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Mothers' Perceptions of Website Information in Solving Behavioral Problems in Children with Disabilities

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MOTHERS' PERCEPTIONS OF WEBSITE INFORMATION IN SOLVING
BEHAVIORAL PROBLEMS IN CHILDREN WITH DISABILITIES

Heather Collins

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Educational Specialist

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BRIGHAM YOUNG UNIVERSITY

GRADUATE COMMITTEE APPROVAL

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ABSTRACT

MOTHERS' PERCEPTIONS OF WEBSITE INFORMATION IN SOLVING BEHAVIORAL PROBLEMS IN CHILDREN WITH DISABILITIES

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This research investigated the needs of mothers in regard to designing an educational website for parents/caregivers of children with disabilities. This research was designed to provide information to inform outreach efforts of Brigham Young University's Family HOPE (Happiness, Optimism, Promise, and Excellence) Project. This project assists families struggling with child behavior problems. Results from this study provided an initial understanding of the potential for a website to offer support to families not directly served through the Family HOPE project.

Participants included 26 adult females, 25 mothers and one female caregiver. Each participant was the primary caregiver of a child with a disability and challenging behaviors. Results from this study indicated that what parents would like to see on a website are modules or lessons to teach how to solve behavior problems, video demonstrations of parents successfully solving children's behavior problems, information about how to solve behavior problems, and blog/posts where parents can post questions and professionals and/or parents who have dealt with similar problems can post answers. This study provided incentive for practitioners, educators, and the human services field to conduct, design, and make available training modules or video demonstrations for parents on dealing with their children's problem behaviors at home. Due to the rise of computer networking via the Internet and advances in multimedia technology, the Internet provides an opportunity to provide services to families with limited access to traditional services (Feil et al., 2008).

When participants were asked where they go to get the most helpful support in solving their child's behavior problem, the majority of respondents reported that they go to the doctor, family, friends, and the Internet for support: Most found these avenues to be helpful in providing that support.

This study's findings offer several implications for practitioners, educators, and other human services professionals. Professionals, particularly school personnel, can increase their efforts to decrease family stress and increase their quality of life by providing support, resources, and expertise related to handling challenging behaviors in children with disabilities. Service providers must be open to exploring technology's potential to enhance their clinical work. It is critical to adapt empirically supported interventions to a nontraditional delivery system, such as the Internet.

Keywords: [behavior, children, disabilities, Internet, website]

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INTRODUCTION

When parents discover that their child has a disability, they experience an array of emotions. Parents may grieve because their child is not like other children. Parents may experience uncertainty because they do not understand their child's disability and how it will impact their family. Some parents seek information to guide them in best helping their child and knowing what resources are available to them. Other parents may feel overwhelmed with the task of caring for their child. No matter what the emotional reaction may be, parents need support in learning how to balance the needs of their family and the needs of their child with a disability.

Parents of children with disabilities begin a journey that takes them into a life of difficult choices, mixed emotions, interactions with many different professionals and specialists, and an ongoing need for information and support. Initially, parents may feel isolated and alone, and not know where to begin their search for understanding, information, and assistance. This research study has been developed to specifically respond to the information needs and support of these parents.

Children with disabilities often exhibit challenging behavior problems (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Beckman, 1991; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Lardieri, Blacher, & Swanson, 2000). Family members may experience high levels of stress trying to cope with these problem behaviors. Family stress is affected by a child's challenging behavior and by the disruption of family routines as a result of the child's disability (Bristol, Gallagher, & Schopler, 1988; Innocenti, Huh, & Boyce, 1992; Smith, Oliver, & Innocenti, 2001). Therefore, families with children with disabilities need professional support as

they work with their children to decrease their children's behavior problems and to reduce the level of parental stress.

The search for available services and support is a challenge for families and one that continues as the child's needs change. Typically, there are many services available within communities, districts, and states to assist parents in meeting the needs of their child with disabilities and behavior problems. In addition, an extensive wealth of research has been published regarding how to help children with disabilities and behavior problems; however, a vast majority of this empirical research is written for a professional audience and is not written in laymen terms (Gavidia-Payne & Hudson, 2002). On the other hand, information that is easy for parents to understand may not be trustworthy for parents of children with disabilities to use in trying to solve their child's behavioral problems (Cline & Haynes, 2001). Further, this information is not compiled in one place for easy access by parents. Therefore, many parents do not have access to easy-to-understand information regarding evidence-based practices for teaching their children with disabilities and challenging behaviors. Without such knowledge, parents are less likely to engage in parenting practices that are likely to increase positive behaviors and decrease inappropriate or challenging behaviors in their children. Evidence of success is critical for developing parental self-efficacy (Bandura, 1997; Bandura, 1999; Coleman & Karraker, 1998, 2000).

