

# From Specialized Clinic-based Tertiary Care to Communities & Prevention



  
**Marcus**  
AUTISM CENTER

**NIH Autism Center  
of Excellence**

**Nathan Call, PhD, BCBA-D**

Assistant Professor, Dept. of Pediatrics  
Emory University School of Medicine

Director, Severe Behavior Program  
Marcus Autism Center

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Assessments Using Telehealth for Children with Autism*

# Problem Behavior in Autism Spectrum Disorder

Although prevalence estimates vary (15%-65%)<sup>1</sup>, problem behaviors are more common in individuals with autism spectrum disorder (ASD) than same age peers

Common problem behaviors include:

- Aggression
- Tantrums
- Self-injury
- Disruptive behavior
- Property destruction
- Pica
- Elopement
- Encopresis





# Examples of Significant Problem Behavior





# Examples of Significant Problem Behavior



# The Impact of Problem Behavior

Problem behaviors directly produce many negative effects on the individual who exhibits them

- Physical harm<sup>1</sup>
- Exclusion from community services and peers<sup>2</sup>
- Stigma

Also negatively affects almost every facet of a caregiver's daily life

- Poorer family functioning<sup>1</sup>
- Lower marital satisfaction<sup>1,2</sup>
- Higher rates of problem behavior in siblings<sup>3,4</sup>
- Parental unemployment<sup>5,6</sup>
- Significant increase in total lifetime costs of care

# Treatment of Problem Behavior in Children with ASD

## **Current state: often limited to crisis stabilization**

- Short-term focus (usually pharmacologic)

## **Successful long-term outcomes require:**

- Function-based treatments
- Levels of service that fit the continuum of severity
- Mediation by caregivers
- Comprehensive/systems approach
- Treatment models that are accessible

