

#### Articles

# Thinking beyond Measurement, Description and Judgment: Fourth Generation Evaluation in Family-Centered Pediatric Healthcare Organizations

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**Background:** Although pediatric healthcare organizations have widely implemented the philosophy of family-centered care (FCC), evaluators and health professionals have not explored how to preserve the philosophy of FCC in evaluation processes.

**Purpose:** The purpose of this article is to illustrate how fourth generation evaluation, in theory, could facilitate collaboration between evaluators and families and uphold the philosophy of FCC in evaluation. Exploration focuses on describing the ways in which fourth generation evaluation is consistent with FCC and outlining a strategy for implementing it within pediatric healthcare organizations.

Setting: Not applicable.

Intervention: Not applicable.

Research Design: Not applicable.

Data Collection and Analysis: Desk review.

Findings: This article clearly demonstrates that current evaluation practices used in healthcare

organizations reflect what some describe as the first three generations of evaluation: and measurement-, description-, judgmentoriented evaluation. While these generations encourage evaluators and health professionals to use systematic and rigorous approaches and techniques, they negate opportunities to explore issues that may surface in more flexible evaluation processes and do little to promote FCC in evaluation. Fourth generation evaluation is based on the constructivist paradigm, and its hermeneutic dialectic process moves beyond these generations, as well as the problems associated with them, to reflect the FCC notions of family participation, partnership, collaboration, respect, and joint decision-making. The collaborative and dialogue-oriented environment of pediatric healthcare organizations provides an ideal context for fourth generation evaluation. Although this evaluation approach is consistent with the philosophy of FCC, more research is required to understand the strengths and limitations of using it in these organizations.

**Keywords:** *family-centered care; pediatrics; fourth generation evaluation; constructivist paradigm* 

Pediatric healthcare organizations have widely implemented the philosophy of widely implemented the philosophy of family-centered care (FCC). This philosophy recognizes that each family is unique; that parents know their children best, and that optimal child functioning occurs within a supportive family context (Rosenbaum, King, Law, King, & Evans, 1998). By adopting FCC, organizations recognize the importance of respecting the needs, priorities, strengths, and decisions of families (Prelock & Hutchins, 2008), as well as the impact that parents and caregivers have on their child or youth's health, development, and adherence to health interventions (Dunst, Trivette, Davis, & Cornwell, 1988). Although the Family-Centered Institute for Care emphasizes that FCC is a novel approach to the planning, delivery, and evaluation of healthcare, researchers and evaluators have not explored how to preserve it in evaluation processes.

This paper suggests one possible evaluation approach that, in theory, could facilitate collaboration among evaluators and families and uphold FCC in evaluation. More specifically, it describes the ways in which fourth generation evaluation (Guba & Lincoln, 1989) is consistent with FCC and outlines a strategy for implementing it within pediatric healthcare organizations.

## Definitions and History of Family-Centered Care

Although there are various definitions for FCC (see Table 1), all allude to the ideas of family participation, partnership, collaboration, respect, or joint decision-making.

Historically, the integration of families into the care process was slow, as health professionals initially viewed families as incapable of raising children who were ill, injured, or disabled (Rosenbaum, et al., 1998). Some also viewed the presence of families in healthcare settings as a nuisance because they asked questions and were critical of health professionals (Lewandowski & Tesler, 2003). However, in the 1950s, Carl Rogers began practicing and writing about client-centered therapy in psychiatry. Rogers advocated for the recognition of clients' capacities and rights to self-direction in treatment, as well as acknowledged the importance of family dynamics in care processes. In the mid-1960s, the Association for the Care of Children in Hospital embraced and expanded his ideas from client- to family-(Bamm centeredness & Rosenbaum. 2008). These actions, combined with other consumer-led movements in education, health, and child development, resulted in a shift away from health professionals controlling the destiny of families children to working in partnership with health professionals (Rosenbaum, et al., 1998). Soon after, governments throughout North America began to develop federal legislation (e.g., Education for All Handicapped Children Act) that validated the importance of FCC. Since then, the concepts of FCC have common practice, become as both educational programs for health professionals and healthcare organizations recognizing are the supporting importance family of relationships as well as the benefits of active family participation in the care of children and youth. However, while many organizations facilitate and welcome family input into the design and implementation of programs and models of care, they do little to promote family engagement in terms of evaluation.

