not promising.
- Daily Living Skills improved in adolescence and early 20s but plateaued during their late 20s.
- Increased rates of medical & psychiatric struggles (20 and 80%) over time (Croen)
- Children demonstrated slight improvements in ADLs between 2 and 22, with a dip in pre-adolescence but scores remained in significantly impaired range.

# Meta-Analysis

## Longitudinal Studies

(Magiati, Tay, & Howlan, *Clinical Psychology Review*, 2014)

- IQ stable (some decrease while others show a large increase).
- Large individual variability although adaptive functioning was relatively low at all time points.
- Diagnostic status remained stable
- Related behaviors showed overall improvement but improvement was mediated by characteristics such as IQ, language, etc. (Lord, 2017)
- Socialization: 50% of the studies reported “poor” or “very poor” outcomes for adults.
- Rates of independent living and employment were low.

# Shorter Range Longitudinal Broad Constructs

- Notable IQ improvements
  - Particularly during preschool and elementary school (Sigman et al., 1999, Joseph et al., 2002, Rapin 2003, Clark et al., 2017), only a few declines were noted.
  - Cognitive outcomes were related to autism severity
- Diagnostic Consistency
  - Differential rates of improvement, some attributed to early autism severity. But, diagnosis seems to overall be reliable and stable. (Clark, Barbaro, Dissanayake, 2017)
- Co-morbidity
  - Co-morbidity in children with ASD falls in the 30 to 80% range (ADHD, anxiety, depression/dysthymia) and persists (Leyver et al., 2006, Kanne et al., 2009, Kim et al., 2012)
  - Co-morbid diagnosis demonstrated lesser improvements (Szatmari et al., 2015) (Lord, specified Hyperactivity at age 3).



# Shorter Range Longitudinal Targeted

Lord 2017 (18m to 3y)

- Globally, therapy improves many areas (e.g., joint attention and requesting)
- IQ improvements
- Ease of engagement (Quality of Rapport and Eye Contact) did not get better. The amount of effort it took the adult to engage the children.
- Family involvement related to improvements in both IQ and ADLS

Other Targets

- Language, joint attention, play skills, engagement, specific social targets, specific adaptive targets.

# Critical Elements

- Correlates of change (type of intervention, dosage, intensity, setting, with whom)
- Critical skill elements important to outcomes
- Matching intervention to child characteristics
- Individual characteristics contributing to change
- Family contributions
- Medical contributions

