

From Specialized Clinic-based Tertiary Care to Communities & Prevention



Marcus
AUTISM CENTER

**NIH Autism Center
of Excellence**

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Assessments Using Telehealth for Children with Autism*

Problem Behavior in Autism Spectrum Disorder

Although prevalence estimates vary (15%-65%)¹, 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 harm¹
- Exclusion from community services and peers²
- Stigma

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

- Poorer family functioning¹
- Lower marital satisfaction^{1,2}
- Higher rates of problem behavior in siblings^{3,4}
- Parental unemployment^{5,6}
- 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:

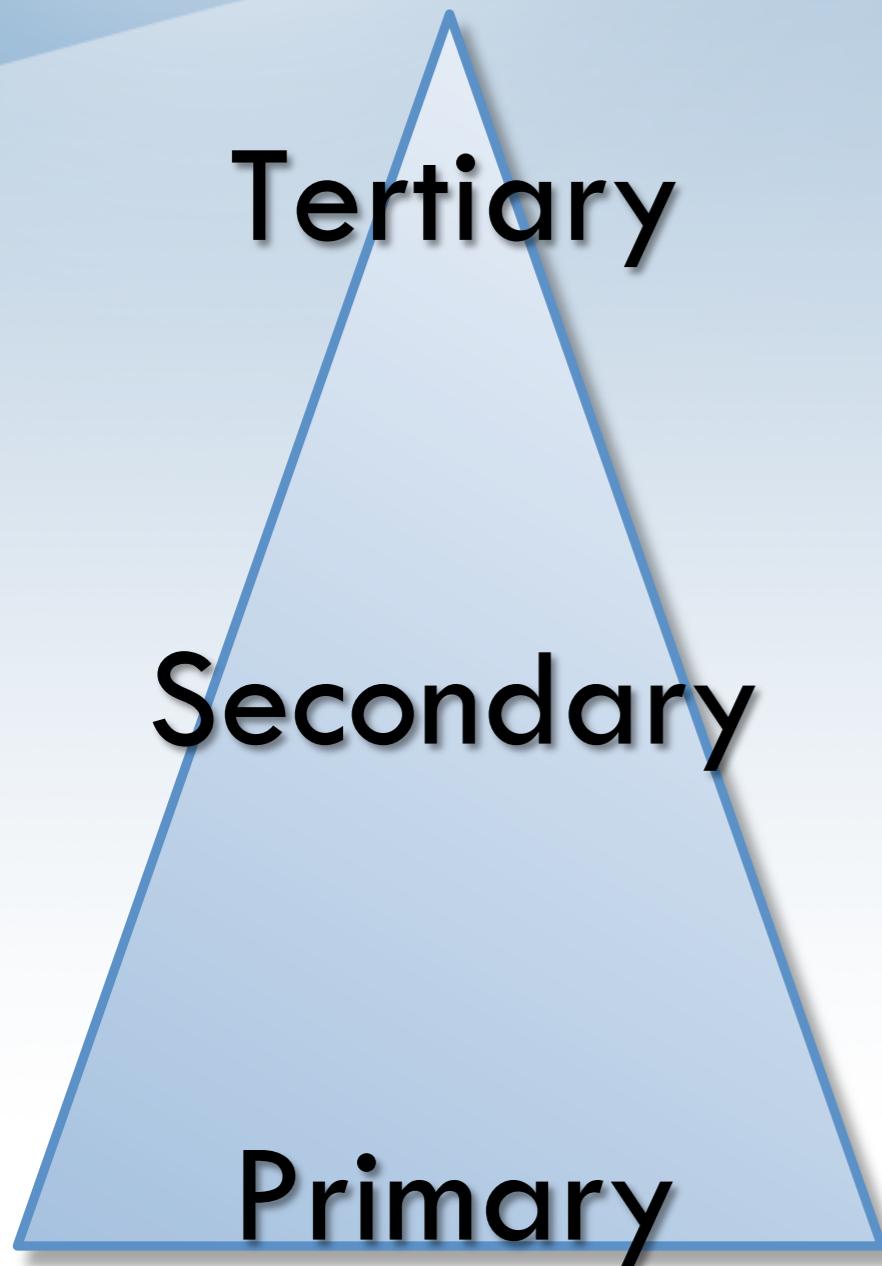
- Function-based treatments
- Levels of service that fit the continuum of severity
- Mediation by caregivers
- Comprehensive/systems approach
- Treatment models that are accessible

