# Professional-family help giving relationships in family support programs

Author Details: Carl J. Dunst-Orelena Hawks Puckett Institute

Abstract. A multiple case study design was used to test the hypothesis that human services program family resource coordinator practices that were consistent with the intent of family support principles would be associated with parent reported positive family outcomes and practices inconsistent with the intent of family support principles would be associated with parent reported negative family outcomes. Family support principles are belief and value statements about how families should be treated by family resource coordinators. Both pattern matching and replication logic were used to perform quantitative and qualitative data analysis. Results confirmed the predicted relationships between family resource coordinator practices and family outcomes. Implications for improving professional-family relationships in the context of help giving exchanges are described.

**Keywords:** family support, family resource coordinator practices, family outcomes, multiple case studies, replication logic, pattern matching

### 1. INTRODUCTION

The aim of family support programs is to strengthen family functioning through provision and mobilization of both informal and formal supports and resources in response to family-identified needs and concerns (Kagan & Weissbourd, 1994; Weissbourd & Kagan, 1989). Family support programs for families rearing a family member with an intellectual, physical, sensory, or other type of developmental disability have become a primary means of ensuring that families have the necessary informational, emotional, instrumental, and other types of support needed to improve family functioning (Kyzar, Turnbull, Summers, & Gómez, 2012; Rizzolo, Hemp, Braddock, & Schindler, 2009). The desired outcomes of family support programs are improved family member well-being, independence, self-efficacy, competence, confidence, and sense of empowerment and family cohesion, life satisfaction, and quality of life (Hecht & Reynolds, 2012; Kyzar et al., 2012).

### 1.1. Family Support Principles

Family support programs differ from other types of human services programs by the use of family support principles for guiding the ways in which family support workers interact, treat, and respond to each family's unique circumstances (Kagan & Weissbourd, 1994; Weissbourd & Kagan, 1989). Family support principles are belief and value statements about how supports and resources ought to be provided by family support program workers and how these workers should treat and interact with family members as part of help giving exchanges (Dunst, 1995). A synthesis of diverse compilations of different sets of family support principles indicated that they can be grouped into the six categories shown in Table 1 (Dunst, Trivette, & Thompson, 1990). The principles shown in Table 1 were used in the study described in this paper as benchmarks against which family support program worker practices were evaluated to determine if the practices were associated with expected outcomes and benefits.

### 1.2. Family Support Program Workers

One unique feature of family support programs for family members with a developmental disability is the assignment of a program staff member to work with a family to help coordinate the different supports and resources a family considers needed for improved family functioning (Lindeke, Leonard, Presler, & Garwick, 2002). These staff have been described as service coordinators (Trute, 2007), case managers (Neal & Gilson, 1996), care coordinators (Ziring et al., 1999), key workers (Sloper, Greco, Beecham, & Webb, 2006) and family resource coordinators (Julian, 1995). The term family resource coordinator is used in this paper to describe the family support program workers whose practices were the focus of investigation.

### 1.3. Purpose of the Study

The purpose of the study described in this paper was to ascertain if family support coordinator practices that were consistent with the intent of family support principles were associated with hypothesized positive family member outcomes (literal replication) and those not consistent with the intent of family support principles were associated with hypothesized poorer or less desirable outcomes (theoretical replication) (Yin, 2014). A multiple case study design was used "to enable comparisons that clarify whether an emergent finding is simply idiosyncratic to a single case or is consistently replicated by several cases" (Eisenhardt & Graebner, 2007, p. 27).

#### 2. METHOD

# 2.1. Participants

The participants were 11 family resource coordinators and 22 parents of a family member with a developmental disability in 11 United States. The states were selected in order to include family support programs that differed in terms of the types and scope of supports and resources that were available to program participants and to ensure geographic diversity. The program director or his/her designee in each program was asked to select a family resource coordinator who "best represented" a staff member who practiced in ways consistent with program expectations. Each family resource coordinator in turn was asked to select two families with whom they worked, one whom he or she considered typical of the majority of families served by the family resource coordinator, and one who had multiple risk factors that required additional supports and resources.

Table 1			Major Categories
	-	 	

# and Examples of Family Support Program Principles

#### Principle Category / Characteristics

### Enhancing a sense of community:

Promoting the coming together of people around shared values and common needs in ways that create mutually beneficial interactions

#### **Examples of Principles**

Family resource coordinator practices should focus on building interdependencies between members of the community and the family unit.

