

OBSTACLES TO CREATING A NEW ONLINE SELF-HELP GROUP FOR PARENTS OF CHILDREN WITH DISABILITIES*

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ABSTRACT

Attempts to create a new online self-help group for parents of children with disabilities encountered technology problems and lack of participation by recruited participants. The quasi-experimental design was abandoned and grounded theory (Straus & Corbin, 1994) was chosen. It was found that participants differed in the amount that they used the discussion board: parents were categorized as major, moderate, minor, or inactive participants. Three applicable learning theories were considered to explain different levels of participation. Borkman's (1999) theory of the stages of experiential development for individuals who participate in self-help groups best fits the data. This study would suggest that experienced self-helpers are best at starting an online group. Newcomers to self-help groups need extra help in connecting with the group.

INTRODUCTION

It was the intent of this study to compare a beginning professionally-led online group as it transitioned to an online mutual aid group. However, technical obstacles prevented the study from following its intended course. When this study

*While this article has not been printed elsewhere, it was based on the doctoral dissertation of Jonathan O. Crook (2004).

was designed, most of what little research had been done focused on pre-existing online groups, not on new online groups; this study differs in that a new online discussion board was designed with self-help/mutual aid guidelines in order to create a self-help group.

As defined here, a self-help group online is one dedicated specifically to peers with the same problem, and closed to peer interaction only. Accordingly, the literature reviewed is of closed online groups (i.e., discussion boards) dedicated to peers that face the same problem. In contrast, list-serves that are open to sufferers of a health condition, medical professionals, family members, researchers, or any interested persons are excluded from the literature reviewed.

There has been a tremendous growth in the number of self-help groups online using discussion boards (Madara, 1999-2000). Although face-to-face self-help groups have been relatively intensively researched (see Kurtz, 1997 and Borkman, 1999, for reviews), the study of online settings is in its infancy (Lombardo & Skinner, 2003-2004; Madara, 1999-2000).

Though online self-help groups deserve scholarly attention, relatively little is known about online self-help groups (Kurtz, 1997; Madara, 1999-2000; Salem & Bogat, 1999-2000). Lieberman (2003-2004) noted that many questions remain unanswered. When studying online self-help groups or comparing them to face-to-face groups, a major issue relates to identifying similarities and differences between face-to-face and online approaches.

Other issues include differences among online approaches: e-mail, discussion boards, and chat rooms. Discussion boards and chat rooms are both group formats; chat rooms are synchronous (real time) online group formats, and discussion boards are asynchronous group discussions that one can participate in when one chooses. Salem and Bogat (1999-2000) found that some out-of-group e-mails took place in online self-help providing extra support and an opportunity for discussion of more personal issues. They also found that there were no designated leaders in online self-help groups.

Lieberman and Goldstein (2005) studied existing online self-help/mutual aid groups dealing with breast cancer. Lieberman and Russo (2001-2002) found that leadership in self-help groups is highly understudied. For group stability, leadership and membership needed to be a mix of old and new members, but old members tended to be the leaders.

The study of self-help/mutual aid groups has generated observation systems to examine the content and process of face-to-face and online interaction in the groups. Salem, Bogat, and Reid (1997) expanded and adapted the face-to-face mutual aid observation system and coding of Roberts and colleagues (1991) to arrive at an observation system that they felt was appropriate for understanding an online self-help/mutual aid group. Roberts and colleagues coding included a total of 12 categories in the general areas of helping behaviors, questioning, task orientation, help-seeking and disclosure, and affective response. In many ways online groups provide similar support as face-to-face groups though many of the

other characteristics defined by Roberts and colleagues were appropriate to describe the group aspects in either medium. Salem et al. (1997) found that humor was more common in online mutual aid groups than in face-to-face mutual aid groups. Other studies of existing face-to-face mutual aid groups have generated observation systems that explain interactions among parents of children with disabilities when they meet for the purpose of helping and supporting one another (Schubert & Borkman, 1994; Solomon, Pistrang, & Barker, 2001).

