

Incorporating Family-Centered Approaches into Research and Practice with Young Children with Autism

Carl J. Dunst, Ph.D.

Senior Research Scientist

Orelena Hawks Puckett Institute

Asheville and Morganton, North Carolina

Presentation prepared for the Autism Speaks' Toddler Treatment Network Meeting, Salt Lake City, Utah, May 13, 2015

Purposes of the Presentation

- Describe the key characteristics of family-centered practices
- Summarize research findings from studies of the relationships between family-centered practices and parent, parent-child, child, and family functioning
- Describe a framework for illustrating how family-centered practices are related to other types of early childhood intervention practices
- Describe research and practice for how specific features of family-centered practices have been incorporated into intervention practices with young children with disabilities

Foundations of Family-Centered Practices

- Family-strengthening value statements
- Family-support principles
- Family-centered practices scales

Family-Strengthening Value Statements

Values are belief statements regarding how persons involved in education, human services, and other kinds of intervention programs **ought** to be treated by help-giving professionals

- Paul Dokecki (1983) was one of the first professionals to propose a values framework for developing policies and practices for strengthening families
- Advocates at the Center on Human Policy (1986) at Syracuse University first articulated “A Statement in Support of Families and Their Children” that included family-strengthening practices

Dokecki, P.R. (1983). The place of values in the world of psychology and public policy. *Peabody Journal of Education*, 60(3), 108-125.

Center on Human Policy. (1986). *A statement in support of families and their children*. Syracuse, NY: Division of Special Education and Rehabilitation, School of Education, Syracuse University.

Family Support Principles

Family support principles are belief statements of how help-giving professionals engage parents and other family members in their children's care and early education

- By far the most influential principles in defining the key features of family-centered practices are those of Terri Shelton and her colleagues (1987) in “Elements of Family-Centered Care”
- The Family Resource Coalition (1987) proposed a set of belief statements that became the foundation for the family support movement in the mid and late 1980s

Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). *Family-centered care for children with special health care needs*. Bethesda, MD. Association for the Care of Children's Health.

Family Resource Coalition (1987). *What are the assumptions of the Family Resource Movement?* Chicago: Author.

Family-Centered Practices Scales

The development of family-centered practices scales permitted operationalization of family-strengthening value statements and family-support principles

- Family-centered practices scales include items that parents or other family members rate in terms of the extent to which a help-giving professional interacts with and treats family members in ways either consistent or inconsistent with the intent of family support principles
- Psychometric analyses of different scales tend to yield similar factor structures

Dunst, C. J., & Espe-Sherwindt, M. (in press). Family-centered practices in early childhood intervention. In S. L. Odom, B. Reichow, E. Barton & B. Boyd (Eds.), *Handbook of early childhood special education*. New York: Springer.

Examples of Family-Centered Practices Scales

- Enabling Practices Scale (Dempsey, 1995)
- Family-Centered Behavior Scale (Petr & Allen, 1995)
- Family-Centered Practices Scale (Dunst & Trivette, 2002)
- Help Giving Practices Scale (Trivette & Dunst, 1994)
- Measure of Process of Care (King et al., 1997)

Examples of Family-Centered Practices Items

- Staff offer help or advice in response to my family's needs
- Staff provide me information about resources available to families
- Staff respect our family's beliefs, values, and customs
- Staff recognize and acknowledge the good things I do as a parent
- Staff provide me information I need to make good decisions
- Staff work with me to accomplish my family's goals and priorities
- Staff support decisions I make for myself and my child
- Staff are responsive to my family's changing situation

Two Types of Family-Centered Practices

- Research that my colleagues and I have conducted has consistently found that there are two distinct types of practices that constitute subcategories of family-centered practices:
 - Relational family-centered practices
 - Participatory family-centered practices
- Confirmatory factor analysis of family-centered practices scale responses indicates that both relational and participatory practices each include two subcategories of practices

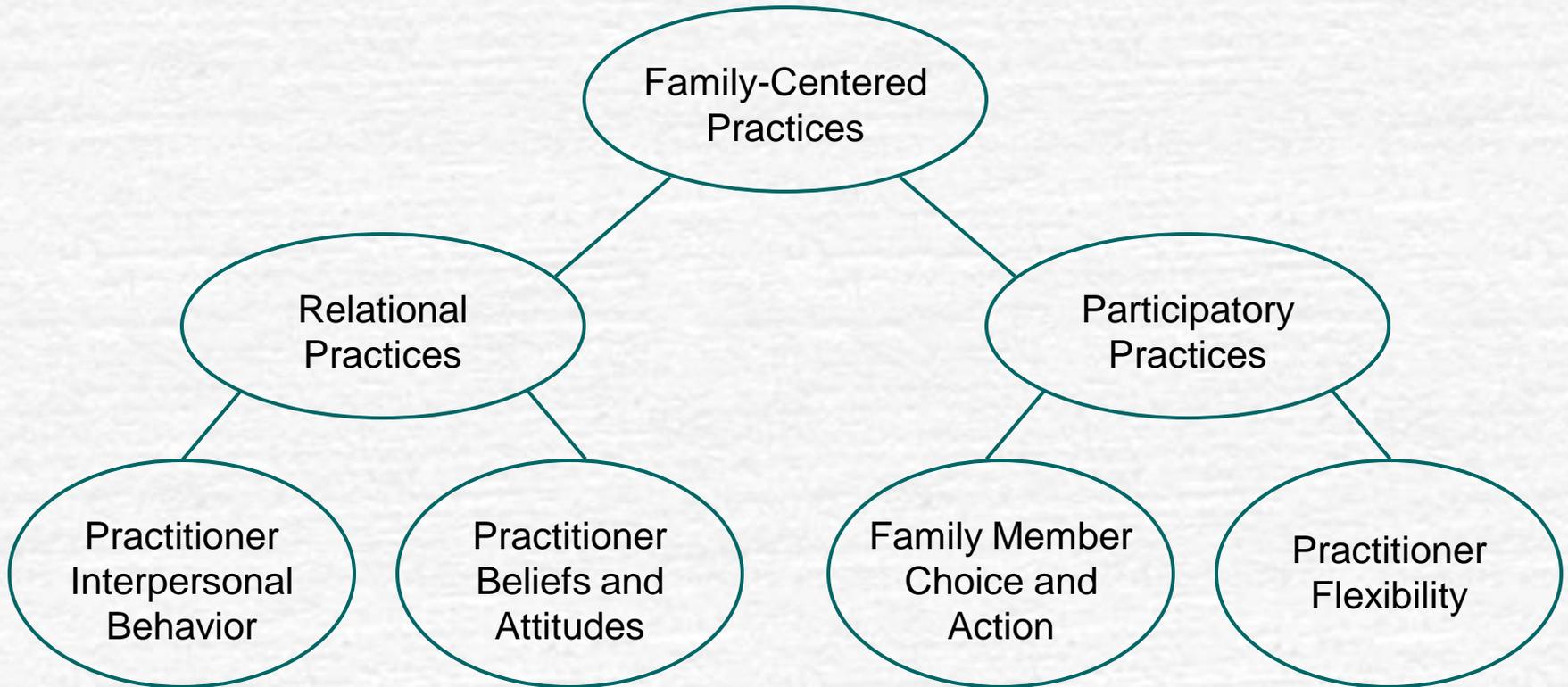
Relational Family-Centered Practices

- Relational practices include behavior typically associated with effective help-giving practice, including, but not limited to, compassion, active and reflective listening, empathy, and effective communication.
- Relational practices also include practitioner beliefs and attitudes about family and cultural strengths, values, and attitudes, and practitioner sensitivity to these beliefs and values as part of intervention practices.

Participatory Family-Centered Practices

- Participatory practices include behavior that actively involve family members in (a) informed choice and decision making, and (b) using existing strengths and abilities as well as developing new capabilities needed to obtain resources or supports and carry out parenting responsibilities.
- Participatory practices also include practitioner responsiveness to and flexibility in how help is provided to children and their families.

Family-Centered Practices



Measuring Adherence to Family-Centered Practices

- Adherence to family-centered principles and practices is measured in terms of parents' judgments of the extent to which staff interact with and treat participants and their family members in ways consistent with the intent of family support principles
- A consumer sciences perspective was used to assess staff adherence to family support principles and practices where consumers (parents) were considered the primary source of evidence that staff interacted with and treated families in ways consistent with the program principles

Measuring Adherence to Family-Centered Practices

- In a typical adherence study or survey, program participants are asked to indicate on a 5-point scale ranging from **never** to **always** the extent to which staff treat or interact with the respondent and his or her family in the ways indicated
- An adherence survey generally includes 5 or 6 relational indicators and 5 or 6 participatory indicators
- Percentage of indicators receiving the highest rating on a 5-point scale indicating that a respondent and his or her family are always treated in the way consistent with the scale indicators