Family resource coordinator practices should emphasize the common needs and supports of all people and base interventions on those commonalities.

#### Mobilizing resources and supports:

Building social support systems that enhance the flow of resources in ways that assist families with parenting responsibilities Family resource coordinator practices should focus on building and strengthening informal support networks for families rather than depend solely on professional support systems.

Resources and supports should be made available to families in ways that are flexible, individualized, and responsive to the needs of the entire family unit.

### Shared responsibility and collaboration:

Sharing ideas and skills by parents and professionals in ways that build and strengthen collaborative relationships

Family resource coordinator practices should employ partnerships between parents and professionals for supporting and strengthening family functioning.

Resources and support mobilization interactions between families and family resource coordinators should be based upon mutual respect and sharing of unbiased information.

### **Protecting family integrity:**

Respecting the family's beliefs and values and protecting the family from intrusion upon its beliefs by outsiders

Resources and supports should be provided to families in ways that encourage, develop, and maintain healthy, stable relationships among all family members.

Family resource coordinator practices should be conducted in ways that accept, value, and protect a family's personal and cultural values and beliefs.

#### **Strengthening family functioning:**

Promoting the capabilities and competencies of families necessary to obtain resources and carry-out parenting responsibilities in ways that have family strengthening consequences

Family resource coordinator practices should build upon family strengths rather than correct weaknesses or deficits as primary ways of supporting and strengthening family functioning.

Resources and supports should be made available to families in ways that maximize the family's control over decision-making power regarding supports they receive.

#### **Promotive human services practices:**

Adoption of consumer-driven human services delivery models and practices that support and strengthen family functioning Family resource coordinators should employ promotion rather than treatment approaches as the framework for strengthening family functioning.

Resources and support mobilization should be consumer driven rather than family resource coordinator driven or professionally prescribed.

### 2.1.1. Family Resource Coordinators

The 11 family resource coordinators were all female except one. They ranged between 20 and 49 years of age with most being between 30 and 39 years of age. Eight coordinators had bachelor's degrees, three had master's

degrees, and one had an associate's degree. The family resource coordinators had an average of 6.58 years experience working in human services programs (SD = 5.92, Range = 2 to 20) and an average of 3.17 years working as a family resource coordinator (SD = 1.95, Range = 1 to 6).

# 2.1.2. Family Members

The adult family members who were sources of the case study data were mostly the mothers of the family member with a disability. The mothers and their children lived in two parent households (73%), single parent households (18%), and foster care parent households (9%). The socio-economic backgrounds of the families were primarily low (45%) and middle (45%) class, with a small percentage of the families having high SES backgrounds (10%). Family income ranged from less than \$US600 per month to\$US4000 per month.

The family members with a developmental disability had an average age of 14.19 years (SD = 12.58, Range = 1 to 42). The developmental disabilities of these family members included physical disabilities (36%), Down syndrome (23%), intellectual disabilities (23%), autism and Fragile X syndrome (9%), and other rare conditions (9%). The families had been involved in the family support programs an average of 4.30 years (SD = 3.83, Range = 1 to 11).

### 2.2. Sources of Case Study Data

An investigator-developed interview protocol was used to obtain adult family member descriptions of family resource coordinator practices and the outcomes associated with the practices. The protocol included 12 questions, two for each of the six family support principles in Table 1. One question for each principle was phrased to elicit descriptions of practices that were

considered consistent with the intent of the principles, and one question to elicit descriptions of practices considered inconsistent with the intent of the principles. After each family member's descriptions of family resource coordinator practices, respondents were asked to describe the consequences or results experienced by the family and individual family members.

### 2.2.1. Unit of Analysis

The unit of analysis was the responses to individual family support principle-family outcome descriptions. The case studies yielded 136 sets of participant responses to the 22 protocol questions. The data were disaggregated for data coding purposes so that the family resource coordinator practices were coded independently of, and without reference to, the families' descriptions of the outcomes associated with the practices. Families' descriptions of the family resource coordinator practices were coded as highly consistent, mostly consistent, neither consistent nor inconsistent, mostly inconsistent, or highly inconsistent with the intent of the six different family support principles. The families' responses to the practices were coded as highly positive, mostly positive, neither positive nor negative, mostly negative, or highly negative outcomes.