Source	Context	Term	Definition
Brewer, McPherson, Magrab, & Hutchins, (1989)	American paediatric healthcare	Family- centered care	Family-centered care is a philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special needs. In this philosophy family should be supported in their natural caregiving and decision-making roles by building on their unique strengths as people and families. In this philosophy, (normative) patterns of living at home and in the community are promoted; parents and professional are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of healthcare.
Dunst Johanson, Trivette, & Hamby, (1991)	Psychology	Family- centered	A combination of beliefs and practices that define particular ways of working with families that are consumer-driven and competency enhancing.
Law et al. (2003)	Canadian Paediatric Rehabilitation; CanChild	Family- centered service	Family-centered service is made up of a set of values, attitudes, and approaches to service for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receives. In family-centered service, the strengths and needs of all family members are considered.
Shields, Pratt, & Hunter, (2006)	Nursing	Family centered care	Family centered care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients.
Viscardis, (1998)	Ontario Paediatric Rehabilitation; Parent group	Family- centered approach	The family-centered approach begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage and enhance the competence of parents in their role as caregivers.

Table 1Definitions of Family-Centered Care

#### *Common Evaluation Approaches and Methods Used in Pediatric Healthcare Organizations*

The current evaluation practices used in healthcare organizations reflect what Guba and Lincoln (1989) described as the first three generations of evaluation: measurement-, description-, and judgment-oriented evaluation. We now turn to a description of these evaluation approaches and provide examples of each within the pediatric healthcare environment.

First Generation Evaluation: Measurement. First seen in the early 1900s during the emergence of scientific management in business and industry, the first generation of evaluation is measurement-oriented (Koch, 1994). In this sense, measurement and evaluation are one and the same (Swenson, 1991). Typically, the evaluator plays a technical role, having knowledge of a variety of data collection instruments that are used to measure the variables named for investigation (Guba & Lincoln, 1989). As Koch (1994) notes, this generations is "typified by early studies in educational research measuring the attributes of school children" (p. 1148).

This approach remains prevalent in healthcare (Swenson, 1991), including pediatric healthcare organizations. It includes the use of family satisfaction surveys, standardized measures to assess patient outcomes, and audit tools to measure quality of care (Koch, 1994). For example, healthcare professionals, who are responsible for evaluation activities, commonly use standardized measures to assess patients' functional abilities pre and post treatment interventions. They also rely heavily on centralized databases that provide information on health service utilization including wait times, emergency room visits, admissions, and lengths stay. Although these quantitative tools, numeric data, and measurementoriented evaluation approaches provide valuable and objective information, they often fail to capture or recognize the unique circumstances and conditions of patients and their families.

Second Generation Evaluation: Description. As described by Guba and Lincoln (1989), the second generation of evaluation focuses on the "description of patterns of strengths and weaknesses with respect to certain stated objectives" (p.28). In this generation, evaluators target programs and their participants as objects of evaluation, describing and measuring them. Although evaluators retain their previously described technical skills, they recognize that measurement in itself is not evaluation. but rather a technique that can be used in evaluation processes (King & Appleton, 1999). In terms of the pediatric healthcare setting, many evaluators rely on standardized nursing care plans to assess patient progress, and thus the effectiveness of treatments and interventions. While these plans facilitate systematic and uniform care approaches to patient and programming as well as data collection and evaluation, they fail to capture the health-related objectives, individual needs, or outcomes of patients and their families.

