Translating the Move and PLAY Study: Thoughts for Families and Practitioners

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Move and PLAY
Movement & Participation in Life Activities of Young Children

"Understanding the Determinants of Motor Abilities, Self Care, and Play for Young Children with Cerebral Palsy"

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Outline of the Session

- What was the Move and PLAY study?
- What did we learn?
- What does this mean for practitioners and families?
- What are your thoughts and questions?

Objectives

At the conclusion of the presentation participants will:

1. Understand the child, family, and service factors which impact motor abilities, self-care, participation, and play of young children with cerebral palsy.
2. Apply the results of the Move & PLAY study to practice decisions related to promoting motor abilities, self-care, participation, and play for young children with cerebral palsy.
3. Identify the importance of collaboration between practitioners and families in the decisions and care of young children with cerebral palsy.

Questions for Reflection

- Are any findings surprising?
- Do the findings support current service provision?
- What changes in service provision will be challenging?
- What child, family, and service factors are missing from the model?
- What are other important outcomes to consider?

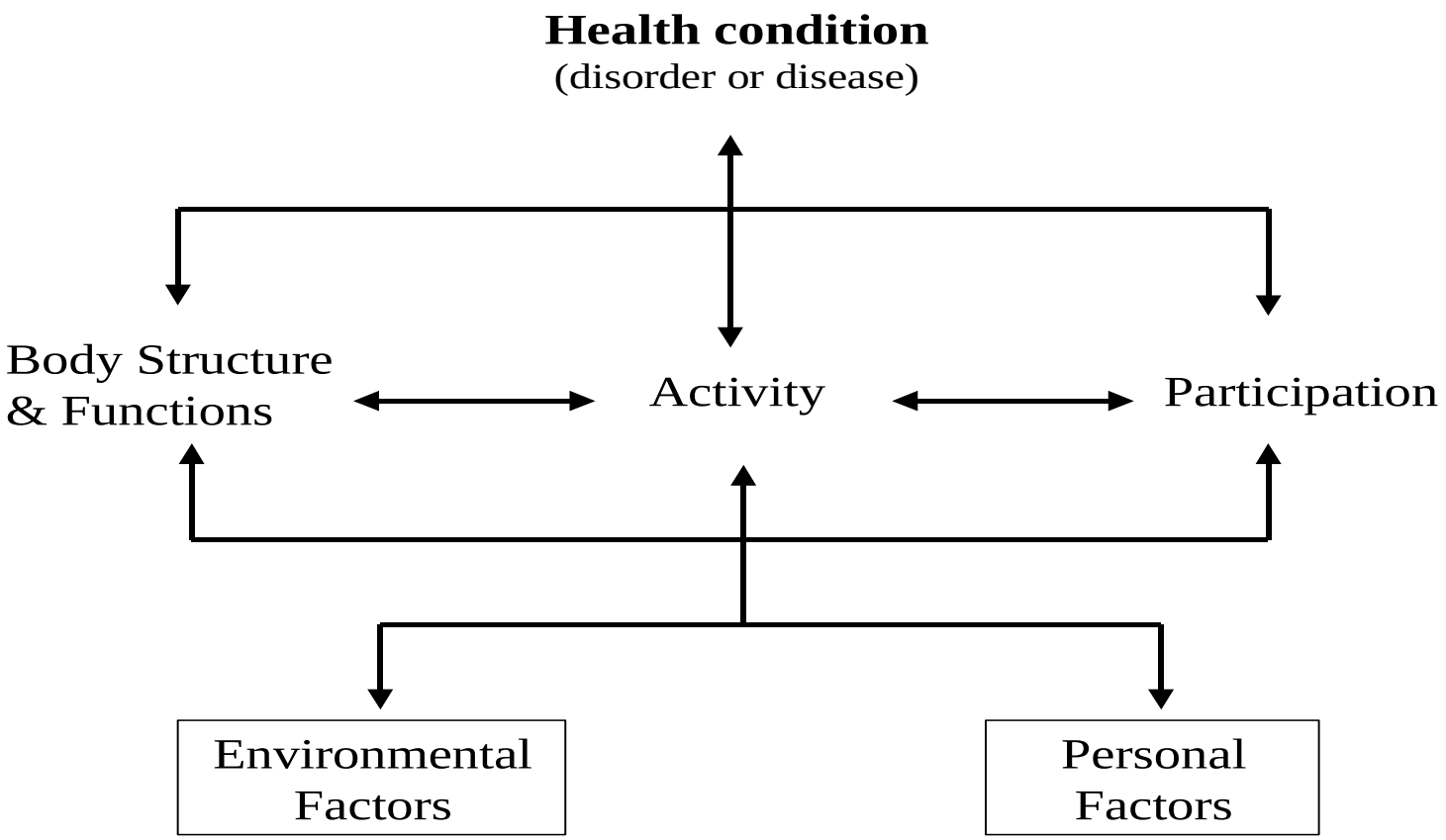
Why was this research conducted?

- Motor ability, self-care, participation in home & community activities, and playfulness are important outcomes for young children with cerebral palsy.
- Information on the factors that enhance these outcomes is particularly needed because families expend considerable time and resources to meet their children's needs.

- Understanding the complex inter-relationships among child, family, and service factors is needed to guide clinical decision making.
  - Current knowledge available on the bi-variate relationships between aspects of the child and outcomes
- Knowledge of **evidence based interventions, supports to families, and community resources** is needed to provide services that are most beneficial.

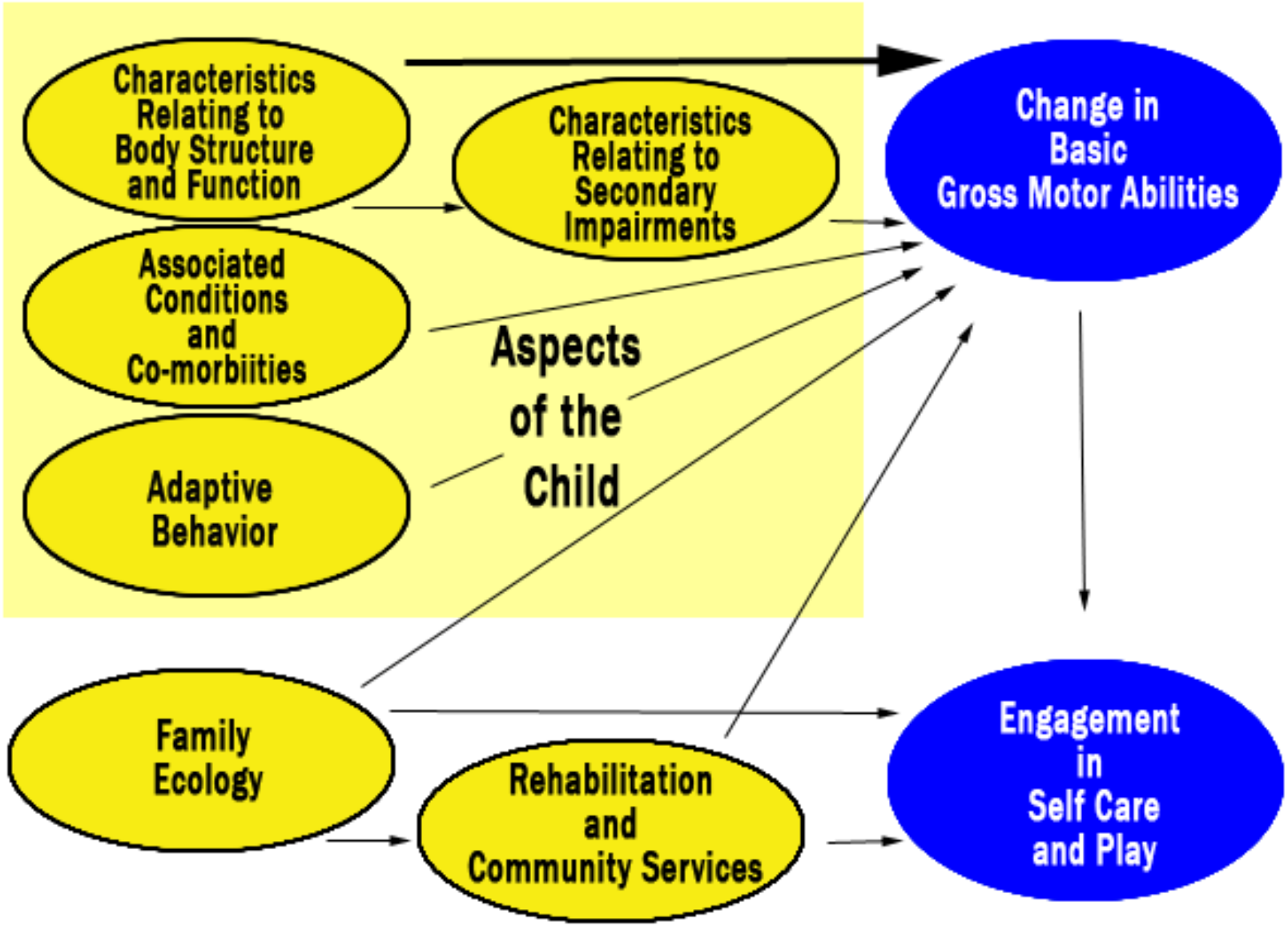
International Classification of Functioning, Disability, & Health

World Health Organization



What was the Move and PLAY study?