Originally this study was intended to examine the content and process of the discussion board of what I presumed to be a homogenous group of parents whose children had learning disabilities. In the original study as planned, what differentiated participants from one another was not considered to be of paramount importance. Borkman's (1999) theory of participants at different stages of self-help/mutual aid development became crucial in understanding the evolving data as the study shifted from comparing professionally led discussions to mutual aid discussions. Borkman theorized that participants entered the self-help/mutual aid process as *Victims*, progressed to a middle stage of development she labeled *Survivors*, and finally progressed to a mature stage of development that could be characterized as either *Thrivor* or *Dogmatic*.

Other theories considered in attempting to understand the emerging data that this study yielded included those of Senge (1990) and Thornburg (2001). Senge wrote about knowledge networks which are often used in the business world where peer sharing of knowledge is valuable. Participants in knowledge networks create new knowledge by interacting in either virtual or face-to-face group learning environments. Thornburg wrote about communities of learning that were comprised of four mytho-classical components that included the campfire (discussion board), watering hole (e-mail), cave (reflection), and plains (trying something different in the real world).

METHODS

The Research Site

The research site for this study was located within a Website for parents concerned about helping their child with disabilities become better readers and writers. The Website, called Literacy Access Online (LAO), was designed to facilitate parent/student dyads where the parent tutors the student using research-based best practices for increasing literacy skills. The LAO site was designed at George Mason University and funded by a grant (LiteracyAccess Online, Steppingstones of Technology CFDA 84 327A, H327A980035-99 and H327A000063) from the United States Department of Education.

As the LAO site itself was evolving prior to and during the time of the study, pilot studies with parents at the university suggested that parents could help one another using the LAO tool as well as engage in wider issues of parenting a child

with disabilities. These pilot studies indicated that parents might want to discuss their individual situations with one another using the online discussion board within LAO. Consequently the discussion board within LAO was designed with self-help/mutual aid principles in mind.

Research Design

A before and after one group quasi-experimental design was planned (Maxwell, 1996). The study was designed to compare the interaction of the new group that had expert involvement with the same group a month later that had peer-only interaction. The intended role of the researcher was that of detached observer, given the quantitative nature of the study design. During the first 4 weeks of the 8-week study, an expert moderator was to facilitate discussions using the discussion board. The discussions were to focus each week on the topic of the week introduced in a Web-cast by an expert in the field for that topic. The topics were: Assistive Technology, Reading Specialty, Special Education, and Self-help/Mutual Aid. Parents were asked to participate by viewing at least two of the live Web-casts that were broadcast over the Internet, one each week for the first month, and by posting at least two messages to the discussion board regarding these topics. During the last 4 weeks of the study, the participants were to use the discussion board without the expert moderation, relying on peer interaction alone. Three data collection points were planned: upon entering the study, after the first 4 weeks, and at the end of the study.

It was thought that the familiarity of expert information would be attractive to and increase the participation of parents in the conversations on the discussion board, thereby creating an environment that would allow the development of supportive mutual aid among them. Having access to expert information and the ability to interact with experts over the Internet during the live Web-casts was also thought to be of tangible value to parents for participating in the study and an incentive to continue the study in the self-help/mutual aid phase of the study at the end of the 4 weeks.

A N of 63 was calculated to be large enough to produce a reasonable effect size when comparing discussions facilitated by expert moderation and interaction in the first 4 weeks with self-help/mutual aid interaction without expert moderation in the final 8 weeks of the study. Since the original thinking anticipated one group only with before and after measures, 63 parents would be a large enough N for that group. The original thinking did not anticipate that sub-groups would be discerned and that these sub-groups would be worthy of study. Consequently, the size of sub-groups of the original N of 63 was not considered in the study design.