The purpose of this study is to gain insight from parents of children with disabilities regarding what they would find helpful in solving their child's challenging behaviors. More specifically, this study will investigate what information parents of children with disabilities and problem behaviors would find useful on a website.

The Brigham Young University Family HOPE (Happiness, Optimism, Promise, and Excellence) Project is a program that works with families that have children with disabilities to help increase the family's quality of life through training the parents in a positive behavior support program in order to change problem behaviors. Results from this study will provide a foundation for understanding how the Family HOPE Project can help families increase quality of life through providing support and information through a website for families who cannot served through the project.

REVIEW OF LITERATURE

Parents of children with disabilities frequently encounter difficulties and struggles that make parenting extremely demanding and stressful. Some of the most difficult challenges they encounter is when their children exhibit challenging behaviors. Research shows that children with disabilities often have greater problem behaviors than those without disabilities (Baker et al., 2002; Baker-Ericzen et al., 2005; Beckman, 1991; Herring et al., 2006; Kersh et al., 2006; Lardieri et al., 2000). Parents may feel as though they are not able to do simple things such as grocery shopping, going to a movie, or attending a community event because of their child's potential behavior problems.

The following section provides a brief summary of several factors related to parents raising children with disabilities. These factors include parental well-being, specific behavior problems, parent knowledge and skill in helping children with disabilities who exhibit challenging behaviors, and where parents obtain information concerning their child's disability.

Caregiver Well-Being

Children with developmental disabilities who exhibit challenging behaviors are at risk for developing additional problems. This population includes children with the diagnosis of autism spectrum disorder, mental retardation, multiple disabilities, developmental delay, and other disabilities that are characterized by cognitive impairment (e.g., Down syndrome). The occurrence of challenging behaviors of children with developmental disabilities is particularly concerning because these behaviors "place the individual [child] and others at risk of serious harm to their physical and psychological well-being" (Gavidia-Payne & Hudson, 2002, p. 33).

Parenting children with developmental disabilities and children with intellectual disabilities who have behavior problems can be extremely taxing. Child behavior is a powerful

predictor of parental well-being for both mothers and fathers (Kersh et al., 2006). Since parents are primary managers of a family's emotional climate, according to developmental models of parenting (Belsky, 1984), parent well-being is vital to the maintenance of a positive family climate (Kersh et al., 2006). Although there are a variety of predictors for parental well-being, this paper defines parental well-being in terms of mental health (including depressive symptomology), parenting stress, and parenting efficacy.

Parental depression. In the *Diagnostic Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association [APA], 2000), the diagnostic criteria for Major Depressive Episode is described as a depressed mood or loss of interest or pleasure in all or almost all typical activities. The episodes must be present for most of the day during at least a two-week period of time. During that time these symptoms cause clinically significant distress or impairment in daily functioning in the workplace, school, or in social activities. An individual may manifest a depressive episode through a depressed mood for most of the day or a markedly diminished interest or pleasure in most activities the individual usually enjoys. The individual may also experience significant weight loss or weight gain and have difficulty sleeping or staying awake at night. Individuals also report restlessness, feeling fatigued and lacking energy to perform daily tasks, and feeling worthless or excessive guilt. Individuals frequently report diminished ability to think or concentrate, difficulty in making decisions, and recurrent thoughts of death and suicidal ideation.

Some individuals experience multiple depressive episodes that lead to Major Depressive Disorder. Major Depressive Disorder is defined by two or more Major Depressive Episodes, generally with two months between the depressive episodes (APA, 2000).

In the United States, women experience major depressive episodes twice as frequently as men (APA, 2000). It appears that the percentage of women experiencing Major Depressive Disorder is between 5 and 9% while the percentage of men who experience Major Depressive Disorder is only between 2 and 3% (APA, 2000).