- Tested a model of child, family, and services hypothesized to help children with cerebral palsy move around, take care of themselves (self-care: feeding, dressing, bathing), participate in and enjoy activities, and be playfull


Characteristics Relating to Body Structure and Function
Characteristics Relating to Secondary Impairments
Change in Basic Gross Motor Abilities
Associated Conditions and Co-morbiities
Aspects of the Child
Adaptive Behavior
Family Ecology
Rehabilitation and Community Services
Engagement in Self Care and Play

Setting and Participants

- 4 regions in the United States and 6 provinces in Canada
- Convenience sample of 429 children with CP and parents
  - Children
    - 242 boys, 187 girls
    - 18-60 months of age (Mean age 3y 2mo, SD 11mo)
    - 70% white
    - Varied gross motor abilities across all GMFCS levels
  - Parents
    - 92% mothers, 69% at least some college level education, median family income $60,000 - $74,999
  - 90% retention rate over one year

Methods

- Prospective cohort study
- Data collected in children's homes or therapy clinics
- 3 data collection sessions over a one-year period
- Data analysis: Structural Equation Modeling

Measures

Time 1: Start of study

Parents:

- Adaptive Behavior: Early Coping Inventory
- Endurance Questionnaire
- Health Problems Questionnaire
- Family Demographic Questionnaire

Therapist Assessors:

- Spasticity: Modified Ashworth Scale
- Quality of Movement: Gross Motor Performance Measure
- Balance: Pediatric Balance Scale & Automatic Reactions of MAI
- Strength
- Spinal Alignment and Range of Motion Measure
- Distribution of Involvement
- Gross Motor Functional Classification System (GMFCS) level
- Motor Ability: Gross Motor Function Measure B&C

Gross Motor Function Classification System (GMFCS)

(Palisano et al, 2008)

	Children 2 to 4 years	Children 4 to 6 years
Level I	Moves by walking without a walking aid	Walks without restrictions
Level II	Walks with a walking aid	Walks without a walking aid
Level III	Walks short distances with a walking aid	Walks with a walking aid
Level IV	Self mobility is limited within a room, transported outdoors	
Level V	Self mobility severely limited	

Measures

Time 2: Mid-point, 6 months later

Parents

- Family Functioning: Family Environment Scale
- Family Expectations of Child Questionnaire
- Service Questionnaire

Time 3: End of study, 1 year after start of study

Parents

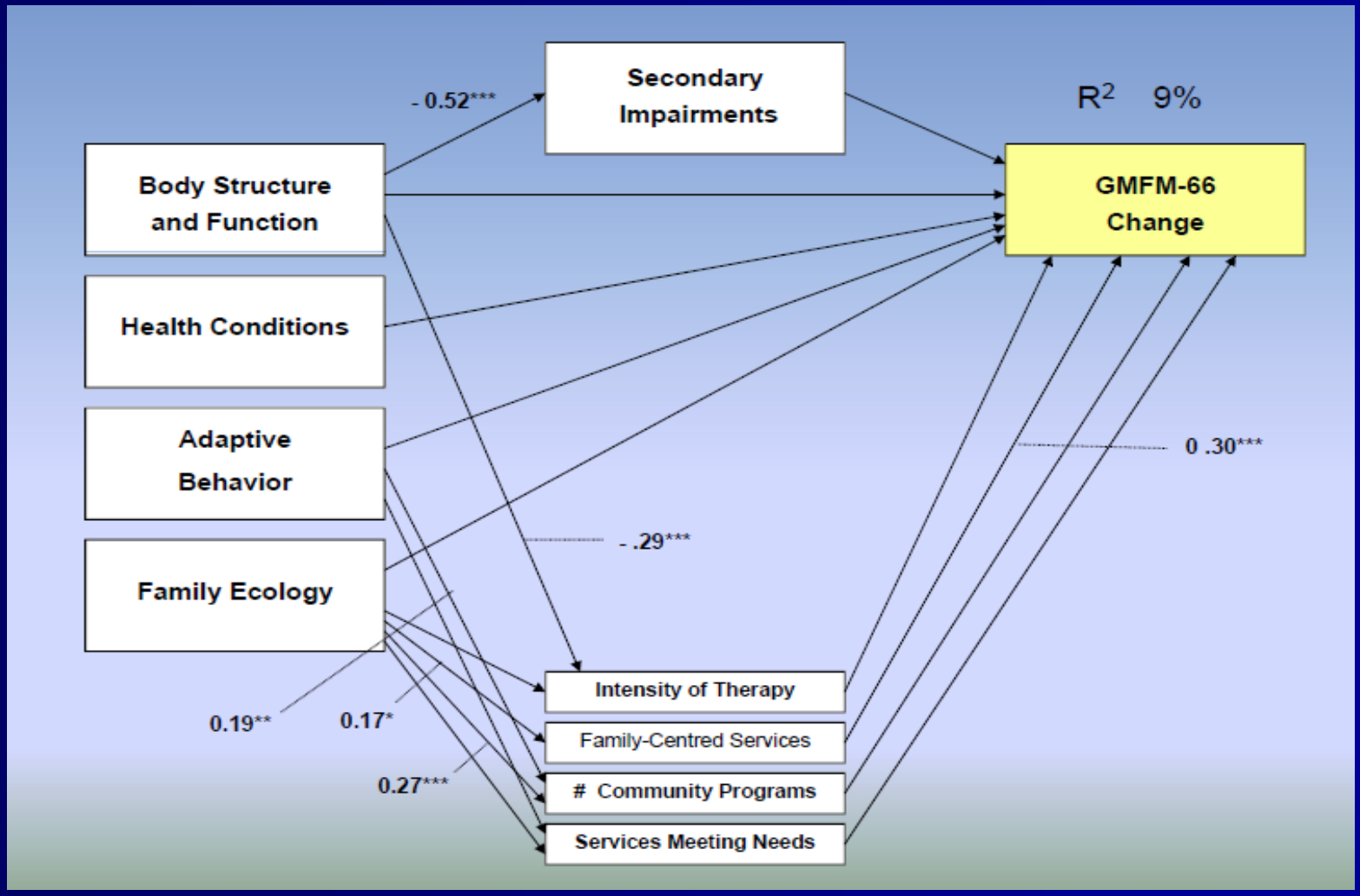
- Self-Care Abilities, Amount and Enjoyment of Participation: Child Engagement in Daily Life Measure