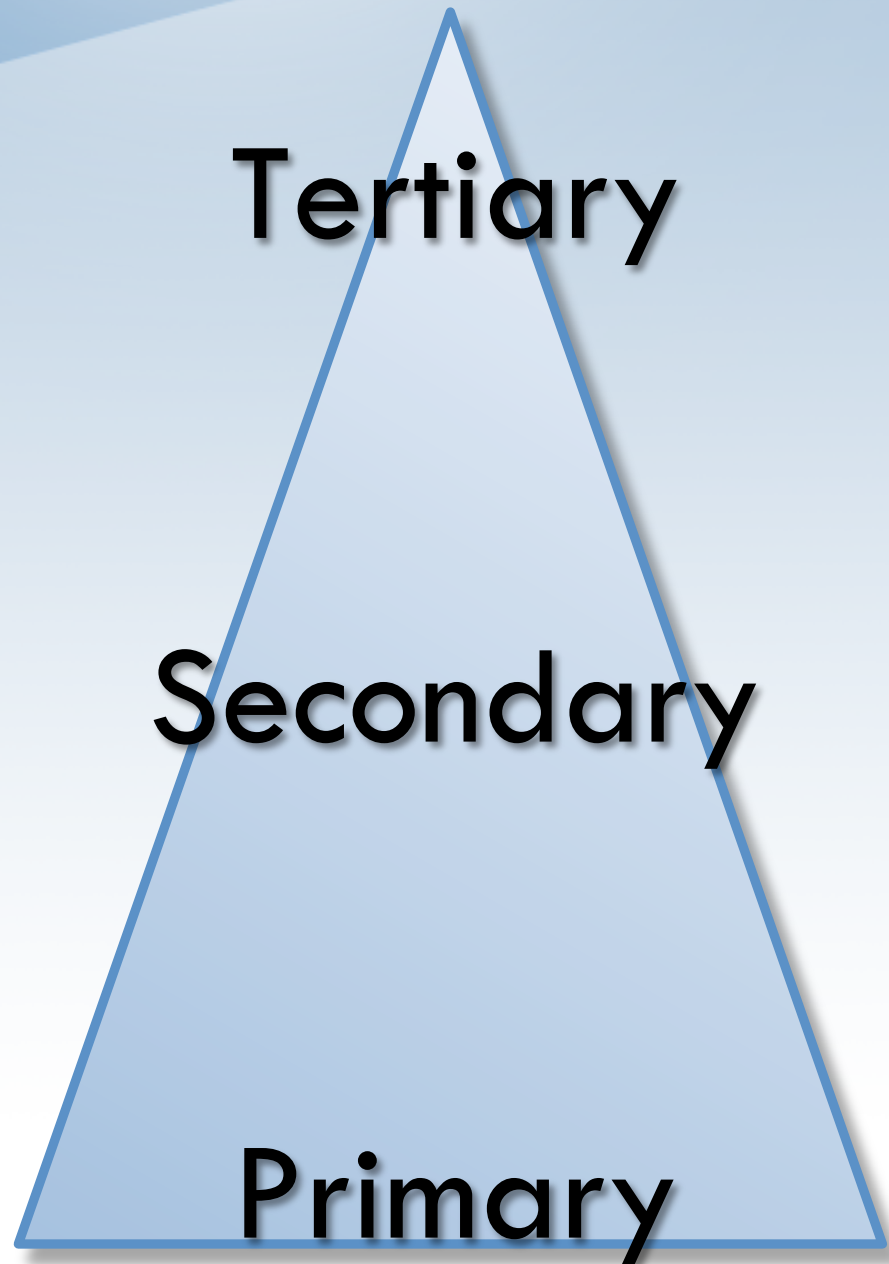


# Function-Based Treatments

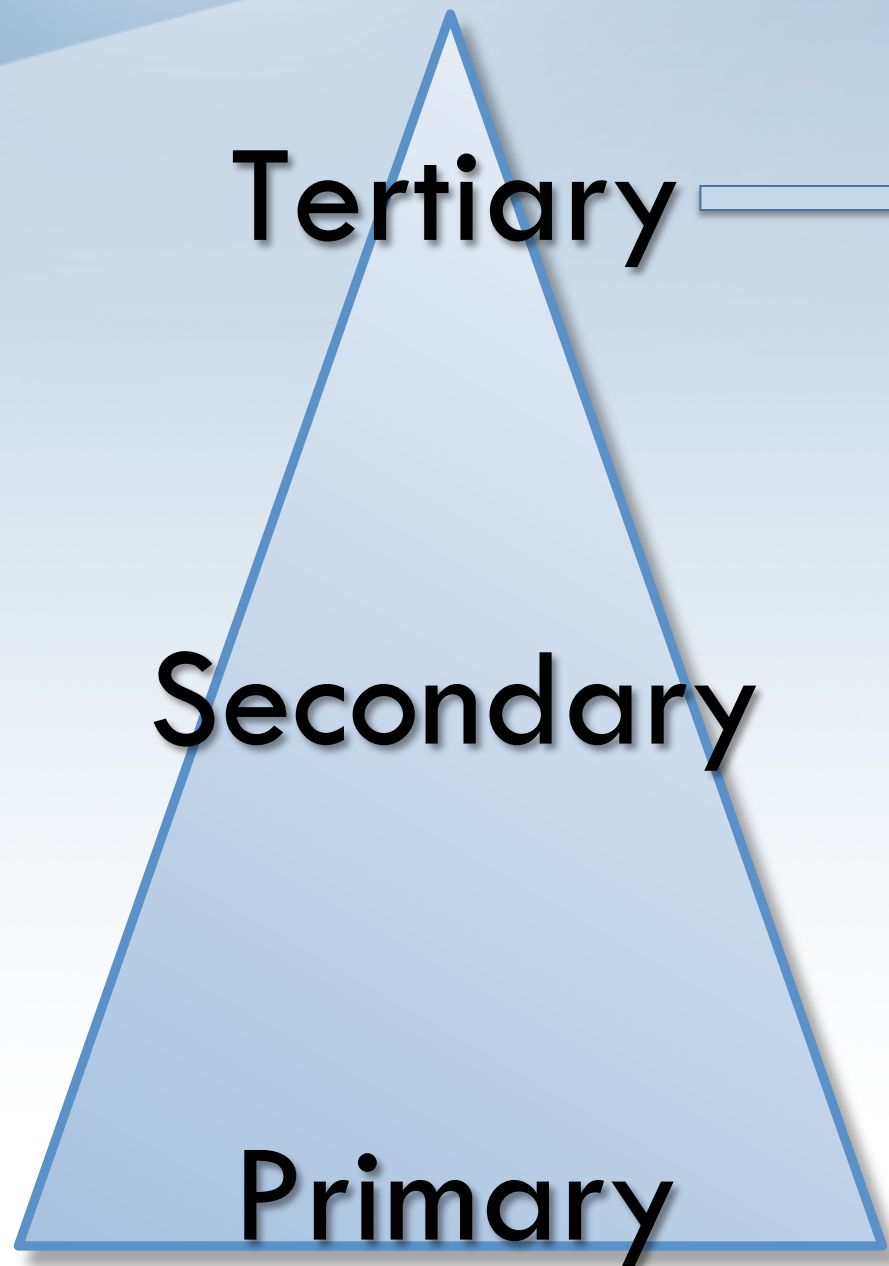
**Behavioral treatments for problem behavior that are based on the type of problem behavior (e.g., aggression vs. self-injury) are largely hit-and-miss**