### 2.2.2. Interrater Agreement

Both the families' descriptions of the practices and the outcomes associated with the practices were independently coded by two researchers with extensive experience with both family support programs and family support principles for determining interrater agreement. Both nonparametric correlations (Nunnally & Bernstein, 1994) and Cohen's kappa (Cohen, 1960) were used to compute interrater agreement for each of the six family support principles. The median correlation and kappa for the family resource coordinator practices were, respectively, .89 (Range = .83 to .96) and .85 (Range = .79 to 1.00), and the median correlation and kappa for the family outcomes were, respectively, .88 (Range = .74 to 1.00) and .85 (Range = .78 to 1.00).

### 2.3. Data Analysis

Both pattern matching and replication logic were used to analyze the case study data (Hak & Dul, 2010a, 2010b). As noted by Hak and Dul (2010a), "pattern matching is the core procedure of theory-testing with cases.

Testing consists of matching an 'observed pattern' (a pattern of measured values) with an 'expected pattern' (a hypothesis), and deciding whether the pattern...results in confirmation of the hypothesis...or results in disconfirmation" (p. 1). According to Yin (2014), case study data that predict and confirm similar results is evidence of literal replication, whereas data that predict and confirm contrasting results for predictable reasons is evidence for theoretical replication.

The measure for ascertaining pattern matching and both literal and theoretical replication was Gamma (Nunnally & Bernstein, 1994). Gamma is a nonparametric measure of the relationship between two ordered variables which were the codes for both the family resource coordinator practices and the family outcomes. Gamma is a strength of association effect size for estimating the shared variance between ordered variables (Ferguson, 2009). The quantitative analysis was supplemented by descriptive findings to illustrate the richness of the families' descriptions.

#### 3. RESULTS

### 3.1. Quantitative Findings

Table 2 shows the results for the relationship between family resource coordinator practices and the family outcomes. Ninety-one percent of the family resource coordinator practices coded as either highly consistent or mostly consistent with family support principles were also coded as having outcomes that were either highly positive or mostly positive. In contrast, ninety-six percent of the family resource coordinator practices coded as either highly inconsistent or mostly inconsistent with family support principles were also coded as having outcomes that were either highly negative or mostly negative. The Gamma for the relationship between the two sets of ordered measures was G = .74, t(24) = 7.55, p = .0000, indicating a large effect size for the relationship between the family resource coordinator practices and families' descriptions of the benefits and outcomes associated with the practices.

Table 2

Matching Results for the Relationships Between Family Resource Coordinator Practices and Family Reported Outcomes

	Family Outcomes					
Family Resource Coordinator Practices	Highly positive outcomes	Mostly positive outcomes	Neither positive nor negative outcomes	Mostly negative outcomes	Highly negative outcomes	
Highly consistent with family support principles	11	27	2	1	0	
Mostly consistent with family support principles	10	42	6	0	0	
Neither consistent nor inconsistent with family support principles	1	6	1	1	0	
Mostly inconsistent with family support principles	0	1	0	6	1	
Highly inconsistent with family support principles	0	0	0	11	9	

### 3.2. Qualitative Findings

## 3.2.1. Literal Replication

The following are examples of family resource coordinator practices coded as consistent with the intent of family support principles and which were associated with positive family outcomes to illustrate literal replication.

**Coordinator practice:** "The program staff gives me total control in deciding what I need and when I need it. When I needed to build a fence around my backyard so my daughter could play outside by herself, the staff encouraged me to spend the (cash subsidy) money in any way I wanted. It was nice to have the choice to spend the money to buy the fence."

**Family outcome:** "Knowing that I had the choice to spend the money to buy the fence felt really great. It was great that the staff cared enough to tailor their (practices) to meet my need."

**Coordinator practice:** "My greatest need was to find someone with new ideas and suggestions about how I could help my child learn to walk. The staff listened to my concerns and made arrangements for a knowledgeable person from out of town to meet me. This person (specialist) showed me how to work with my son, which was very helpful."

Family outcome: "It was great. It gave me a sense of hope. It made me feel great."

**Coordinator practice:** "They always ask me what I need and I tell them. They never question (my requests). For example, the staff say it's all right when I say there aren't very many people who can care for my child." **Family outcome:** "I felt good, supported, and respected."

### 3.2.2. Theoretical Replication

Examples of family resource coordinator practices coded as inconsistent with the intent of family support principles and which were associated with negative family outcomes and that illustrate theoretical replication include the following.

**Coordinator practice:** "I can never get a respite care when I need it. They (the program staff) are never flexible. They want to do things around their own schedule. When I keep asking, their attitude is, 'So what; Tough!"