# The Outcome Pyramid

Long Range Broad Construct Outcomes

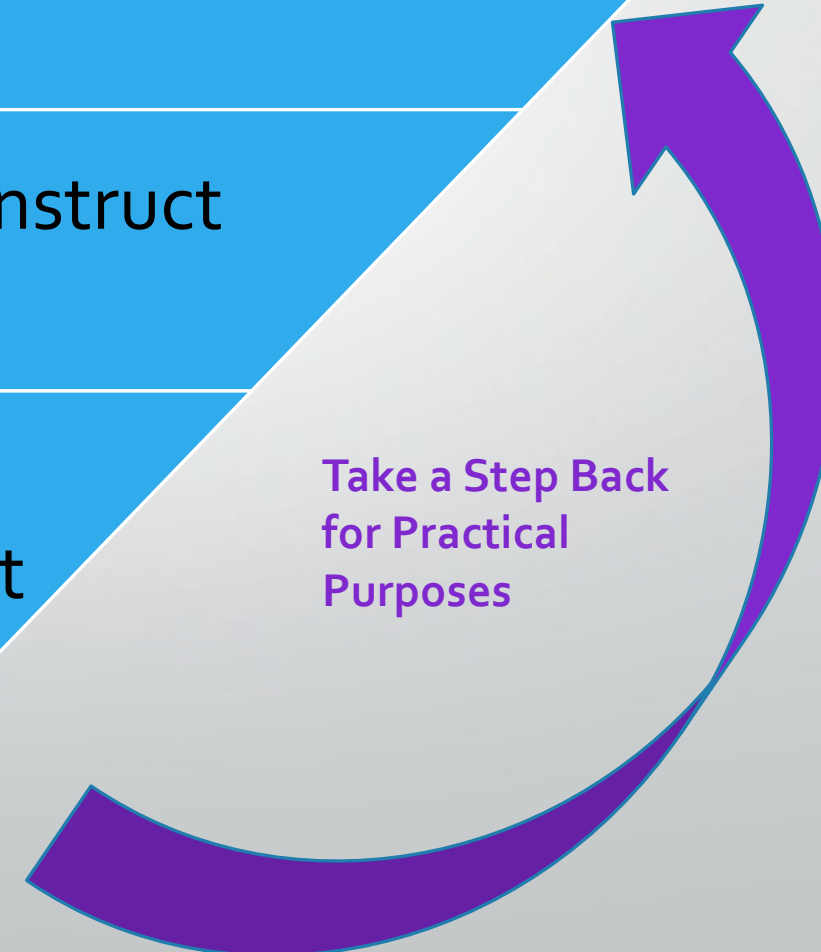
Shorter Range Broad Construct Outcomes

Shorter Range Targeted Construct

Critical Elements & Intervention

Community  
Therapy  
Impacts

Take a Step Back  
for Practical  
Purposes



# Broad Thoughts Summary

IQ



- Predictive
- Changes positively Hooray!

"Autism"



- We are getting very good at early diagnosis

Behavior



- Improvements in symptom and other maladaptive behaviors Hooray!

Social Skills



- Improvements but a huge concern throughout lifespan (impaired)

Adaptive Skills



- Inconsistent results over time
- Remain in the "deficient" range with declines in adolescence & adults

Comorbidities



- Become more prevalent in later life for those with these concerns

# Community Therapy

- Academic/Cognitive
- Behavioral Therapy
- Speech
- Occupational
- Physical
- Social Skills and Targeted Engagement
- Adaptive Skills
- Counseling/Psychologist
- Pharmacological
- Medical/biomedical

# Sample – High Access

- ECPHP families. Greater Los Angeles Area
- 2-6 years of age at time 1. 6-10 years of age at time 2. Four Year span.

Caregiver		Income (in 10,000)		Ethnicity		Highest Level of Education	
Mother	58 (83%)	30-40	2 (3%)	African Am	2 (3%)	High school	1 (1%)
Father	9 (13%)	40-50	3 (4%)	Asian Am	8 (11%)	Some college	10 (14%)
Other	2 (3%)	50-60	2 (3%)	Caucasian	55 (79%)	Completed college	24 (34%)
NR	1 (1%)	60-80	5 (7%)	Hispanic	5 (7%)	Graduate/professional	34 (49%)
		80-100	6 (9%)	NR	0	NR	1 (1%)
		>100	47 (67%)				
		NR	5 (7%)				

# Change in Behavior, Social Skills, and Adaptive Abilities

	Time 1	Time 2	T Score
<b>Behavioral Difficulties <sup>a</sup></b>	65.0 (10.2)	58.0 (9.62)	3.97***
<b>Social Skills <sup>b</sup></b>	70.0 (11.4)	76.0 (17.9)	3.33***
<b>Adaptive Abilities <sup>b</sup></b>	73.5 (13.2)	64.5 (18.1)	3.85***

Initial (Time 1) and Follow Up (Time 2) Mean and Standard Deviation Scores by Three Domains (Behavioral, Social, and Adaptive)

