Evaluation and Program Planning 43 (2014) 1–8

Contents lists available at ScienceDirect

Evaluation and Program Planning

journal homepage: www.elsevier.com/locate/evalprogplan

A survey of program evaluation practices in family-centered pediatric rehabilitation settings

Katherine A. Moreau [a,b,*], J. Bradley Cousins [a]

[a] University of Ottawa, Vanier Hall, 136 Jean Jacques Lussier Road, Ottawa, ON K1N 6N5, Canada
[b] Children's Hospital of Eastern Ontario Research Institute, 401 Smyth Road, Ottawa, ON K1H 8L1, Canada

ARTICLE INFO

Article history:
Received 17 January 2013
Received in revised form 1 October 2013
Accepted 10 October 2013

Keywords:
Program evaluation
Family-centered service
Canadian
Rehabilitation
Survey

ABSTRACT

Program evaluation is becoming increasingly important in pediatric rehabilitation settings that adhere to the family-centered service (FCS) philosophy. However, researchers know little about the specific evaluation activities occurring in these settings or the extent to which evaluators/service providers uphold FCS in their program evaluation activities. Through a questionnaire survey, this study aimed to document evaluators/service providers' perceptions of the level of program evaluation occurring in their Canadian pediatric rehabilitation centers. It also investigated the extent to which evaluators/service providers perceive program evaluation practices at their centers to be consistent with the FCS context of Canadian pediatric rehabilitation settings. The findings suggested that the amount of evaluation activities occurring within the respondents' centers is variable; that the majority of individuals working in program evaluation do not have formal training in it; and that the respondents' centers have limited resources for evaluation. The study also showed that staff members believe their centers' evaluation activities are somewhat consistent with FCS philosophy, but that improvements are needed.

1. Introduction

To make evidence-based decisions about resource allocation, program improvements, or continued program involvement, government officials, program managers, service providers, and recipients, need to know if programs are working and what they are achieving (Newcomer, Hatry, & Wholey, 2004). This is especially true within Canadian government-funded pediatric rehabilitation centers where resources are limited but demands for services and programs continue to increase. Under such circumstances, program evaluation is becoming increasingly important as it enables various stakeholder groups to examine the extent to which programs are reaching, for example, their target audiences and anticipated outcomes.

Rossi, Lipsey, and Freeman (2004) suggest that there are five forms of program evaluation: needs assessment, assessment of program theory, assessment of program process, impact assessment, and efficiency assessment. They suggest that evaluators should first consider the need for a program and then progress sequentially to assess the conceptualization and design of a program (program theory), the program operations, implementation, and service delivery (program process), program outcomes and impact, and then program costs (program efficiency). By moving through the various forms, evaluators can focus on questions suitable for the implementation stage and current situation of programs, avoiding premature, higher-order evaluations that will likely produce limited information (Rossi et al., 2004).

While a literature review of published evaluations in the pediatric rehabilitation sector shows that service providers have engaged in some of these forms of evaluation, including program process (Goldbeck & Babka, 2001) and program impact (Conant, Morgan, Muzykewicz, Clark, & Thiele, 2008; Davies et al., 2005; Swaine, Pless, Friedman, & Montes, 2000), little is known about the specific evaluation activities used in these settings (Moreau & Cousins, 2011). The paucity of empirical evidence concerning evaluation is not necessarily surprising or restricted to the rehabilitation field as evaluation experts have been calling for more and better quality research on evaluation in all sectors (Cousins & Earl, 1999; Henry & Mark, 2003; Mark, 2008; Smith, 1993). Yet, despite increased demands for program evaluation in rehabilitation as well as research on evaluation, only one other empirical study by Flynn, Glueckauf, Langill, and Schacter (1984) has examined program evaluation practices in rehabilitation centers for children and adults with disabilities. Almost 30 years ago, these authors surveyed 67 facilities and found that almost none had fully developed program evaluation systems. They also found that the amount of evaluation activities occurring in these

* Corresponding author at: Children's Hospital of Eastern Ontario Research Institute, 401 Smyth Road, Ottawa, Ontario, Canada K1H 8L1.
Tel.: +1 613 737 7600x4125.
E-mail address: kmoreau@cheo.on.ca (K.A. Moreau).

0149-7189/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.evalprogplan.2013.10.002

centers varied substantially (Flynn et al., 1984). Since no additional studies on evaluation have been conducted within the last 30 years, it is now time to re-examine the evaluation practices in rehabilitation settings to see if and how program evaluation has evolved and where improvements are still needed.