**Family outcome:** "I thought (the staff member) was just another nasty person I was going to have to deal with. I don't want to think this, but oh, what a b\_\_\_\_."

**Coordinator practice:** "They tell me what services my daughter needs. Sometimes I don't think she needs it, yet the staff go ahead with it anyway."

**Family outcome:** "I feel like I don't have any say about what is done with my daughter. It feels like they run things, and that makes me feel mad."

Coordinator practice: "When I made a decision to have my child cared for by someone else, the family resource coordinator did not respect my decision and tried to make me feel guilty about what I wanted to do."

Family outcome: "It (what the family resource coordinator did) made me feel guilty and like a bad parent. It also made me mad because the support coordinator didn't really know what it was like to have to care for my child only by myself all the time."

These contrasting descriptions of the help giving practices of the family resource coordinators illustrate the differential consequences associated with family resource coordinator practices that are either consistent or

inconsistent with the intent of family support principles. The examples demonstrating literal replication show that the relationships between family resource coordinator practices consistent with the intent of family support principles and positive family outcomes were predictably replicated, whereas the examples for demonstrating theoretical replication show that contrasting results were predictably replicated for family resource coordinator practices inconsistent with the intent of family support principles (de Vaus, 2001).

### 4. DISCUSSION

Results from the case studies showed that family resource coordinator practices that were consistent with the intent of family support principles were associated with positive family outcomes whereas practices that were inconsistent with the intent of family support principles were associated with negative family outcomes. The pattern of results and both literal and theoretical replication (Hak & Dul, 2010b; Yin, 2014) indicate that hypothesized relationships were found in almost all cases. As noted by de Vaus (2001), "We gain confidence in experimental results...from our capacity to predictably replicate results and to predictably fail to replicate results (i.e., we anticipate that an intervention will have effects under specific conditions but not under other conditions)" (p. 262).

The robustness of replication is reflected by the fact that 90% of the participants' responses provided evidence for literal replication, 96% of their responses provided evidence for theoretical replication, and only 7% of the participants' responses did not provide evidence for either type of replication. Although not explicitly a focus of investigation, the results also indicate considerable consistency within the participants' responses (similar results for different family support principles) and between the participants' responses (similar results for different participants in different family support programs).

Results similar to those described in this paper were reported in a study by Dunst et al. (1988) where parents of children with complex health impairments were asked to describe both empowering and disempowering experiences with social network members and the consequences of the contrasting experiences. Almost identical results were reported by Dunst et al. (1993) for service coordinator help giving practices aligned with family support principles and the child and parent outcomes associated with the use of the practices. The findings from these two studies, those reported in this paper, and results from quantitative literature reviews (e.g.,Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 2007; King, Teplicky, King, & Rosenbaum, 2004) indicate that the manner in which family resource coordinator practices (as well as the practices of other help giving professionals) matter a great deal if positive results are to accrue from professional-family help giving relationships.

### **4.1.** Implications for Practice

Findings indicate that professional-family help giving relationships in family support programs are more likely to be associated with positive benefits if family resource coordinator practices are aligned with the intent of family support principles. Just as family support principles were used as benchmarks against which family resource coordinator practices were judged as either consistent or inconsistent with the intent of the principles, family support principles could also be used for mentoring or coaching family support program workers to promote their understanding and use help giving practices that mirror the intent of family support principles (Dunst & Trivette, 2007). Family support principles could also be used by family resource coordinators to do self-evaluations of their own practices to identify areas to improve their help giving behavior with family support program participants (Wilson & Dunst, 2004).

#### 4.2. Conclusion

Multiple case studies like the one described in this paper, which employ both quantitative and qualitative methods for data collection, data analysis, and hypothesis testing, can be especially useful for identifying patterns of relationships in case study data. This was found to be the case in the study described in this paper in

terms of investigating professional-family help giving relationships and the effects of different family resource coordinator practices on family outcomes.