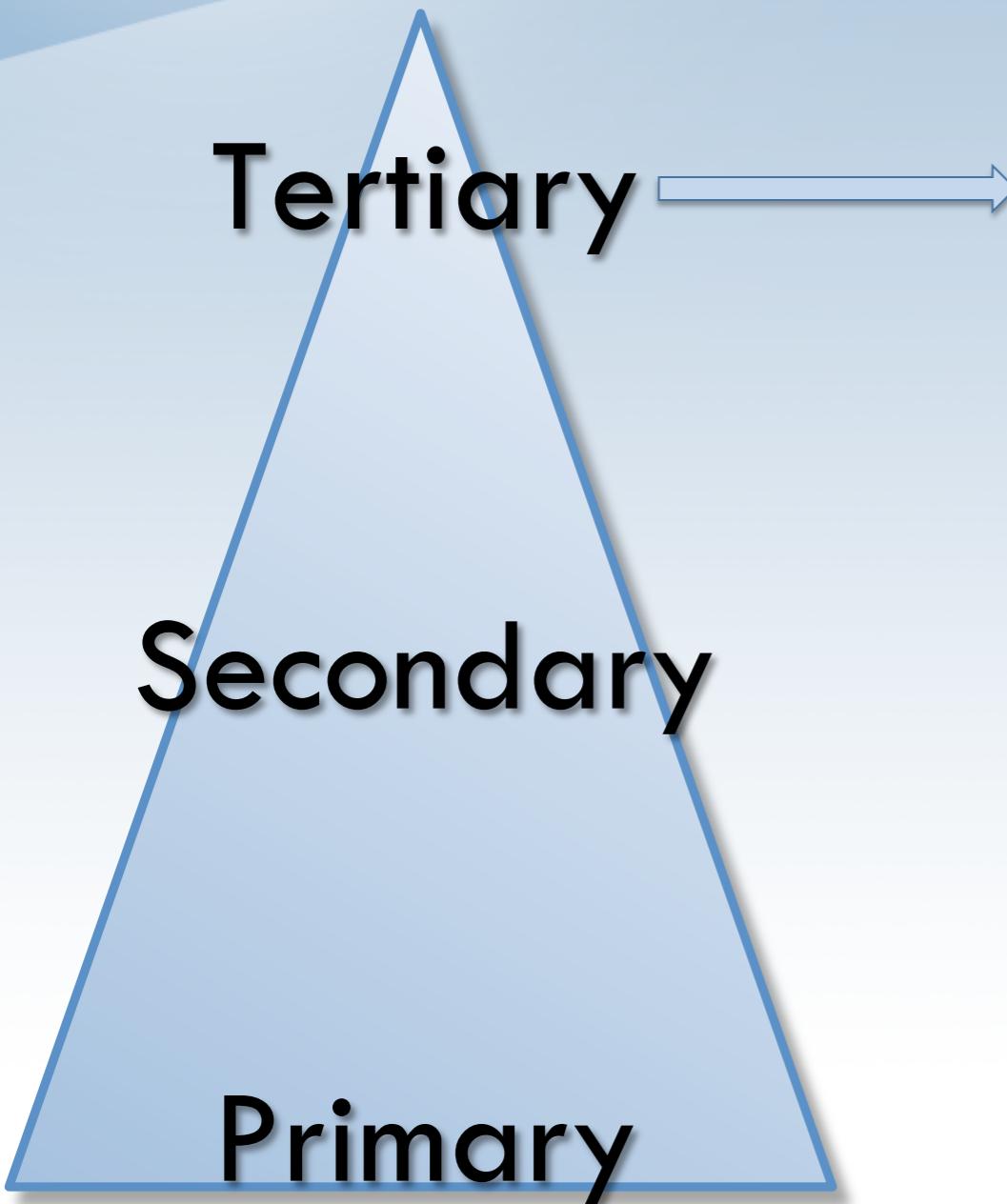
Function-Based Treatments

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^{1,2}

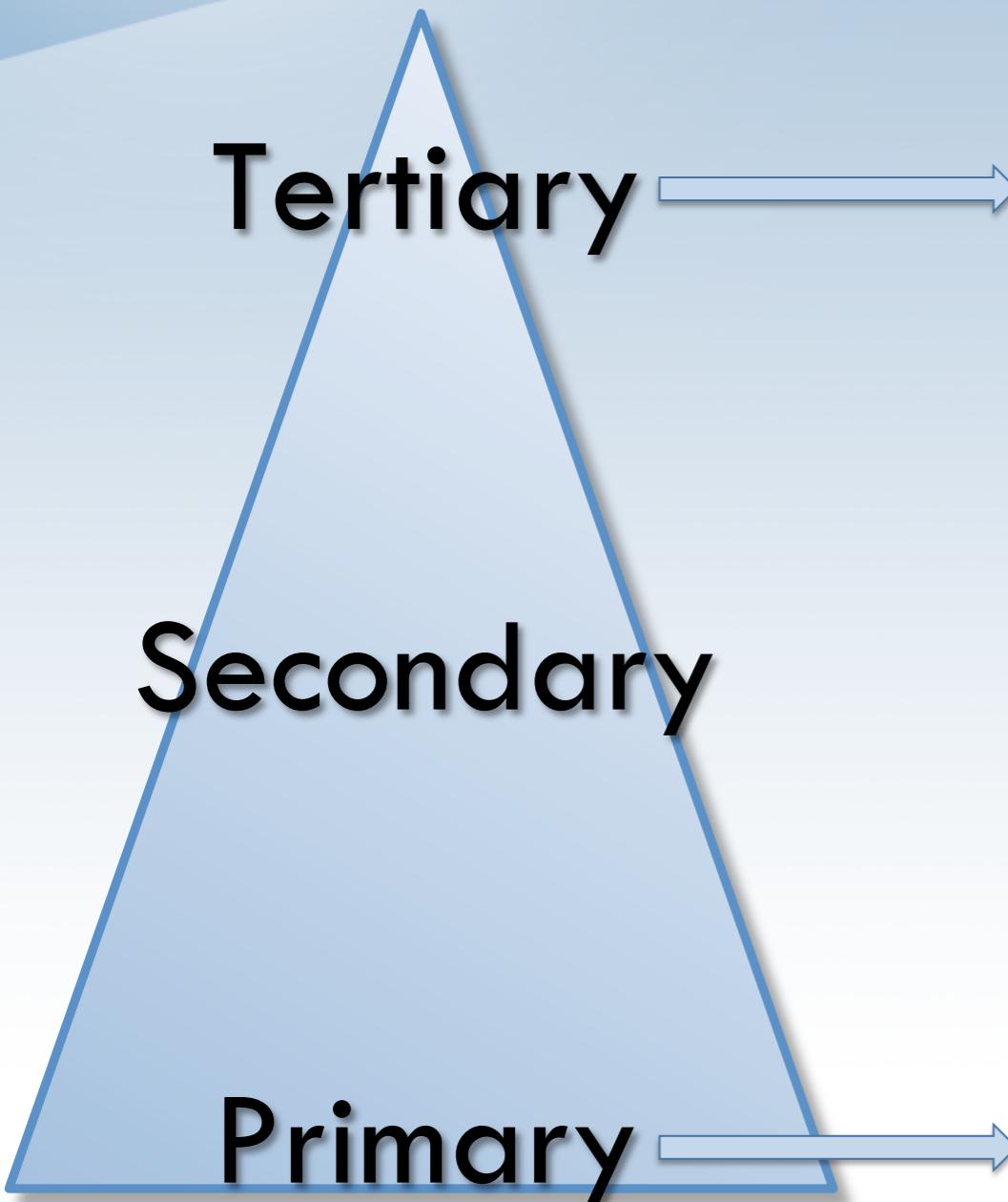