Example of a Family-Centered Practices Scale for Measuring Adherence

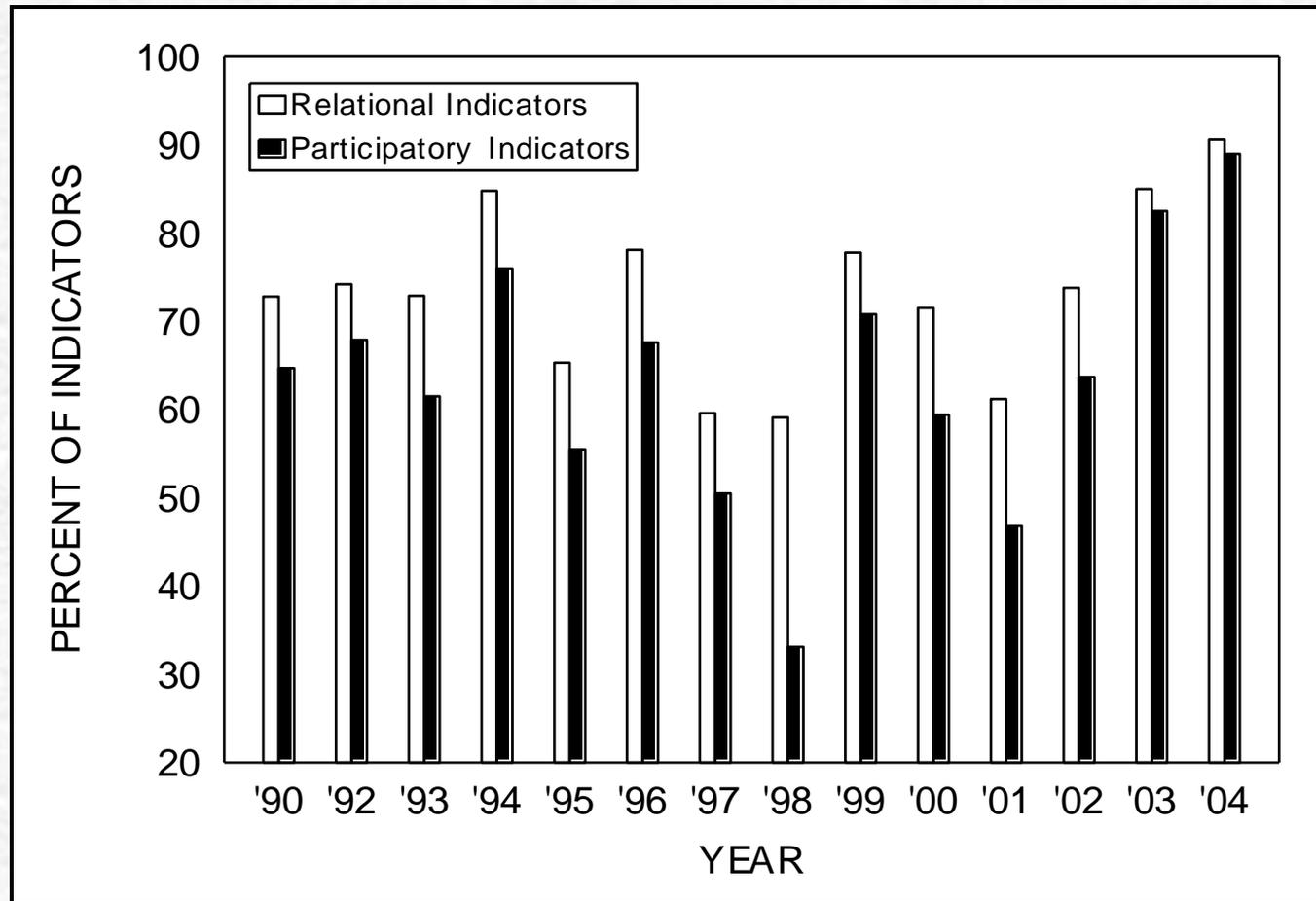
| EXPERIENCES WITH FAMILY RESOURCE CENTER STAFF | | | | | |
|--|-------|-------------|------------------|------------------|--------------|
| Staff sometimes differ in how they interact with and treat children and their families. Please indicate how the Family Resource Center staff interacts with and treats you. | Never | Very Little | Some of the Time | Most of the Time | All the Time |
| Really listen to my concerns or requests | 1 | 2 | 3 | 4 | 5 |
| See my child and family in a positive, healthy way | 1 | 2 | 3 | 4 | 5 |
| Provide me information I need to make good choices | 1 | 2 | 3 | 4 | 5 |
| Are responsive to my requests for advice or assistance | 1 | 2 | 3 | 4 | 5 |
| Try hard to understand my child and family's situation | 1 | 2 | 3 | 4 | 5 |
| Recognize my child and family's strengths | 1 | 2 | 3 | 4 | 5 |
| Help me be an active part of getting desired resources | 1 | 2 | 3 | 4 | 5 |
| Are flexible when my family's situation changes | 1 | 2 | 3 | 4 | 5 |
| Encourage me to get what I want for myself | 1 | 2 | 3 | 4 | 5 |
| Are sensitive to my personal beliefs | 1 | 2 | 3 | 4 | 5 |
| Support me when I make a decision | 1 | 2 | 3 | 4 | 5 |
| Recognize the good things I do as a parent | 1 | 2 | 3 | 4 | 5 |

Sources of Information for Measuring Adherence to Family-Centered Practices

- Eighteen (18) studies conducted between 1990 and 2004 at the Family, Infant and Preschool Program (Morganton, NC)
- One thousand ninety-six (1,096) program participants
- Thirteen thousand five hundred eleven (13,511) indicators

Dunst, C.J., & Trivette, C.M. (2005). *Measuring and evaluating family support program quality*. Winterberry Press Monograph Series. Asheville, NC: Winterberry Press.

Degree of Adherence to Relational and Participatory Family-Centered Practices



Research on the Relationships Between Family-Centered Practices and Parent, Family, and Child Behavioral Functioning

My colleagues and I, as well as other researchers, have investigated the manner in which family-centered practices are related to parent, family, and child outcomes for more than 25 years. Our research has involved the use of different research methodologies for investigating the influences of family-centered practices on parent, family, and child outcomes

- Basic research studies
- Meta-analyses of family-centered practices research studies
- Structural equation modeling investigations
- Meta-analytic structural equation modeling studies

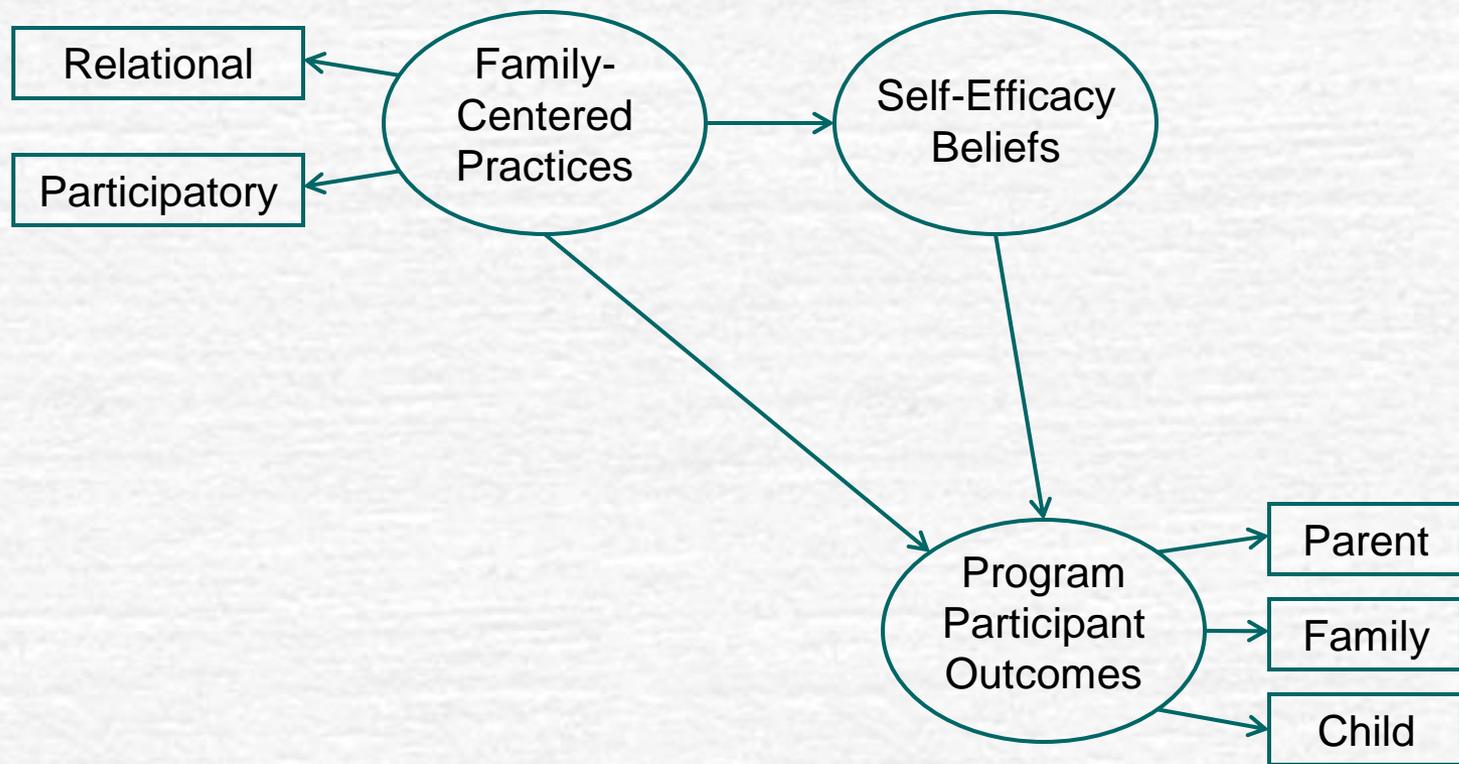
Research Syntheses of Family-Centered Practices Studies^{a,b}

- Meta-analysis of 52 studies conducted by more than 20 researchers and research teams in seven different countries
- Weighted average correlation coefficients were used as the sizes of effects for the relationships between family-centered practices and parent, child, and family outcomes

^a Dunst et al. (2007). Meta-analysis of family-centered help-giving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378.

^b Dunst et al. (2008). *Research synthesis and meta-analysis of studies of family-centered practices*. Winterberry Press Monograph Series. Asheville, NC: Winterberry Press.