Studies suggest that some stressors, such as financial hardship or loss of employment, may actually contribute to major depressive episodes that lead to Major Depressive Disorder (APA, 2000). Another such stressor may be the birth of a child with a disability (McCubbin & Patterson, 1983).

Research on parents' mental health has focused largely on depressive symptomology (Kersh et al., 2006), especially with mothers of children with disabilities. Contemporary research is consistent with early views that mothers of children with disabilities have increased depressive symptomology, compared with mothers of typically developing children (Kersh). Also, mothers of children with disabilities carry a disproportionately heavy burden, resulting in more depressive symptoms than fathers of young boys with developmental disabilities (Bristol et al., 1988).

A study conducted by Smith, Innocenti, Boyce, and Smith (1993) focused on depression in mothers of children with disabilities using the Center for Epidemiological Studies Depression Scale (CES-D). Their research included 48 mothers of children between the ages of 39 to 59 months (24 boys and 24 girls) with severe developmental delays, Down syndrome, cerebral palsy, and motor or sensory impairments. Smith et al. found that the sample of mothers reported a significant amount of depression as compared to the CES-D normative population. Also, the mothers were nearly one standard deviation above the mean, suggesting significant symptoms of depression.

Though extensive research has been conducted with families raising children with developmental delays (DD), it is not clear whether the primary caregivers of these children are at an increased risk for depressive symptomology. A study conducted by Feldman, McDonald, Serbin, Stack, Secco, and Yu (2007) focused on this very issue using the Beck Depression Inventory (BDI) to measure depression levels of 178 primary caregivers (primarily biological mothers) of 2-year-old children with or at risk for DD. Feldman et al. found that 20% of caregivers scored above the BDI clinical cut-off for depression, 20% suffered with mild depressive symptoms, and 60% of the caregivers reported no depressive symptoms. Parents with elevated BDI score reported significantly less social support and parent efficacy, more child behavior problems, and relied more on escape-avoidance coping strategies than the non-depressed group. Escape-avoidant coping includes the use of less than optimal behavior management techniques. For example, an escape-avoidant parent may be quick to give in to child misbehavior, reinforcing negative behavior.

Parents' reactions to children with developmental delay (DD) with autism may be different from those to children with DD without autism. Olsson and Hwang (2001) conducted a study with 207 mothers and 167 fathers of children with a diagnosis of autism or an intellectual disability without autism. The control group consisted of 204 mothers and 185 fathers of children who did not have a disability. Olsson and Hwang discovered that the mothers who had a child with a disability reported higher levels of depression than mothers in the control group. The fathers in the sample reported more depression when their child had autism only. The mothers of children with autism had higher levels of depression than the mothers of children with an intellectual disability. This study also found that the mothers who had a child with a disability reported higher levels of depression than the fathers of children with disabilities.

Parental stress. Parental stress is described as the “ongoing relationship between a person and environmental factors” (Plant & Sanders, 2007, p. 110). Stress refers to the emotion experienced when a situation is perceived as demanding, challenging, or threatening, and the person in the situation does not have an adequate coping response. Parents of children with disabilities can potentially perceive any of the numerous tasks associated with care-giving as demanding or threatening.

A great deal of research has focused on parenting stress. It has been found that, “parenting stress, especially stress related to the child’s temperament, often appears to be higher in families in which a child has a disability than in other families and [appears] to increase over the childhood years” (Kersh et al., 2006, p. 884). In a study conducted by Innocenti et al. (1992), 725 parents of children with disabilities were given the Parenting Stress Index (PSI) and were compared to surveys of families without children with disabilities. The PSI measures characteristics of stress related to parenting: (a) stress related to the perception of the child’s contribution of a stressful relationship, and (b) the impact parenting has on other areas of a parents’ life. Results showed significantly higher stress ratings in parents of children with disabilities.

An additional study conducted by Smith et al. (2001), 880 parents of children with developmental delays were given assessments measuring their parental distress, parent-child dysfunctional relationship, and the difficultness of their child. Family functioning was measured in an 18-item questionnaire investigating (a) perception of support from family, friends, social groups, and professional services; (b) a measure of time and financial resources available; and (c) a survey evaluating the presence or absence of life-straining events within the past year. Smith et al. (2001), Investigating these factors, Smith et al. found that family functioning

variables, which included family support, resources, life events, and a lack of resources, seemed to be the greatest predictor of parenting stress.

