Chapter 74

Parental Communication about the Needs of Their Children:
As Expressed in an Online Support Group

Joan E. Aitken
Park University, USA

ABSTRACT

The purpose of this chapter is to analyze parental use of an online support group about their children with disabilities. A content analysis was conducted of 1,718 emails from a listserv support group for parents of children who have been diagnosed as eligible for special education services. The findings suggest that parents use the group for the following purposes: (a.) expressive story-telling, (b.) seeking and giving advice, (c.) seeking or offering validation or encouragement, (d.) seeking or providing information, (e.) seeking or suggesting resources, and (f.) sharing celebrations and telling success stories for hope. Parents often discussed: How to deal with professionals (e.g., teachers, physicians), family, testing and diagnosis of disability, communicating with educators and the school context, Individualized Education Program (IEP) team meetings and reports, and family dynamics. The communication skills parents are most concerned about are writing and reading.

INTRODUCTION

Access to private opinions about children is a difficult area to research. With the advent of online discussion groups, however, many parents are willing to disclose information about their ideas and feelings about their children. This online phenomenon provides research information in multiple

ways. First, one can analyze the overall functions of the online discussion support group. Second, one can analyze what individual group members have to say about their communication with educators about their children with special needs.

The purpose of this chapter is to examine the nature of parental communication about their school-age children who have been diagnosed as eligible for special education services. First, by examining the group's communication functions,

the educator can better understand the needs of parents of children with exceptionalities. Second, teachers may gain insights into more effective instruction for children with developmental disabilities. For the purpose of this research, a content analysis was used to consider parental concerns in communicating with and about their children with educators during their participation in an online support group.

The Nature of Online Support Groups

With the advent of electronic listservs and the Internet, opportunities for support and information-sharing have increased through the use of online communities. These groups are available on a range of topics, which can bring together people from diverse locations. Online support groups have provided a new area of research interest. Royal (2005), for example, analyzed research about the Internet and women. There seemed to be equal access, but less comfortable participation by women and a less welcoming context for women. Ye (2006) found that international students in an online support group received more information and felt less stress. Kuster (2007) also found information value in online groups, including the fact that support groups can provide information through Internet links. There is some question about the reasons people select an online discussion group instead of a face-to-face group. These reasons may include frequency of interaction, availability, a sense of anonymity, convenience, and the lack of pressure to talk in a group. Mesch (2006), for example, suggested that people with low self-esteem were more likely to be frequent Internet users.

These groups provide opportunities for learning and empathy for people who share interests or concerns. There are numerous online groups specifically for people with interests in or concerns about children with disabilities. An updated version of the ERIC Clearinghouse on

Disabilities and Gifted Education list includes 55 different online discussion groups on the topic of learning disabilities and special education (http://www.hoagiesgifted.org/eric/ld-sped.html). The value of online support groups can be as important to the members as a face-to-face support groups are to their members (Turner, Grube, & Meyers, 2001). Further, the sense of anonymity in the nature of online interaction may actually increase the quality and depth of member responses through personal disclosure, reciprocity, and personal acceptance (VanLear, Sheehan, Withers & Walker, 2005).

Creating Narratives

Narratives were an essential component of the discussion in this support group. Story-telling is a crucial communication skill, which requires cognitive, knowledge, and language skills (Soto & Harmann, 2006). Communication scholars, educators, and psychologists have examined the purpose and effects of story-telling in many contexts. For example, story-telling helps people to make sense of their experiences through interpretative processing, particularly when using reflection about difficult experiences (Bochner, Ellis, & Tillmann-Healy, 1997; Koenig Kellas & Trees, 2006). Self-disclosure about difficult situations can have positive effects on an individual's well-being (Clark, 1993; Pennebaker, 2003). Thus, story-telling can be viewed as important for personal and therapeutic reasons in multiple contexts. Genereaux and McKeough (2007) contended that narratives are crucial in meaning-making and social-psychological understanding.

Black (2008) suggested that people in groups mediate differences based on their dialogic interactions, which can be particularly important in an online group. Koenig, Kellas and Trees (2006) observed that families used joint-narratives to make collaborative sense of experiences. Kyratzis (2005) suggested that story-telling is a primary way that families convey values and culture to

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