A Continuum of Service Models





A Continuum of Service Models

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



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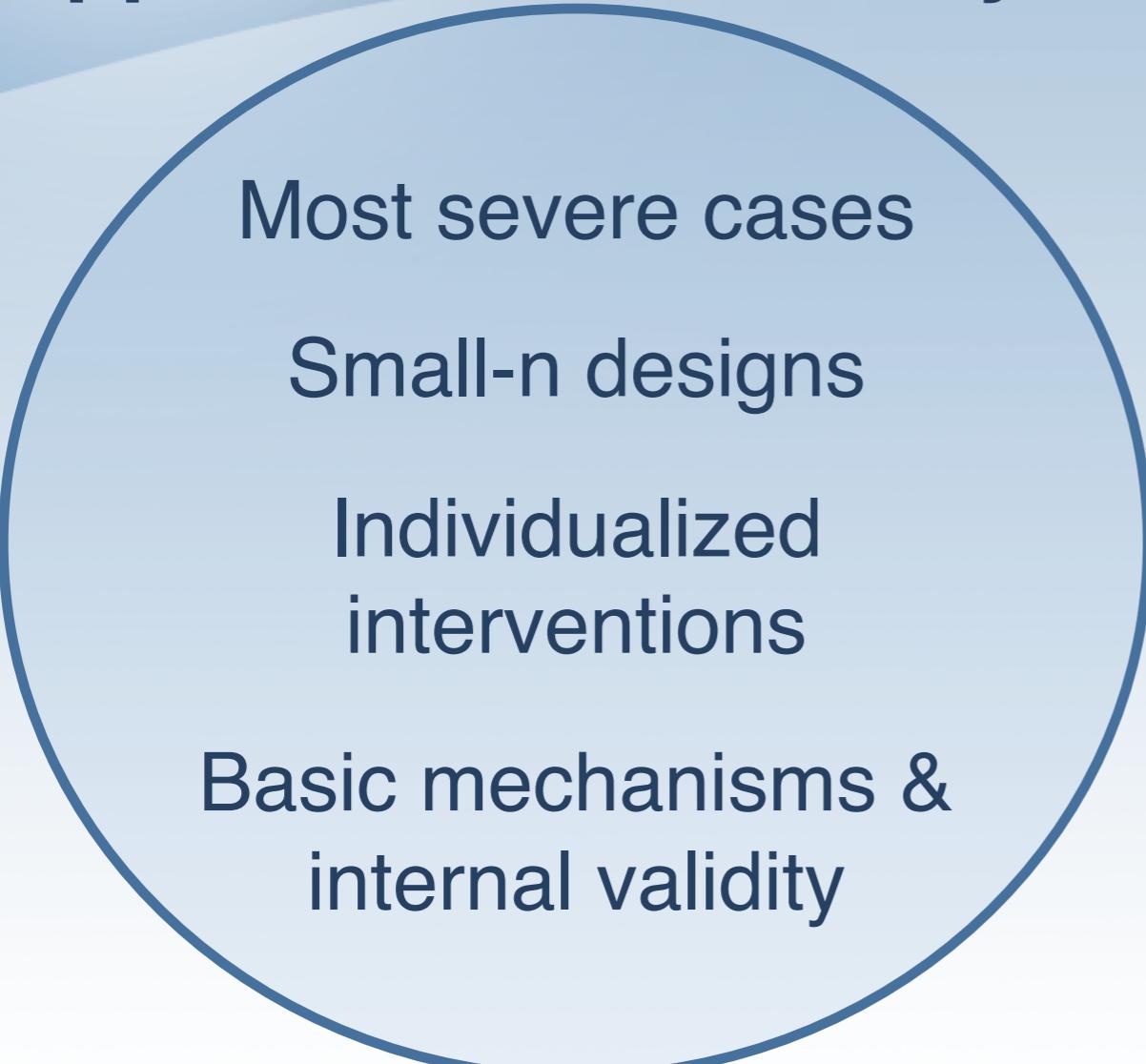
- Lowest severity/highest prevalence
- Small investment of resources
- More providers
- Rooted in clinical psychology

