

Roots of Evidence-Based Patient- and Family-Centered Practices: What We Have Learned from Three Decades of Research

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Aims and Goals of the Session

- Describe a line of research and practice spanning more than 30 years focusing on the key characteristics of family-centered practices and the effects of use of these practices on parent, family, and child functioning
- Describe the types of research that have been conducted over the course of three decades
- Summarize findings from different lines of research to illustrate the complex relationships between family-centered practices and parent, family, and child outcomes

Types of Family-Centered Research and Research-Related Activity

- Operationally define family-centered practices and the particular behavior indicators of this approach to working with families
- Develop and validate scales and instruments for measuring practitioner use of family-centered practices
- Measure practitioner adherence to family-centered practices and the relationships between variations in adherence to variations in parent, family, and child functioning
- Meta-analyses of studies of family-centered practices by different practitioners in different service-delivery settings in different countries
- Structural equation modeling studies of the direct and indirect effects of family-centered practices on parent, family, and child outcomes mediated by parent self-efficacy beliefs
- Meta-analytic structural equation modeling studies of the pathways through which family-centered practices have direct and indirect effects on parent, family, and child outcomes

Foundations of Family-Centered Practices

Contemporary definitions and descriptions of family-centered practices are grounded in belief and value statements for how professionals should interact with, treat, and involve families in their children's care

- Center on Human Policy. (1986). *A statement in support families and their children*. Syracuse, NY: Division of Special Education and Rehabilitation, School of Education, Syracuse University
- Family Resource Coalition. (1987). *What are the assumptions of the Family Resource Movement?* Chicago: Author
- 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

Operationally Defining Family-Centered Practices

- The key characteristics of different sets of principles, value statements, and elements of family-centered practices and care were used to develop “behavioral indicators” for this approach to working with families
- A decision was made to investigate family-centered practices as a particular approach to professional help giving so as to be able to determine if practitioners were interacting with, treating, and involving parents in ways consistent with the intent of family-centered principles, value statements, and elements
- A review of the help giving practices literature was conducted to determine if the behavioral indicators had an evidence base that showed that the use of the behavior was associated with positive help receiver outcomes

Family-Centered Practices Scales

- Findings from our review and analysis of the help giving practices literature were used to develop a number of different family-centered practices scales and to evaluate their psychometric properties
- The scales that we developed include, but are not limited to:

Helpgiving Practices Scale (3 versions)

Family-Centered Practices Scale (3 versions)

Two Types of Family-Centered Practices

Research that my colleagues and I have conducted investigating the psychometric properties of our family-centered practices scales 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

Relational Family-Centered Practices

- Relational practices include behavior typically associated with effective clinical 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 involves family members in (a) informed choice and decision making, and (b) using existing strengths and abilities as well as developing new capabilities needed to be actively involved in their children's care and interventions
- Participatory practices also include practitioner responsiveness to and flexibility in how help is provided to children and their families

Different Terminology for Describing Relational and Participatory Family-Centered Practices

Family-Centered Scales

Relational Practices

Participatory Practices

*Measure of Process
Scale*

Respectful/
Supportive Care

Enabling and
Partnership

*Enabling Practices
Scale*

Comfort

Autonomy

*Family/Professional
Collaboration Scale*

Supportive
Understanding

Accessing
Services

Research on Family-Centered Practices at the Family, Infant and Preschool Program

- Measuring program staff use and adherence to family-centred practices from a consumer sciences perspective^a
- Meta-analysis of the relationships between program staff use of family-centred practices and parent, family, and child behaviour and functioning^b

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

^bDunst, C. J., Trivette, C. M., & Hamby, D. W. (2006). *Family support program quality and parent, family and child benefits* (Winterberry Monograph Series) Asheville, NC: Winterberry Press.

Family, Infant and Preschool Program Studies

- Eighteen (18) studies conducted between 1990 and 2004
- One thousand ninety-six (1,096) program participants
- Participants' children had identified disabilities, developmental delays, or were at-risk for poor outcomes for medical or environmental reasons
- Parents and their children received home-based services, attended family support or resource programs, or were involved in other types of community-based activities offered by the Family, Infant and Preschool Program
- In each study, participants completed a family-centered practices scale, several self-efficacy belief scales, and measures of parent, family, parent-child, and child behavior and functioning

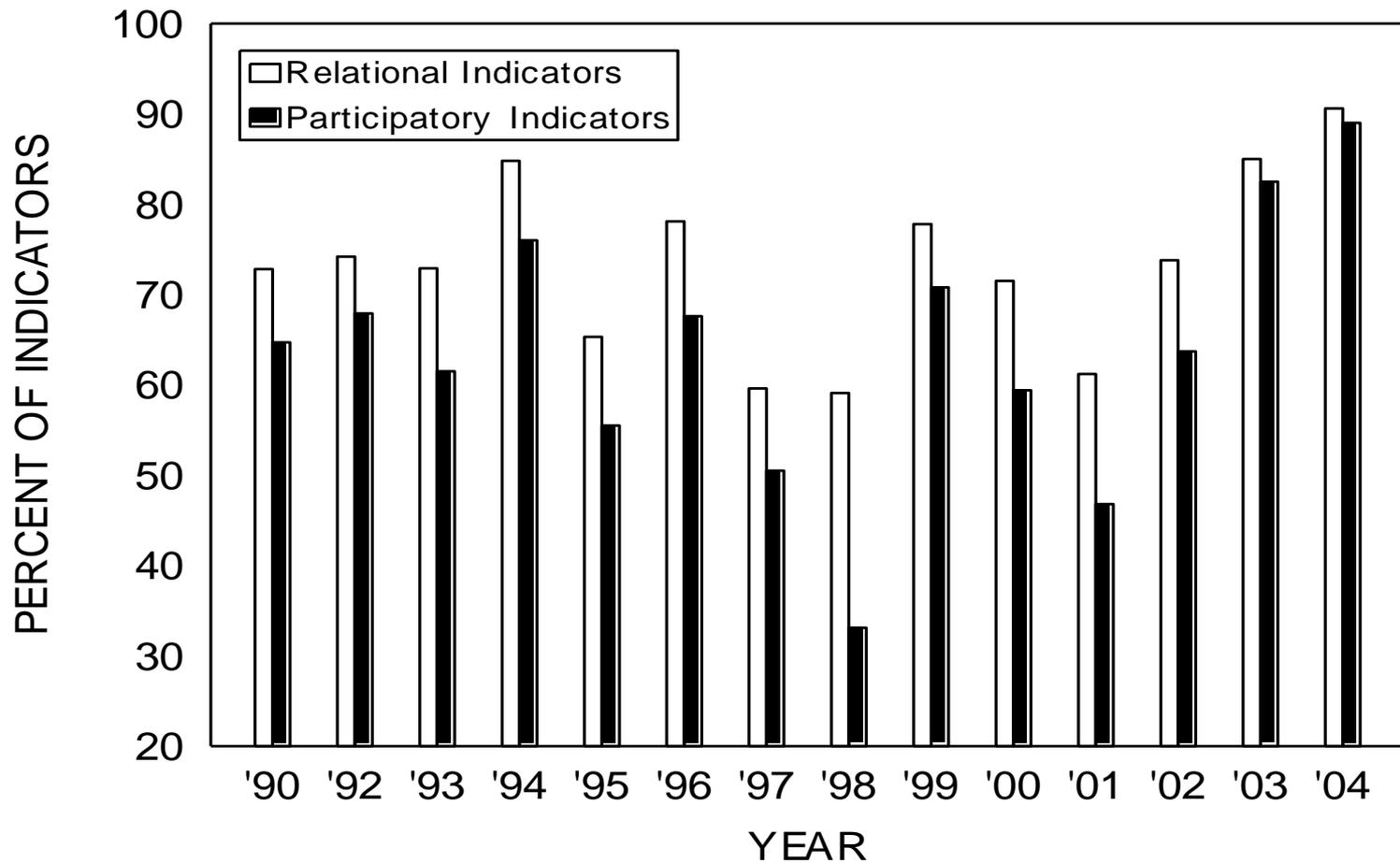
Measuring Adherence to Family-Centered Practices

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

Measuring Adherence to Family-Centered Practices

- In a typical adherence study, 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
- A typical survey includes 5 or 6 relational family-centered practice indicators and 5 or 6 participatory family-centered practice indicators
- Degree of adherence is measured in terms of the 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

Degree of Adherence to Family-Centered Practices



Meta-Analysis of Family-Centered Practices Research^{a, b}

- Assess the extent to and manner in which the use of family-centered practices are directly and indirectly related to (a) parent involvement in their children's learning and early education, (b) parenting confidence and competence, (c) parent and family well-being, and (d) child behavior and development ***mediated by parents' self-efficacy beliefs***
- Self-efficacy beliefs were a main focus of evaluating the indirect effects of family-centered practices based on findings from research highlighting the importance of these types of belief appraisals in terms of influencing parents' behavior

^aDunst, C.J., Trivette, C.M., & Hamby, D.W. (2007). Meta-analysis of family-centered helping practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378.

^bDunst, C.J., Trivette, C.M., & Hamby, D.W. (2008). *Research synthesis and meta-analysis of studies of family-centered practices*. Asheville, NC: Winterberry Press.