Framework for Investigating the Influences of Family-Centered Practices on Parent, Family, and Child Outcomes



Effect Sizes for the Relationship Between Relational and Participatory Family-Centered Help-Giving Practices and the Outcome Measures

| Outcome Measures | Relational Practices | | Participatory Practices | |
|---------------------------------|----------------------|------------|-------------------------|-----------|
| | Effect Size | 95% CI | Effect Size | 95% CI |
| Participant Satisfaction | | | | |
| All Measures Combined | 0.64**** | 0.62-0.65 | 0.59**** | 0.56-0.61 |
| Satisfaction with Staff | 0.67**** | 0.63-0.72 | 0.38**** | 0.34-0.42 |
| Satisfaction with Program | 0.63**** | 0.62-0.65 | 0.67**** | 0.65-0.70 |
| Self- Efficacy Beliefs | | | | |
| All Measures Combined | 0.61**** | 0.59-0.63 | 0.59**** | 0.57-0.61 |
| Practitioner Control | 0.62**** | 0.59-0.65 | 0.62**** | 0.59-0.66 |
| Program Control | 0.70**** | 0.66-0.73 | 0.67**** | 0.64-0.70 |
| Life Events Control | 0.32**** | 0.26-0.38 | 0.39**** | 0.35-0.43 |
| Program Resources | | | | |
| All Measures Combined | 0.36**** | 0.30-0.43 | 0.44**** | 0.38-0.51 |
| Parent/Child Supports | 0.26**** | 0.17-0.36 | 0.37**** | 0.28-0.46 |
| Program Helpfulness | 0.47**** | 0.37-0.56 | 0.52**** | 0.43-0.61 |
| Child Behavior | | | | |
| All Measures Combined | 0.24**** | 0.20-0.29 | 0.27**** | 0.22-0.32 |
| Positive Child Behavior | 0.25**** | 0.19-0.31 | 0.34**** | 0.27-0.41 |
| Negative Child Behavior | 0.25**** | 0.18-0.31 | 0.20**** | 0.11-0.30 |
| Behavioral Competence | 0.24**** | 0.14-0.34 | 0.18*** | 0.08-0.28 |
| Well-Being | | | | |
| All Measures Combined | 0.26**** | 0.24-0.29 | 0.27**** | 0.23-0.30 |
| Personal Well-Being | 0.27**** | 0.25-0.30 | 0.26**** | 0.22-0.30 |
| Family Well-Being | 0.18**** | 0.11-0.27 | 0.29**** | 0.23-0.37 |
| Parenting Behavior | | | | |
| All Measures Combined | 0.13**** | 0.07-0.19 | 0.21**** | 0.16-0.27 |
| Confidence | 0.16** | 0.06-0.27 | 0.26**** | 0.18-0.35 |
| Competence | 0.05 | -0.07-0.18 | 0.11* | 0.01-0.21 |
| Enjoyment | 0.15** | 0.05-0.26 | 0.24**** | 0.16-0.32 |

*p < .05. **p < .01. ***p < .001. ****p < .0001.

Indirect Effects of Family-Centered Practices on Parent, Child, and Family Outcomes

- The conceptual model guiding the meta-analyses of family-centered practices research includes hypotheses about the indirect effects of those practices on outcomes of interest
- Results consistently indicate that the effects of family-centered practices on parent, child, and family outcomes are mostly indirect mediated by self-efficacy beliefs (as well as other variables) depending on the outcomes constituting the focus of investigation
- The more “distal” the outcomes are from the use of family-centered practices, the more the effects are indirect on outcomes of interest

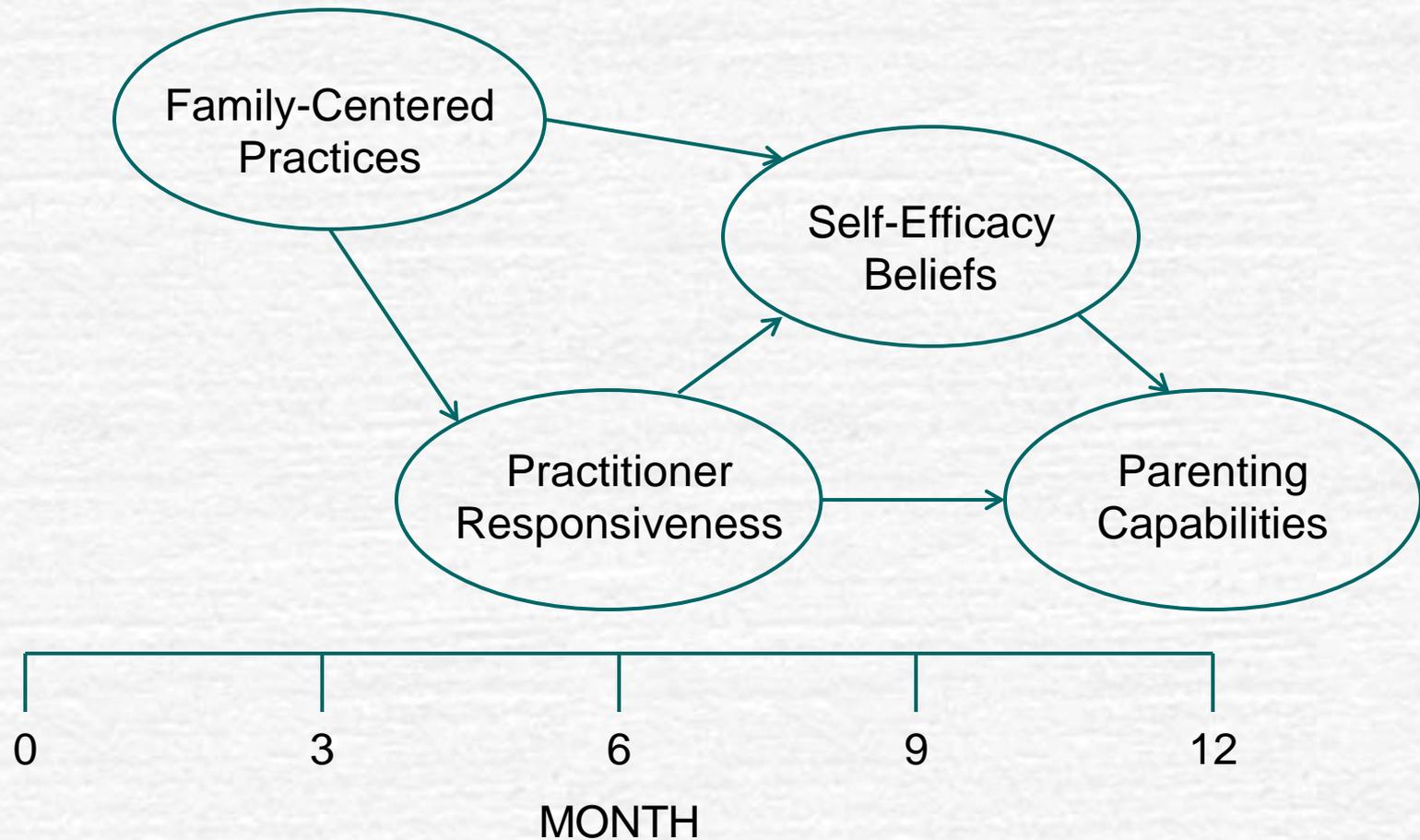
Example of the Indirect Effects of Family-Centered Practices on Parenting Competence and Confidence

Small-scale perspective study of the indirect effects of family-centered practices on parenting behavior mediated by both self-efficacy beliefs and practitioner responsiveness to family concerns

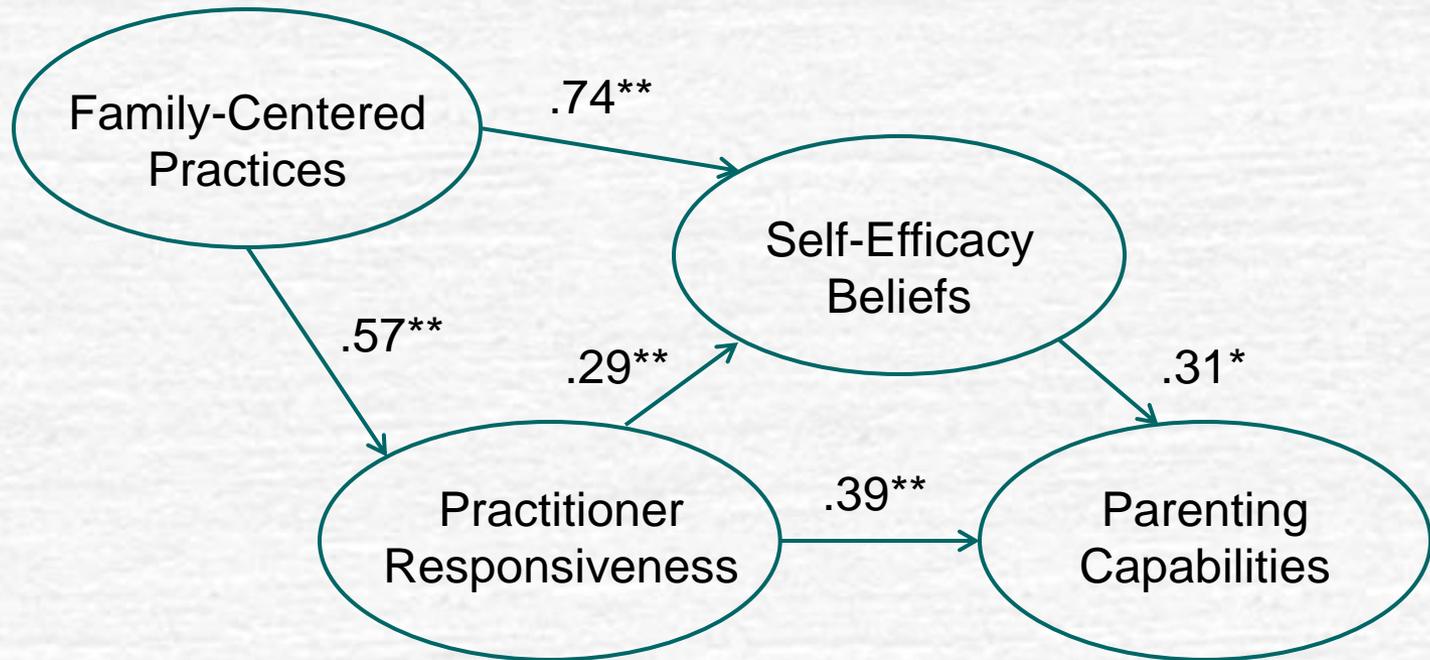
Study Characteristics

| | |
|-----------------------------|---|
| <i>Participants:</i> | 100 parents of young children with and without disabilities participating in community-based family resource programs |
| <i>Measures:</i> | Relational and participatory family-centered practices, practitioner responsiveness to family concerns, parent self-efficacy beliefs, and parenting competence and confidence |
| <i>Methodology:</i> | Structural equation modeling for testing the hypothesized relationships among the variables in the model |

Model for Evaluating the Indirect Effects of Family-Centered Practices on Parenting Competence and Confidence