In addition, family stress can also result from a “lack of information about coping with preadolescence problems and about managing the daily life of children or adolescents with disabilities” (Dyson, 1997, p. 267). If families had the tools to solve problems of child behavior in a family context, then they may begin to overcome a myriad of care giving challenges; and in so doing, build a life with their child that is characterized by less stress, increased satisfaction, and greater success (Dyson, 1997; Floyd & Gallagher, 1997; Lucyshyn, Horner, Dunlap, Albin, Ben, 2002; Lustig & Akey, 1999). Parenting children with disabilities who have behavior problems may disrupt normal family patterns. Bristol et al. (1988) found that parents of developmentally disabled children had more disruptions in daily life than did parents of nondisabled children, which can cause greater levels of stress.

Parental stress is often related to the severity and intensity of a child’s problem behavior (Hastings, 2002; Lardieri et al., 2000). Even though parents of children without a disability may struggle with child problem behaviors, parents of children with disabilities often report more stress due to greater severity of problem behaviors (Baker et al., 2002; Baker-Ericzen et al., 2005, Floyd & Gallagher, 1997). Such stress can have an effect on how parents view their ability to effectively parent their child with a disability.

Parental efficacy. Self-efficacy is the extent to which an individual believes certain events will occur as a result of personal effort (Bandura, 1997; Bandura, 1999). Bandura (1977) described four ways people gain information concerning their personal effort. They include the following (a) a synthesis of past performances, “enactive mastery experience” (Bandura, 1997, p. 80), (b) observations and images of the self, or others similar to the self, performing the desired

task “vicarious experience” (Bandura, 1997 p. 86), (c) verbal feedback or reinforcement given by respected individuals or others of authority “verbal persuasion” (Bandura, 1997, p. 101), and (d) feedback an individual receives from the given task “physiological and affective states” (Bandura, 1997, p. 106). Essentially, through these four sources described by Bandura individuals develop cognitions that will predict the amount of effort they will devote towards certain tasks. Past experiences of success or failure make predictions about an individual’s future performance. Successful experiences promote a perception that one will achieve success in similar situations in the future. Similarly, failed experiences in the past have an effect on the success or failure of a similar event in the future. As a result, those with low self-efficacy will avoid or give up on a given task. On the contrary, an increase of self-efficacy will encourage larger amounts of effort and determination to complete a given task (Bandura, 1999; Cervone, 2000).

Parenting efficacy is a specific domain of general self-efficacy and has been defined as “one’s perceived ability to exercise positive influence on the behavior and development of one’s children” (Coleman & Karraker, 1998, p.58). Parenting efficacy research emphasizes parental confidence in their capability to fulfill their roles and to successfully nurture positive child behavior and development. Parents with greater overall self-efficacy report higher rates of parenting self-efficacy (Coleman & Karraker, 1998, 2000). Parents who report high parenting efficacy also report lower amounts of stress, are more involved in their parenting, have a greater sense of hope for the future, and report having children with mild temperaments (Jackson, 2000; Jackson & Huang, 2000). Low parent efficacy in parents with children of disabilities is associated with a high incidence of child behavior problems (Kersh et al., 2006).

For parents to effectively perform their roles as caregivers, problem-solving skills are essential elements of a parent's repertoire (Gavidia-Payne & Hudson, 2002). Parenting efficacy is increased through actual experiences with children, observation of others working with children, and programs that provide opportunities for success (Coleman & Karraker, 1998, 2000).

Given the evidence that the relationship between parental well-being and behavior problems in children with disabilities is noteworthy; interventions which address this population of children with behavior problems need to be considered (Kersh et al., 2006). Parents play a vital role in the prevention of problem behavior, given their enormous influence in shaping and maintaining exchanges with their children. Research displays repeatedly that parents are instrumental in the teaching, learning, and in minimizing delays of their children learning and maintaining pro-social behavior (Gavidia-Payne & Hudson, 2002). Therefore, it is crucial that parents receive accurate behavior information early.