Studies Included in the Meta-Analysis

- 52 studies conducted by 23 researchers or research teams in 7 different countries
- 12,211 study participants whose children were involved in early intervention programs, preschool special education programs, elementary schools, family support programs, mental health programs, neonatal intensive care units, specialty clinics, rehabilitation centers, or physician practices
- The parents' children were an average of 71 months of age at the time the studies were conducted
- Sixty-one (61) percent of the children had a developmental disability or identified condition (e.g., Down syndrome, cerebral palsy), 12% had a developmental delay, 6% were at risk for poor outcomes, 8% had mental health related disabilities, and 13% were typically developing

Study Measures and Constructs

Study Measures

Instruments/Constructs

Family-Centered Practices

Family-Centered Behavior Scale
Family/Professional Collaboration Scale
Enabling Practices Scale
Help-Giving Practices Scale
Family-Centered Practices Scale
Brass Tacks
FOCAS
Measure of Process of Care
Family/Provider Relationship Instrument
Family Focused Intervention Scale

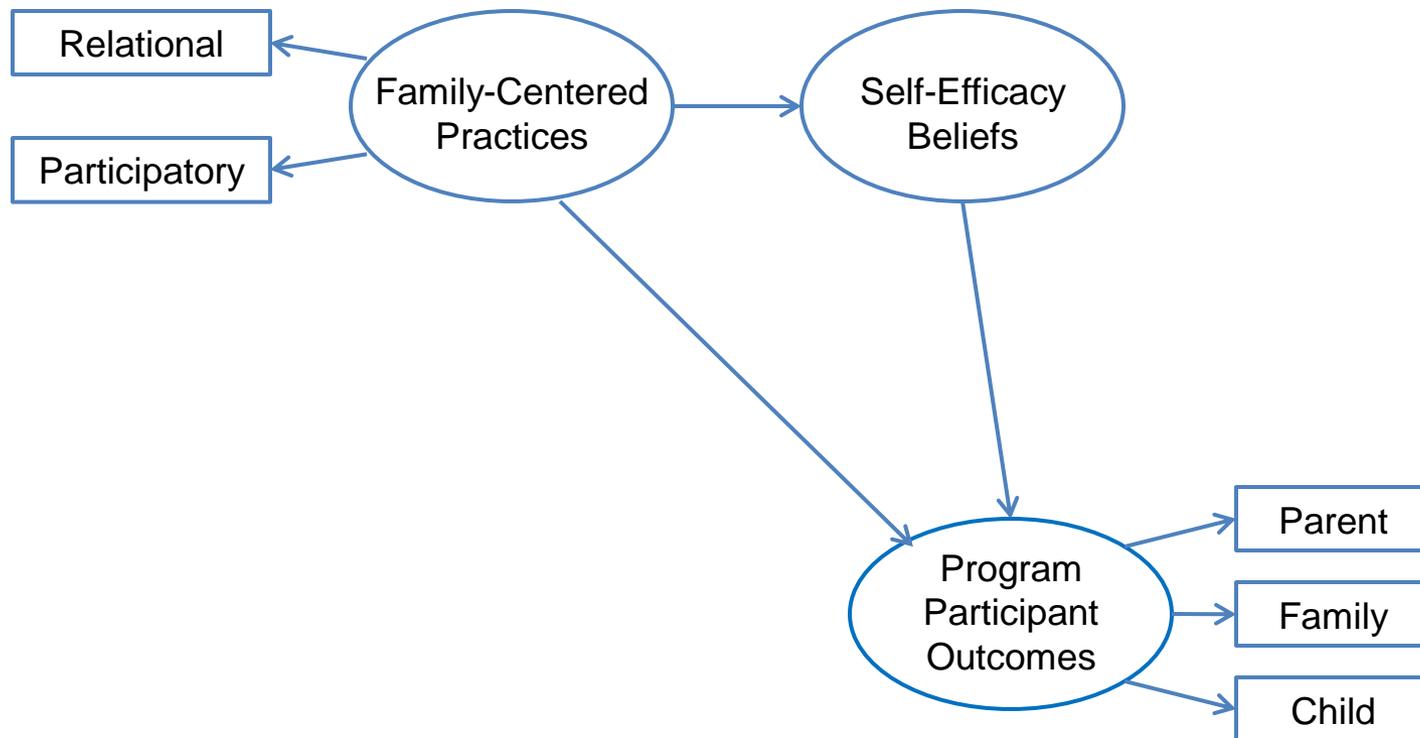
Outcome Measures

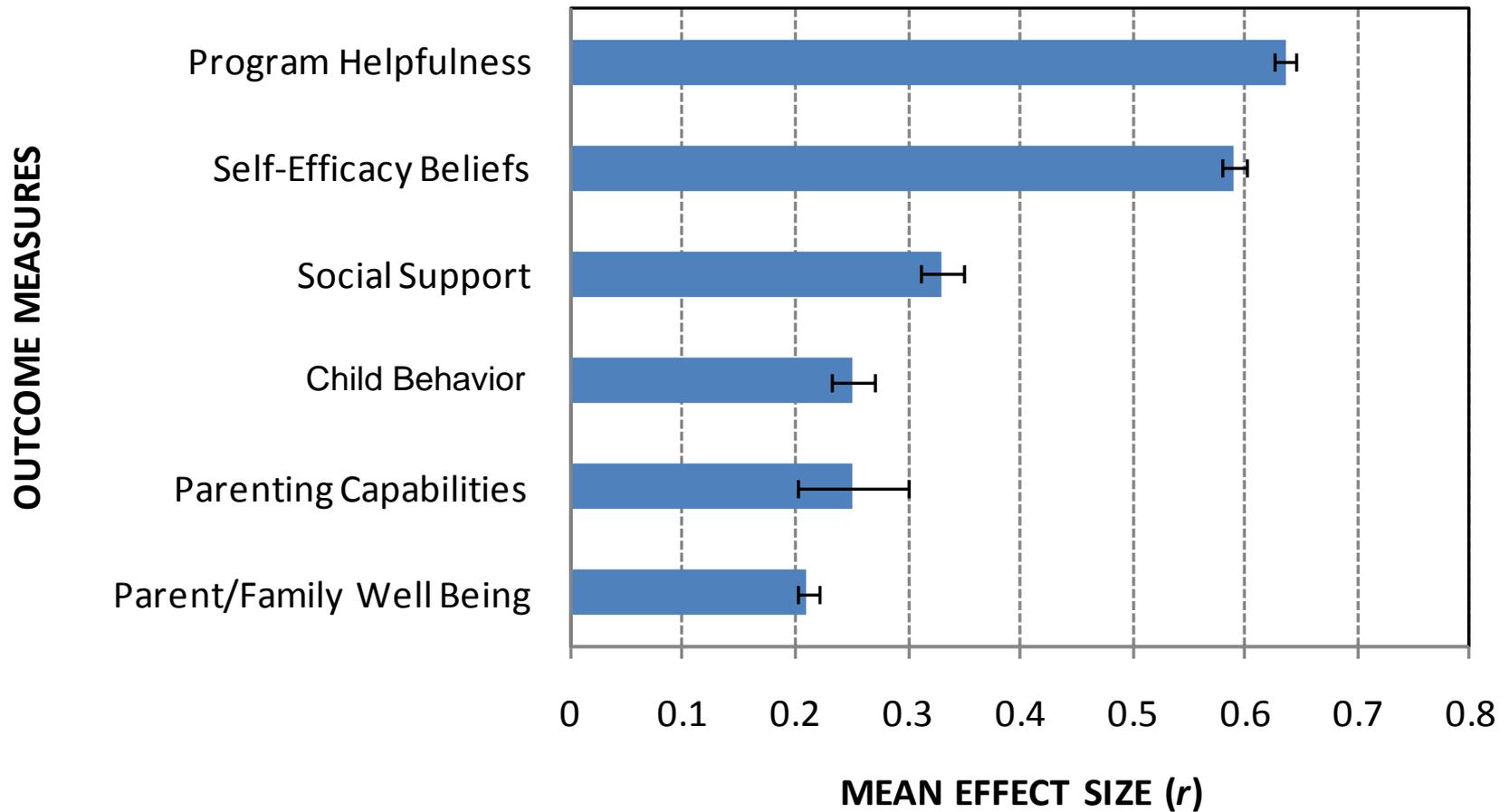
Program participant satisfaction, parent self-efficacy beliefs, parent empowerment, parenting capabilities, personal well-being, family functioning, social support, child functioning, child health