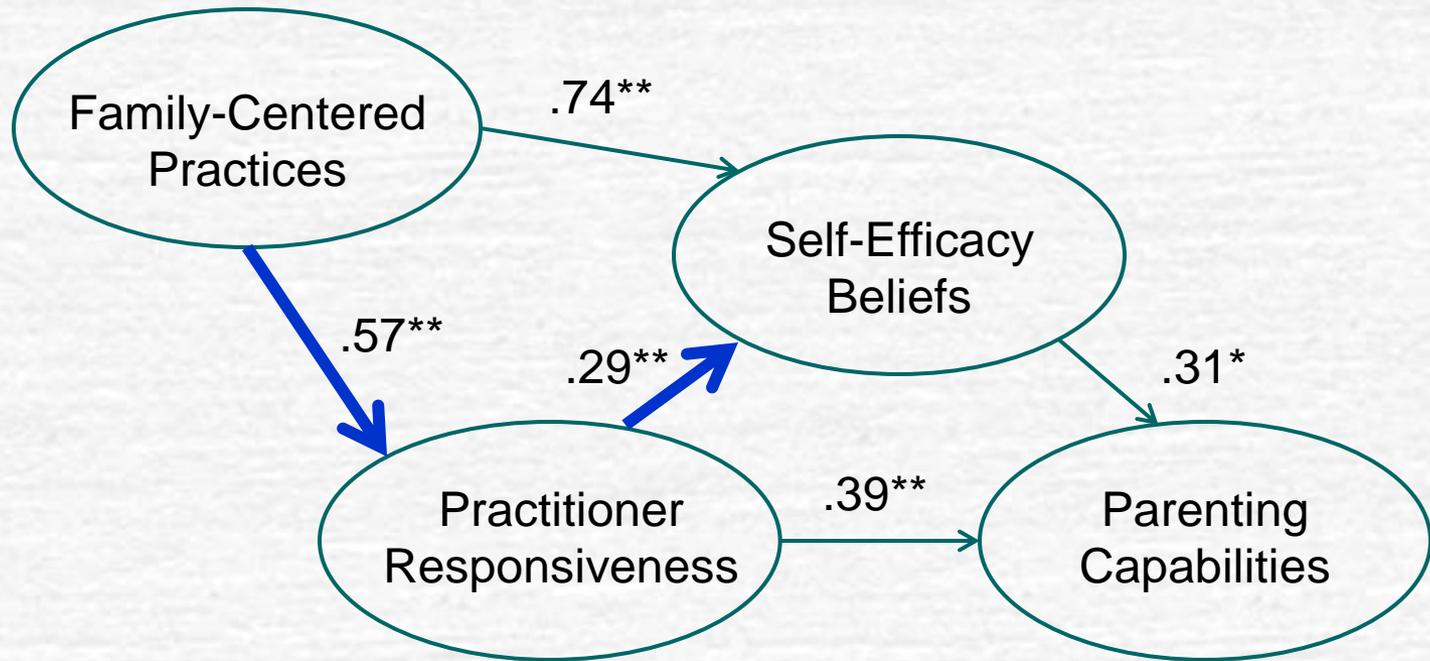


Standardized Parameter Estimates for the Relationships Among Measures in the Model



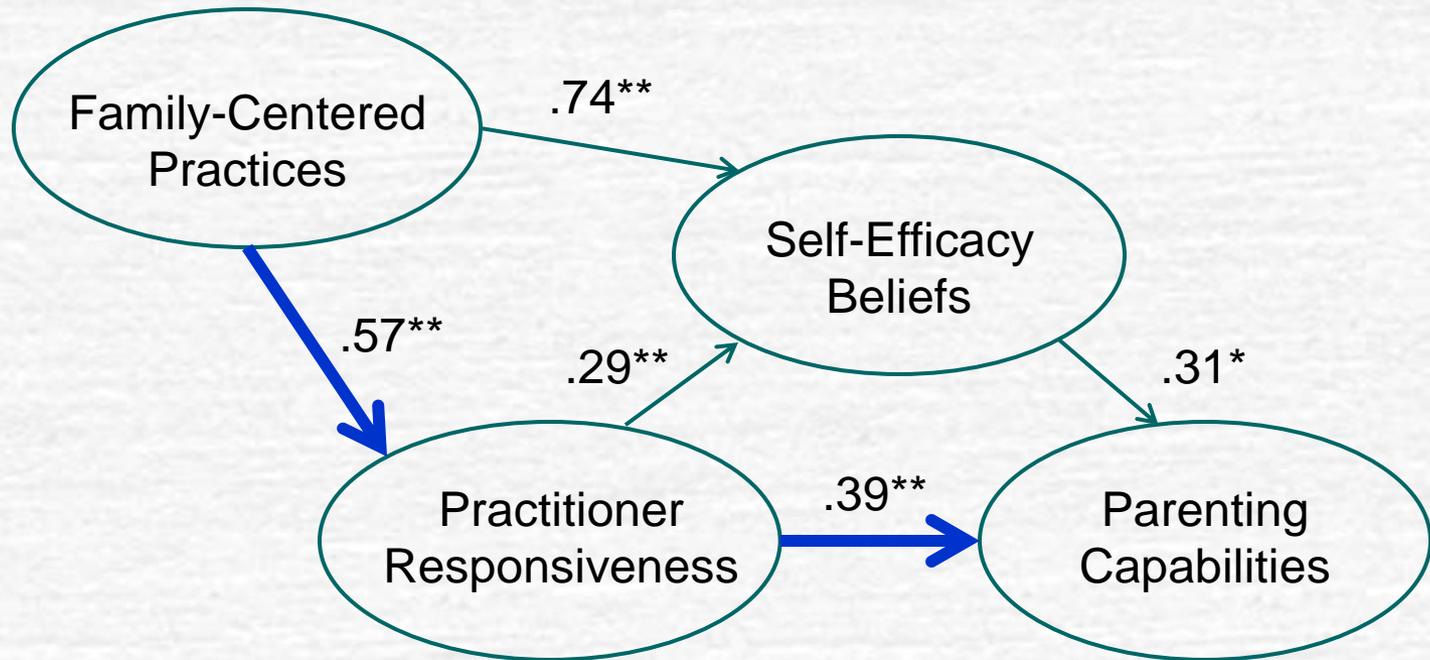
* $p < .05$. ** $p < .001$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



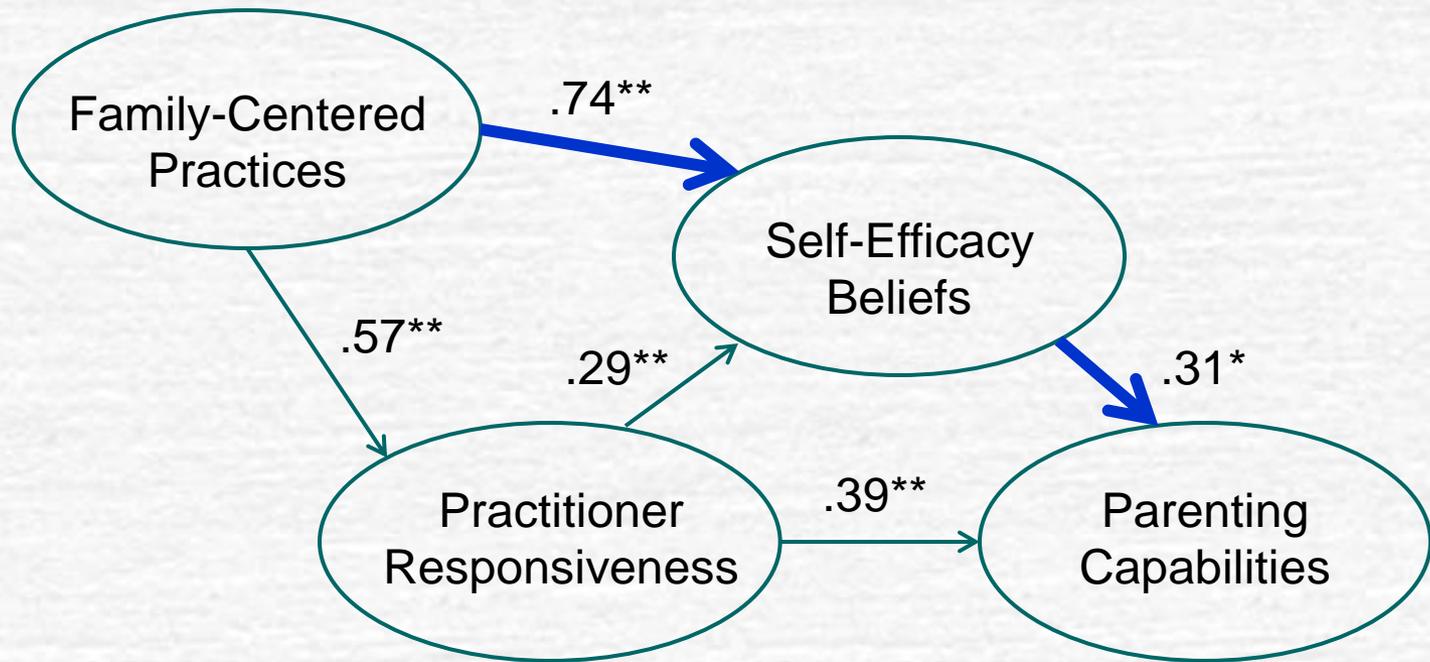
* $p < .05$. ** $p < .001$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