The quasi-experimental design could not be followed due to the limitations and failure of the Web-cast technology. The Web-cast technology failed for two reasons: 1) parents were able to use only one media player for the Web-cast, requiring them to download this particular media player from the Internet; and

2) even when they obtained this media player, they were unable to see or hear the Web-cast, though in two instances parents were able to type in questions using the Web-cast technology. In my role as researcher, I sent a general e-mail to all participants after each failed Web-cast to tell them how to access Web-cast information they had missed since it had been archived and hyper-linked within the LAO Website. In response to these technical difficulties, the majority of parents did not participate, that is, they did not post messages to the discussion board. Therefore, participation in the study as it was originally designed was limited because of these failures and there were an insufficient number of messages to pursue the original quasi-experimental portion of the mixed research design.

THE PARTICIPANTS AND RECRUITMENT

The larger LAO site was designed for students between 8 and 14 years of age. Criteria for participation in the study were that parents have a child in this age range with any disability, including, but not limited to, blindness, deafness, traumatic brain injury, dyslexia, and attention deficit disorder.

To recruit participants, about 200 e-mails were sent to organizations that had an online presence that was determined to be of interest to parents of children with disabilities such as dyslexia, developmental delays, and attention deficit disorder. Most of these sites belonged to organizations within the United States. A few examples of these sites are: Parent Educational Advocacy Training Center, Learning Disabilities Association of Virginia, Ionline.org, and Assistive Technology Loan Fund Authority (ATLFA).

Parents were recruited online to minimize the chances that differences in parental computer literacy were influencing the participation of different parents. Parents responded to the solicitation e-mail by clicking on a hyperlink that directed them to a Webpage that asked them questions designed to determine if they met the study requirements outlined above. They submitted this data by clicking a button on the Webpage that sent this data to me. I reviewed this data and either admitted or rejected the respondents depending upon whether or not they met the study requirements. Parents who did not meet the requirements of the study were directed to other resources. Sixty-three parents who met the study requirements were directed to a Webpage that detailed the requirements of the Institutional Review Board of George Mason University which assured them of confidentiality and informed them of potential risks and benefits to them and their children that might result from their participation in the study. It also included information about what the study would ask of them. Parents initiated the process of enrolling in the study and consented to the conditions of participation by clicking on a button labeled "I agree." The "I agree" hyperlink took them to the pre-study questionnaire that was submitted via Internet.

INSTRUMENTS AND DATA COLLECTION

Quantifiable information about participants and their background was gathered by the pre-study online questionnaire after the process of recruiting them for the study and before the study began. After the expert portion of the study was over at the end of the first 4 weeks of the study a questionnaire about their experience was posted online to which they were to respond. A similar questionnaire was posted online at the end of the study.

Participant demographic information was solicited at two times in two questionnaires prior to beginning the study as detailed above. Questions included age, gender, education level, age(s) of children, disabilities of children, marital status, and rural/urban residence. Since this study was conducted in an online environment without any face-to-face contact, eight questions in the initial questionnaires were duplicated to deal with the possibility of fraudulent identities which can happen online. This strategy was devised to increase the reliability and validity of the study. It was determined that no parent was giving information to the study that was incongruent with previous responses. In other words, participants were who they said they were.

In addition to demographic data, the study planned to collect data about the participant use of the Website from computer logs which recorded information about which Webpages were viewed within the larger Website as well as how much time the parent spent viewing these pages. Qualitative data was gathered from the posts of participants to the discussion board. Copies of all e-mails between the researcher and participants were kept and dated for later content and process analysis.

EVOLUTION OF THE STUDY

The recruitment of 45 parent participants took place in October 2003, and rolling enrollment continued until the end of November 2003, when a total of 63 participants had enrolled. Of the 63 participants, 61 were from the United States, one was from Ireland, and one lived in Africa. Sixty-one mothers and two fathers volunteered to participate in the study.

When a parent enrolled in the study, an e-mail was sent to the participant informing them that the study began with the first Web-cast and of the timetable for the four Web-casts (or later in the study the e-mail included links to the saved streaming video available online). The e-mail gave them directions on how to access the Web-casts and the discussion board. While parents were able to access the discussion board, no parent was able to view the Webcasts live due to technical difficulties. As a result of this barrier to participation in the study as it was designed, I sent e-mails to the participants suggesting they access the expert Web-casts as streaming video by clicking on a hyperlink within the Website. Rather than being interactive as planned, the expert Web-casts became

more like video lectures that could be accessed at any time the parent chose. I also suggested, by e-mail, topics about which parents could post messages to the discussion board. However, only 10 parents did post one or more messages to the discussion board in the first 4 weeks.