Third Generation Evaluation: Judgment. In the third generation of evaluation, evaluators assume the role of a judge while retaining their earlier technical and descriptive functions (Guba & Lincoln, 1989). In order for judgment about the merit and worth of the evaluand to occur,

standards or bases for comparison must be established. In our view, this element is differentiates third generation what evaluation from previous generations. In pediatric healthcare relation to organizations, best practice guidelines and service standards fit well within this generation. Health professionals develop these guidelines and standards bv combining the best available scientific evidence from experts in the field. Evaluators then use them as a benchmark for judging evaluation findings and informing healthcare decision-making. However, in most cases, these guidelines and standards are not family, patient or context specific.

## Overall Consequences of Using the First Three Generations of Evaluation in Pediatric Healthcare Organizations

While these generations of evaluation evaluators working encourage in healthcare organizations to use systematic and rigorous approaches and techniques, they negate opportunities to explore issues that may surface in more flexible evaluation processes and do little to promote FCC. Since there is an overemphasis placed on measurement tools and quantitative methods, these first three generations are, at times, superficial and mechanistic (King & Appleton, 1999). They result in the evaluation of patient care and programs as homogeneous and fixed interventions that are applied to passive and 'de-contextualized' children, youth, and families (Clark, MacIntyre, & Cruickshank, 2007).

Although evaluation practices and findings may have direct effects on patients and their families, many

evaluators exclude these individuals from discussions and decision-making processes about evaluation. Instead, they use families and patients simply as data sources (i.e., people from whom data is extracted). In this sense, the evaluation decisions tend to be evaluatoror healthcare professional-centered rather than family-centered. Evaluators, in collaboration with other healthcare professionals, have the sole authority to determine what questions they will pursue as well as how they will collect and interpret data (Guba & Lincoln, 1989). Moreover, while many programs and models of care emphasize the importance of recognizing families' values, these values are rarely acknowledged or reflected in the evaluation approaches or methods used. In hopes of creating 'objective' evaluations including 'objective' data collection instruments, evaluators often overlook these values or consider them secondary to their own.

## Fourth Generation Evaluation and Pediatric Healthcare Organizations

Fourth generation evaluation moves beyond the measurement, description, and judgment generations, and the problems associated with them. This holistic approach includes considerations of the human, political, social, cultural, and contextual elements that are a part of patient care, programs and evaluations (Guba & Lincoln, 1989). Guba and Lincoln (1989) stated the following:

Fourth generation evaluation is a form of evaluation in which the claims, concerns, and issues of stakeholders serve as organizational foci (the basis for determining what information is needed), that is implemented within the

methodological precepts of the constructivist inquiry paradigm. (p. 50)

Based on relativist ontology, this constructivist paradigm allows for multiple, socially constructed realities. Epistemologically, it asserts that evaluators cannot separate themselves from evaluands as it is within this interaction that data are created. In this sense, evaluators must, as Guba and Lincoln (1989) suggest, use a hermeneutic dialectic process and carry out their inquiries "in a way that will expose the constructions of the variety of concerned parties, open each to critique in the terms of other constructions, and provide the opportunity for revised or entirely new constructions to emerge" (p.89). This process is the primary strength of fourth generation evaluation.

#### *The Strengths of Fourth Generation Evaluation*

Hermeneutic Dialectic Process. One of the major strengths of fourth generation evaluation is its involvement of multiple stakeholder groups who bring multiple perspectives to the evaluation through the use of a hermeneutic dialectic process (Lay & Papadopoulos, 2007). This process reflects the FCC notions of family participation, partnership, collaboration, respect, and joint decision-making and allows evaluators to tease out the various constructions (i.e., stories) that children. vouth, their families, and other staff members hold. Evaluators still use objectives and standards, but through the hermeneutic dialectic process. all stakeholders have the task of working collaboratively to translate these objectives and standards into relevant statements for evaluation. This constructivist method provides a more indepth understanding of the social and family dynamics present within programs and models of care. Through open communication, evaluators embrace the political, social, and cultural contexts of their programs, and in partnership with families, select appropriate evaluation Moreover, during methods. the translation all stakeholders process, become active participants in the building links with evaluation. one another and developing support networks. Most importantly, this process gives equal footing to patients, families and evaluators in decision-making processes. Through self-interpretation, children, youth, families, and staff are able to bring their own stories and experiences to the evaluation. Koch (1994) notes that "in the process of interpretation, the reference points are the claims, concerns, and issues product that are the of self interpretations" (p. 1151). It then becomes the task of the evaluator, in collaboration with all the stakeholders, to produce a synthesis of all the claims, concerns, and issues (CCIs) put forward.