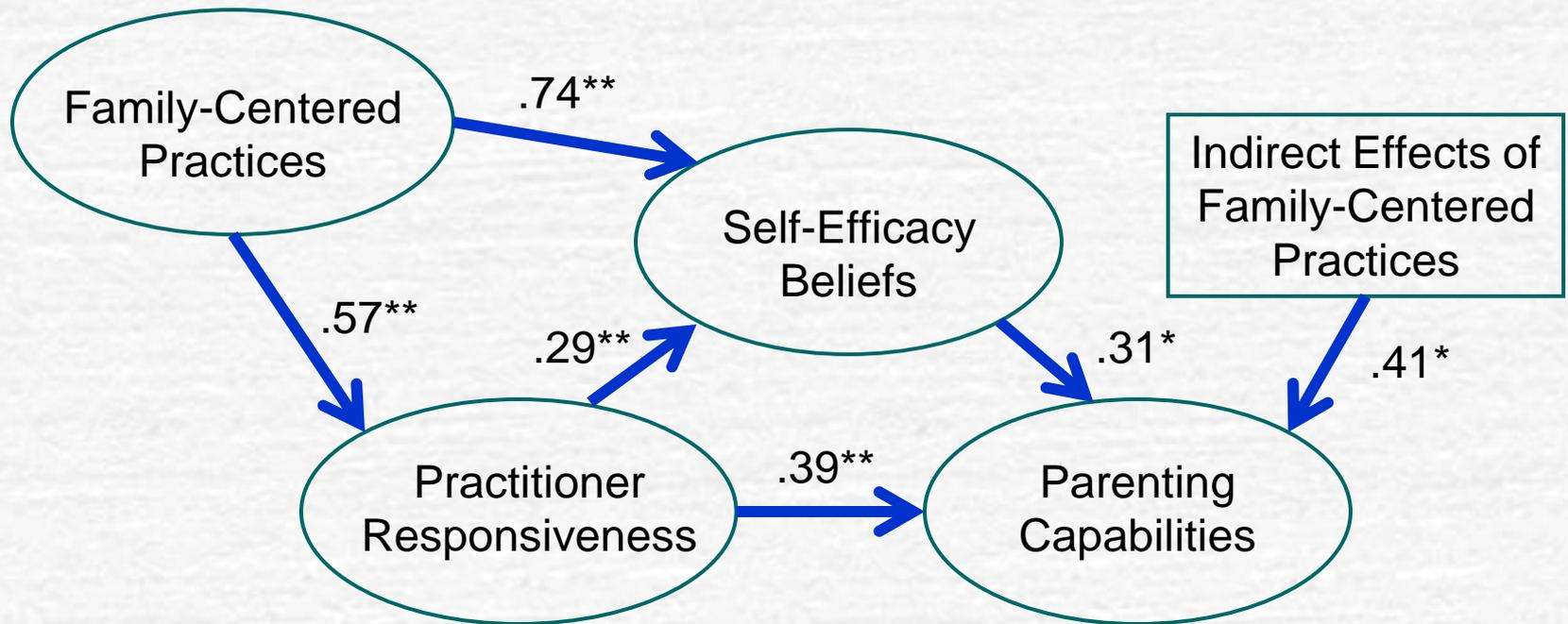
* $p < .05$. ** $p < .001$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



* $p < .05$. ** $p < .001$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model

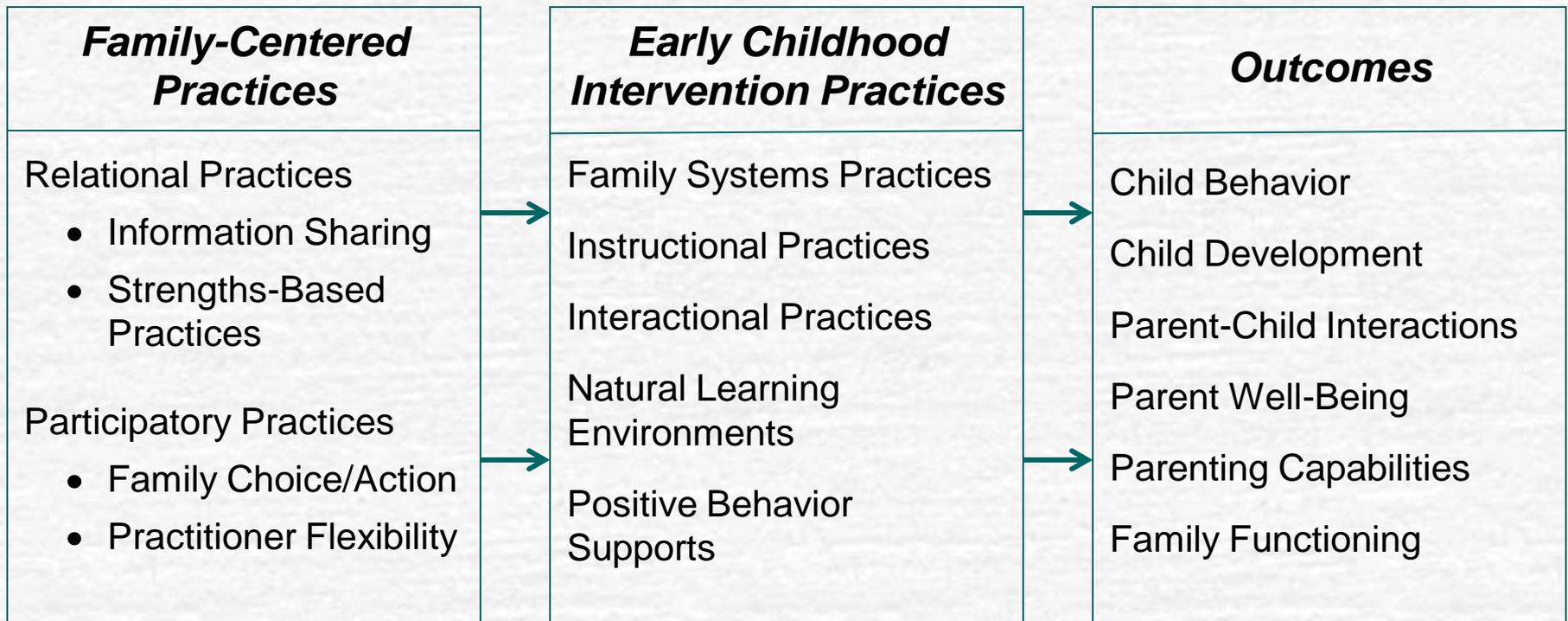


* $p < .05$. ** $p < .001$.

Placing Family-Centered Practices in a Broader-Based Framework of Early Childhood Intervention

- Family-centered practices are conceptualized as a particular way in which other early childhood intervention practices are implemented by practitioners where the goal is strengthening parent capacity to obtain family-identified supports or resources and to promote child learning and development
- Emphasis is placed on the strengths-based and capacity-building (participatory) elements of family-centered practices to promote, support, and enhance family competence and confidence

Proposed Relationships Among Family-Centered Practices, Early Childhood Intervention Practices, and Child, Parent, and Family Outcomes



Examples of Strengths-Based Capacity-Building Interventions

- Interest-based everyday child learning
- Caregiver-mediated everyday child learning
- Strengths-based everyday child learning

Effects of Interest-Based Child Learning Opportunities on the Social-Affective Behavior of Young Children with Autism

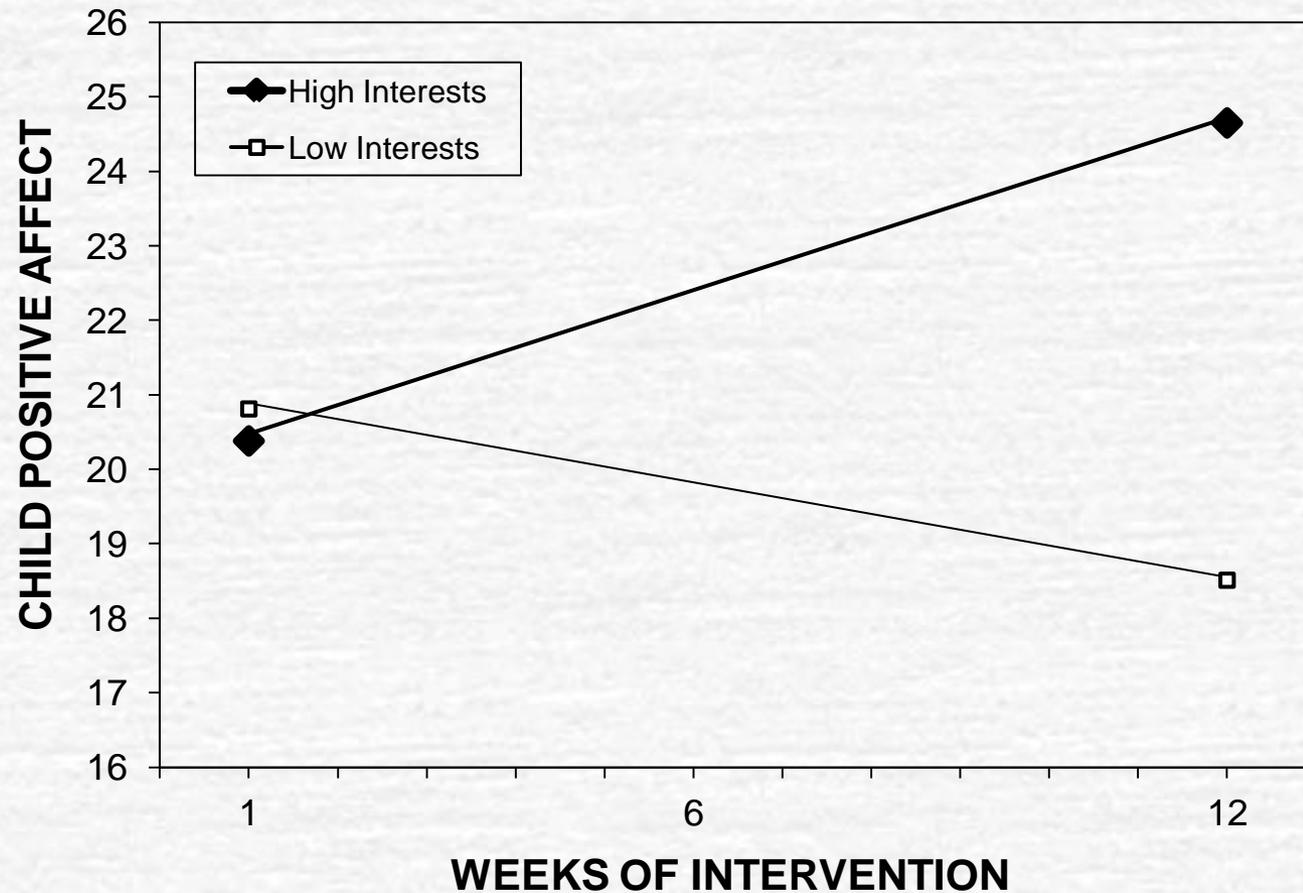
- Purpose:** Compare the effects of interest-based vs. noninterest-based child learning on changes in young children's social-affective behavior
- Participants:** Seventeen children, 17-70 months old, with autism and their mothers
- Outcomes:** Investigator-administered and parent-completed rating scales of child positive and negative affect and child social responsiveness
- Methodology:** Linear growth curve analysis of between group changes in child behavior

Trivette, C. M., & Dunst, C. J. (2011). Consequences of interest-based learning on the social-affective behavior of young children with autism, *Life Span and Disability*, 14(2), 101-110.