### **5. REFERENCES**

- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20, 37-46.
- de Vaus, D. (2001). Research design in social research. Thousand Oaks, CA: Sage.
- Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education*, 28, 42-52. doi:10.1177/0271121408316699
- Dunst, C. J. (1995). Key characteristics and features of community-based family support programs. Chicago, IL: Family Resource Coalition.
- Dunst, C. J., & Trivette, C. M. (2007). Attending to family support program quality: Program staff practices provide excellent benchmarks for assessing adherence to family support principles. Asheville, NC: Winterberry Press.
- Dunst, C. J., Trivette, C. M., Davis, M., & Cornwell, J. (1988). Enabling and empowering families of children with health impairments. *Children's Health Care*, 17, 71-81. doi:10.1207/s15326888chc1702\_2
- Dunst, C. J., Trivette, C. M., Gordon, N. J., & Starnes, A. L. (1993). Family-centered case management practices: Characteristics and consequences. In G. H. Singer & L. L. Powers (Eds.), *Families, disability, and empowerment: Active coping skills and strategies for family interventions* (pp. 89-118). Baltimore, MD: Brookes.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378. doi:10.1002/mrdd.20176
- Dunst, C. J., Trivette, C. M., & Thompson, R. B. (1990). Supporting and strengthening family functioning: Toward a congruence between principles and practice. *Prevention in Human Services*, 9(1), 19-43. doi:10.1300/J293v09n01\_02
- Eisenhardt, K. M., & Graebner, M. E. (2007). Theory building from cases: Opportunities and challenges. *Academy of Management Journal*, 50(1), 25-32. doi:10.5465/AMJ.2007.24160888
- Ferguson, C. J. (2009). An effect size primer: A guide for clinicians and researchers. *Professional Psychology: Research and Practice*, 40, 532-538. doi:10.1037/a0015808
- Hak, T., & Dul, J. (2010a). Pattern matching. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encyclopedia of case study research* (pp. 664-666). Thousand Oaks, CA: Sage.
- Hak, T., & Dul, J. (2010b). Replication. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encyclopedia of case study research* (pp. 805-807). Thousand Oaks, CA: Sage.
- Hecht, E., & Reynolds, M. (2012). Building a national agenda for supporting families with a member with intellectual and developmental disabilities. Washington, DC: U.S. Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities.
- Julian, D. J. (1995). Resources for single parent families. *Marriage & Family Review*, 20(3-4), 499-512. doi:10.1300/J002v20n03 10
- Kagan, S. L., & Weissbourd, B. (Eds.). (1994). *Putting families first: America's family support movement and the challenge of change*. San Francisco, CA: Jossey-Bass.
- King, S. M., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology*, 11, 78-86. doi:10.1016/j.spen.2004.01.009
- Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. A. (2012). The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Research & Practice for Persons with Severe Disabilities*, *37*(1), 31-44. doi:10.2511/027494812800903247

- Lindeke, L. L., Leonard, B. J., Presler, B., & Garwick, A. (2002). Family-centered care coordination for children with special needs across multiple settings. *Journal of Pediatric Health Care*, *16*, 290-297. doi:10.1067/mph.2002.121917
- Neal, S. H., & Gilson, B. (1996). Case management. In P. J. McLaughlin & P. Wehman (Eds.), *Mental retardation and developmental disabilities* (2nd ed., pp. 283-295). Austin, TX: Pro-Ed.
- Nunnally, J. C., & Bernstein, I. H. (1994). Psychometric theory (3rd ed.). New York: McGraw-Hill.
- Rizzolo, M. C., Hemp, R., Braddock, D., & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends. *Intellectual and Developmental Disabilities*, 47(2), 152-155. doi:10.1352/1934-9556-47.2.152
- Sloper, P., Greco, V., Beecham, J., & Webb, R. (2006). Key worker services for disabled children: What characteristics of services lead to better outcomes for children and families? *Child: Care, Health and Development, 32*, 147-157. doi:10.1111/j.1365-2214.2006.00592.x
- Trute, B. (2007). Service coordination in family-centered childhood disability services: Quality assessment from the family perspective. *Families in Society*, 88, 283-291. doi:10.1606/1044-3894.3626
- Weissbourd, B., & Kagan, S. L. (1989). Family support programs: Catalysts for change. *American Journal of Orthopsychiatry*, 59, 20-31. doi:10.1111/j.1939-0025.1989.tb01632.x
- Wilson, L. L., & Dunst, C. J. (2004). Checking out family-centered helpgiving practices. In E. Horn, M. M. Ostrosky, & H. Jones (Eds.), *Family-based practices* (pp. 13-26). Longmont, CO: Sopris West.
- Yin, R. K. (2014). Case study research: Design and methods (5th ed.). Thousand Oaks, CA: Sage.
- Ziring, P. R., Brazdziunas, D., Cooley, W. C., Kastner, T. A., Kummer, M. E., Gonzalez de Pijem, L., . . . Perrin, J. M. (1999). Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, 104, 978-981.