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

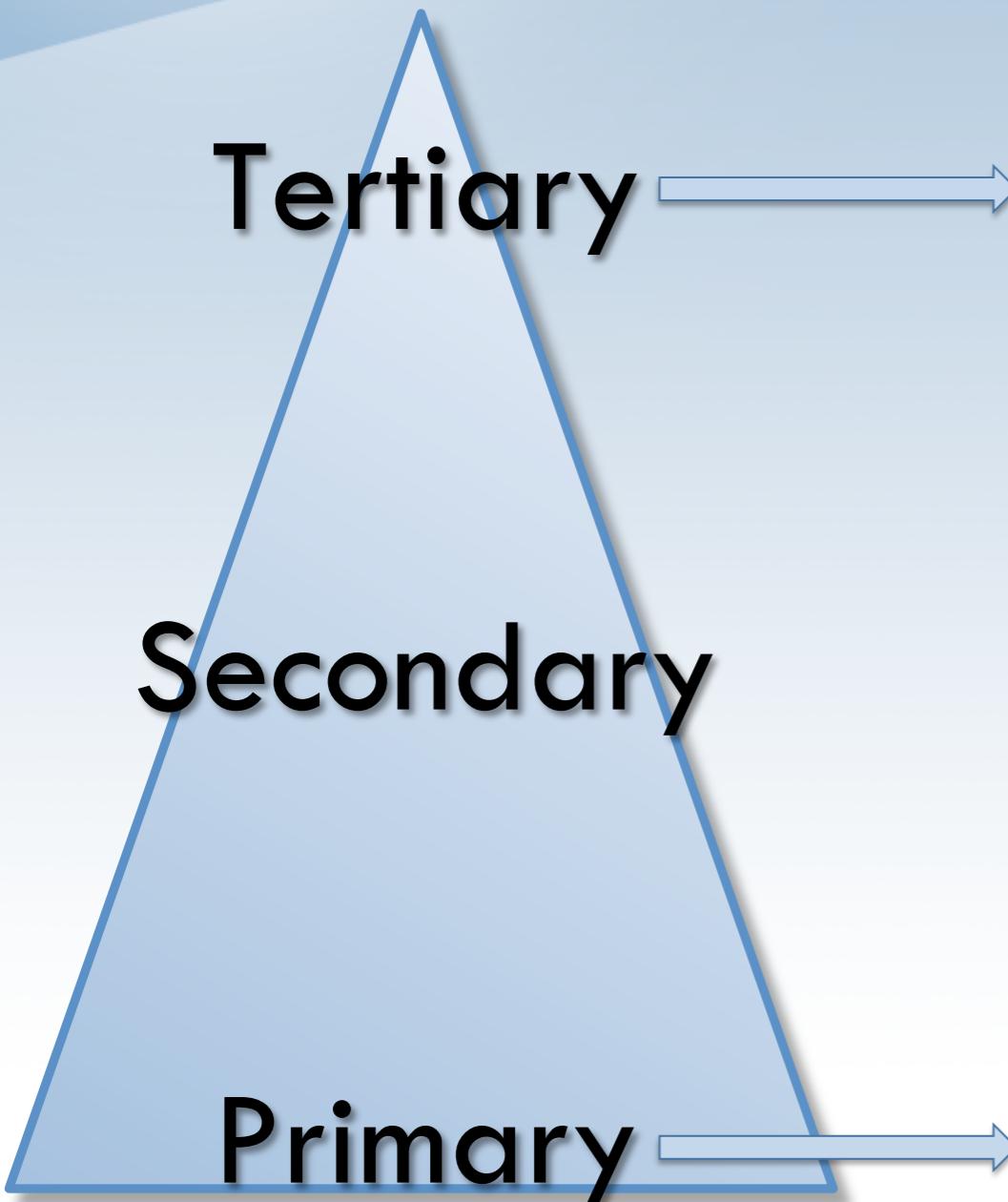
Group designs

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