Method of Analysis

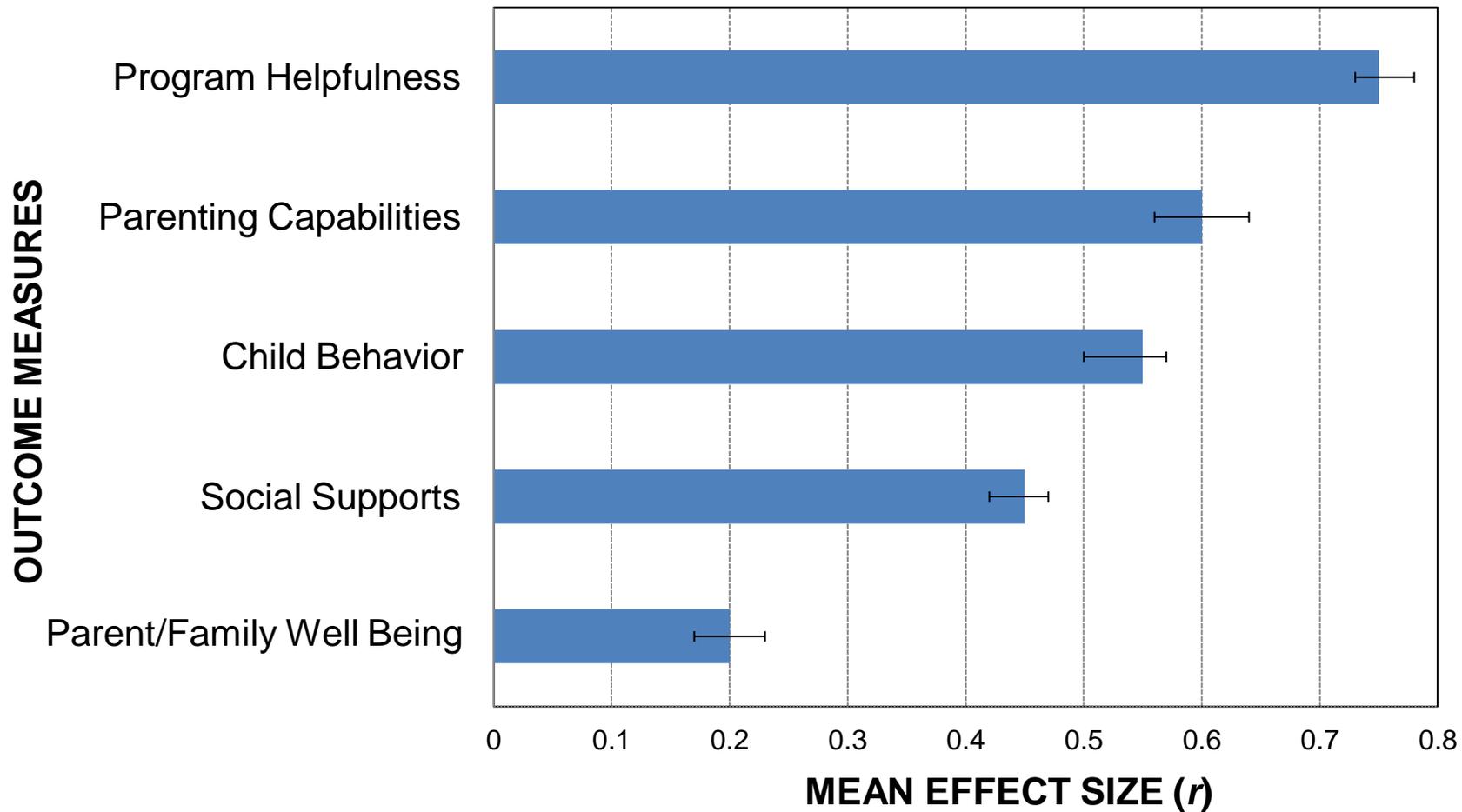
- The weighted average correlations among the independent and dependent variables were used as the effect sizes for the relationships between the family-centered practices measures and the study outcomes
- The 95% confidence intervals for the effect sizes were used to determine (a) the precision of the weighted average correlations and (b) if the correlations differed significantly from zero (a confidence interval not including zero indicates that the weighted average correlation is significant at $p < .05$ level.)

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

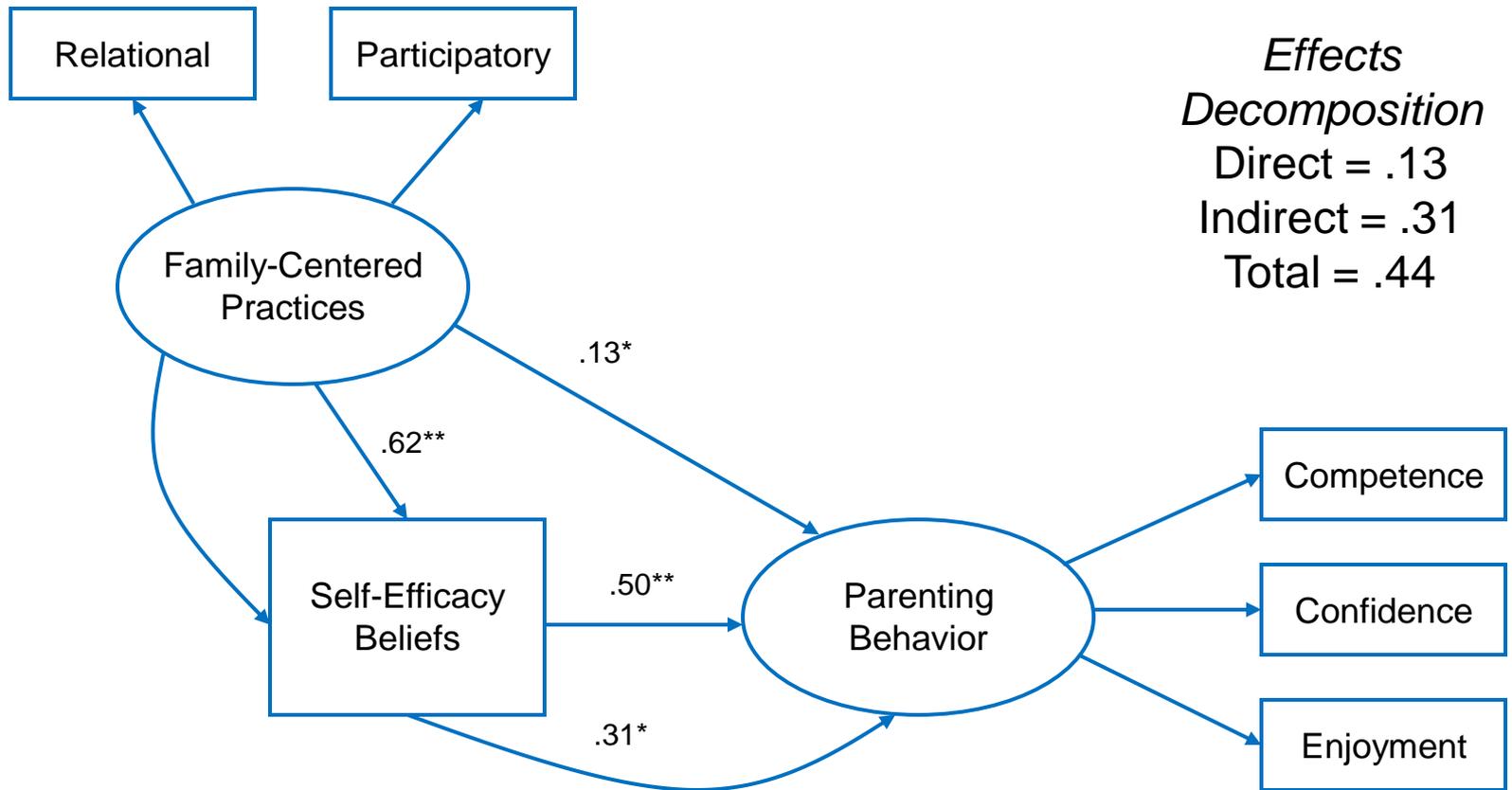




Direct Effects of Family-Centered Practices on Parent, Family, and Child Behavior and Functioning



Direct Effects of Parent Self-Efficacy Beliefs on Parent, Family, and Child Behavior and Functioning



Direct and Indirect Effect of Family-Centered Practices on Parenting Behavior

(NOTE. Straight lines are direct effects; the curved line is indirect effect)

Evaluating the Indirect Effects of Family-Centered Practices on Parenting Behavior