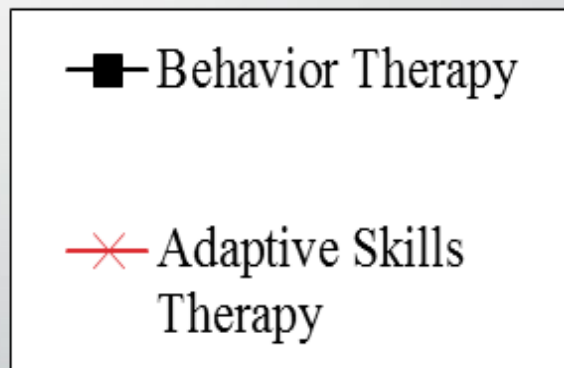
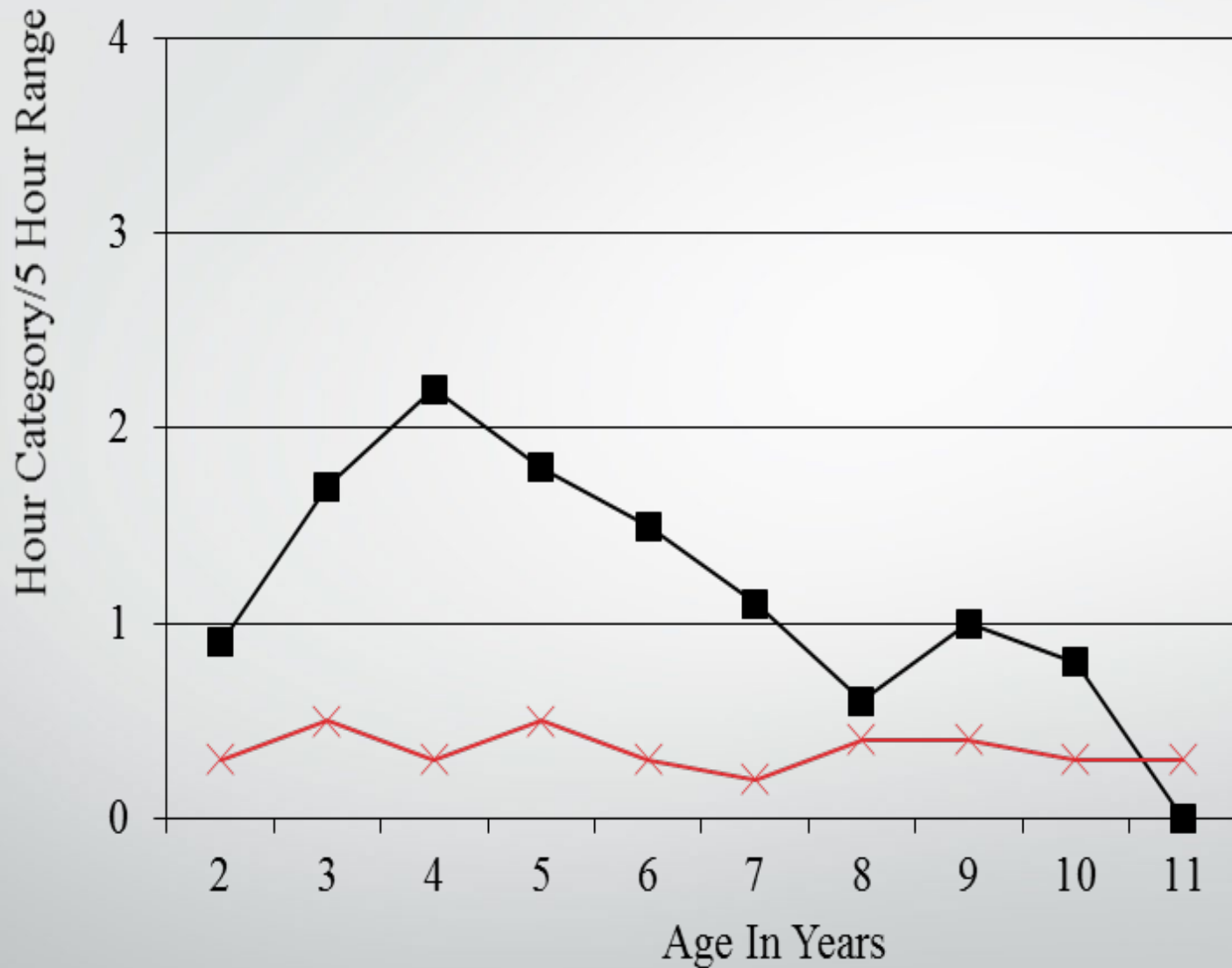
\*\*\*  $p < .001$

<sup>a</sup>CBCL – Child Behavior Checklist; T50-T64=within normal limits, T65-T69=subclinical, T=70 and above = clinical.