Behavior Problems of Children with Disabilities

Research demonstrates that problem behaviors are more prevalent in children with an intellectual disability than those without a disability (Schwartz, Taylor, Drotar, Yeates, Wade, & Stancin, 2003; Baker et al., 2002; Gavidia-Payne & Hudson, 2002; Hastings, 2002; Floyd & Gallagher, 1997; Einfeld & Tonge, 1996). This was demonstrated in a study by Floyd and Phillippe (1993) who found that children with an intellectual disability displayed higher rates of non-compliant behavior than a comparison group of children without an intellectual disability. Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low (2003) sampled the parents of 205 children with and without developmental delays or intellectual disabilities, and the results indicated that children with developmental delays exhibited a higher rate of behavior problems than their peers

without delays. Results of this study also indicated that parents of children with higher rates of behavior problems report more stress than parents of children with fewer behavior problems. A study conducted by Eisenhower, Baker, and Blacher (2005) included 213 families with at least one child age three to five with or without an intellectual disability (ID). The study included different disabilities present among these children including Down syndrome, cerebral palsy, and autism. The following conclusions were made from data collected from mothers: the overall rates of problem behavior in the ID groups were high, with 38.2% scoring in the borderline or clinical range, compared with 10.3% of the typically developing children.

There is a range in severity of problem behaviors depending upon the severity of a child's disability (Hawley, 2003; Liwag, 1989; Schwartz et al., 2003), as those with more severe disabilities often engage in more severe problem behaviors. For example, an Australian study conducted by Einfeld and Tonge (1996) suggests that in the New South Wales (NSW) region, 40.7% of those with an intellectual disability ages 4-18 years could be classified as having severe emotional and behavior disorders. This study also concluded that disruptive and antisocial behaviors were more prominent in those with mild intellectual disabilities; whereas, self-absorbed and autistic behaviors were more frequently associated in children with severe intellectual disabilities.

Tantrums are most apparent in typically developing children; however, there are a variety of problem behaviors children with disabilities display depending on the type and severity of the child's disability and the environment. Many children with autism have problem behaviors such as tantrums, self-injurious actions, obsessions, compulsivity, or poor social skills (Baker-Ericzen et al., 2005; Ben-Tall, 1999).

Herring et al. (2006) highlights the importance of addressing emotional and behavioral problems through early support and intervention with very young children with autism and/or developmental delay. Research shows that behavior and emotional problems occur in a wide range of developmental disabilities and persist into adolescence and adulthood (Herring et al., 2006). Lemanek, Stone, and Fishel (1993) found that autistic children presented the highest frequency of non-compliant behavior compared with the behavior of children without an intellectual disability, children with an intellectual disability, or language impairment. Given that behavior problems in children with disabilities often persist into adolescence and adulthood, parents need to gain parenting skills and information early to deal with their child's problem behaviors.

For children with a traumatic brain injury (TBI), problem behaviors often include mood fluctuations, aggression, temper tantrums, hyperactivity, or poor social skills (Hawley, 2003, 2004; Schwartz et al., 2003). These behaviors often increase as the severity of the TBI increases (Hawley, 2003; Schwartz et al., 2003).

A considerable body of literature exists such that we are able to design effective behavioral interventions; however, the literature is spread throughout a number of fields of knowledge and research (e.g., parenting, disability, assessment). Furthermore, while research in the area of effective interventions with problem behaviors in children with disabilities has made considerable advances, there continues to be gaps in the research on the development of practical applications for "parent friendly" programs; behavioral supports for families are often not accessible and usable by families (Gavidia-Payne & Hudson, 2002). In addition, Gavidia-Payne & Hudson (2002) suggests that we need to "adopt a new applied science where the needs of consumers (i.e., parents and children) are addressed more systematically and frequently, and

where the environments, systems, and contexts where they operate are as thoroughly addressed as is the behavior of individuals with intellectual disability” (p. 50).

Parent Knowledge and Skill in Addressing Challenging Behaviors

The family is extremely important to the development, education, and behavioral support of a child with a disability (Erwin, 1996). Throughout the life of a child with a disability the family is the primary source of continuity, and is the most powerful influence on a child’s development (Dunlap & Fox, 1996).

Parents become the experts on their child with a disability; they possess in-depth knowledge about their child’s strengths, needs, preferences, and idiosyncrasies. Parents become experts on supporting and accommodating their child with a disability in the context of family life through years of experience in raising their child, reading literature on children with disabilities, and interacting with professionals (Dunlap, Robbins, & Darrow, 1994; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996).