Treatment components selected based upon the purpose the behavior serves for the individual (i.e., its “function”) are consistently more effective<sup>1,2</sup>

# A Continuum of Service Models



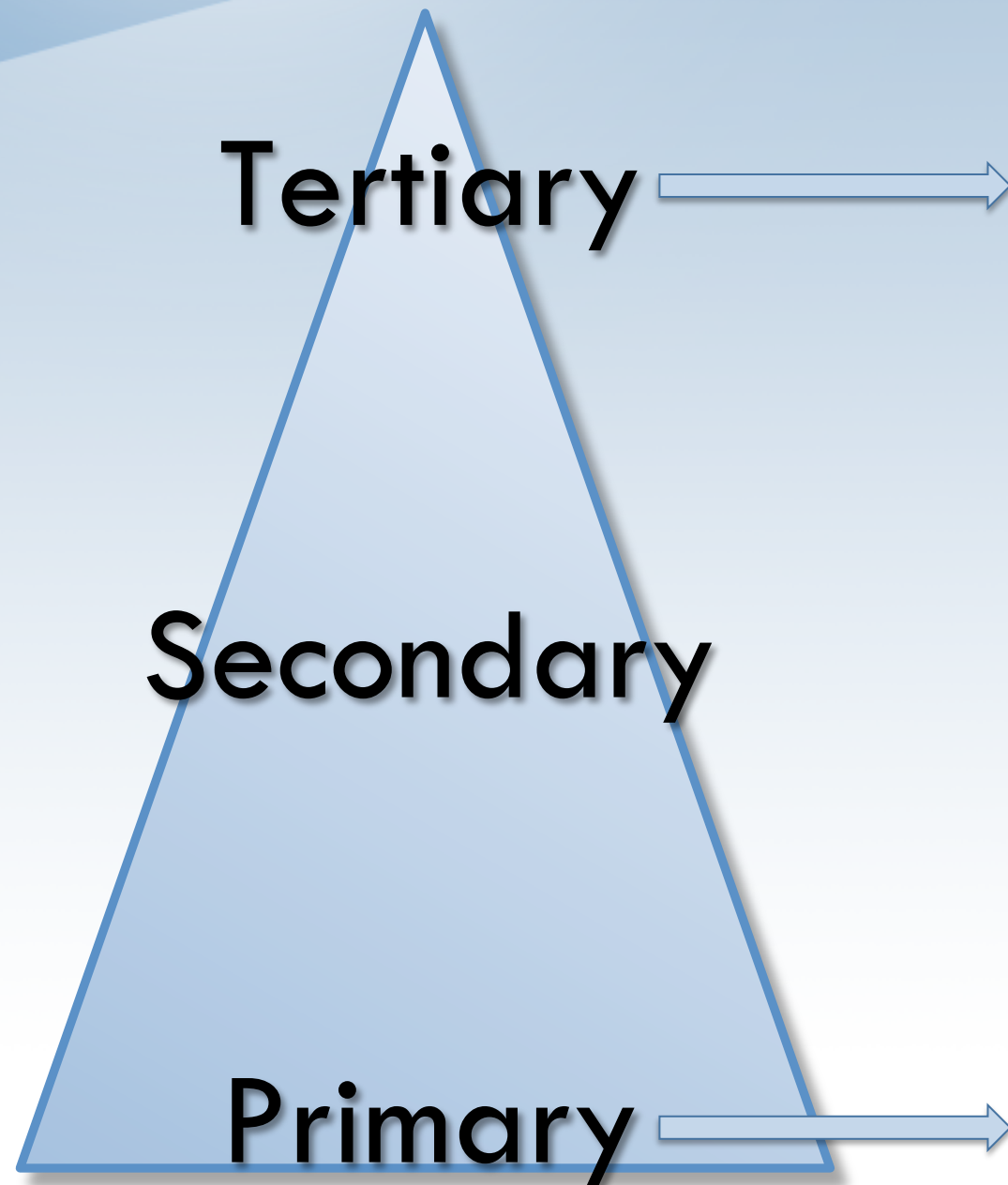
# A Continuum of Service Models



- Highest severity/lower prevalence
- High investment of resources
- Extremely few providers
- Rooted in applied behavior analysis



# A Continuum of Service Models



- Highest severity/lower prevalence
- High investment of resources
- Extremely few providers
- Rooted in applied behavior analysis

- Lowest severity/highest prevalence
- Small investment of resources
- More providers
- Rooted in clinical psychology

# Unifying Differing Perspectives/ Approaches

**Two groups of clinicians/researchers have been working independently on developing behavior treatments for problem behavior in children with ASD**