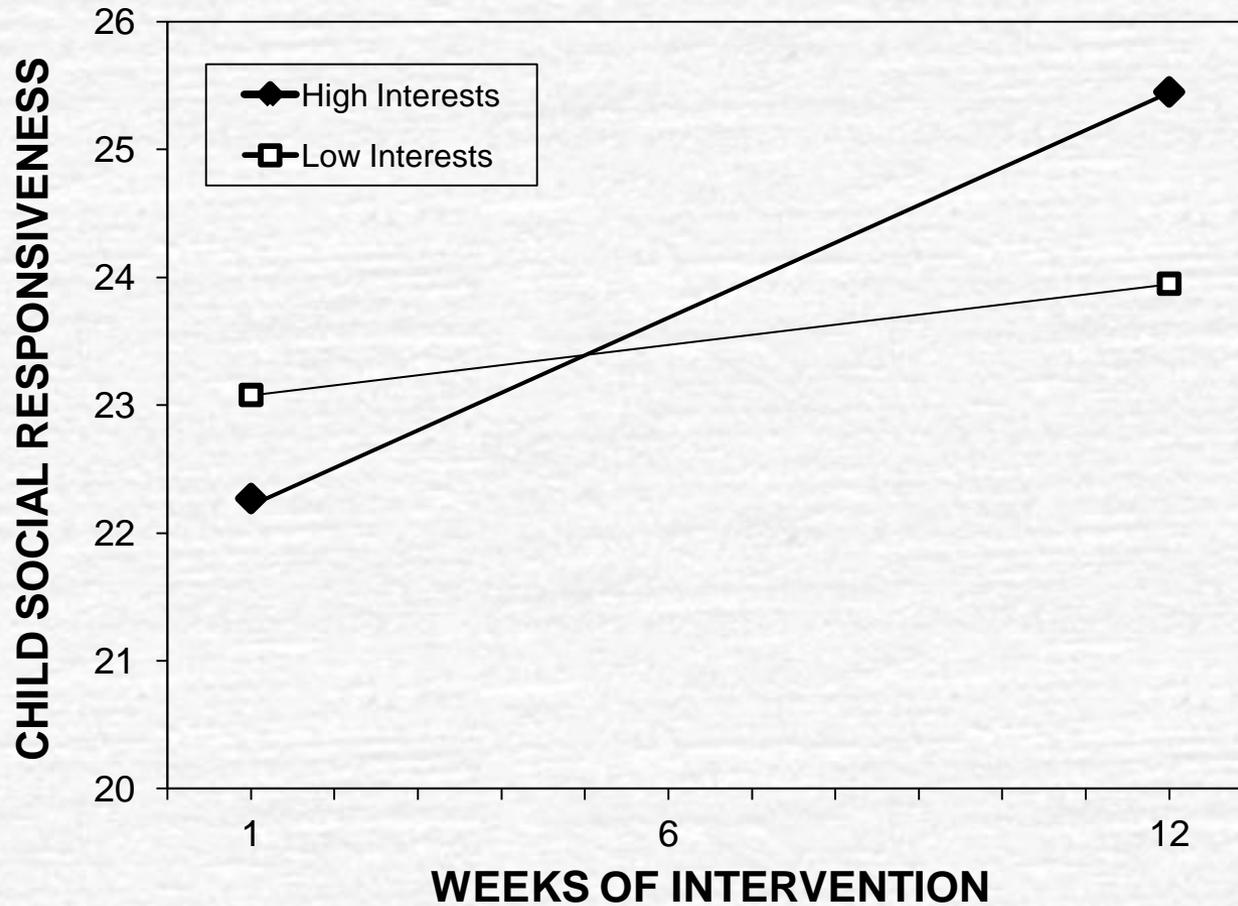
Interest-Based Child Learning Opportunities

- Investigator-developed protocol was used to have mothers identify their children's interests and preferences (people, objects, and events that maintained child engagement , and the activities that the children liked to do, enjoyed doing, got them excited, etc.)
- Mothers then selected everyday activities in the home and community that provided opportunities for interest-based exploration and learning
- Mothers used an everyday activity schedule or daily reminder list (depending on their preference) to engage their children in the child-specific activities and used a modified responsive teaching procedure to reinforce child engagement

Effects of Interest-Based Learning on Child Positive Affect



Effects of Interest-Based Learning on Child Social Responsiveness



Capacity-Building Caregiver-Mediated Everyday Child Learning

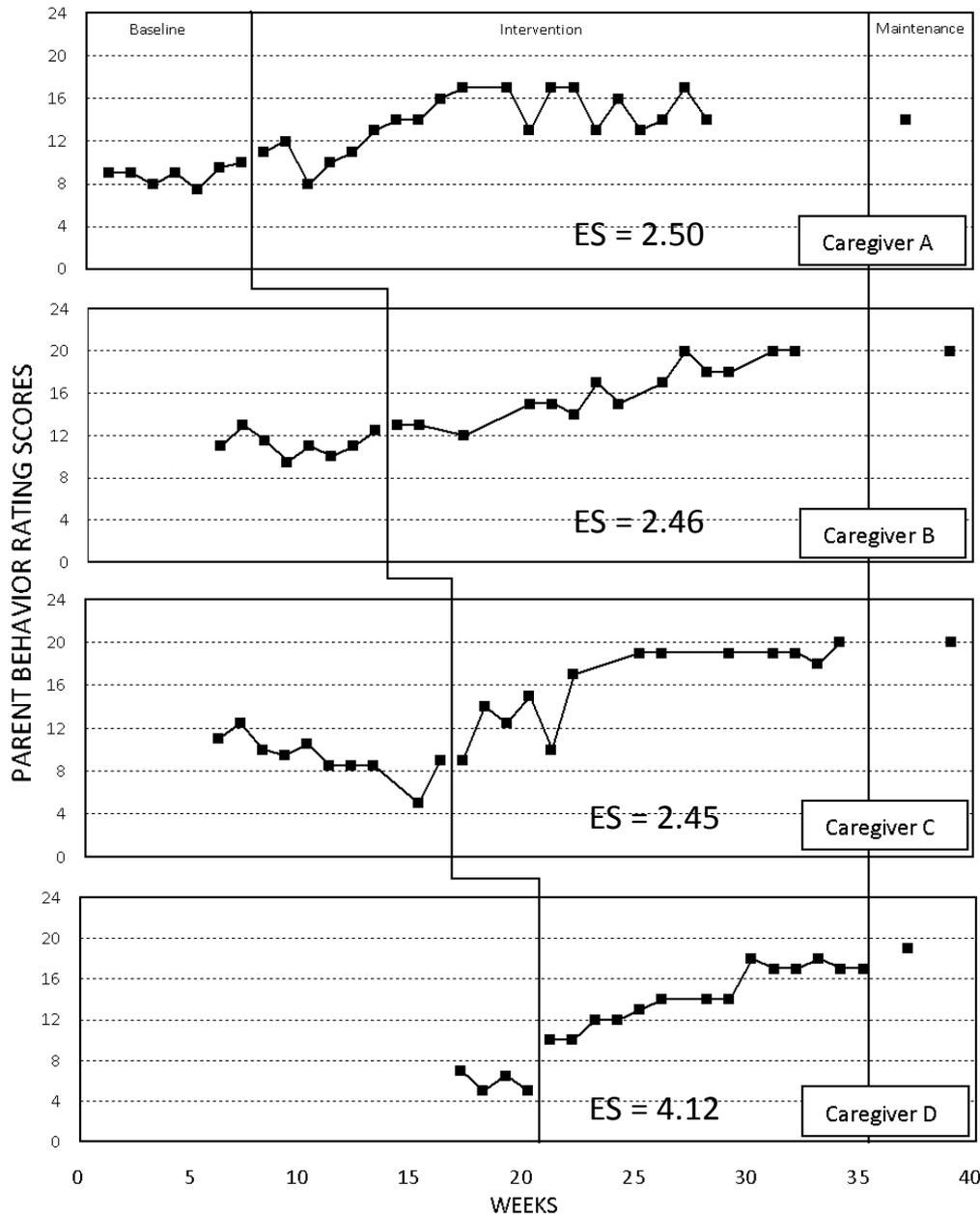
- Purpose:** Determine the extent to which the use of caregiver-mediated everyday child learning was associated with improvements in caregiver skills, competence, and confidence
- Participants:** Three mothers and one grandmother of preschool aged children with disabilities or developmental delays
- Outcomes:** Measures of parenting behavior (skills) and parenting self-efficacy beliefs (confidence and competence)
- Methodology:** Multiple baseline design across study participants

Swanson, J., Raab, M., & Dunst, C.J. (2011). Strengthening family capacity to provide young children everyday natural learning opportunities. *Journal of Early Childhood Research*, 9(1), 66-80.

Caregiver-Mediated Early Intervention Practices

- Study participants used child interest-based everyday activities as sources of child learning opportunities where the participants supported and encouraged child learning in the activities using responsive teaching procedures.
- Participants identified their children's interests, the everyday activities that were sources of interest-based learning opportunities, and the responsive caregiver behavior that was used to engage and sustain child engagement in interest-based everyday child learning.
- An early childhood practitioner used family capacity-building practices and participatory parenting experiences and opportunities to support and encourage the caregivers' use of the natural environment and responsive teaching practices.