Carl J. Dunst

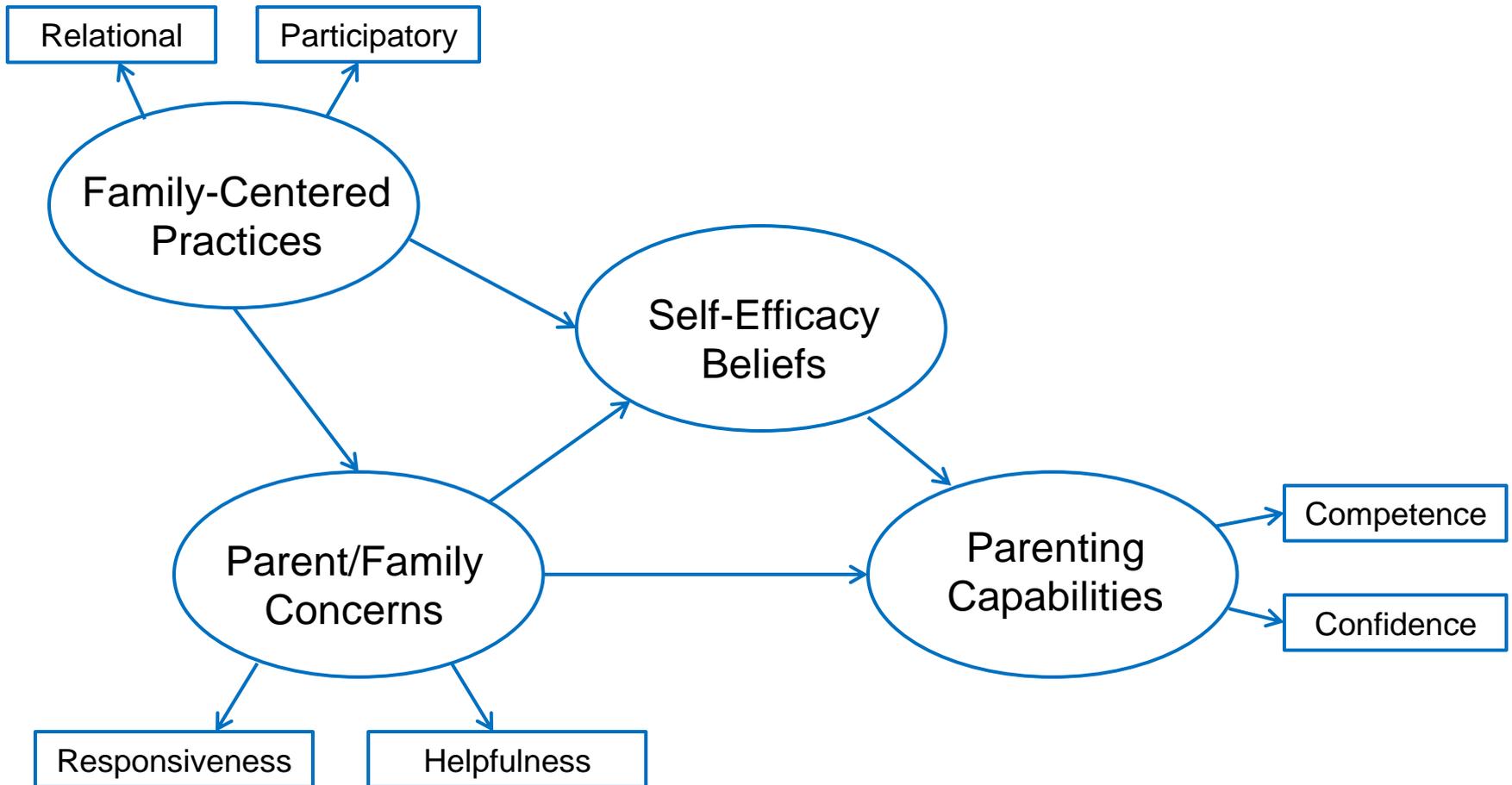
Carol M. Trivette

Participants: 100 parents of young children with and without disabilities participating in community-based family resource programs

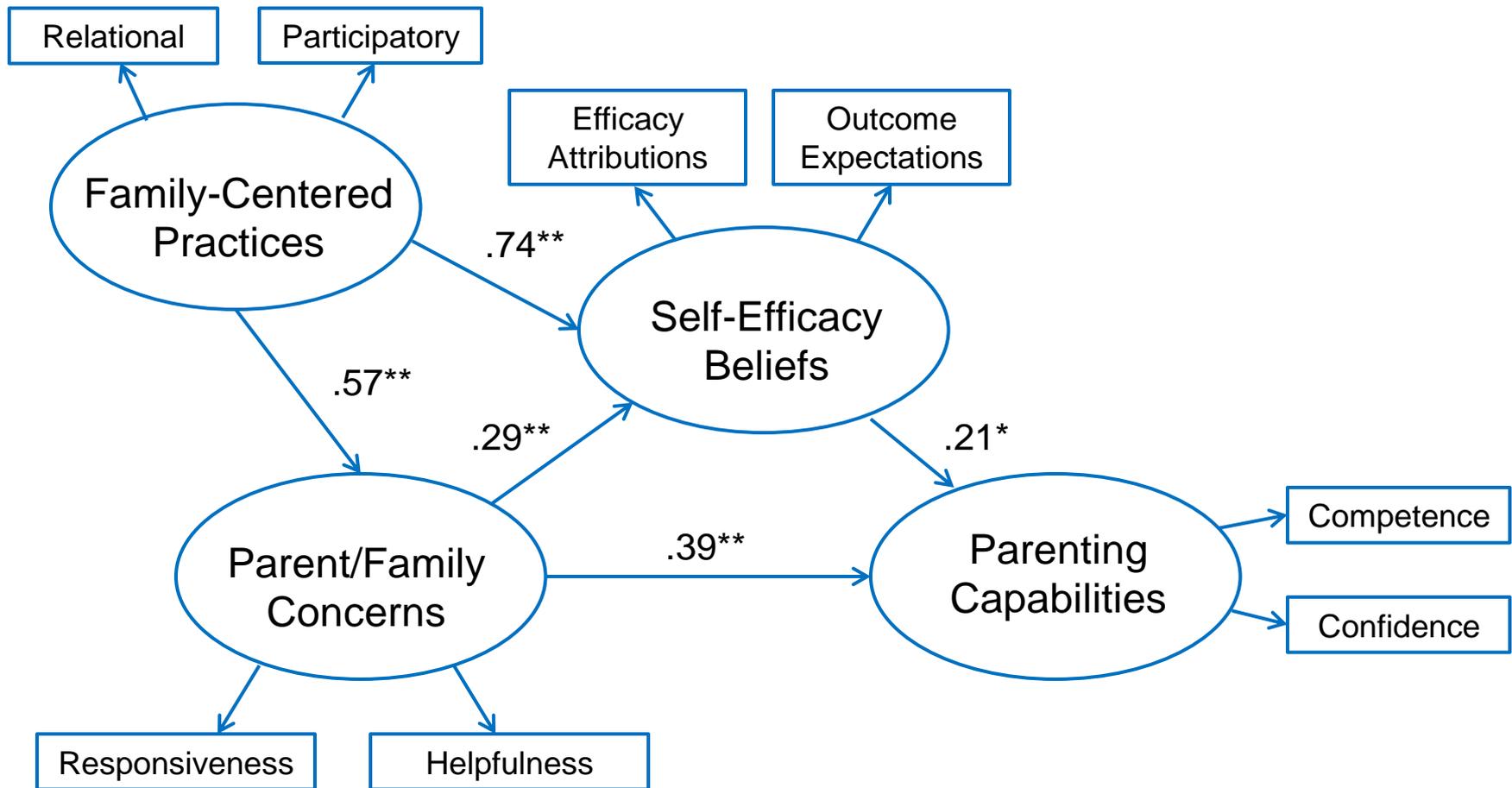
Measures: Relational and participatory family-centered practices, practitioner responsiveness to family concerns, parents' judgments of the helpfulness of practitioner advice and guidance, parent self-efficacy beliefs, and parenting competence and confidence

Method of Analysis: 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

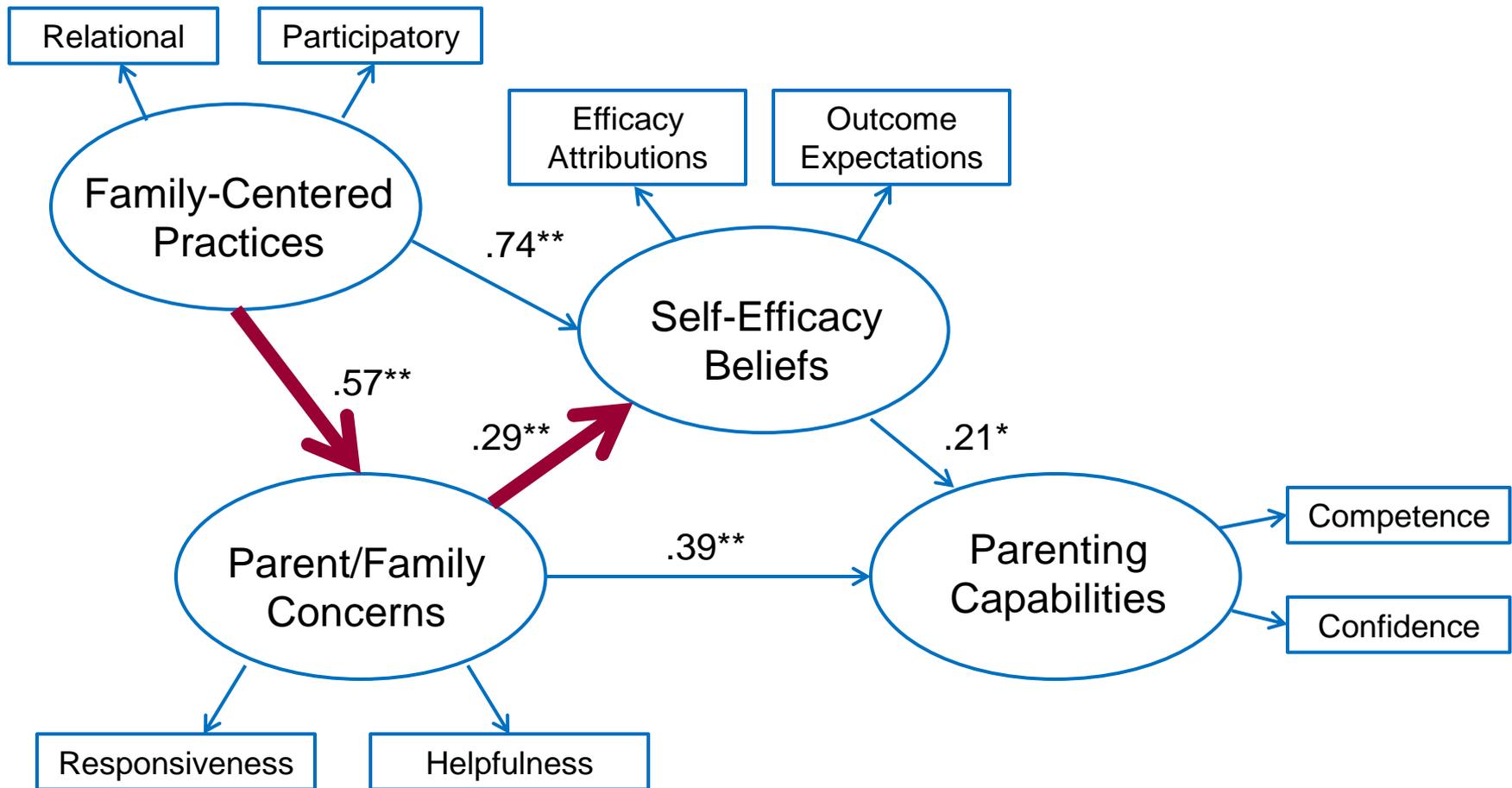


Standardized Parameter Estimates for the Relationships Among Measures in the Model