Therapist Assessors

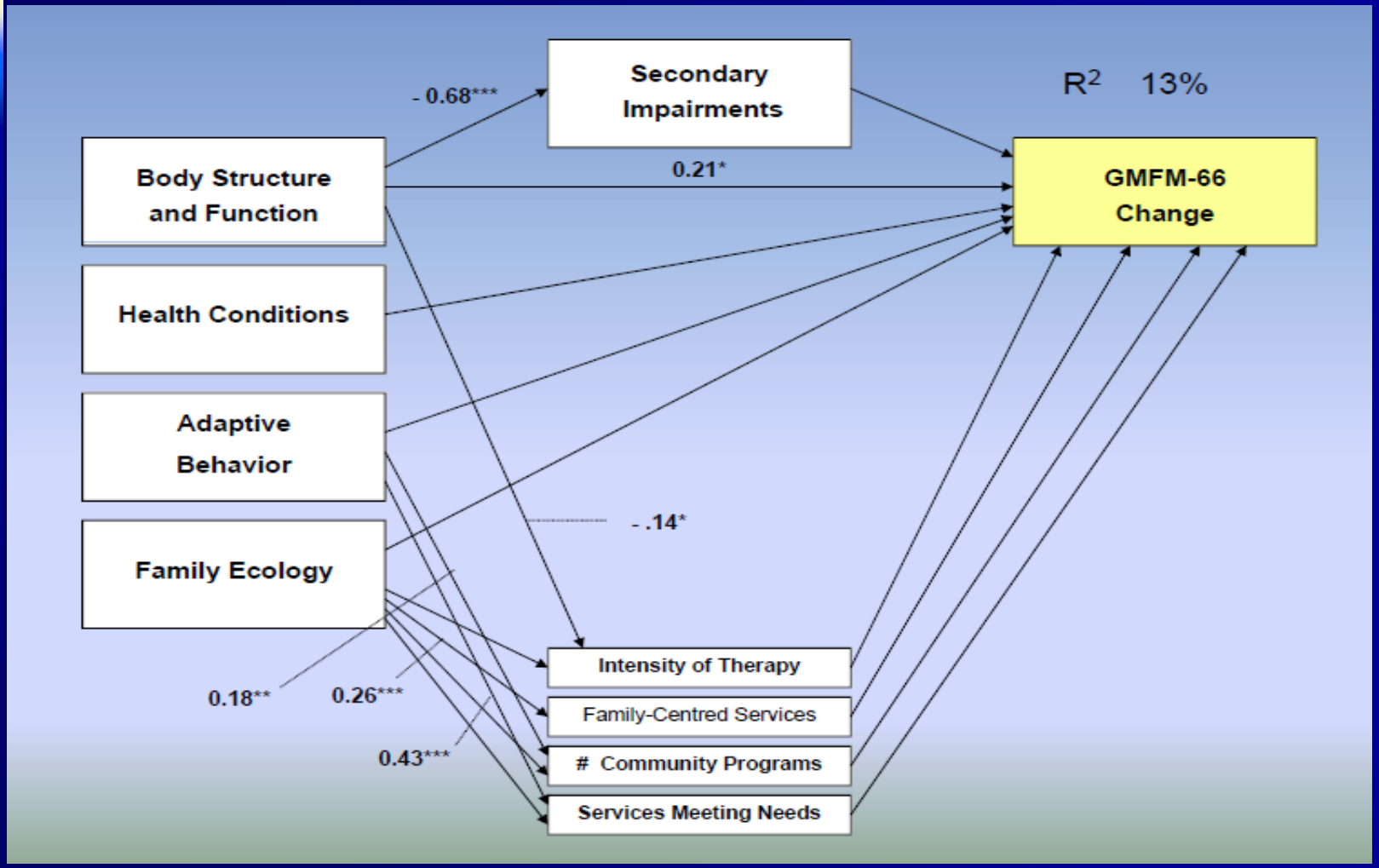
- Playfulness: Test of Playfulness
- Motor Ability: Gross Motor Function Measure B &C

MOVING

What did we learn about Change in Motor Function: Results for Children in GMFCS Levels I and II



What did we learn about Change in Motor Function: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Change in Motor Function?

GMFCS Levels I & II

- Model explained 9% of the variability in children's change in motor function

GMFCS Levels III, IV, V

- Model explained 13% of the variability in children's change in motor function

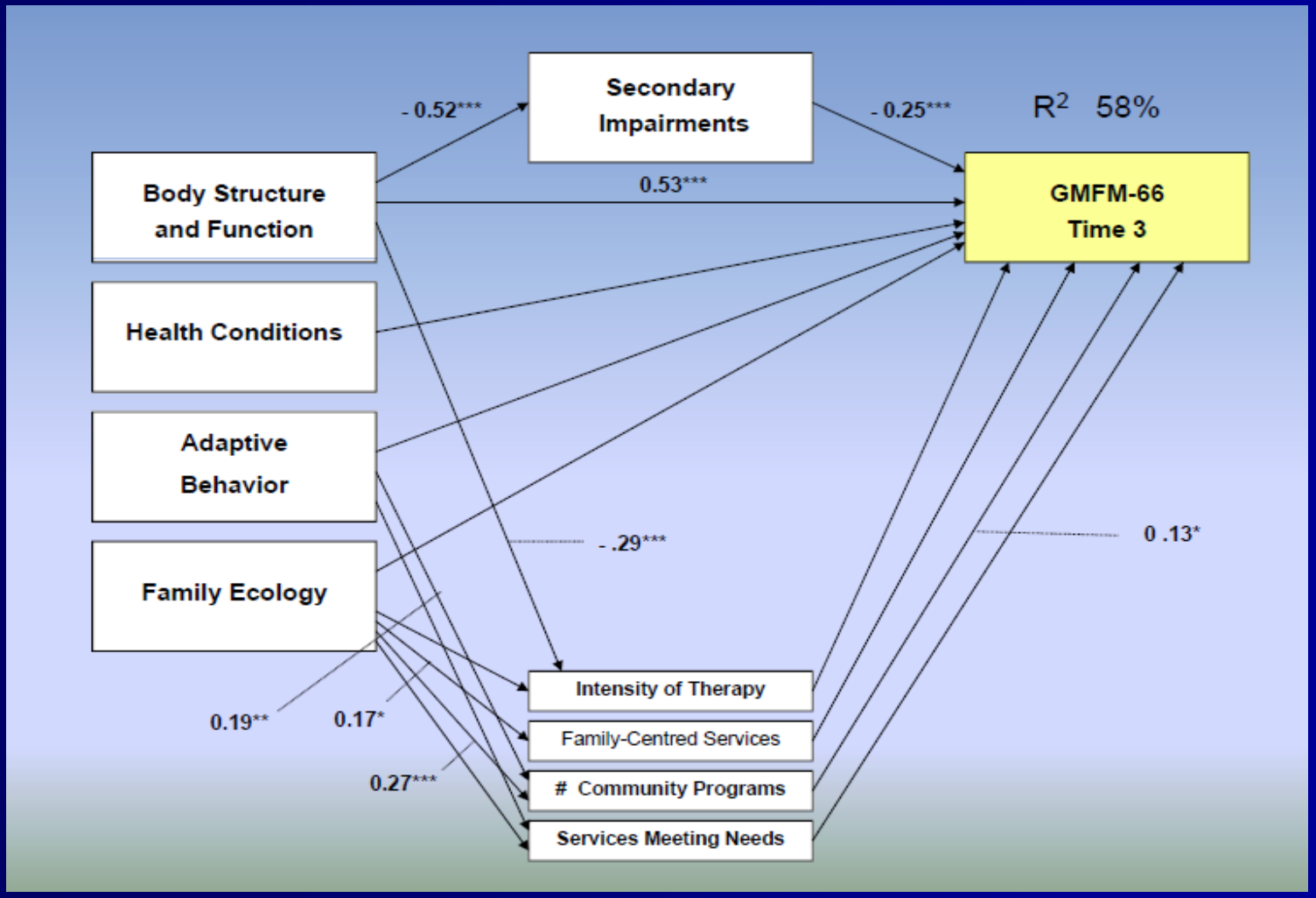
Higher change in motor function was related to:

- Greater Family Centeredness of Services
- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved

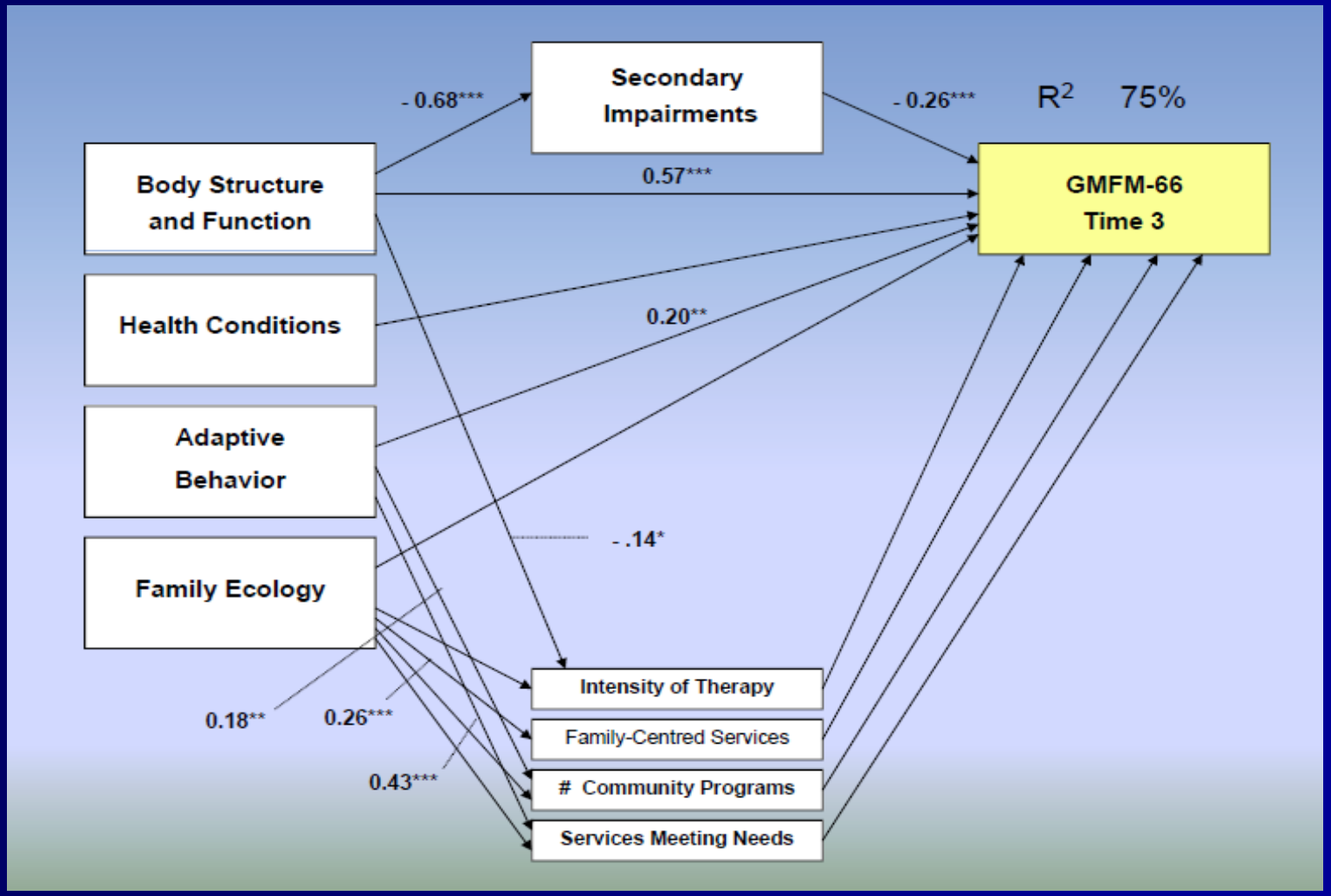
How can practitioners and families support children's Change in Motor Function?

- Recommended focus of services includes:
  - Focus on family centered care
  - Optimize gross motor abilities
    - Enhance balance
    - Prevent secondary impairments
- Predicting change in motor function is complex

What did we learn about Motor Function: Results for Children in GMFCS Levels I and II



What did we learn about Motor Function: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Motor Function?

GMFCS Levels I & II

- Model explained 58% of the variability in children's motor abilities

GMFCS Levels III, IV, V

- Model explained 75% of the variability in children's motor abilities

Higher motor abilities were related to:

- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Higher strength, fewer ROM limitations and better endurance
- Greater participation in community recreation programs

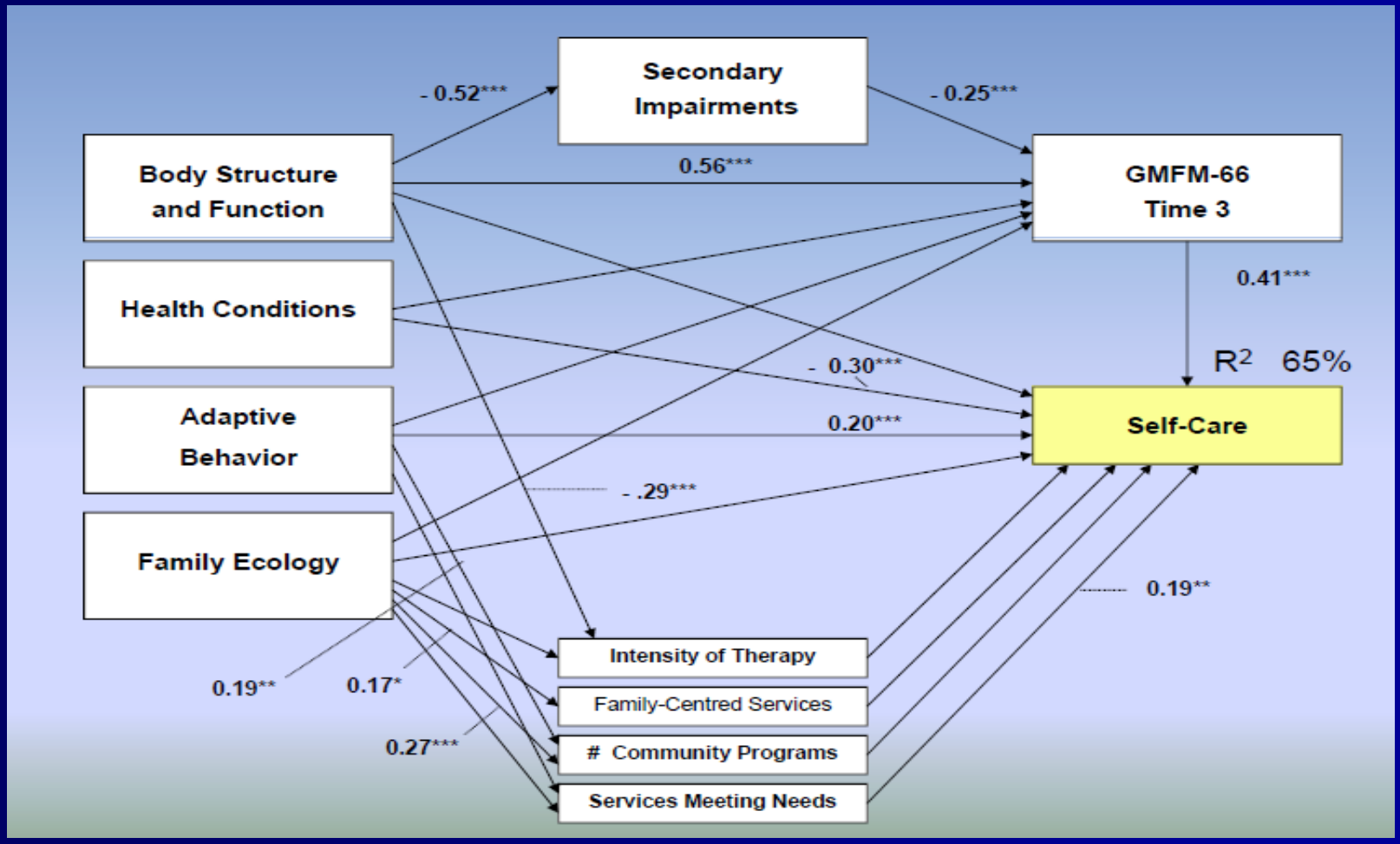
- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Higher strength, fewer ROM limitations and better endurance
- More effective adaptive behavior

How can practitioners and families support children's Motor Function?