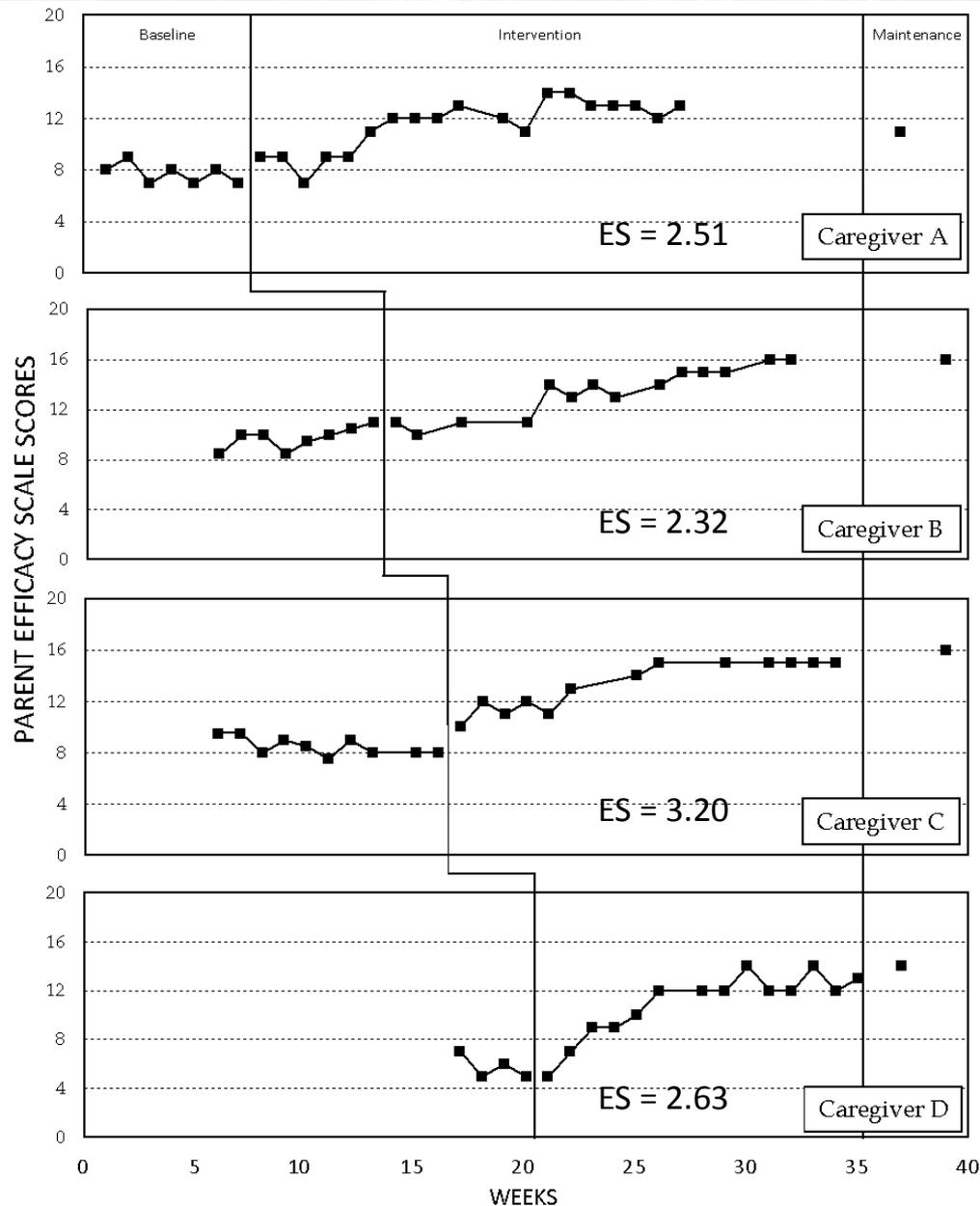
Parenting Skills



Adoption and use of everyday activities as sources of interest-based child learning opportunities strengthened and promoted parents' skills in using the natural learning environment practices

(NOTE. ES = Estimated Cohen's *d* effect size for the baseline vs. intervention phase differences)

Parenting Confidence and Competence



Findings also showed that promoting caregivers' use of everyday activities as sources of interest-based child learning opportunities had the effect of strengthening parenting self-efficacy, competence, and confidence beliefs

(NOTE. ES = Estimated Cohen's *d* effect size for the baseline vs. intervention phase differences)

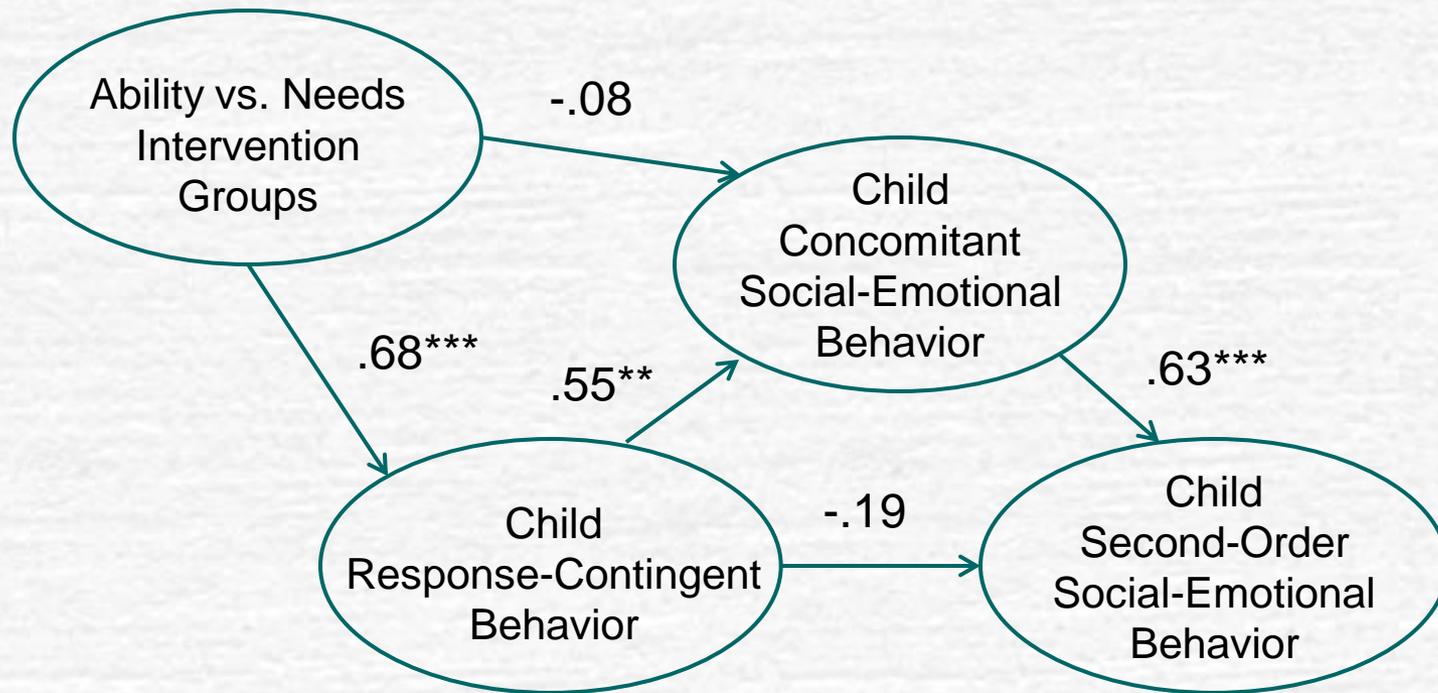
Effects of Strengths-Based Child Learning Opportunities on Child Contingency Learning and Social-Emotional Behavior

- Purpose:*** Compare strengths (ability)-based vs. deficit (needs)-based interventions to promote child acquisition of response-contingent behavior and contingency awareness
- Participants:*** Forty-eight children with significant developmental delays and their parents
- Outcomes:*** Non-prompted child behavior associated with reinforcing consequences and child social-emotional responses
- Methodology:*** Structural equation modeling of the effects of the contrasting interventions on child learning and social-emotional behavior

Contrasting Types of Contingency Interventions

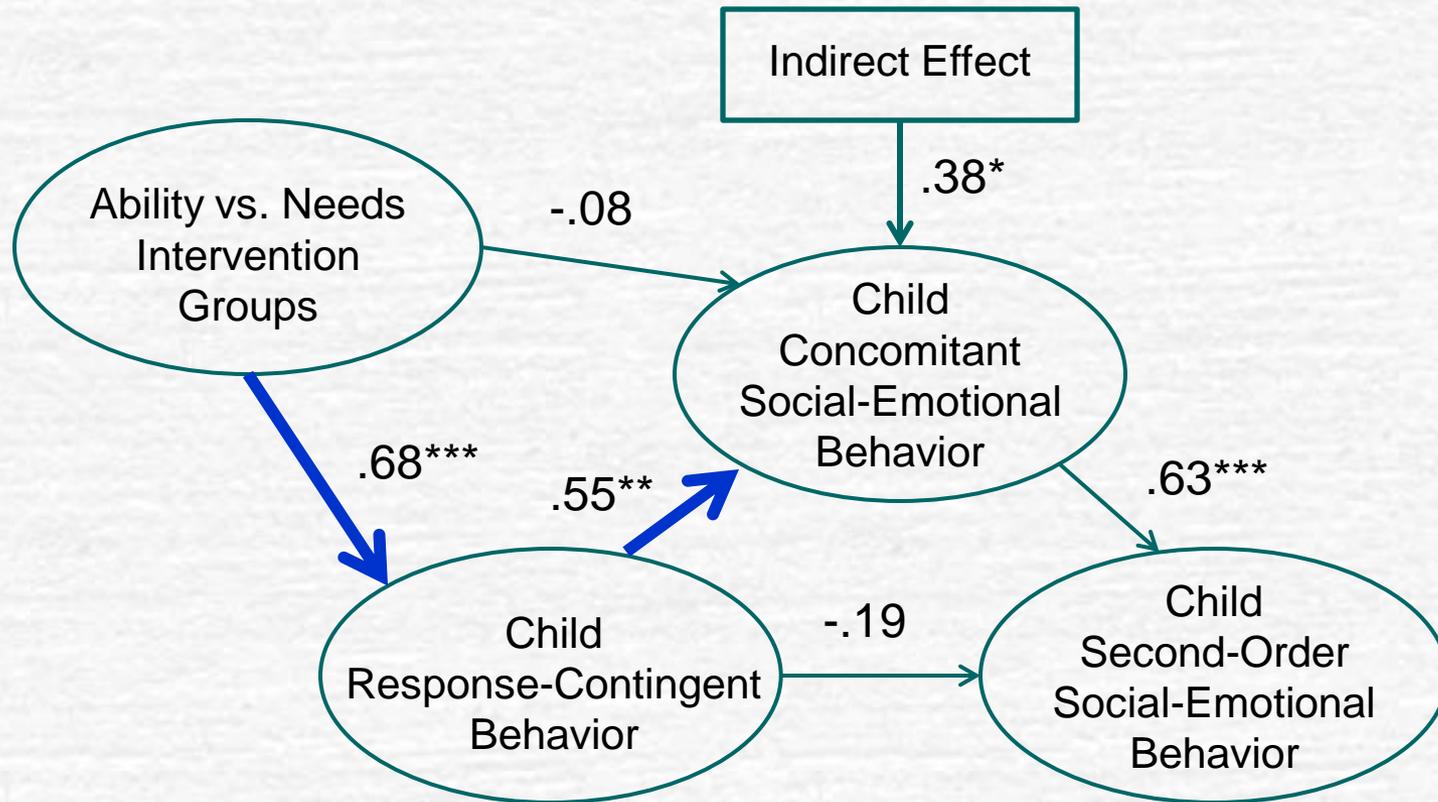
- Parents of the children in the ability-based group were first interviewed to identify behavior that the children produced but which were not used intentionally to elicit reinforcing consequences
- Children in the needs-based group were administered a developmental scale to identify behavior the children had not yet mastered to determine intervention targets
- Contingency learning games were used with both groups of children to engage them in activities where child behavior resulted in interesting or reinforcing consequences