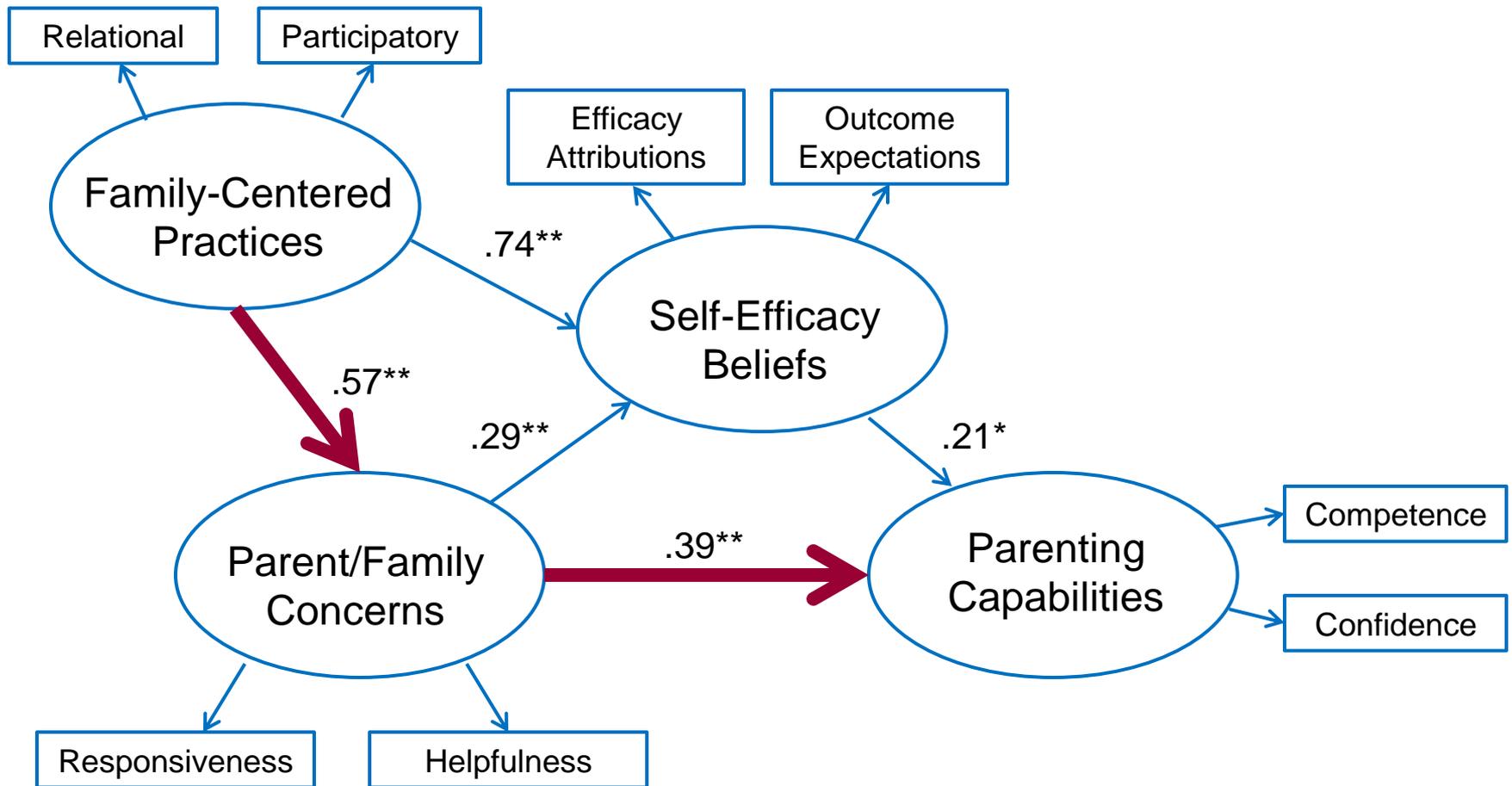
* $p < .05$ ** $p < .001$.

Standardized Parameter Estimates for the Relationships Among Measures in the Model