# Unifying Differing Perspectives/ Approaches

## Applied Behavior Analysis

Most severe cases

Small-n designs

Individualized  
interventions

Basic mechanisms &  
internal validity



# Unifying Differing Perspectives/ Approaches

## Applied Behavior Analysis

Most severe cases

Small-n designs

Individualized  
interventions

Basic mechanisms &  
internal validity

## Clinical Psychology

Less severe cases

Group designs

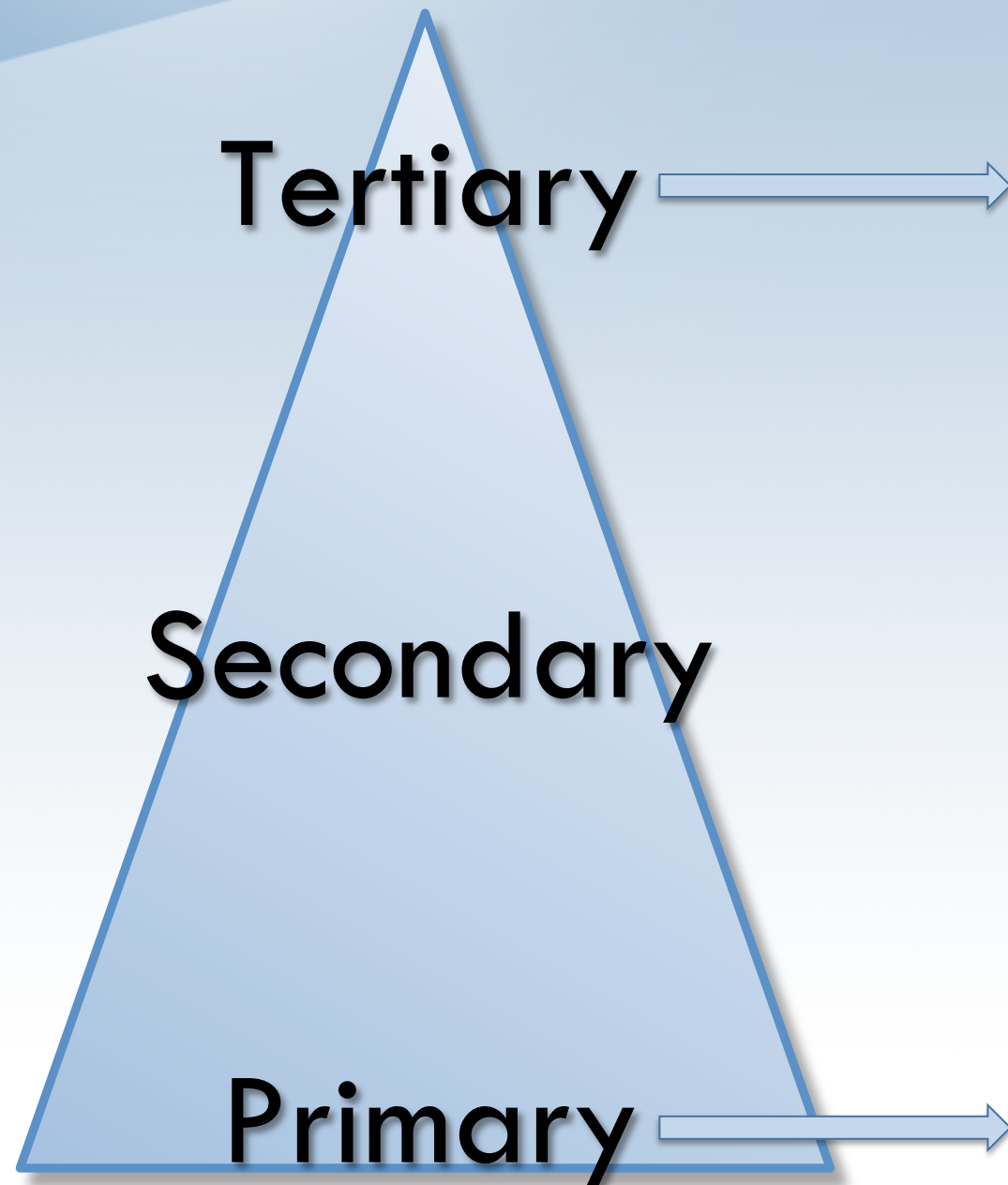
Manualized  
interventions

Exportability &  
external validity

**Challenges/Opportunities:** Bridge the divide between perspectives

- Address the questions that remain unanswered on each side using whatever methods are most appropriate