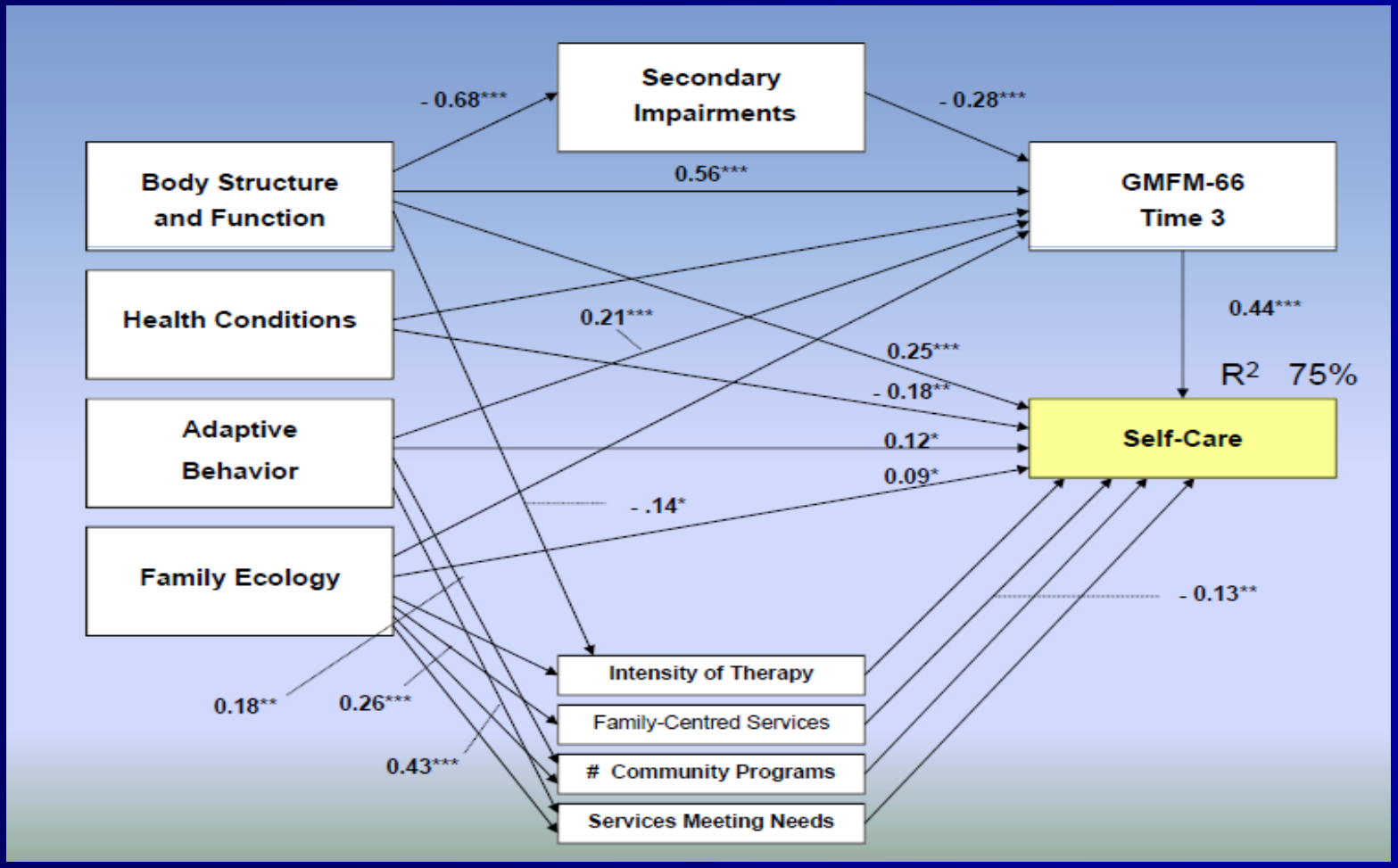
- Recommended focus of services includes:
  - Optimizing abilities
    - Improve balance
    - Prevent secondary impairments
  - Fostering adaptive behavior
    - Encourage and support the child's self-awareness, adaptability, motivation, persistence, and interactions with people in real-life situations
  - Assist families in accessing and collaborate with community programs for their children

Taking Care of Yourself

What did we learn about Self-care: Results for Children in GMFCS Levels I and II



What did we learn about Self-care: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Self-Care?

GMFCS Levels I & II

- Model explained 65% of the variability in children's self-care abilities

GMFCS Levels III, IV, V

- Model explained 75% of the variability in children's self-care abilities

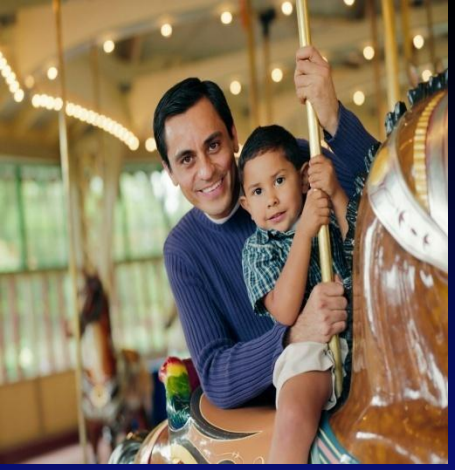
Higher self-care abilities were related to:

- Higher motor abilities
- Better health
- More effective adaptive behavior
- Extent service met needs

- Higher motor abilities
- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Better health
- More effective adaptive behavior
- Stronger attributes of families
- Parent's weaker perceptions of family-centeredness of services

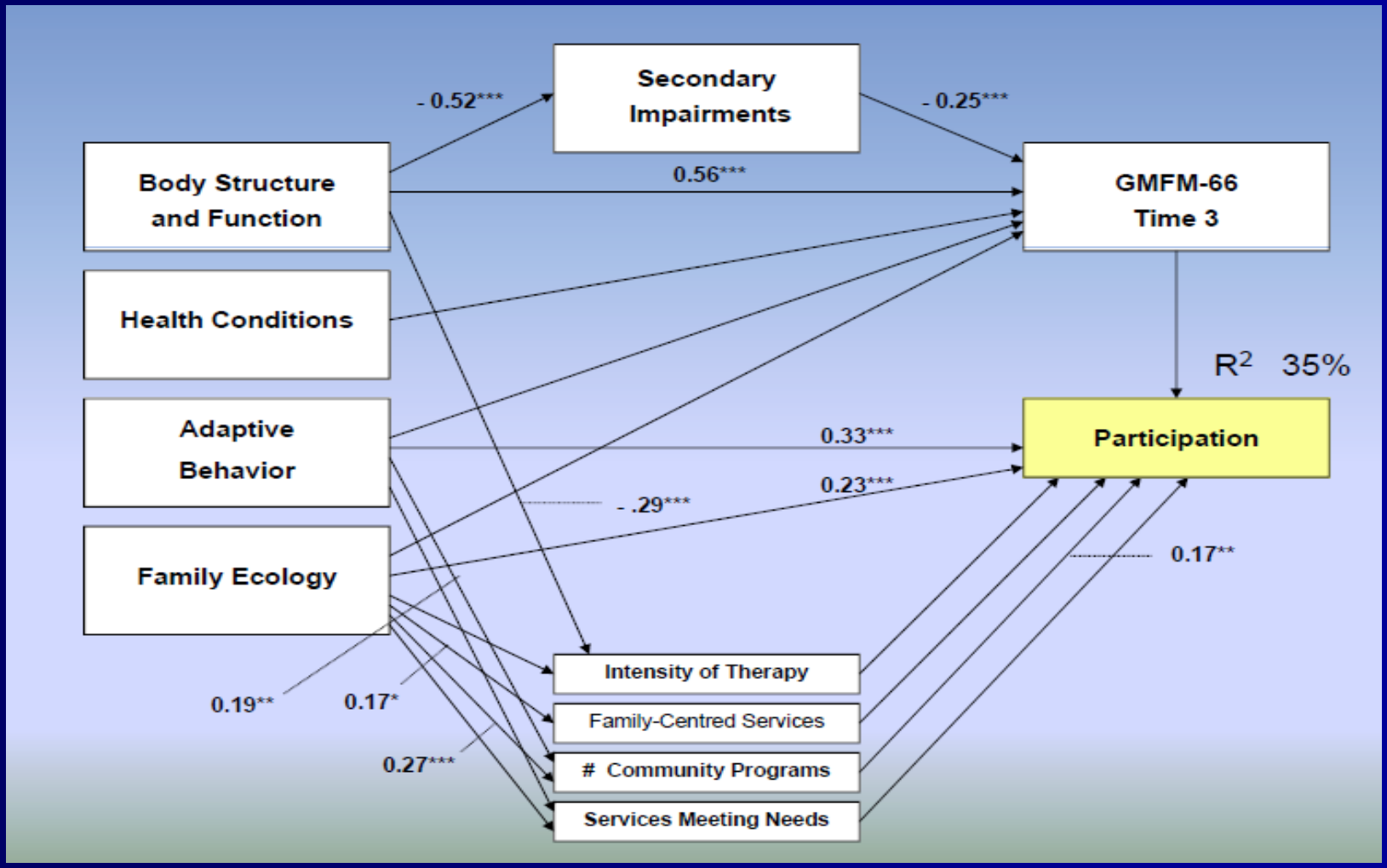
How can practitioners and families support children's Self-care?