*Claims, Concerns, and Issues.* Fourth generation evaluation is responsive to all stakeholders who have a right to have their CCIs heard and considered in the evaluation. The approach takes into account the needs and concerns of patients, families, and staff.

Guba and Lincoln (1989) describe the following:

A claim is any assertion that a stakeholder may introduce that is *favorable* to the evaluand... A concern is any assertion that a stakeholder may introduce that is *unfavorable* to the evaluand...[whereas] an issue is any state of affairs over which reasonable people may disagree. (p. 40)

For instance, a claim in a pediatric family-centered speech-language group intervention may be that the group atmosphere relieves families' feelings of isolation by providing access to other families who share similar concerns and frustrations. Α concern for this intervention may be that each family is not receiving enough one-on-one time with the speech-language pathologist. Lastly, an issue may involve the role that families play in speech-language therapy. Specifically, some may believe that the role of the family should be observational, whereas others may advocate that the family's role should be interactive. Nonetheless, most stakeholders hold divergent views and the evaluator, in collaboration with the stakeholders, must tease out these views.

Fourth *Collaborative* Process. Joint generation evaluation requires discussions among stakeholders to develop a shared evaluation agenda and a deeper understanding of, among other things, the complexities of the programs and the individuals they serve. The evaluator facilitates communication and collaboration among multiple and diverse stakeholder groups. The goal is to develop a common construction and consensus regarding program improvements (Swenson, 1991). However, the process needs to be collaborative because, without collaboration, the goal of reaching consensus or of honoring individual constructions is limited.

By honoring individual constructions, the evaluation also honors stakeholders' values. Under this model, evaluators do not simply pass judgment on which constructions, values, or CCIs are most appropriate or place certain stakeholders' views above those of others. Instead, evaluators act as mediators, negotiating with stakeholders to collect data, perform analyses, refine evaluation processes, and discuss the various constructions and CCIs that are the foci of the evaluations. In this sense, fourth generation evaluation is done *with* children, youth, and their families rather than *on* them. Both families and their values are included in every aspect of the evaluation, including the design, implementation, interpretation, and dissemination of results.

## Implementing and Applying Fourth Generation Evaluation in Family-Centered Pediatric Healthcare Organizations

In general, few have attempted to examine fourth generation evaluation through direct application (Huebner & Betts, 1999), and there are no proven ways of implementing it in pediatric healthcare organizations. There are, however, some documented examples of its use in (Moffitt nursing & Wuest. 2002). community healthcare centers (Sylvain & Talbot, 2002); maternity, antenatal, postnatal acute care settings (Watson, Turnbull, & Mills, 2002); and outpatient clinics (Clendon, 2003). For instance, Moffitt and Wuest (2002) described how they used the fourth generation approach to evaluate the cultural curriculum of a nursing program in Northern Canada. In their research, they reflected on their evaluation experiences and described how the interactive and dialectic nature of fourth generation evaluation was consistent with the aims of the evaluand. Additionally, Sylvain and Talbot (2002) used fourth generation evaluation to assess а consensus-based nursing intervention model in a community

healthcare setting. In their article, they stated how selected patients, their and nurses developed the spouses, through intervention model shared partnerships. constructions. and collaboration. Given this collaborative process of development, the authors noted that the hermeneutic nature of fourth generation evaluation was most appropriate for evaluating the intervention model, as it required the interpretation and validation of various stakeholders' experiences. While these examples help to illustrate that researchers and practitioners have application of fourth explored the generation evaluation within certain healthcare settings, there is still a lack of critical reflection on its implementation and use, particularly within pediatric healthcare organizations. Nevertheless, this paucity of reflections and examples does not necessarily mean that fourth generation evaluation is not being used in these organizations, but may rather be a reflection of resistance from health or journals medical to publish 'unconventional' or 'unscientific' evaluation studies. Given this potential situation and the gaps in the literature, we now present one possible way of implementing and applying fourth generation evaluation in family-centered pediatric healthcare organizations.