Given the significant changes in the landscape of these centers over the last 30 years, it is also important to investigate the extent to which the evaluative approaches and methods are congruent with the rehabilitation context (Moreau & Cousins, 2011). As laid out in the *Encyclopedia of Evaluation*, context is the site, location, environment, or milieu that surrounds a program (Mathison, 2005). The context of many pediatric rehabilitation programs is now more family-centered rather than medically focused. While the history of this transition from medically-focused to family-centered service is outlined elsewhere (Moreau & Cousins, 2011), it is important to note that since the 1950s, pediatric rehabilitation centers have witnessed a shift away from health professionals controlling the destiny of children to families controlling the process in partnership with health professionals (Rosenbaum, King, Law, King, & Evans, 1998). Today, the concepts of family-centered service (FCS) are common, as pediatric settings recognize the importance of supporting family relationships and families' rights as well as the benefits of active family participation in the care of and programming for children and youth. Academics have documented that FCS, often referred to as a philosophy, affects the outcomes of program recipients. They have shown that the FCS philosophy of supporting families in meeting the needs of their children enhances adherence to interventions and treatments (Dunst, Trivette, Davis, & Cornwell, 1988) and thus improves children's health and developmental outcomes as well as family well-being (Reva, Allen, & Petr, 1998). Moreover, investigators have demonstrated that family-centered environments, which involve families in health-care decisions, often enhance both children's and families' sense of competence and understanding of conditions, illnesses, and the care provided.

While a review of the literature reveals that researchers from various contexts have used different terminology to define FCS philosophy (Moreau & Cousins, 2011), all allude to similar concepts, including the idea of family participation, partnership, collaboration, respect, or joint decision-making (Franck & Callery, 2004). Given that the present study focused on the evaluation of family-centered programs within Canadian pediatric rehabilitation settings, we used the following definition developed by Law et al. (2003), which is accepted and used at the pediatric rehabilitation centers of the individuals who participated in this study:

> 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. (p. 2)

The push to incorporate this form of FCS into all aspects of professional practice, including program evaluation continues to develop. For instance, the Institute for Patient- and Family-Centered Care (2012) suggests that families and service providers should work in partnership to plan, deliver, and evaluate health care services. Law et al. (2003) also advocate that families should be involved in all aspects of care and collaborate with service providers to make informed decisions about the services that they and their children receive and need. However, despite these suggestions and advocacy, many experts working in the health and rehabilitation field believe that the push for accountability and evidence-based decisions results in, for example, families being seen as sources of data rather than collaborators in evaluation processes (Humphries, 2003; Kitson, 2002). Moreover, the Institute for Patient- and Family-Centered Care (2012) and others working in this area provide minimal guidance on how to uphold FCS philosophy in evaluation. As such, the notion of engaging families in evaluation and embracing the family-centered context of programs in program evaluation practice is challenging. Essentially, it requires evaluators/service providers to capture families' voices, values, and perspectives in the evaluation, and to hear and involve families in the evaluation design and implementation (Long, 2006). Some individuals, especially those trained in traditional research and evaluation approaches, might hesitate to collaborate with families because they believe that their active involvement might affect the rigor of the evaluation and result in role ambiguity (Jivanjee & Robinson, 2007). That said, the extent to which FCS philosophy is integrated into evaluation practices within pediatric rehabilitation has not yet been investigated.

Recognizing that no additional studies exist in this area, we conducted a study to document evaluators/service providers' perceptions of the level of program evaluation (i.e., needs assessment, assessment of program theory, assessment of program process, impact assessment, efficiency assessment) that is occurring in their Canadian pediatric rehabilitation centers. As part of this study, we also aimed to investigate the extent these individuals perceived program evaluation practices at their centers to be consistent with the FCS context of Canadian pediatric rehabilitation settings. This paper reports on the findings of this study and concludes with some recommendations for future research in this area.

2. Method

2.1. Setting

This study focused on program evaluation activities in government-funded Canadian pediatric rehabilitation centers. These centers offer a range of rehabilitation and treatment services to children and youth under 19 years of age who have developmental-behavioral conditions, neuromotor/neurological conditions, physical disabilities, musculoskeletal diagnoses, or sensory impairments (Canadian Network for Child & Youth Rehabilitation, 2012). While the programs offered at each pediatric rehabilitation center vary, they all provide a broad range of assessment, treatment, and community programs to children and youth. Common programs offered at these centers include: (a) augmentative communication programs, (b) blind and low vision programs, (c) seating and mobility programs, (c) respite programs, (d) recreation programs, (e) child development programs, (f) acquired brain injury programs, (g) autism programs, and (h) early childhood education programs. As such, these centers employ a range of service providers, including behavior consultants, dietitians, early childhood educators, family resource workers, nurses, occupational therapists, psychologists, physicians, physiotherapists, recreation therapists, social workers, and speech-language pathologists.

Of the 29 centers associated with the Canadian Network of Child Youth Rehabilitation (CN-CYR), 28[1] received an invitation for their evaluators/service providers to participate in the study. The CN-CYR is a group of organizations and members within the

[1] One center was excluded because it is the lead author's place of employment. The author's close involvement with this center might have influenced the potential respondents and the evaluation practices at this center and thus, introduced a form of bias to the study.