- Recommended focus of services includes:
  - Optimize gross motor abilities
    - Enhance balance
    - Prevent secondary impairments
  - Promote health
  - Foster adaptive behavior
    - Self-awareness, adaptability, motivation, persistence, problem-solving, and interactions with people in real-life situations
  - Support family's role in nurturing their children
  - Address family priorities and needs for their child

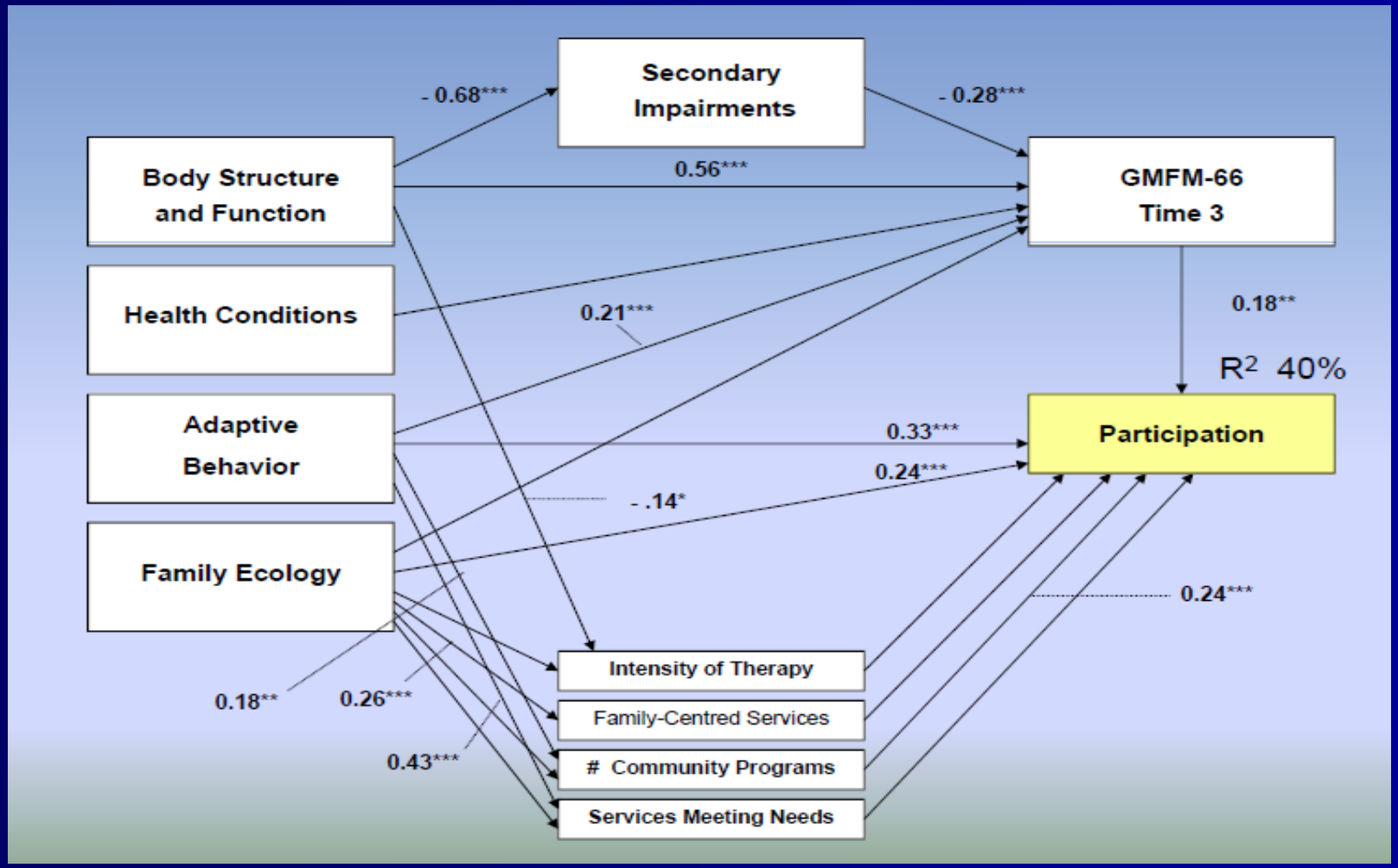


Participation

What did we learn about Amount of Participation: Results for Children in GMFCS Levels I and II



What did we learn about Amount of Participation: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Amount of Participation?

GMFCS Levels I & II

- Model explained 35% of the variability in children's participation abilities

GMFCS Levels III, IV, V

- Model explained 40% of the variability in children's participation abilities

More participation in family & recreation activities was related to:

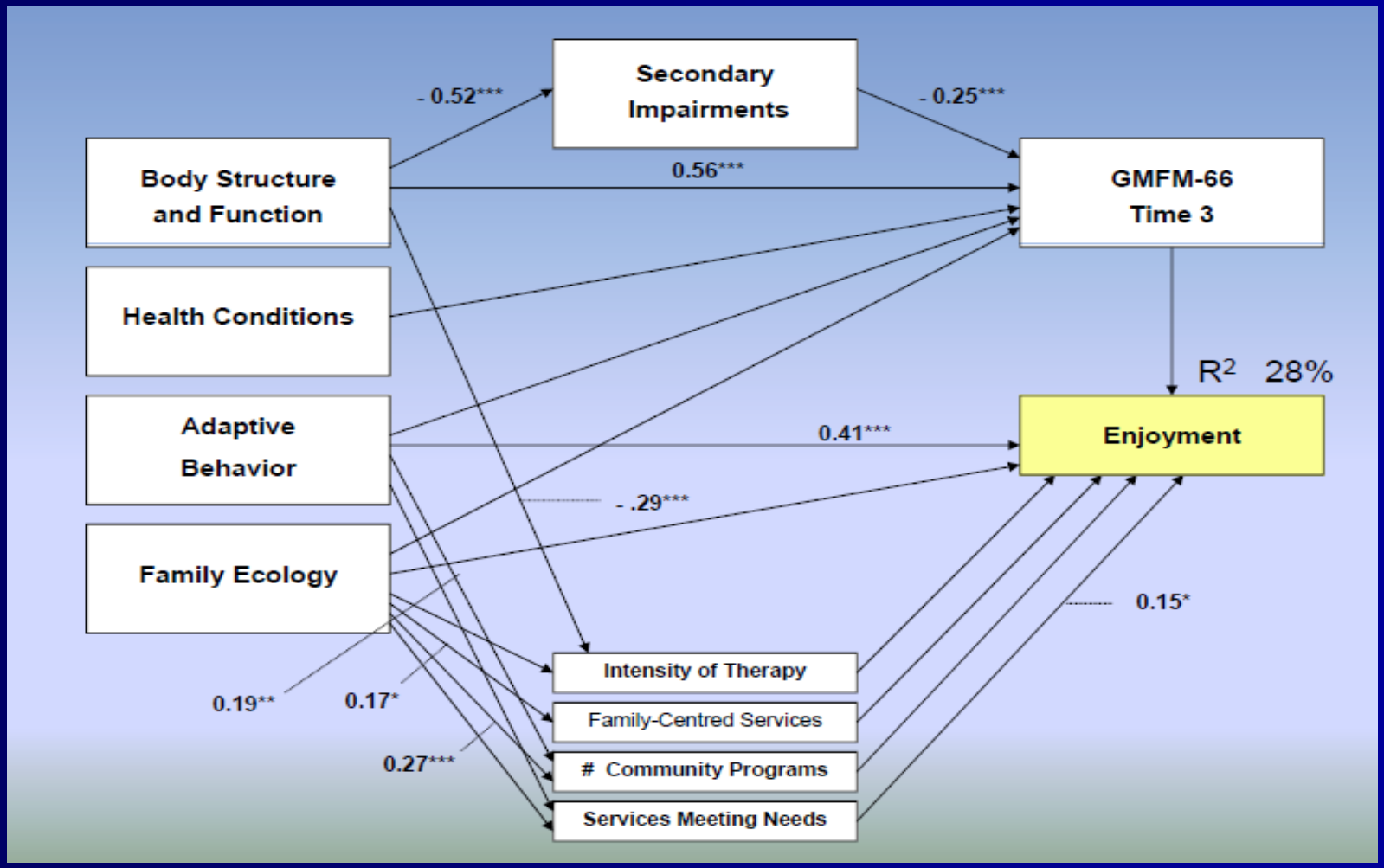
- More effective adaptive behavior
- Stronger attributes of families
- Greater involvement in community programs