#### Implementing Fourth Generation Evaluation in Pediatric Healthcare Organizations: Groundwork

Although the implementation of fourth generation evaluation is context-specific and non-linear, we have created an action plan for implementing it within pediatric healthcare organizations. Similar to the transition from the medical- to familycentered model of care, this implementation process or groundwork takes time, as we argue that organizations need to complete several steps before using it for evaluation purposes. The steps used to implement FCC are practical to set the stage for fourth generation evaluation.

Specifically, drawing on Lewandowski and Tesler's (2003) work on the implementation of FCC as a guide, organizations need to do the following: (a) conduct an assessment of the evaluation practices used, (b) gain and maintain stakeholder motivation and commitment to fourth generation evaluation, and (c) establish working groups to educate others about this approach.

#### Assessment of the Evaluation Practices Used

Prior to implementing fourth generation organizations evaluation. need to ascertain the current state of evaluation. following questions guide The this process: assessment (1) What are stakeholders' (i.e., families, staff, leaders, and managers) views (i.e., CCIs) about evaluation? (2) What kinds of evaluation practices are being used within organizations and programs? and (3)What kinds of evaluation resources are available? Essentially, evaluators need to acquainted become with their organizations and programs, talk to a wide range of stakeholders, and become participant observers within their own environment. As Guba and Lincoln (1989) note:

Humans collect information best and most easily through the direct employment of their senses: talking to people, observing people, observing their activities, reading their documents, assessing the unobtrusive signs they leave behind,

responding to their non-verbal cues. (p. 176)

### *Stakeholder Motivation and Commitment to Fourth Generation Evaluation*

Similar to the successful implementation of FCC, the implementation of fourth generation evaluation requires all stakeholders to buy into the method. Thus, conversations between families and other groups need to occur. Evaluators leading these conversations need to use a variety of constructivist teaching practices to inform and educate individuals about fourth generation evaluation. Since many stakeholders may have existing views about evaluation and since organizations cannot mandate the use of a specific evaluation approach, evaluators need to expose stakeholders to learning experiences that will enable them to construct their own understanding of fourth generation evaluation in synergy with their existing views and knowledge (Osborne & Freyberg, 1985). Energized by the idea, some stakeholders may embrace fourth generation evaluation, while others may feel threatened, anxious, and insecure about the idea of changing their practices. Regardless, evaluation as Lewandowski and Tesler (2003) state, "change usually begins with a small group of 'core believers' who share a vision and are willing to do what it takes to make the vision a reality" (p. 62).

Given this conception, the best way to begin is to obtain buy-in from the organization's Family Advisory Committee (FAC) or its equivalent. These committees, which are present in most pediatric healthcare organizations, comprise a team of people representing a cross-section of patients, families, and clientele that the organization serves. They provide management and staff with ongoing feedback from families on how to achieve the best quality of care. Since most FACs circulate material to their members over the Internet through a contact list, they can therefore assist with initiatives to educate stakeholders about the potential benefits of fourth generation evaluation and encourage them to buy into the idea of changing evaluation practices.

#### *Establish Working Groups to Educate Others about Fourth Generation Evaluation*

Each organization should also establish a working group made up of representatives from various stakeholder groups who promote and assist with the implementation of fourth generation evaluation. Initially, this working group can review the practice site assessments as well as the levels of motivation for and commitment to fourth generation evaluation. Based on these assessments and levels, the group can begin to develop and set realistic goals and strategies for change in terms of evaluation practice. It may also develop a motivating mission statement to inform others as to why change evaluation practices in is desirable. In addition, this working group can select and implement a fourth generation evaluation of a specific program and reflect on its experiences.

