



## Brief online surveys to monitor and evaluate facilitated peer support groups for caregivers of children with special needs



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### ABSTRACT

**Background:** There have been few systematic evaluations of experiences of participating in peer support groups for parents and other caregivers of children with special needs. In Australia, facilitated groups are available to caregivers in community settings, through a nationally funded program, MyTime. Mechanisms for ongoing monitoring and evaluation have not yet been instituted.

**Aim:** To establish whether brief, online surveys can be used for monitoring and evaluating peer support groups for caregivers of children with special needs.

**Methods:** Two brief, online surveys, with both fixed-choice and open-ended questions, were developed.

All caregivers who attended any MyTime group during a 1-month period were invited to participate. **Results:** Of 89 caregivers who expressed interest in participating, 54 and 31 respondents completed respectively. Respondents represented a variety of backgrounds and circumstances. Responses revealed both positive and negative aspects of group participation. Linked data on expectations and experiences provided important feedback for the program.

**Conclusion:** Brief, online surveys are a suitable mechanism for ongoing monitoring and evaluation of peer support group programs for caregivers.

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## 1. Background

### 1.1. Current evidence regarding peer support groups for parents and other carers of children with special needs

Parents and other primary carers (henceforth referred to as “caregivers”) of children with special needs provide constant, medically complex and emotionally demanding care for their dependent child(ren) at home, usually without any periods of regular relief from caregiving and often with little social recognition of their circumstances (Hartman, Radin, & McConnell, 1992). This carries adverse health and social consequences, including severe parental fatigue, compromised mental health and reduced quality of life (Bolch, Davis, Umstad, & Fisher, 2012; Emond & Eaton, 2004; Johnson & Kastner, 2005; MacDonald, 2008).

Peer support is a term used widely to describe emotional and practical support exchanged between people who share similar

experiences and has been shown to be particularly valuable for caregivers of children with special needs (Law, King, & Stewart, 2001; Solomon, Pistrang, & Barker, 2001). The opportunity to talk to other people who have similar life circumstances can reduce social isolation, increase self-acceptance, self-confidence, self-efficacy and sense of personal worth and assist parents to feel more competent in managing everyday problems (Davies & Hall, 2005; Solomon et al., 2001).

Shilling et al. (2013) conducted a systematic review of 17 quantitative and qualitative studies on experiences of one-to-one and group peer support for parents of children with special needs. They found evidence from qualitative studies of benefits of peer support in general, for example shared social identity and the opportunity to learn practical information and be inspired by others. These benefits were found to be consistent across children’s medical conditions, and across one-to-one and group peer support contexts. However, the review (2013) concluded that quantitative studies did not show strong evidence of these perceived benefits, and there was little data from parents who had had a negative experience of peer support.

Of the 17 studies included in this review, most assessed one-to-one peer support. Only five pertained to peer support groups. These studies (Bull, 2003; Kingsnorth, Gall, Beayni, & Rigby, 2011; Law

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et al., 2001; Lo, 2010; Solomon et al., 2001) all used qualitative interview or focus group discussion methods. They concluded that parents who attend such groups may experience increased empowerment and sense of social inclusion (Law et al., 2001) and share and learn practical information, including about new treatments, sources of support and services (Papageorgiou & Kalyva, 2010). The review concluded however that there was a need for more robust evaluation of peer support programs and identified assessment of expectations of peer support programs, and whether these expectations are realized as requiring specific attention (Shilling et al., 2013).

### 1.2. MyTime facilitated peer support groups for parents and other family carers of children with special needs

MyTime facilitated peer support groups are funded by the Australian Government Department of Social Services. The aim of the MyTime program is to provide an opportunity for parents or other caregivers of children with special needs to socialize, obtain information, share ideas, and provide support to and be supported by other caregivers (Parenting Research Center, 2009). Over 260 groups operate throughout Australia. MyTime participation is provided free of charge to caregivers who are eligible for the Carer Allowance (Child), which is a social protection benefit paid to people who have caregiving responsibilities for children with special needs living with them at home. Groups consist of 4–12 caregivers (mostly parents) of children with special needs, a facilitator, and a play helper. Most groups meet weekly for 2 h during school terms but some have less frequent meetings of longer duration. Children are cared for in an adjacent area with activities provided by play helpers, allowing caregivers to engage in the group activities without interruption. The program is coordinated centrally by the Parenting Research Center (PRC) (Parenting Research Center, 2009) and delivered by local community organizations with expertise in the provision of services in areas of special needs, family support, parenting and children with complex special needs.