Standardized Parameter Estimates for the Relationships Among Measures in the Model



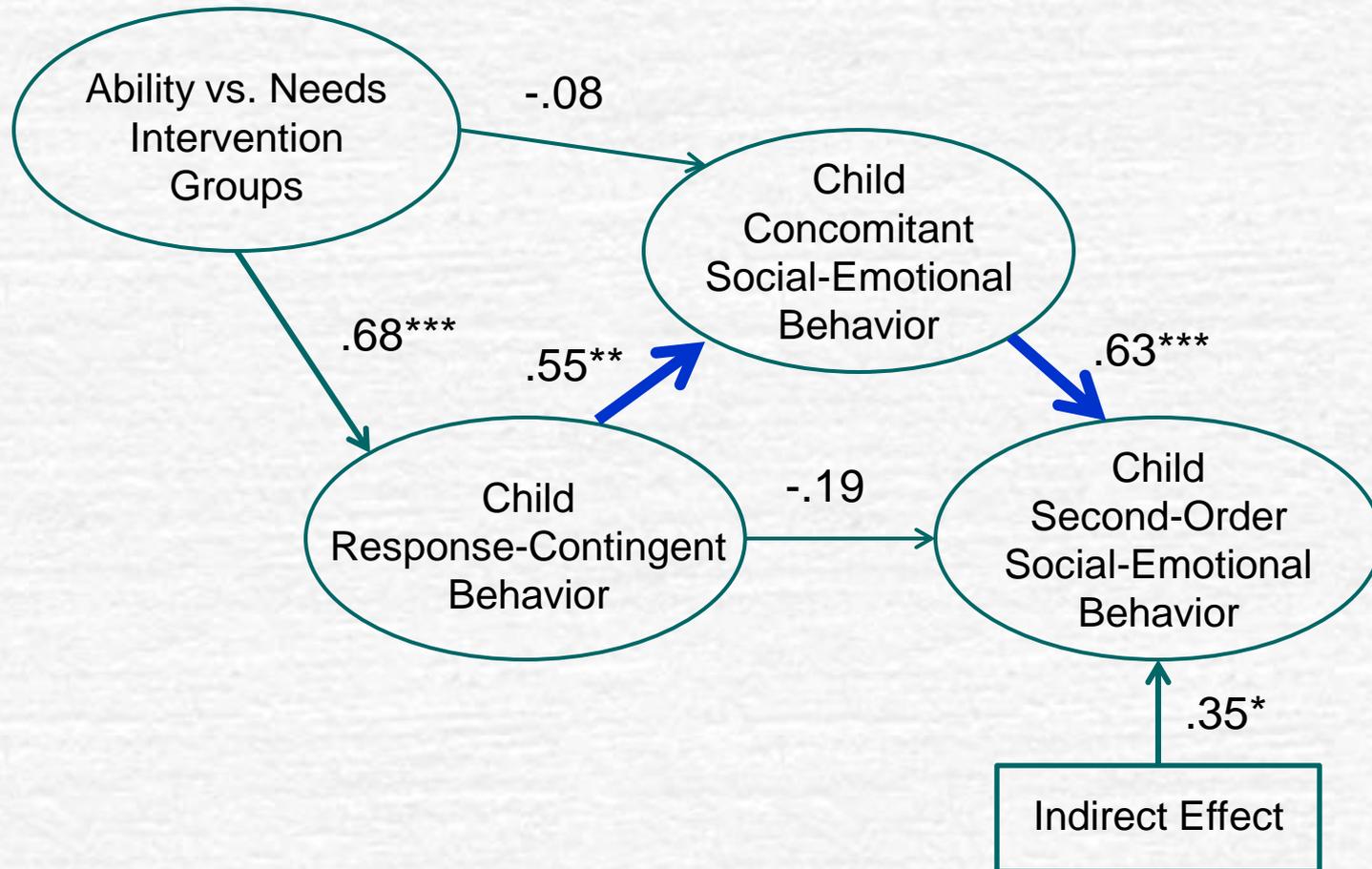
$^{**}p < .001$. $^{***}p < .0000$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



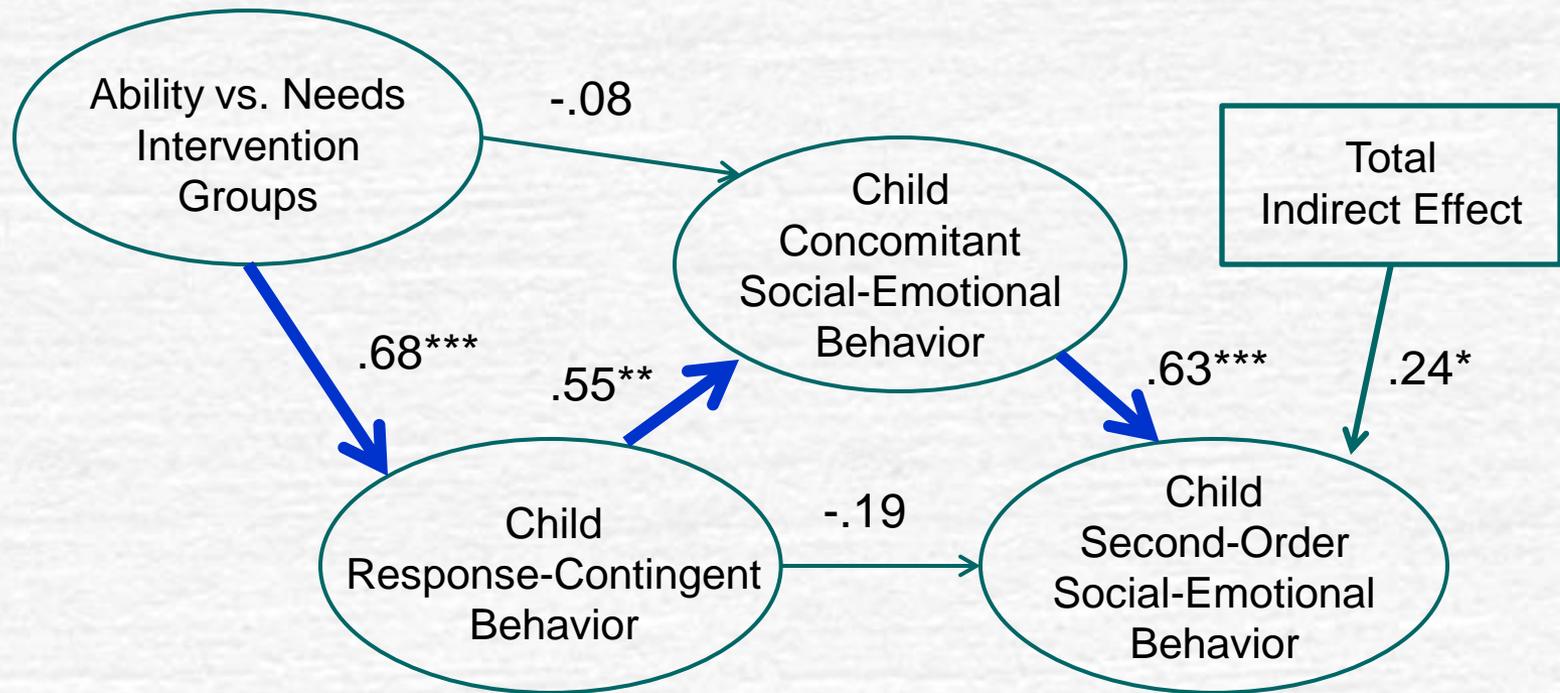
* $p < .01$. ** $p < .001$. *** $p < .0000$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



* $p < .01$. ** $p < .001$. *** $p < .0000$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



* $p < .01$. ** $p < .001$. *** $p < .0000$.

Some Final Thoughts

- Research indicates that family-centered practices are both directly and indirectly related to parent, child and family outcomes depending on how proximal or distal the outcomes are to family-centered help-giving
- Family-centered practices are best conceptualized as particular types of help-giving behavior that are used to implement other types of early childhood intervention practices
- Research on the use of capacity-building family-centered practices indicates that they have positive effects on different aspects of child and family functioning
- Additional research is needed to determine if the effects of family-centered practices on outcomes of interest are mediated by the efficacy of other types of early childhood intervention practices

The PowerPoint is available at
www.puckett.org