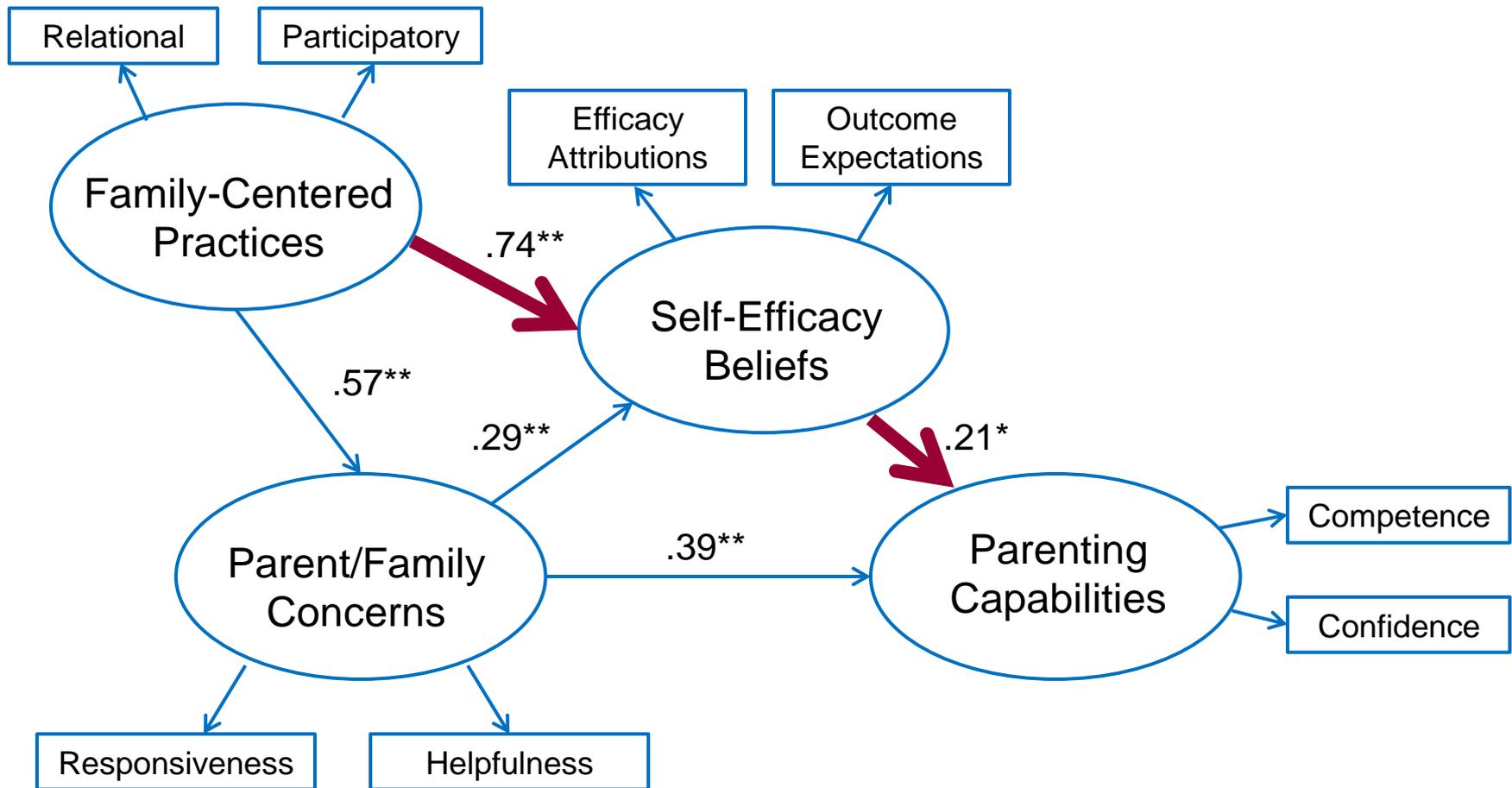
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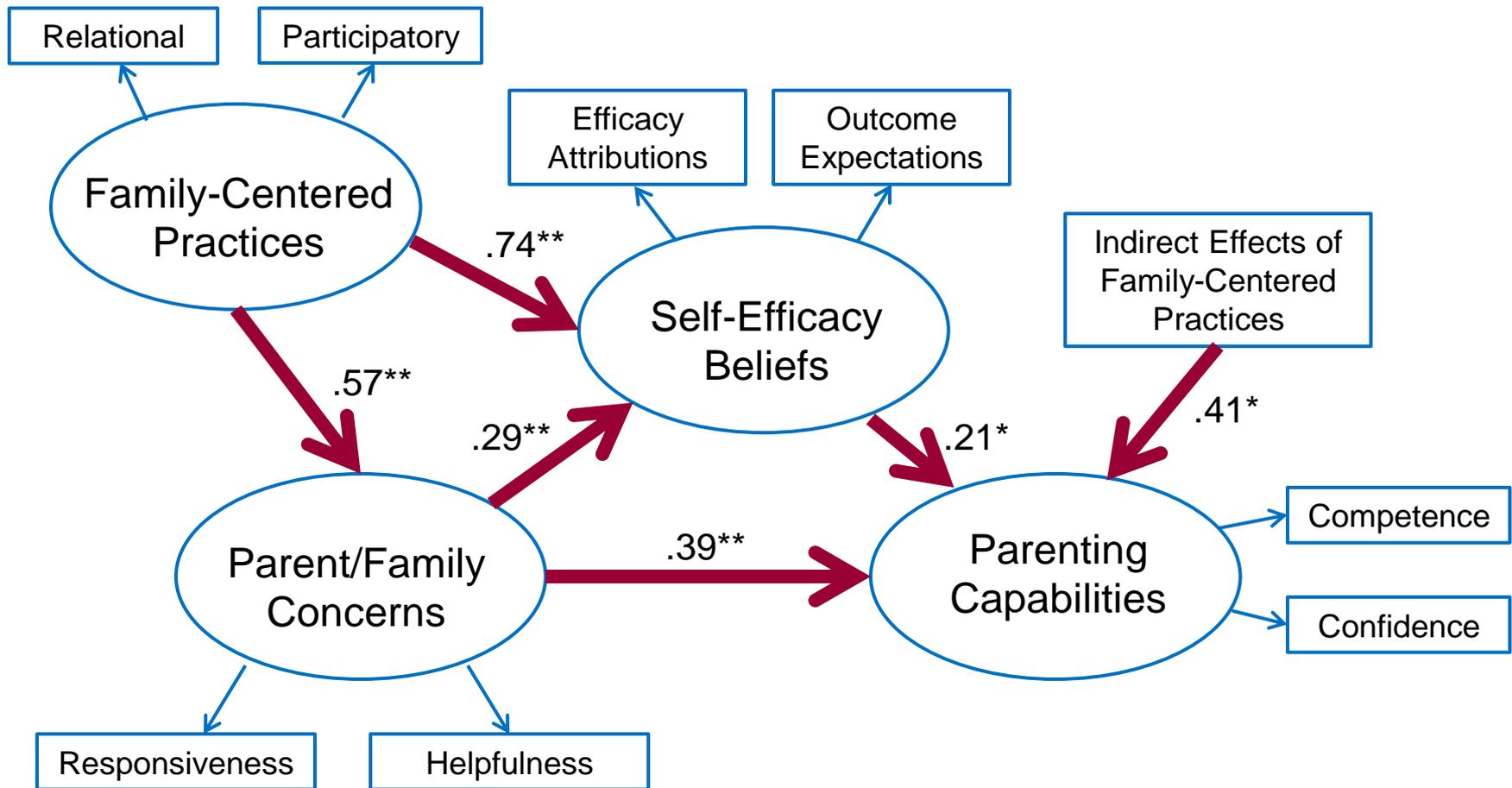
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Standardized Parameter Estimates for the Relationships Among Measures in the Model



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Standardized Parameter Estimates for the Relationships Among Measures in the Model



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

Meta-Analytic Structural Equation Modeling of the Influences of Family-Centered Care on Parent and Child Psychological Health^a

Carl J. Dunst Carol M. Trivette

Studies: 15 investigations of family-centered care that included measures of family-centered practices, self-efficacy beliefs, parent psychological health, and child psychological health

Sample: N= 2,948 parents and their children

Family-Centered Care Measures: Help-Giving Practices Scale, Family-Centered Practices Scale, and Enabling Practices Scale

Hypothesis: Based on contentions in the published literature, family-centered practices were expected to be directly related to parent psychological health and parent health in turn related to child psychological health. Based on our own research, the relationships between family-centered care and parent and child health were expected to be indirect and mediated by self-efficacy beliefs

^a *International Journal of Pediatrics*, 2009, Article ID 576840

Relationship Between Parent Participation in the Care of their Hospitalized Children and Child Psychological Health

- Fifty-five (55) years ago, Sir Harry Platt^a, an orthopedic surgeon in London, contended that the emotional and psychological needs of both parents and their children be addressed to maximize the benefits of child health care
- One recommendation of the *European Association for Children in Hospital*^b was: Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families
- Davies^c noted that although advances have been made with regard to parent participation in the care of their hospitalized children, there continues to be a need for research on professional-parent relationships and the effects on both parent and child health

^aMinistry of Health. (1959). *Platt report: The welfare of children in hospital*. London: HMSO.

^bNOBAB. (1988). *The Nordic chapter for children and youth in health and hospital care*. Goteborg, Sweden: Author.

^cDavies, R. (2010). Marking the 50th anniversary of the Platt Report: From exclusion to toleration and parental participation in the care of the hospitalized child. *Journal of Child Health Care*, 14(1), 6-23.

Meta-Analytic Structural Equation Modeling

Meta-analytic structural equation modeling (MASEM) is a procedure for combining data (e.g., correlations) from multiple studies (meta-analysis) and using the combined data set to evaluate the fit of a model to the patterns of relationships among the variables in the model (structural equation modeling). Recent advances in data analysis procedures make meta-analytic structural equation modeling potentially useful for evaluating the effects of different kinds of intervention practices on outcomes of interest. Dr. Mike Cheung at the National University of Singapore has developed methodological procedures^{a, b} to prepare and analyze data to perform a MASEM

^aCheung, M. W. L. (2009). *TSSEM: A LISREL syntax generator for two-stage structural equation modeling* (Version 1.11) [Computer software manual]. Singapore: Author. Available at <http://courses.nus.edu.sg/coursepsycwlm/internet/tssem.zip>.

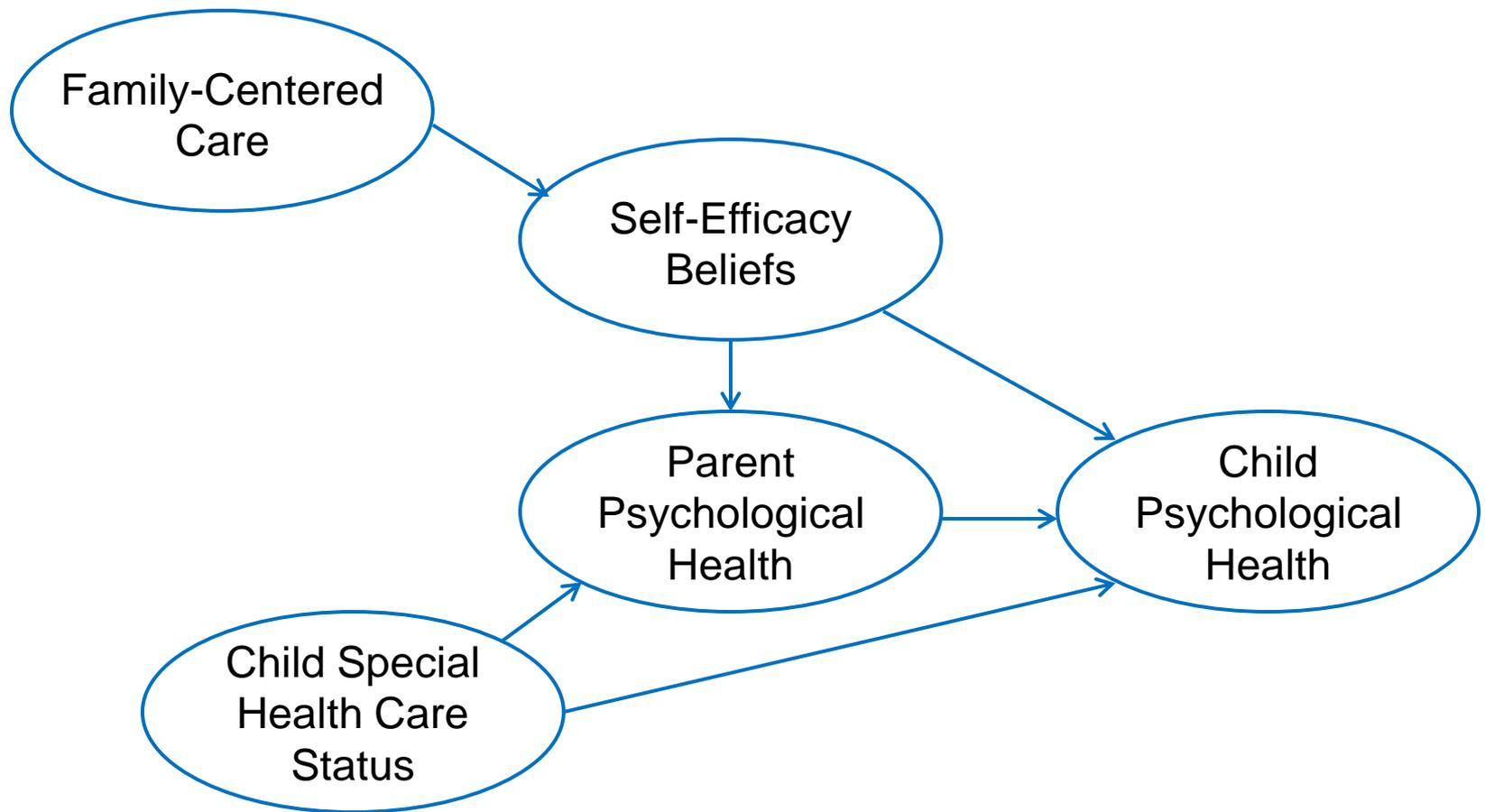
^bCheung, M. W. L. (2014). Fixed- and random-effects meta-analytic structural equation modeling: Examples and analyses in R. *Behavior Research Methods*, 46, 29-40.