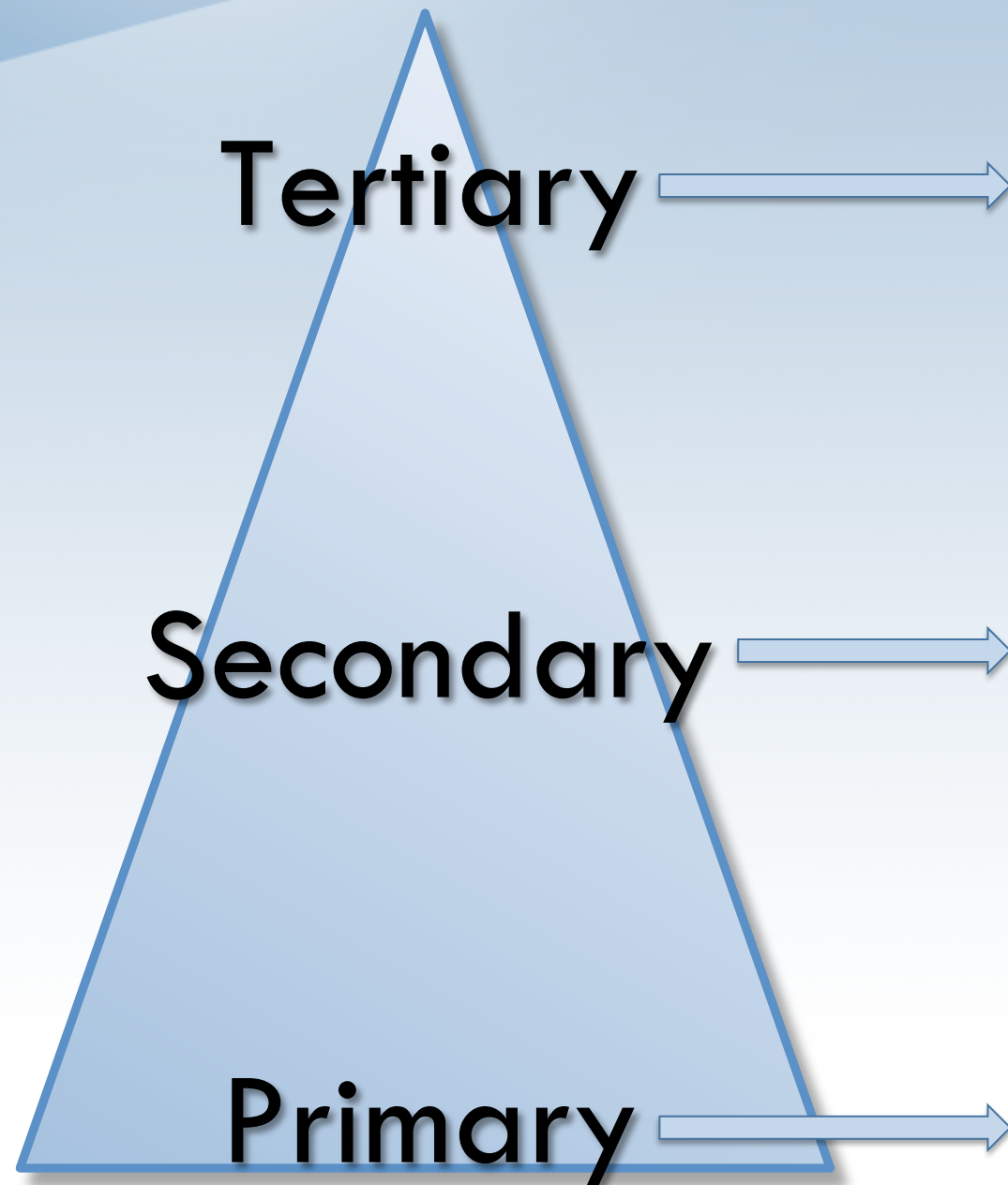
# A Continuum of Service Models



- Highest severity/lower prevalence
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- Lowest severity/highest prevalence
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- Rooted in clinical psychology

# A Continuum of Service Models



- Highest severity/lower prevalence
  - High investment of resources
  - Extremely few providers
  - Rooted in applied behavior analysis
- 
- Moderate intensity/high prevalence
  - Relatively modest investment of resources
  - Limited providers
- 
- Lowest severity/highest prevalence
  - Low investment of resources
  - More providers
  - Rooted in clinical psychology