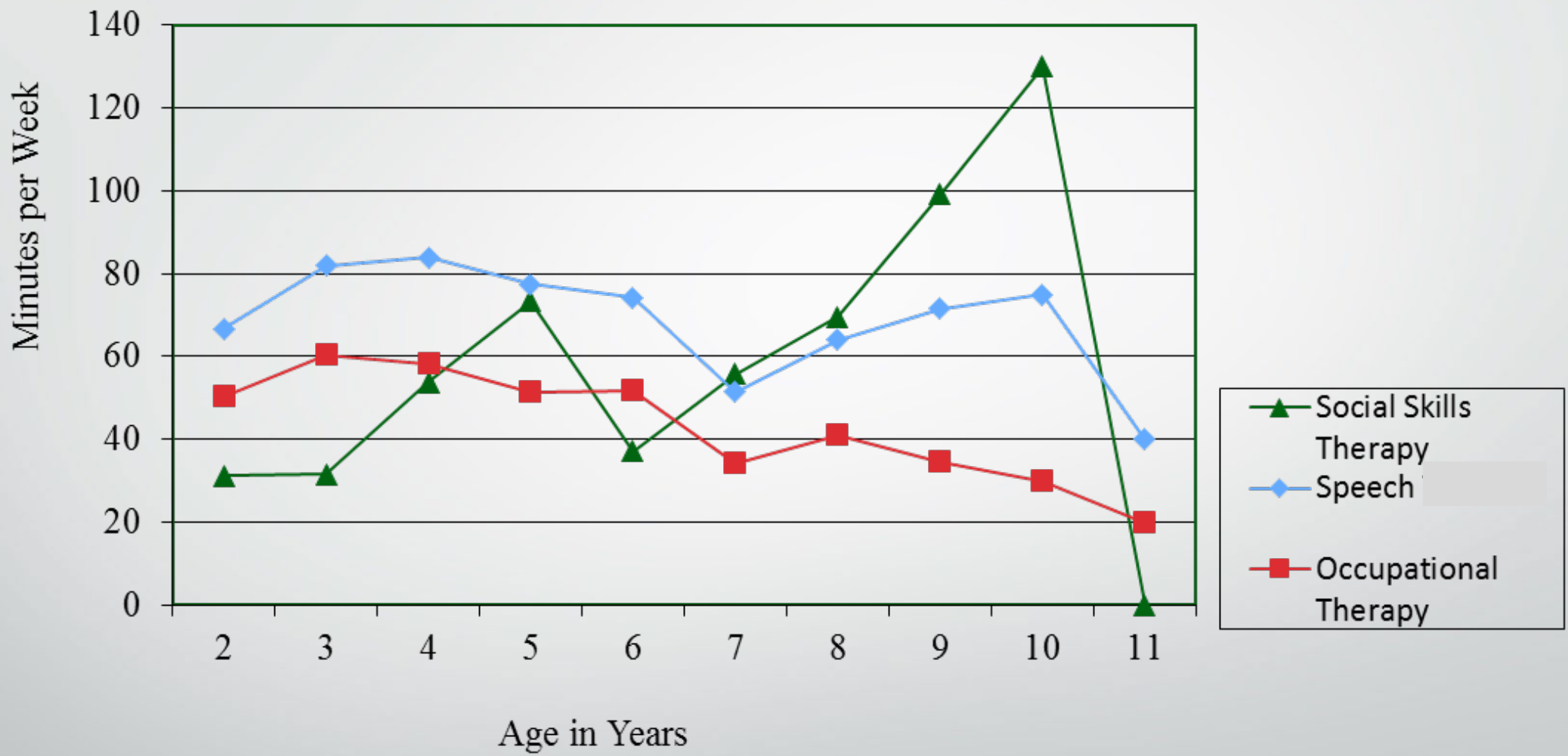
<sup>b</sup>VABS at Time 1 – Vineland Adaptive Behavior Scales, Subscales: DLS=Daily Living Skills, SO=Social Skills; (mean = 100, SD = 15)

<sup>b</sup>ABAS at Time 2 – Adaptive Behavior Assessment System Subscales: PR=Practical Skills, SO=Social Skills; 100= mean, 15= standard deviation

0=0 hours  
1=1-5 hours  
2 = 5-10 hours  
3=10-15 hours  
4=15-20 hours







# Relationship between Outcome and Therapy Type and Hours over Time - BEHAVIORAL

- Time 1, no relationship between severity of symptom and behavioral service provision. *Young children are getting a lot of behavioral services regardless of symptom presentation.*
- Over time, as behavior difficulties increased, services increased. With a decrease in behavior difficulties, services decreased

Remember, children are improving overall!

# Relationship between Outcome and Therapy Type and Hours over Time – SOCIAL

## SOCIAL SKILLS

- No relationship between social skills therapy hours at time 1, time 2, or change over time. *Young children are not getting social skills at high intensity and amount is unrelated to symptom presentation.*
- Relationship between **speech therapy** at initial and over time. Initially, more impaired social skills received more speech. Over time, as social skills improved, speech therapy decreased

Remember, improvements in social skills over time but still in the impaired range of development.