Two-Stage Structural Equation Modeling^a

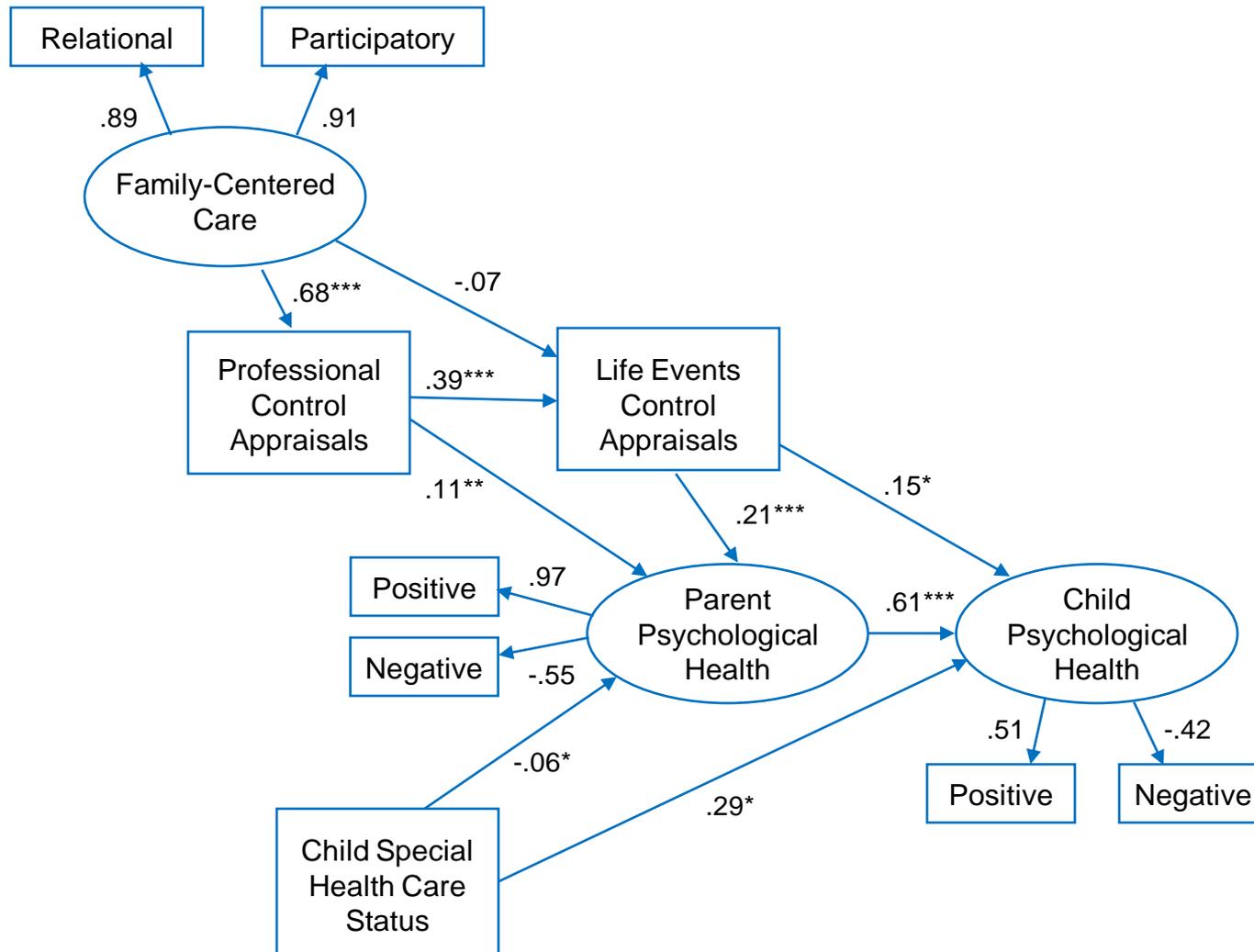
- Stage 1.** Test the homogeneity of a pooled correlation matrix and produce a weighted pooled correlation matrix. This involves two steps:
- 1A. Testing the homogeneity of a pooled matrix
 - 1B. Producing a weighted correlation matrix if the pooled matrix is homogeneous
- Stage 2.** Test the fit of a hypothesized model to the patterns of relationships among the variables in the pooled matrix using SEM. Two types of statistics are used to evaluate it:
- 2A. Testing the fit of a model to the patterns of correlations among the variables in the model
 - 2B. Estimate the strength of the relationships between the variables in a model

^aCheung, M. W. L., & Chan W. (2005). Meta-analytic structural equation modeling: A two-stage approach. *Psychological Methods*, 10(1), 29-40.

Structural Equation Model for Evaluating the Effects of Family-Centered Care, Self-Efficacy Beliefs, and Child Special Health Care Status on Parent and Child Psychological Health