#### Applying Fourth Generation Evaluation: Plan

Once the groundwork for fourth generation evaluation is set in motion, evaluators can apply fourth generation evaluation to programs. Guba and Lincoln (1989) provide some operational

guidelines for carrying out fourth generation evaluation. Below is a snapshot of these guidelines, which have been tailored for use within pediatric healthcare organizations.

Initiating a Formal Contract. Since fourth generation evaluation is a relatively new concept that has not been widely understood within the health field, the specific organization should initiate an evaluation agreement with the evaluation team prior to starting the evaluation. Given that the intention of using this approach within pediatric healthcare organizations is to embrace FCC and thus facilitate family participation, partnerships, collaboration, respect, and joint decision-making between evaluators and families. all those involved should receive a copy of this contract. This will ensure the transparency of the objectives and rationales of those who initiated the evaluation. In addition to the usual elements that appear in a contract (e.g., budget, timeframe), other items that should be included are a brief summary of methodology fourth the used in generation evaluation as well as a description of the impact that it may have on those involved.

Conducting The Evaluation Using The Hermeneutic Dialectic Process. The preliminary steps in conducting a fourth generation evaluation often involve the selection of a team of evaluators (e.g., individuals with expertise in evaluation, the constructivist paradigm, qualitative and quantitative data collection), the arrangement of logistics, as well as the assessment and understanding of the program's political and cultural characteristics. completed. Once the evaluation team can collaboratively identify stakeholder groups placed at risk

by the evaluation and negotiate the potential participants. Once the selected stakeholder groups and individual participants agree to take part, the hermeneutic dialectic process can begin multiple with the formation of hermeneutic circles consisting of 10 to 12 members, representing the various stakeholder groups.

Through engaging in discussions within these circles, stakeholders can develop descriptions (i.e., constructions or stories) of the program, identify and probe CCIs that emerge, and conclude with joint constructions or negotiated agreements on the various CCIs of the program, if possible. Next, to enlarge these constructions and agreements, the systematically evaluation team can introduce documentary existing information (e.g., documents and records, professional literature) that may impact and inform the stakeholders' perceptions and views of the program. After reviewing this information in the hermeneutic circles, stakeholders will be able develop a shared construction of the state of the program, a list of agreed-upon CCIs that require action plans, and a list of other CCIs upon which they could not reach consensus (Guba & Lincoln, 1989).

Although the completion of the initial hermeneutic circle process should result in the resolution of many stakeholders' CCIs, other items may require more attention. To prioritize these unresolved items, all stakeholders should engage in another hermeneutic process. Depending allotted the resources for the on evaluation, items deemed lower in priority be reserved for subsequent mav evaluations. Once the stakeholders reach consensus on which unresolved CCIs will be the focus of the current evaluation, the evaluators, in collaboration with the collect stakeholder groups, can

information (e.g., through interviews, surveys) in relation to the CCIs. Working with the stakeholders, the evaluators can prepare an agenda for negotiation by organizing the collected information in a way that illuminates each unresolved CCI. Representatives from each of the stakeholder groups can then form hermeneutic circles begin the to negotiation process.

Throughout the this process. evaluators the mediators are and facilitators of the circle. the as stakeholders discuss the unresolved CCIs. review the newly collected information, and develop joint constructions of the program. These negotiations end either when the stakeholders reach some level (program-specific) of consensus on the unresolved CCIs or when the evaluation resources are exhausted. Once this occurs, all those involved in the evaluation process develop a case study report that illuminates their joint constructions of the program and how they make sense of it. Inevitably, this evaluation process raises additional questions and leaves some CCIs unresolved. Therefore the entire process can, if resources permit, be continuous or "recycled" (Guba & Lincoln, 1989).

#### *Considering the Limitations of Fourth Generation Evaluation in Pediatric Healthcare Organizations*

While there potential are many advantages to the use of fourth generation pediatric evaluation in healthcare organizations, there are some evident limitations that require consideration prior to implementation. First, it is important for evaluators working in these settings recognize that to fourth generation evaluations cannot incorporate

the interests of everyone involved in evaluation processes, and thus additional questions may arise around the prioritization of interests (i.e., whose interests should be included in the evaluation?). Furthermore, evaluators must also be cognizant that many organizations have pediatric limited resources for evaluation and therefore. external funding may be required to, for example, compensate families for their participation and provide staff with dedicated time to become involved in the collaborative and holistic approaches of fourth generation evaluation.