Monitoring and evaluation of such groups is essential in order to determine whether they are meeting caregivers' needs and program objectives. The objective of the MyTime peer support groups is to ensure that caregivers: develop relationships with other parents of children with special needs, have an increased knowledge of caring for a child with special needs; and feel supported in their caring role. A range of positive and negative experiences of participating in MyTime groups have been reported (Hammarberg, Sartore, Cann, & Fisher, 2014) based on semi-structured interviews with MyTime group members. Such interviews can take up to 60 min (Hammarberg et al., 2014). Caregivers of children with special needs are generally time-poor, and, in order for monitoring and evaluation to be incorporated into routine program implementation, brief, anonymous methods which capture a range of positive and negative experiences are required.

The Internet is being used increasingly as a vehicle for data collection because it permits complex questionnaires to be administered feasibly, confidentially, efficiently and more cost-effectively than conventional survey methods (Best, Krueger, Hubbard, & Smith, 2001). In addition, automatic prompts limit the volume of unanswered questions or responses that are not in the range of options that has been offered (Bälter, Bälter, Fondell, & Lagerros, 2005; Bälter & Bälter, 2005; Kongsved, Basnov, Holm-Christensen, & Hjollund, 2007; Lee, Kavanaugh, & Lenert, 2007; Russell, Boggs, Palmer, & Rosenberg, 2010). In Australia, almost every household with children under 15 years of age has access to the Internet at home (96%) (Australian Bureau of Statistics, 2014).

The aim of this study was to establish whether brief, online surveys can be used for monitoring and evaluating peer support

group programs for caregivers of children with special needs. In particular, this study aimed to establish whether brief, online surveys elicit responses consistent with data collected in lengthier qualitative interviews with caregivers, capture both positive and negative experiences of participating in peer support groups for caregivers, and are sensitive to differences between expectations of support and benefit from the program, and subsequent experience of support and benefit from the program.

## 2. Methods

Approval to undertake the project was obtained from the Monash University (Reference 2012000979) and Parenting Research Center (PRC) (Reference 14/2102) Human Research Ethics Committees.

### 2.1. Participants and recruitment

All caregivers who attended a MyTime facilitated group anywhere in Australia during mid-July to mid-August 2012 and who had an e-mail address recorded in the PRC database were invited to participate. There were no exclusion criteria, but caregivers with no e-mail address or Internet access could not be invited to participate.

In order to protect privacy, consent to participate was obtained in two stages. A description of the study and an expression of interest to participate were e-mailed to potential participants by the co-ordinating organization, the Parenting Research Center (PRC). Contact details for those who agreed to have them released were forwarded by the PRC to the research team who then sent a personalized e-mail invitation to complete the surveys. Consent to participate was indicated by completion of the online survey.

### 2.2. Data sources

Based on the themes which emerged from the interviews with MyTime members (Hammarberg et al., 2014), two brief study-specific self-report surveys were developed in collaboration with the co-ordinators of the MyTime program. The surveys include fixed-choice and open-ended questions. The survey questions and response options are provided in Appendices 1 (Survey 1) and 2 (Survey 2). Survey 1 took approximately 5–10 min to complete, while Survey 2 took approximately 15–20 min.

### 2.3. Procedure

The surveys were hosted by an independent online survey company. To increase response rates to the online surveys (Bhinder et al., 2010; Derby, Haan, & Wood, 2011; Hunter, Corcoran, Leeder, & Phelps, 2013; McCabe, Diez, Boyd, Nelson, & Weitzman, 2006; Reynolds & Stiles, 2007), potential participants were e-mailed invitations to complete the surveys, unique online links to the surveys were included in the e-mails, and participants were given the option to save a partly completed survey draft and continue answering later. Participation in surveys was tracked using an online survey platform. One reminder was sent to participants who had not completed the survey within 2 weeks of receiving the invitation. Three months after completion of Survey 1, participants who had completed it were sent an invitation to complete Survey 2, again with a unique survey link. The independent online survey company provided a spreadsheet with linked respondent numbers for Surveys 1 and 2. No other information was included in this spreadsheet.

Non-identifying demographic characteristics of all caregivers who were invited to participate were retrieved from the database by a PRC officer and provided to the research team.

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