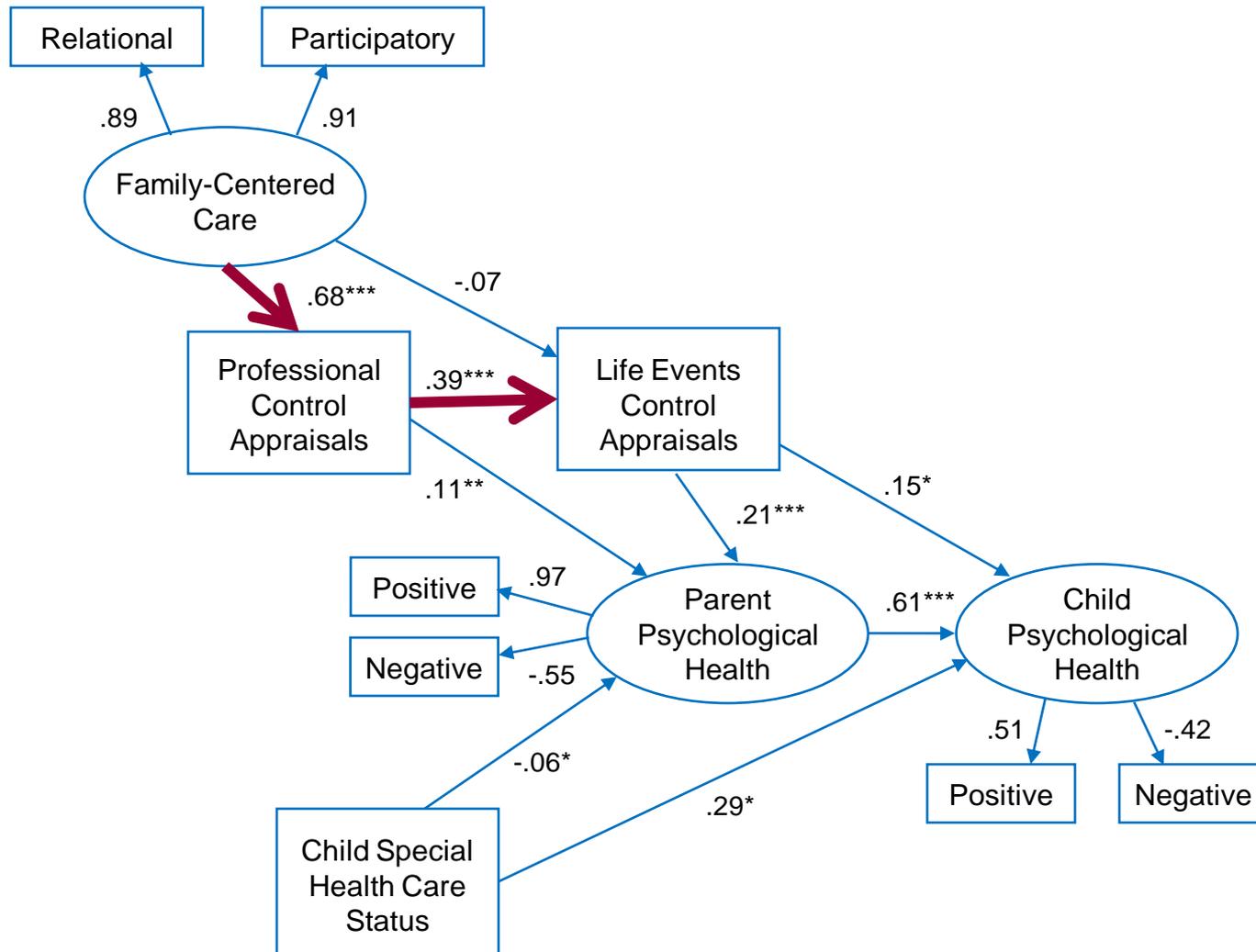


Meta-Analytic Structural Equation Modeling Results



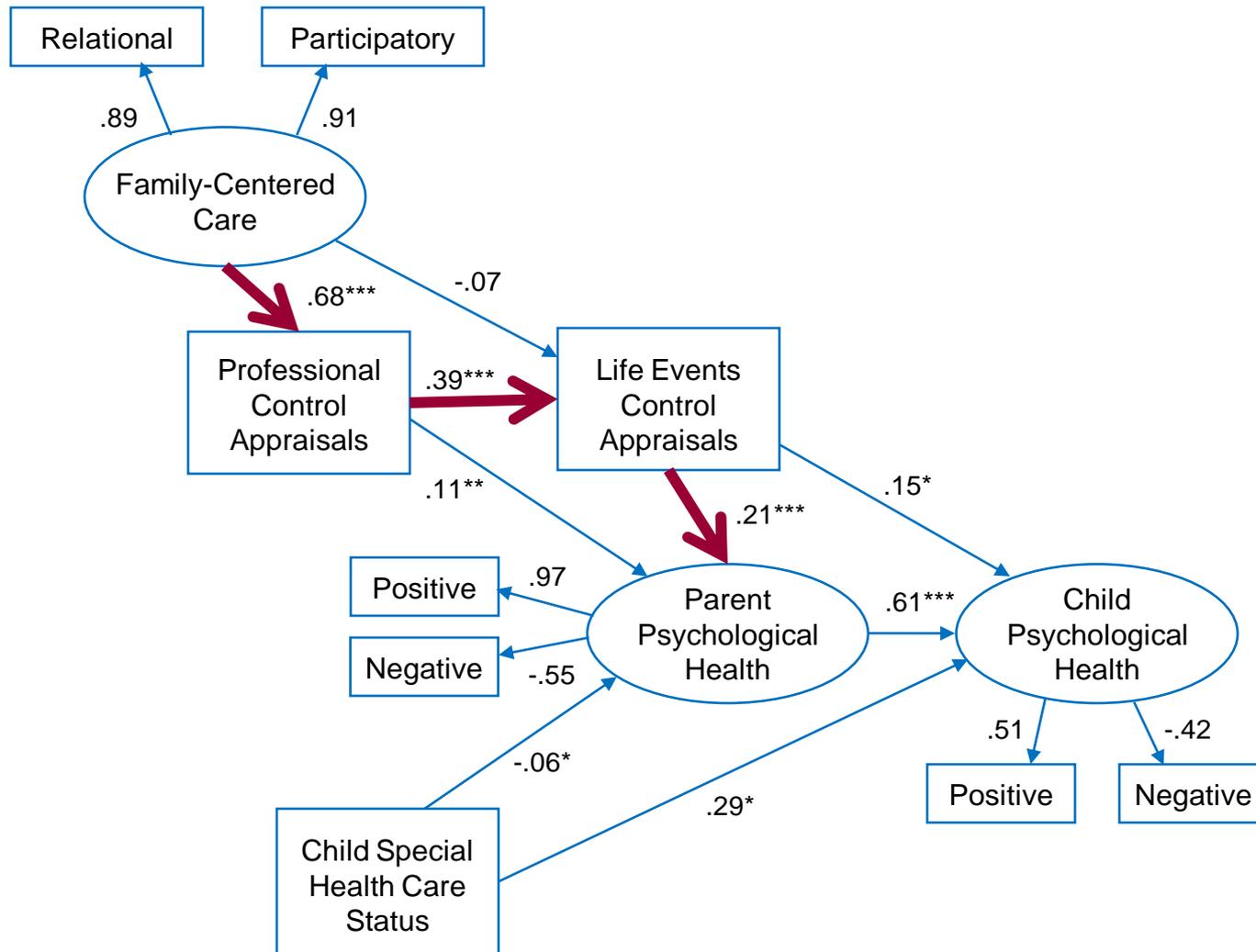
* $p < .01$, ** $p < .001$, *** $p < .0001$.

Meta-Analytic Structural Equation Modeling Results



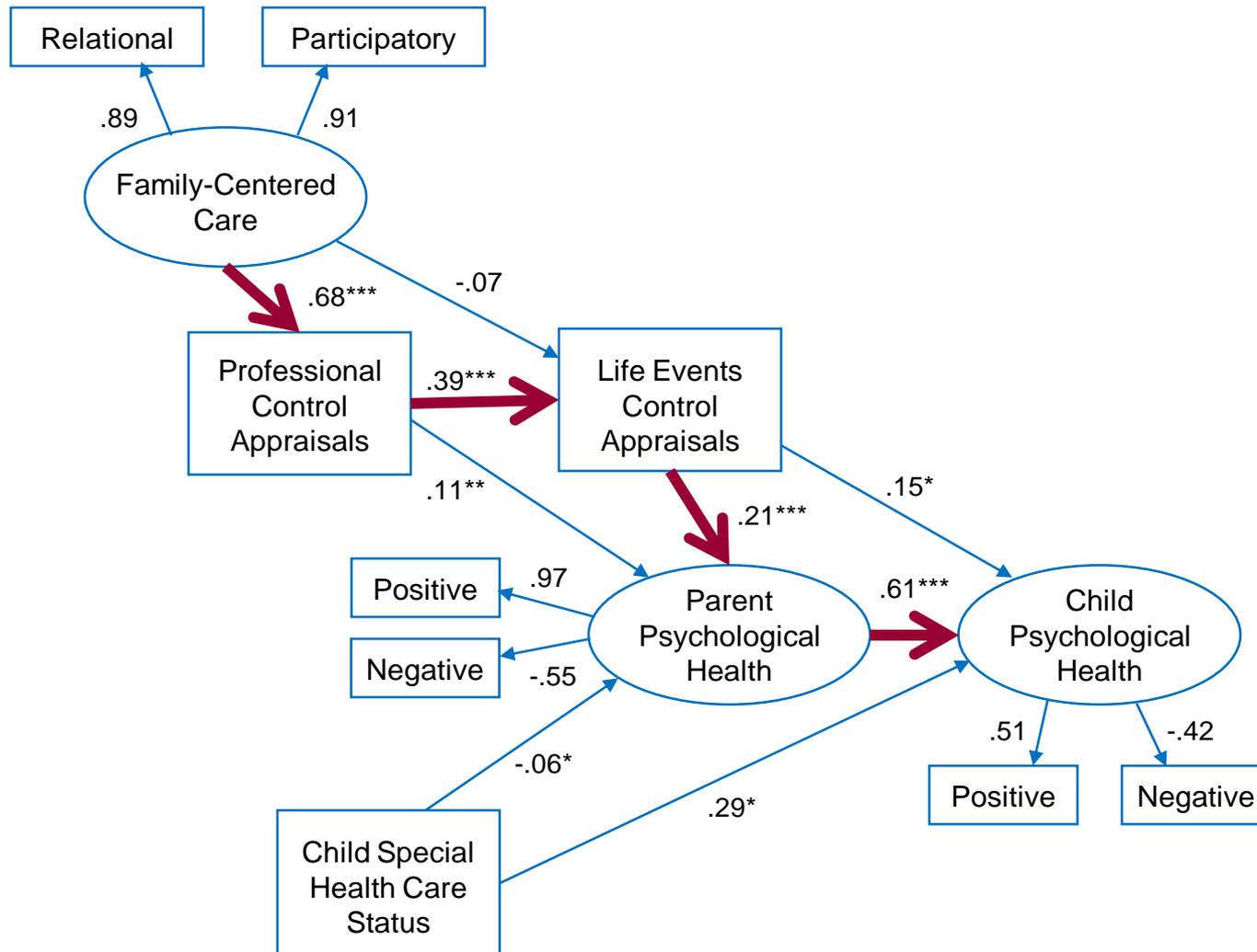
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Meta-Analytic Structural Equation Modeling Results



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Meta-Analytic Structural Equation Modeling Results



* $p < .01$, ** $p < .001$, *** $p < .0001$.

Observations and Reflections on Family-Centered Practices Research

- The effects of family-centered practices need to be understood in the context of complex social and organizational ecologies, and research methods used to evaluate the use of the practices, need to be able to capture those complexities
- Research using SEM and MASEM is especially promising for identifying the direct and indirect effects of family-centered practices on parent, family, and child functioning and the mediators of those relationships
- Advances in understanding the benefits of family-centered practices are likely to be made if careful attention is paid to the mediators of the relationships between the use of these practices and parent, family, and child outcomes

PowerPoint presentation is available at
www.puckett.org