# Caregiver Mediated Treatment

**Behavioral treatments for problem behavior are usually caregiver mediated**

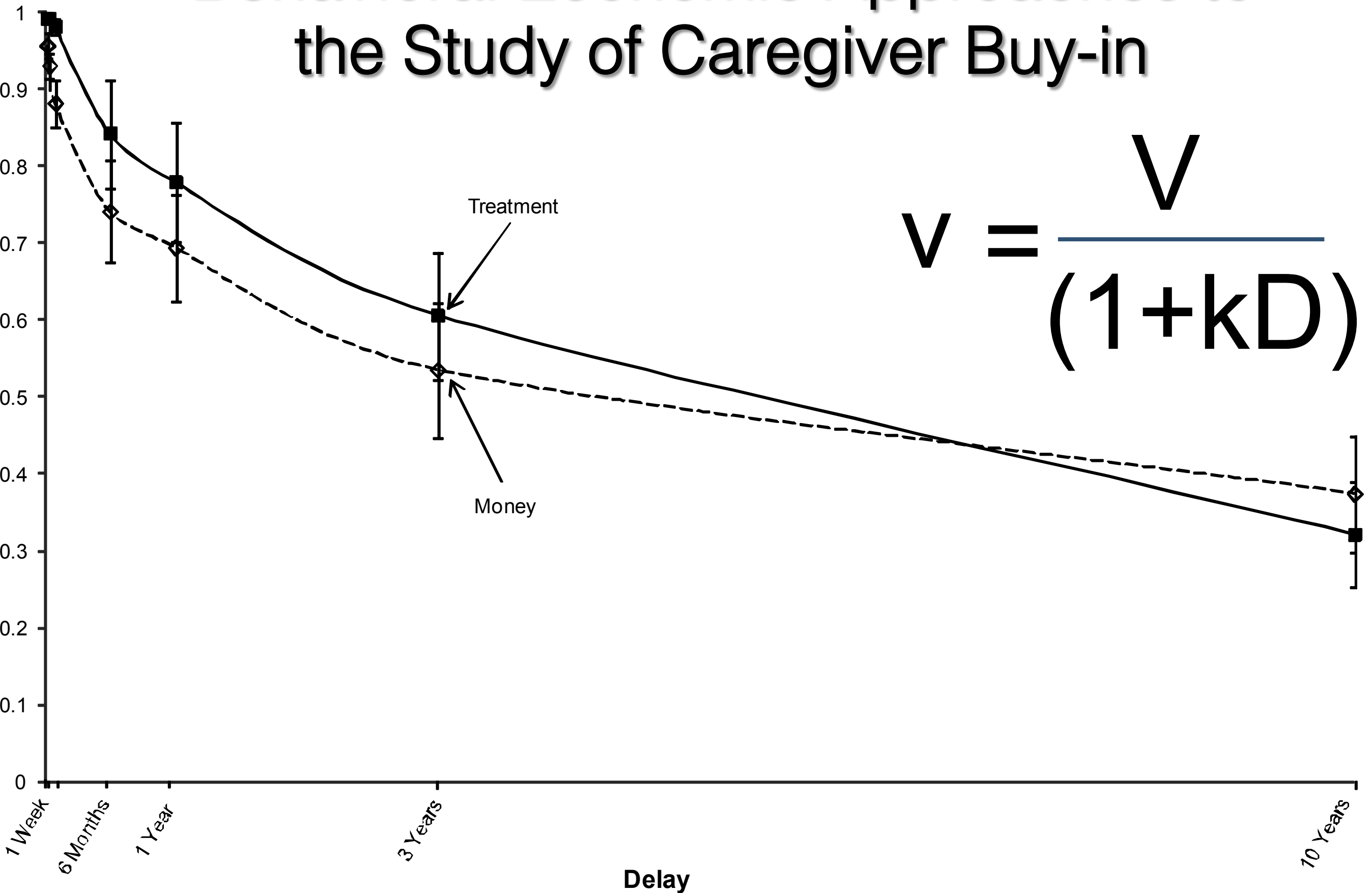


Buy-in is almost always high initially, but sometimes degrades

**Challenge/Opportunity:** Studying factors that affect caregiver buy-in are as important as research on refining treatment procedures

**Delay to treatment outcome**  
**Effort required to implement treatment**

# Behavioral Economic Approaches to the Study of Caregiver Buy-in



## Caregiver implementation of treatments is often limited by extraneous factors

- Poverty, underemployment, lack of social supports
- Pre-admission assessment of the environment and identification of barriers to treatment success
- Care coordination to provide wrap-around services

**Challenge/Opportunity:** Care coordination is generally unreimbursed



**Limited number of providers lead to waiting lists and less availability for rural populations**

## Telehealth

- Clinic-to-clinic
- Clinic-to-home

**Challenge/Opportunity:** poor reimbursement and unclear regulation of telehealth

Joanna Lomas Mevers

Mindy Scheithauer

Sarita Miller

Stephanie Kincaid

Jennifer Hodnett

Andrea Reavis

Ally Coleman

Sarah Wymer

Seth Clark

Natalie Parks

Megan Wiggins

Christina Simmons

Courtney McCracken

Scott Gillespie

Thank You

The logo for the Marcus Autism Center, featuring a stylized white arc above the word "Marcus" in a serif font, with "AUTISM CENTER" in a smaller sans-serif font below it.

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of Excellence