- More effective adaptive behavior
- Stronger attributes of families
- Greater involvement in community programs
- Higher gross motor abilities

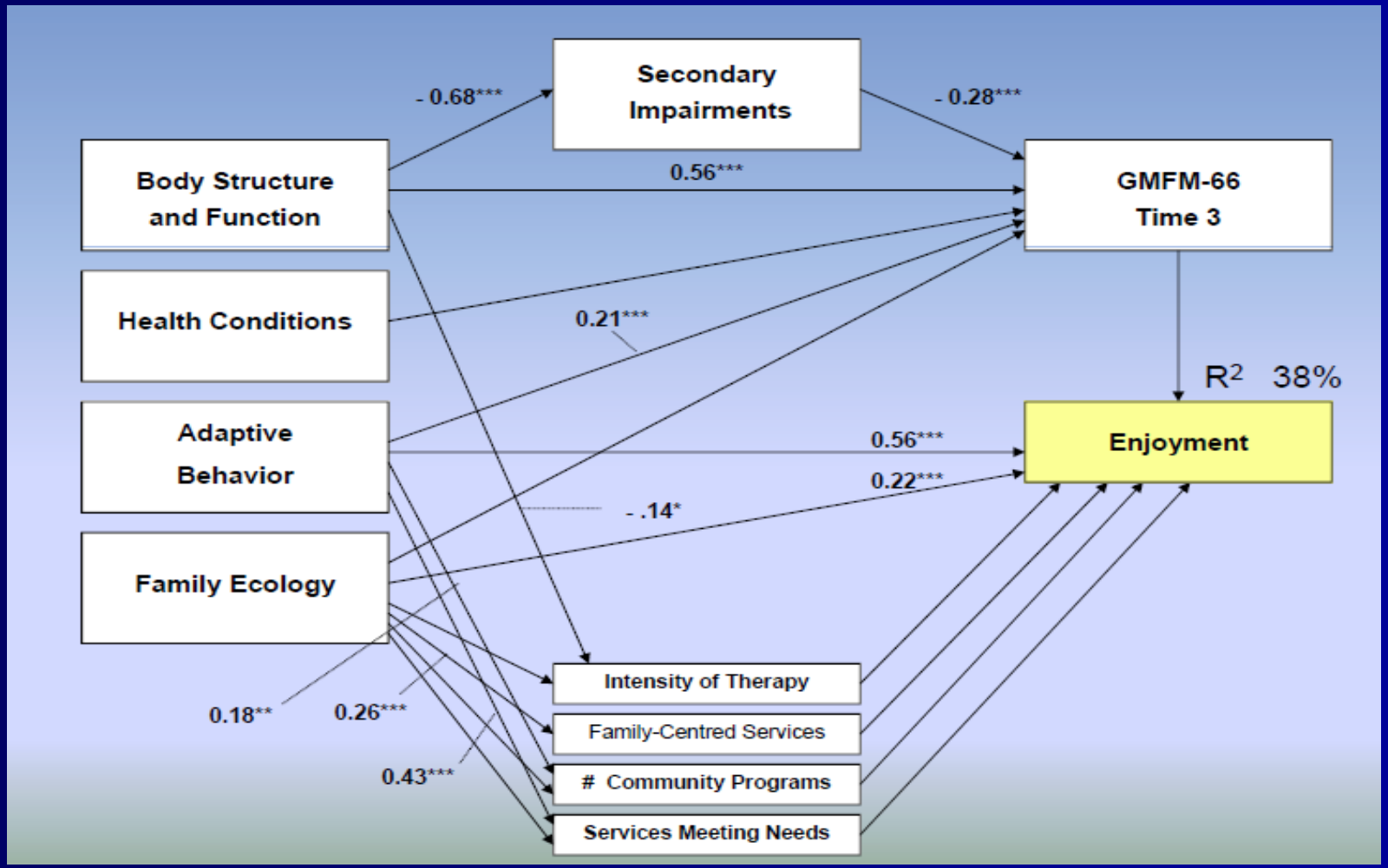
How can practitioners and families support children's Participation?

- Recommended focus of services includes:
  - Foster adaptive behavior
    - Self-awareness, adaptability, motivation, persistence, problem-solving, and interactions with people in real-life situations
  - Support family's role in nurturing their children
  - Assist families in accessing and collaborate with community programs for their children
    - Services in natural environments
  - Optimize gross motor abilities
    - Enhance balance
    - Prevent secondary impairments

What did we learn about Enjoyment of Participation: Results for Children in GMFCS Levels I and II



What did we learn about Enjoyment of Participation: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Enjoyment of Participation?

GMFCS Levels I & II

- Model explained 28% of the variability in children's enjoyment abilities

GMFCS Levels III, IV, V

- Model explained 38% of the variability in children's enjoyment abilities

Higher Enjoyment was related to:

- More effective adaptive behavior
- Extent services met needs

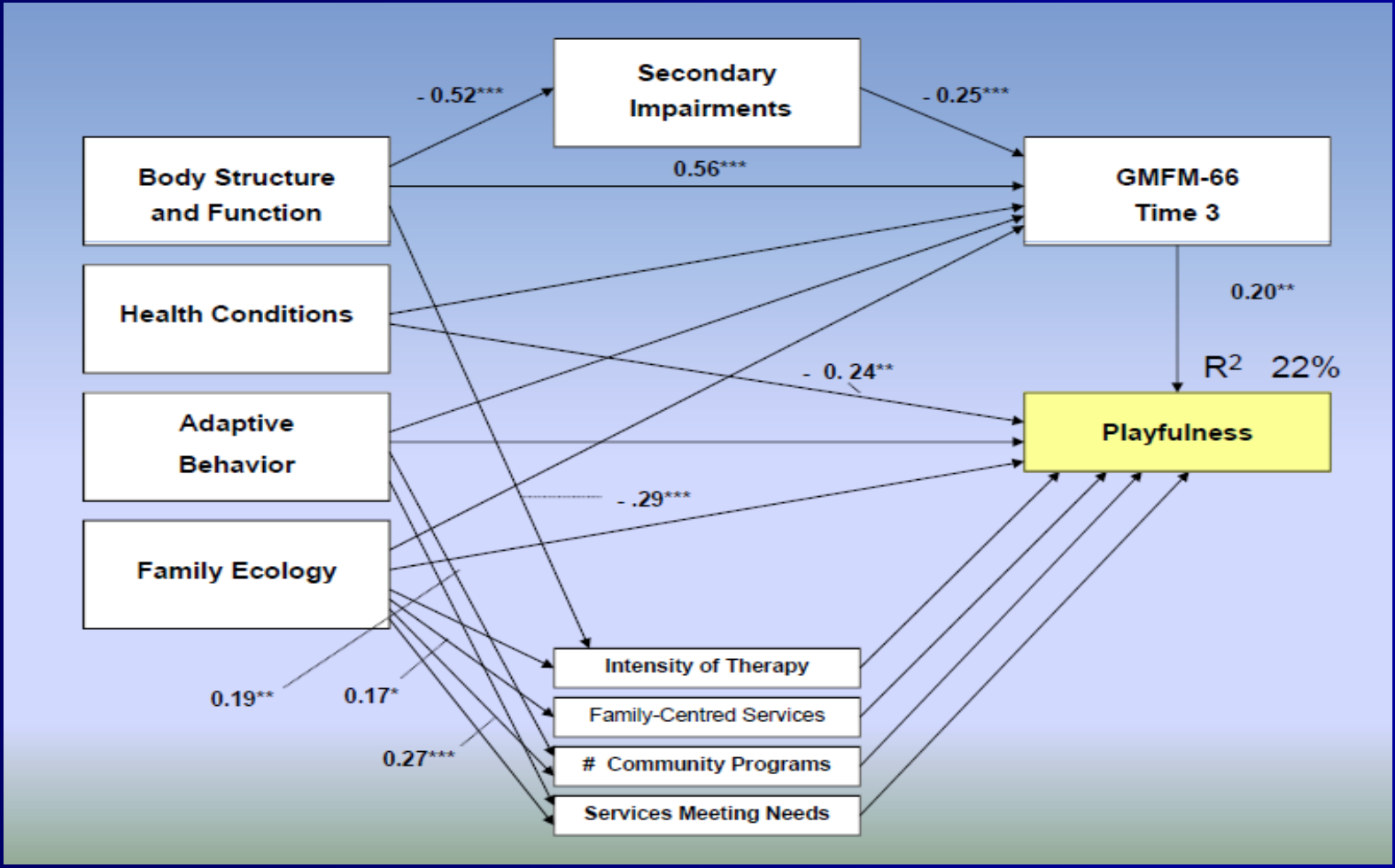
- More effective adaptive behavior
- Stronger attributes of families