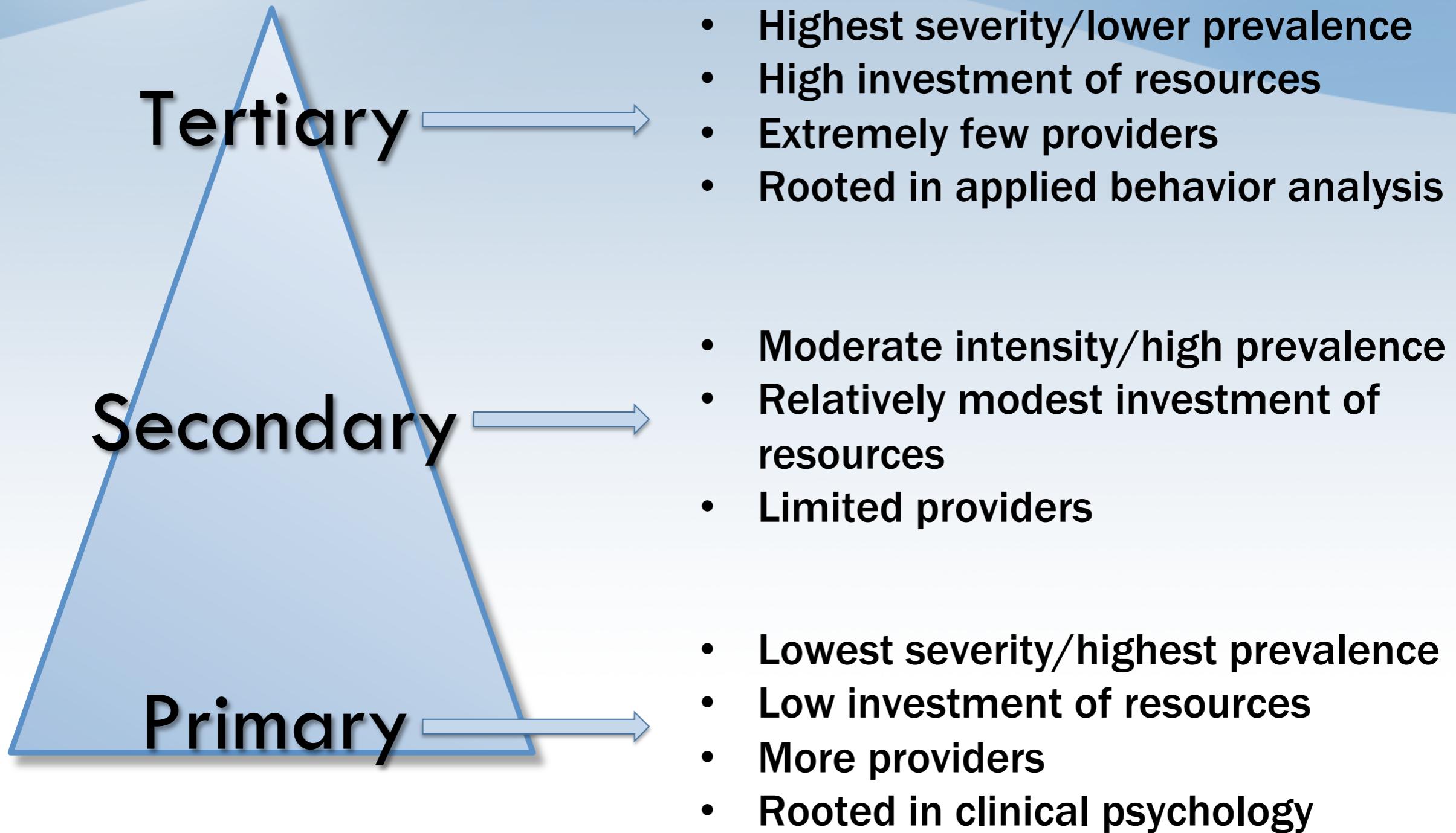


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A Continuum of Service Models