## Conclusion

Many service providers in pediatric healthcare organizations have extensive training in FCC—an approach that involves the development of a shared agenda for care. including an understanding of the wider context of each family. The collaborative and dialogue-oriented environment of these organizations provides a good setting for fourth generation evaluation. As this paper has shown, fourth generation evaluation is more congruent with the philosophy of FCC, but more research is required to fully understand the strengths and limitations of its application in healthcare organizations.

## References

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives* of *Physical Medicine and Rehabilitation, 89*(8), 1618-1624.

- Brewer, E., McPherson, M., Magrab, P., & Hutchins, V. (1989). Familycentred, community-based, coordinated care for children with special health care needs. *Pediatrics, 83*(6), 1055-1060.
- Clark, A. M., MacIntyre, P. D., & Cruickshank, J. (2007). A critical realist approach to understanding and evaluating heart health programmes. *Health*, *11*(4), 513-539.
- Clendon, J. (2003). Nurse-managed clinics: Issues in evaluation. *Journal of advanced nursing*, 44(6), 558-565.
- Dunst, C. J., Johanson, C., Trivette, C., & Hamby, D. (1991). Family-oriented early intervention policies and practices: Family-centred or not. *Exceptional Children, 58*, 115-126.
- 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*(2), 71-81.
- Guba, E., & Lincoln, Y. (1989). *Fourth* generation evaluation. Newbury Park: Sage.
- Huebner, A., & Betts, S. (1999). Examining fourth generation evaluation. *Evaluation 5*(3), 340-358.
- King, L., & Appleton, J. V. (1999). Fourth Generation Evaluation of Health Services: Exploring a Methodology That Offers Equal Voice to and Consumer Professional Stakeholders. Qualitative Health Research. 9(5),698-710. doi: 10.1177/104973299129122072
- Koch, T. (1994). Beyond measurement:Fourth-generation evaluation in nursing. *Journal of advanced nursing, 20*, 1148-1155.

- Law, M., Rosenbaum, P., King, G., King, S., Burke-Gaffney, J., & Moning-Szkut, T. (2003). How does familycentred service make a difference? London, ON: CanChild Centred for Childhood Disability Research.
- Lay, M., & Papadopoulos, I. (2007). An exploration of fourth generation evaluation in practice. *Evaluation*, *13*(4), 495-504.
- Lewandowski, L., & Tesler, M. (2003). Family-centered care: Putting it into action. Washington, DC: Society of Pediatric Nurses.
- Moffitt, P., & Wuest, J. (2002). Spirit of the drum: The development of Cultural Nursing Praxis Canadian Journal of Nursing Research, 34, 107-116.
- Osborne, R., & Freyberg, P. (1985). Learning in Science: The implications of children's science. Auckland: Heinemann Publishers.
- Prelock, P., & Hutchins, T. (2008). The role of family-centred care in research: Supporting the social communication of children with autism spectrum disorder. *Topics in Language Disorders, 28*(4), 323-339.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Familycentred service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics 18*(1), 1-20.
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *Journal of clinical nursing, 15*(10), 1317-1323.
- Swenson, M. (1991). Using fourth generation evaluation in nursing. *Evaluation & the health profession, 4*, 323-329.
- Sylvain, H., & Talbot, L. (2002). Synergy towards health: A nursing

intervention model for women living with fibromyalgia and their spouses *Journal of advanced nursing*, *38*(3), 264-273.

- Viscardis, L. (1998). The family-centred approach to providing services. *Pediatrics 18*(1), 41-53.
- Watson, J., Turnbull, B., & Mills, A. (2002). Evaluation of the extended role of the midwife: The voices of midwives. *International Journal of Nursing Practice, 8*(5), 257-264.