How can practitioners and families support children's Enjoyment of Participation?

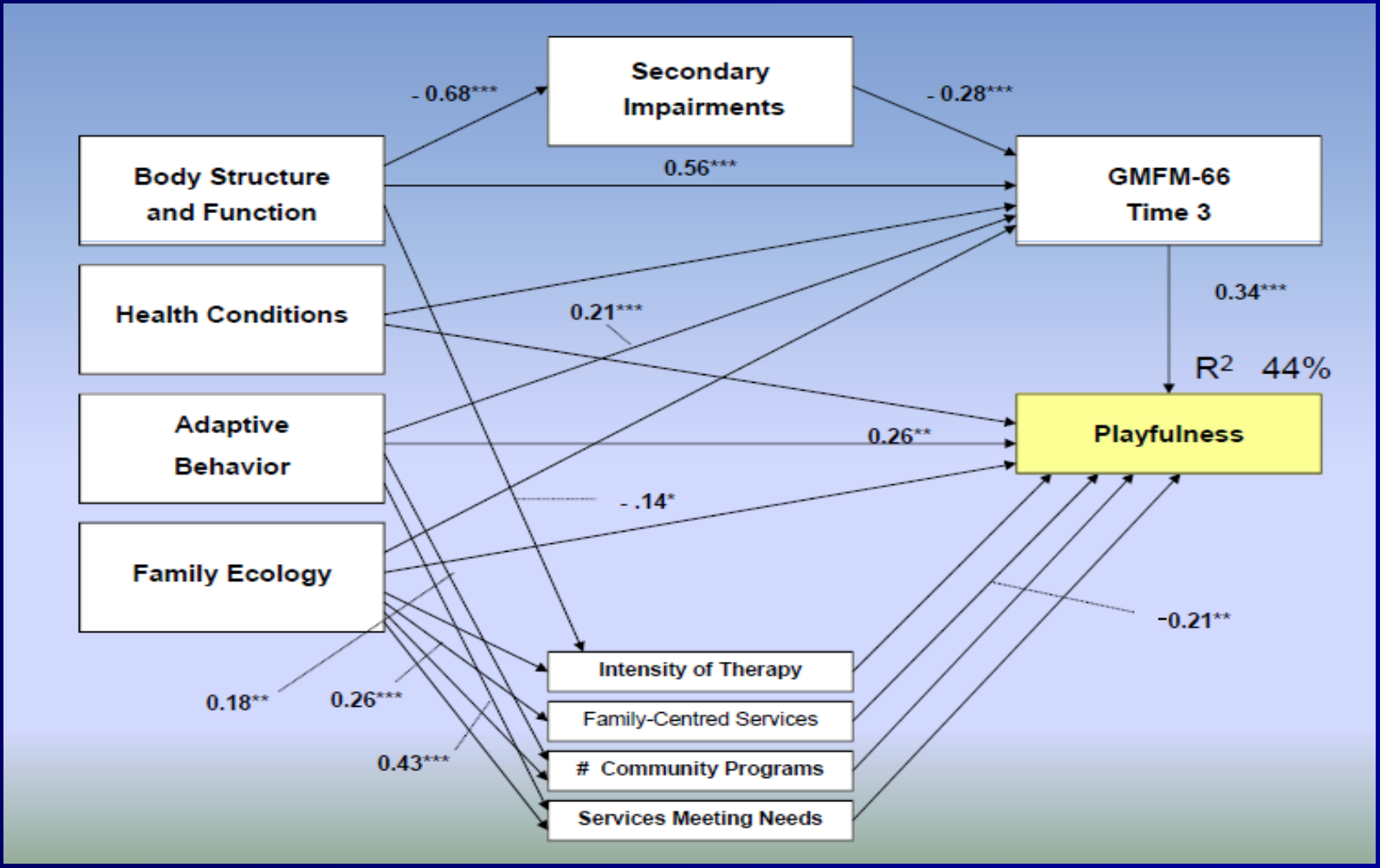
- Recommended focus of services includes:
  - Foster adaptive behavior
    - Self-awareness, adaptability, motivation, persistence, problem-solving, and interactions with people in real-life situations
  - Support family's role in nurturing their children
  - Address family priorities and needs for their child

Playfulness

What did we learn about Playfulness: Results for Children in GMFCS Levels I and II



What did we learn about Playfulness: Results for Children in GMFCS Levels III, IV, and V



What did we learn about Playfulness?

GMFCS Levels I & II

- Model explained 22% of the variability in children's playfulness abilities

GMFCS Levels III, IV, V

- Model explained 44% of the variability in children's playfulness abilities

Higher Playfulness was related to:

- Better health
- Higher gross motor abilities

- Higher gross motor abilities
- More effective adaptive behavior
- Parent's weaker perceptions of family-centeredness of services

How can practitioners and families support children's Playfulness?

- Recommended focus of services includes:
  - Optimize gross motor abilities
    - Enhance balance
    - Prevent secondary impairments
  - Promote health
  - Foster adaptive behavior
    - Self-awareness, adaptability, motivation, persistence, problem-solving, and interactions with people in real-life situations

Case Study: "Juan"

- 40-month-old boy who was a participant in the Move & PLAY study with spastic diplegia, GMFCS level III
- Lives with two adults and one sibling
- Annual household income: $15,000 – 29,000 (USD)

Case Study: Decision making Supporting Juan's Outcomes

Determinants

- Balance > 75th percentile
- Strength < 25th percentile
- Range of motion 50th percentile
- Endurance < 25th percentile
- Adaptive behavior < 25th percentile
- Health < 25th percentile
- Motor abilities: 40th percentile
- Attributes of family < 25th percentile
- Family-centeredness of services: 50th percentile
- Community programs: 25th percentile

Outcomes

- **Motor abilities: 40th percentile**
- **Self-care: 50th percentile**
- **Participation <25th percentile**
- **Enjoyment: 25th percentile**
- **Playfulness: 50th percentile**

What is a logical plan of care for Juan?

What are the key messages for families & service providers?

Child and family attributes are important influences to child outcomes

- Need to foster Adaptive Behavior: Key attribute for gross motor abilities, self-care, participation, and playfulness
- Appreciate the complexity of factors that together contribute to child outcomes
- Partner to ensure that families have the necessary resources to support their children's development and function

- For children with higher motor function
  - Health impacted self-care abilities and playfulness
  - Important to monitor and optimize children's overall health
- For children with limited self-mobility
  - Models provided greater understanding of the outcomes
  - Children may need a range of supports to enhance outcomes
  - Families may need guidance on how to adapt activities and environments to enable their children to be playful and participate in family and community activities
- Health Promotion and Prevention
  - Support daily physical activity that incorporates balance, muscle strengthening, flexibility, and cardiovascular exercises

Thoughts and Discussion

- Are any findings surprising?
- Do the findings support current service provision?
- What changes in service provision will be challenging?
- What child, family, and service factors are missing from the model?
- What are other important outcomes to consider?

For More Information

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http://www.canchild.ca/en/ourresearch/moveplay.asp