Caregiver Mediated Treatment

Behavioral treatments for problem behavior are usually caregiver mediated

Caregiver
buy-in

Treatment
fidelity

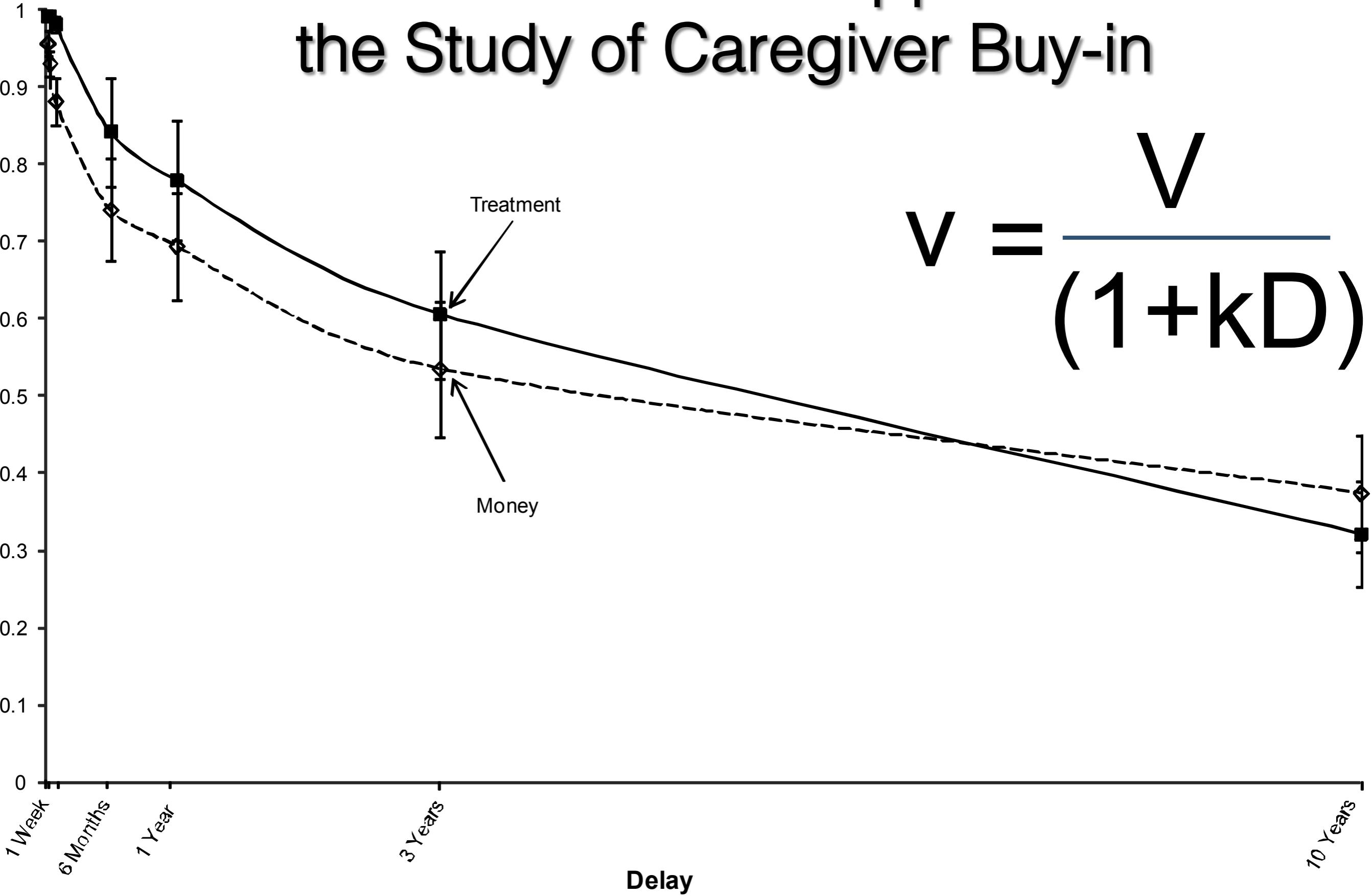
Positive
outcomes

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



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Mindy Scheithauer

Sarita Miller

Stephanie Kincaid

Jennifer Hodnett

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Scott Gillespie

Thank You

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