Because of mounting technical difficulties with the Web-casts, the study needed to be modified because participants could not access the Web-casts to interact with the experts and consequently did not have the intended information available to them which was to serve as the content for their first posting to the discussion board. The initial research design did not include the analysis of e-mails. Due to the technical difficulties, many more e-mails than anticipated were sent between the investigator and the participants. These e-mails discussed the difficulties encountered in trying to access the Web-casts, motivations to overcome these difficulties, and background about the participants and their interaction with their child. While there was decreased opportunity to participate in the expert discussions because of the technical difficulties, there was more communication between the researcher and the parents and therefore more information available through the e-mails with the researcher. Many of the parents who volunteered for the study failed to use the discussion board even as I continued to e-mail requests urging them to do so. As will be discussed later, these barriers to participation turned out to generate results that were not anticipated but are believed to be important.

With each failure to produce an interactive Web-cast during the first 4 weeks, it became more obvious that the quantitative portion of the study would not materialize. With the consent of my dissertation committee, I began to embrace the unintended role of participant-observer that evolved for me. My role as a participant-observer was enhanced by being the father of two children with disabilities, an experience that I emphasized in e-mail and the discussion board over any knowledge I might have as an expert. Despite this, some parents may have continued to perceive me as an expert, but I made a deliberate effort to communicate my experience as a father of two children with disabilities. In trying to be less of an expert figure in the study and to diversify leadership, I asked each of the five participants who stood out as participating most to introduce a topic during the last 4 weeks of the study and to monitor responses to their topic from other parents on the discussion board.

As a consequence of the technological barriers, I sent general e-mails to the parents explaining changes to the study. With one exception, the frequent participants replied to these general e-mails with personal e-mails that sought my help to overcome the barriers and for help with their individual situations. The infrequent participants e-mailed me to seek understanding for their unique situation or to bond with the researcher. Though it could have happened, I know of no e-mails that were sent from one participant to another during the course of the study.

As the study progressed, the analysis of the e-mails received from participants became more important as a major source of data. At the end of the first month when the expert information part of the study ended, I sent a general e-mail to the

participants directing them to complete the mid-study questionnaire, but only one person completed it.

At the end of the study, I sent a general e-mail to all the participants directing them to complete the end-of-study questionnaire, but only one parent completed it. The lack of completion of the mid-study and end-of-study questionnaires which were to provide quantitative data confirmed the failure of the original study design.

I needed information from all the participants about their experiences in the study and why they chose to participate as actively or inactively as they had. Given the lack of response to the end-of-study questionnaire, I sent another general e-mail to all parents asking them to respond to me by e-mail telling me about their experience in their own words. Only four parents responded to this e-mail. Still at a loss for a sufficient response from the study participants, I personalized an e-mail to each parent with information about their child that they had provided in the pre-study questionnaire and asked them to tell me their experiences by replying to my e-mail. This yielded a total of 43 responses and became my primary qualitative data about their response to participation in the study.

FINDINGS

The 63 parents consisted of 61 mothers and 2 fathers. Two parents withdrew in the middle of the study and are not included in the following demographics. The 61 parents each had a child with disabilities between the ages of 8 and 14 years that they intended to tutor using the LAO Website. The children were 72% ($N = 44$) boys and 28% ($N = 17$) girls which corresponds to the male/female ratio among children with disabilities in the United States (Doren, Bullis, & Benz, 1996). The children's disabilities were extensive, as they averaged 2.6 disabilities or more. The disabilities ranged from attention deficit disorder, learning disabilities, emotional disorders, autism, traumatic brain injury, and developmental delays.