Parents of children with disabilities often have a difficult time balancing the needs of their child with a disability with the needs of their family. Professionals can help families decrease their stress and increase their quality of life by providing support, resources and expertise, and allowing the locus of control to lie within the family (Bennett & DeLuca, 1996). Professionals who are the most helpful are those who work within the family structure to help empower family members to make positive changes (Bennett & DeLuca, 1996). Bennett & DeLuca (1996) conducted a qualitative study with families raising children with disabilities investigating bonadaptation. *Bonadaptation* is the process by which families restore balance by the parents’ ability to promote the development of individual family members and their willingness to maintain their family unit so it can accomplish its life cycle tasks. Parents reported

wanting to feel empowered when raising their child with a disability through a knowledge of best practice, flexibility of the professional, and being an active participant in the decision making process.

When professionals recognize, accept, and value the importance of the family in offering behavioral supports to children with disabilities, they are more likely to work with families as partners and colleagues. In so doing, professionals and parents are more likely to participate in a reciprocal process of listening and learning about ways to best educate and support children with disabilities and problem behaviors (Lucyshyn et al., 2002).

Programs, like the Family HOPE (Happiness, Optimism, Promise, and Excellence) Project, that are based on positive behavior support may be able to provide the success experiences needed to increase parenting efficacy and problem-solving skills. In the Family HOPE Project, families raising children with disabilities and challenging behaviors are provided with in-home support for 8-10 weeks to analyze one target behavior, create and implement a behavior plan, and evaluate results of the plan. The project uses a positive behavior support framework where parents refrain from fixing or extinguishing the problem behavior through external controls, such as rewards and punishments which are coercive strategies. Instead, they focus on understanding why the problem behavior is occurring in an effort to teach an alternative positive behavior. Families involved in this project have the chance to increase their chances of success during a crisis or hardship, such as a severe challenging behavior, which may improve their self-efficacy and family quality of life. However, the provision of in-home training is limited to very few families. Many other families seeking information and training find alternative sources when in-home training is not available.

Parent Information Seeking in Addressing Challenging Behaviors

Due to the rise of computer networking via the Internet and advances in multimedia technology, there is now an opportunity open to provide services to families with limited access to traditional services (Feil et al., 2008). Research has been conducted on five interactive computer-mediated intervention programs for parenting support and information (Dunham, Hurshman, Litwin, Gusella, Ellsworth, & Dodd, 1998; MacKenzie & Hilgedick, 1999; Gordon, 2000; McCullough, 2001; Munneke, 2001). Each program ranged in difficulty from networked computer terminals, personal computers with animated graphics, to the remote transmission of video. First, Dunham et al. offered online support and supplied information to single mothers of young infants, and found that those mothers who were socially isolated were more likely to spend time online. MacKenzie and Hilgedick developed a Computer-Assisted Parenting Program (CAPP) that provided four sessions of behavior parent training and found that their program positively affected parental involvement and limit-setting. Gordon's research found that an interactive CD-ROM parent-training program was effective in reducing child problem behaviors, improving parent knowledge of positive parenting skills and increasing the use of those skills, reducing maternal depression, and enhancing family functioning. McCullough used a fully interactive audio-visual interface to supplement speech and language therapy for children with disabilities. Results found substantial improvements in the children's communication skills. The increases in receptive, expressive vocabulary and vocal imitation skills were achieved more quickly than in the previous two months 'traditional' therapy approach. Finally, Munneke's research investigated the prospective effectiveness of a computer-based parent-training program designed to supplement therapist-delivered parent training. The program resulted in an increase in positive child behaviors and decrease in child noncompliance.

Increasingly, parents engage in *interactive health communication*, which is “the interaction of an individual—consumer, patient, caregiver or professional—with or through an electronic device or communication technology to access or transmit health information or to receive guidance and support on a health-related issue” (Robinson, Patrick, Eng, Gustafson, 1998, p. 1264). More than 70,000 websites disseminate health information. An estimated 18 million adults in the US sought health information online in 1998. Recent estimates range from 60 to 100 million adults, most at least once a month (Cline & Haynes, 2001). Parent’s access online health information in three primary ways: searching directly on web pages, participating in support groups and consulting with health professionals (Cline & Haynes).