# Relationship between Outcome and Therapy Type and Hours over Time -- ADAPTIVE

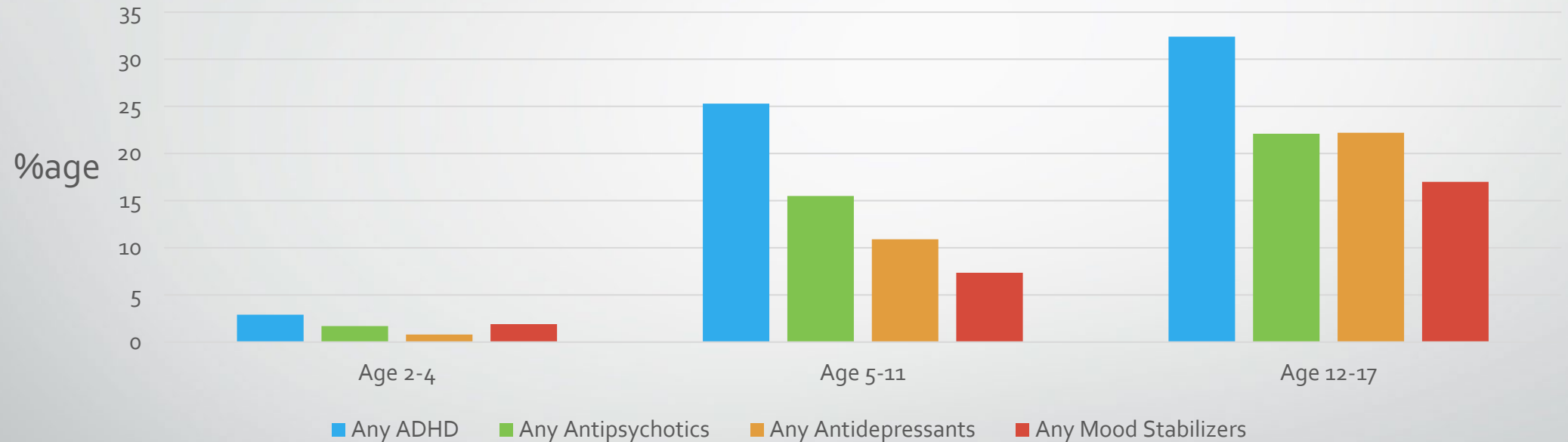
## ADAPTIVE

- No relationship between adaptive skills therapy hours at time 1, time 2, or change over time. *Young children are not getting adaptive skills therapy at high intensity and it's unrelated to symptom presentation.*
- At time 2, more **Occupational Therapy** was related to higher impairments in adaptive skills.

Remember, adaptive skills remain significantly impaired over time.

# Relationship between Outcome and Therapy Type and Hours over Time -- COMORBIDITY

- Therapy Type: Medication: Croen (re-printed with permission)



- Therapy Type: Medication & Therapy (Freeman et al.)
  - 7 out of 70 (10%) had received at least an hour of counseling for 1 year.
  - 21 out of 70 (30%) had tried or were on one or more medications

Type of Therapy	Broadly "How we are doing"	Gold Standard.
Academics/Cognitive School	Service is persistent throughout 3-21 years of age	School/Education 30 hrs. per week
Behavioral	Present, early & intense, over time adjusted to need – hooray!	40 hours per week for young children. Older get remainder from school hours
Speech	Present and adjusted to need – Language outcomes good, Potentially help socially	Yes
Occupational	??? Could be helping with adaptive skills	Yes
Physical	???	?
Social Skills and Targeted Engagement	Present and helping but not enough	Yes
Adaptive Skills	Not present	No
Counseling/Psychologist	Rarely present	?
Pharmacology	Present in older but unclear impact	?
Medical	???	?

# Food for Thought: Let's ADAPT

## Simple Punch Line:

- We need more adaptive therapy
- Social skills therapy is effective but we need more of it

## Complex Struggles:

- Stepping back and taking a broader perspective misses outliers
- Who is going to do the adaptive therapy?
- How do we address this with an educational system that is highly focused on academics.
- How do we address this with parents that have strong preferences about educational systems.
- Awareness of this issue.