The parents whose children were 8-14 years were older: 38% ($N = 23$) were 40 or younger, 59% ($N = 36$) were 41 or older, and 3% ($N = 2$) did not respond. Fifty percent were white ($N = 30$), 7% ($N = 4$) were black, 7% ($N = 4$) were other, and 36% ($N = 22$) no answer. Forty-eight percent ($N = 29$) of parents were married, 18% ($N = 11$) listed their marital status as single, and 34% ($N = 21$) did not answer the question. The educational level of the parents was relatively high: 34% ($N = 21$) had some college or less, 32% ($N = 19$) were college graduates or had graduate work, but 34% ($N = 21$) did not answer the question.

In analyzing the messages that parents contributed to the discussion board, frequency of participation on the discussion board became the most important and visible kind of information about the parents. Five parents participated most extensively in the study by posting five or more messages to the discussion board; these parents were labeled *Major Participants*. They were characterized by their determination to overcome the unintended barriers of the study in order to

help their child with disabilities. *Major Participants* used the discussion board to overcome barriers, to seek help for their individual situations, and to offer help and understanding to others.

Six parents participated by posting at least one and up to four messages to the discussion board: these parents were called *Moderate Participants*. Forty-two parents posted no messages on the discussion board, only responding to my end of study e-mail: these parents were *Minimal Participants*.

Overcoming the barriers to participation in the study separated the *Major Participants* from the *Moderate Participants* and the *Minor Participants*. *Major Participants* used e-mails and the discussion board to overcome these barriers.

For example, when unable to submit a post directly to the discussion board one day, one major participant e-mailed me in order to solve her temporary problem, "Will you please post this reply to Tony for me, for some reason, the post will not go through . . . gives me a server error message." The same *Major Participant* wrote, "I can't seem to find the replies to messages. When I click on a post heading, I see the original post, and then see that there is a reply . . . but can't find out where to read them."

Another *Major Participant* replied, "I have been having the same problem with reading replies. (Thanks Sue for asking . . . inquiring minds want to know! :)" To which the first replied, "So glad to figure this out. Oh the marvels of technology . . . I am sure one of my kids could have figured it out in a snap."

In contrast to the problem solving spirit of the *Major Participants*, one *Minimal Participant*, wrote in an e-mail, ". . . but I just found it too time consuming to try to figure out where I was supposed to go/do in terms of the research and when I tried to use the site I found that it didn't seem to be a learning opportunity for my son. Mostly, it seemed confusing and time consuming and the benefits were not clear to me."

Another *Minimal Participant* wrote, "Yes I was interested in participating and learning more to help my son in the area of literacy. Three things happened that made it difficult for me to participate. First, the times were difficult for where we live in Montana. Second, I could not figure out if I ever accessed sessions. Finally, most importantly, we lost our computer and I am just today reconnecting us."

The 10 remaining parents were labeled *Inactive*, with two exceptions who withdrew from the study during the 3 months that it spanned. With two exceptions, examination of the data showed that there were no demographic differences. In the general population, boys with identified disabilities outnumber girls two to one, but parents who participated more in this study were as likely to have a daughter as they were to have a son. The other exceptional demographic difference among parents was that the more parents participated, the less likely they were to have completed college. More study on this is necessary since the number of parents in this study is small.

Another gender difference emerged between fathers and mothers. Only two fathers volunteered to participate in the study, and they were both *Minimal*

Participants. Culturally, one might expect that mothers would be more involved in their child's education than fathers. However, the significance of the low number of fathers in comparison with mothers volunteering in this study is not understood.

Given the differing levels of parental participation, what factors distinguished one group from another? Three key theories of learning that apply to online learning environments and self-help groups were considered to explain the differing levels of participation. The theories included Thornburg's (2001) archetypal learning environments as they apply to online learning, Senge's (1990) knowledge network theory, and Borkman's (1999) theory of the stages of experiential development for individuals.

Thornburg's (2001) archetypal learning environments were developed to describe technology tools online that mirror face-to-face learning environments. These include the campfire (a group or class in face-to-face learning environments and discussion board online), watering hole (one-to-one personal discussion in face-to-face and e-mail online), the cave (personal reflection in person or online), and the plains (trying something new in person or online). These archetypes conform to the 12-step self-help model derived from Alcoholics Anonymous, where the campfire mirrors the group, the watering hole mirrors the sponsor relationship, the plains reflects trying out sober behaviors, and the cave reflects the emphasis on meditation and prayer.

Senge's (1990) knowledge network theory applies both to online and face-to-face business situations where building knowledge among peers is valued. As such it is also an appropriate model for understanding an online self-help discussion board that is not professionally led. Thornburg's theory was of some use in understanding the role of e-mail in addition to the discussion board. Senge's knowledge network theory did not adequately explain how the experiential learning that was taking place built to create new knowledge as eloquently as Borkman's description of the *Victim*, *Survivor*, and *Thriver* described the attitudes of parents who participated in the study.

First stage newcomers in Borkman's theory of individual development of experiential knowledge are called *Victims* and are defined as having victim-like behavior by not taking responsibility for their behavior, not problem solving, and not asking for help. Second stage participators known as *SURVIVORS* act less like victims and begin to problem solve and ask for help. The third stage *THRIVORS* take responsibility for their own behavior, solve problems, and ask for help from peers whose experiential knowledge they trust. These various characteristics of Borkman's stages correspond to levels of participation that were defined in this study.

Major Participants saw themselves as people who were able to take existing resources and use them to get what they wanted for their child with disabilities; this coincides with Borkman's concept of a *Thriver*. However, Borkman's *Thriver* is the person who has been in recovery the longest. This

implies that cultivating *Thrivors* may be a key to starting a new online self-help group. This needs more study.

The *Minimal Participants* responded only to the end-of-study personalized e-mail and to the initial questionnaire. Analysis of the end-of-study e-mails revealed that *Minimal Participants* always cited outside circumstances for their low participation. This coincides with Borkman's definition of a *Victim*, someone new to recovery. It suggests that the people who need an online self-help/mutual aid discussion board the most may be those who are least likely to use a new one. However, when a one-to-one communication such as a personal e-mail is used, parents in this category are more likely to respond. This suggests that e-mail may be a powerful tool in creating a new online discussion board for the purpose of self-help/mutual aid.

It is notable that the *Minimal Participants* cited Thanksgiving and Christmas as a reason that they did not participate as they had intended. However, *Major* and *Moderate Participants* did not cite the holidays as a difficulty in participating.

Thrivors used this new online discussion board. *Victims* found outside reasons to explain their lack of participation. *Survivors* populated a middle ground: e-mail with me as the participant-observer encouraged participation in the discussion board while the survivors showed a preference for e-mail and one-to-one communication that was biased more toward being helped than helping others.

While self-help/mutual aid is the focus of this article, it must be noted that the children of the mothers use of the discussion board varied from what one would expect given reports on children of disabilities in our nation. There are twice as many boys with disabilities as girls with disabilities nationally (Doren, Bullis, & Benz, 1996; Wagner et al., 1991). Yet in this study that was not true. It is true for the number of mothers who volunteered for the study, but for the mothers who participated in the study they were more likely to have a daughter than one would expect from the national statistics. Due to the small sample, further study of this phenomenon with larger samples, if repeated, might suggest that boys with disabilities may be less likely to get extra attention from mothers than daughters. Understanding and verifying this finding bears further study for our educational system and our society as well as for creating a self-help/mutual group online or face-to-face.

This study, which began with an experimental design that had to be abandoned because of the behavior of the participants, is not the only case of self-help researchers having to end an experiment; Kaufman et al. (1994) had to end their experiment when the randomized control group behaved similarly to the experimental group in attending a self-help group. Self-helpers seem to have a mind of their own.

This study would suggest that starting a new online group would best be accomplished by identifying a number of *Thrivors* who are willing to dedicate themselves to starting to a new online discussion group. Using e-mail to create a

one-to-one relationship is another means of communication that can be considered in starting a new online discussion group. E-mail may be a means of engaging *Survivors* and *Victims* prior to their readiness to participate fully in the discussion boards.

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