Critics question the quality of online health information. Because anyone can develop an Internet website, parents access information directly from credible scientific sources (e.g., Medline, Healthfinder) as well as sources of unknown credibility (e.g., quacks and charlatans). The Internet is uncontrolled and unmonitored; Internet pages mislead consumers into believing they are authoritative by looking official. Well-meaning individuals may provide inaccurate information or promote unproven remedies based on personal experience. “Because the Internet is unregulated, accuracy, currency and bias vary; inaccurate information is disseminated widely” (Cline & Haynes, 2001, p. 679). Adelhard and Obst (1999) found that more than half of health information websites offer unreliable information. In only a few hours, an initiative by the Federal Trade Commission identified over 400 websites and Usenet newsgroups contained misleading and fictitious claims and products for six diseases (Federal Trade Commission, 1997).

More experienced users of the Internet are more critical of the quality of health information than less experienced users (Cline & Haynes, 2001). However, “in medicine, the

ability to review scientific literature critically, to identify major research flaws, and to interpret correctly the clinical implications of research findings, are skills acquired through training” (Ayonrinde, 1998, p. 449). Consumers may then misjudge information, be inundated with so much information, they become overloaded, easily confused, and misinformed. Without consumers possessing the skills to discern and review scientific literature critically, many consumers still “1. Fail to recognize that key information is missing, 2. Fail to distinguish between biased and unbiased information, 3. Fail to distinguish between evidence-based and non-evidence based claims, and 4. Misunderstand health information intended for health professionals” (Cline & Haynes, p. 680).

Information found through online health sources may influence medical decision making and help consumers to manage their own care. Approximately 47% of consumers seeking health information reported that their findings influenced their treatment decisions (Pew Internet and American Life Project, 2000c). One of the most common topics researched is children’s health (Cline & Haynes, 2001). Optimists believe this will lead to better-informed decisions by consumers, more sound treatment decisions, increased patient satisfaction, and a stronger professional-client relationship, resulting in better medical outcomes (Ayonrinde, 1998). Pessimists deem that medical outcomes could be reduced or weakened by consumers who interpret health information incorrectly and then try inappropriate treatments (Cline & Haynes).

The human services field has been slower to adopt technology in important areas, such as behavioral assessment, prevention/intervention work with families, and disseminating evidence-based practices. Despite the hesitance, “it is clear that people are becoming more and more dependent on technology in their everyday lives, especially for interpersonal interactions and knowledge seeking” (Self-Brown & Whitaker, 2008, p. 319). The human services field must be

open to exploring how technology can enhance research and clinical work. The use of multimedia technology within a healthcare framework is not new, but its application within computer-mediated interventions for parent training and support is poorly documented.

Computer-mediated interventions have become possible due to the increase of computer and Internet access in American households. The number of households with computers increased from 8% to more than 60% between 1984 and 2003. In addition, Internet access and usage has tripled, from 18% to more than 54%, from 1997 to 2003 (Day, Janus, & Davis, 2005). Presently, 73% of all American adults use the Internet (Madden, 2006). This is an increase of 7% in only one year; from 133 million in January 2005 to 147 million in February 2006. There continues to be less Internet access among lower income families and families living in rural areas. However, Internet access continues to improve amongst these two groups. Currently, 52% of homes in rural areas (Bell, Reddy, & Rainie, 2004) and 38% of homes with incomes less than \$25,000 per year (Day et al.) report having access to the Internet.

Families located in rural areas and poor families are unable to access provided services and programs due to the absence of public (or reliable private) transportation, lack of medical insurance coverage, limited flexibility in work schedules, and lack of child care (Feil et al., 2008). These conditions are deteriorating further as the security for disadvantaged persons is weakened by reduced state and federal resources. Given the documented effectiveness of early intervention, it is extremely unfortunate that access to these programs is severely limited for many high-need families (Connell, Sanders, & Markie-Dadds, 1997; Olds, 2003; Sanders, 1999). Therefore, it is critical that empirically supported interventions be adapted for a nontraditional delivery system (e.g., Internet).

Statement of Problem

An extensive wealth of research has been published regarding how to help children with disabilities and behavior problems; however, a vast majority of this empirical research is written for a professional audience and is not written in laymen terms (Gavidia-Payne & Hudson, 2002). On the other hand, information that is easy for parents to understand may not be trustworthy for parents of children with disabilities to use in trying to solve their child's behavioral problems (Cline & Haynes, 2001). Further, this information is not compiled in one place for easy access by parents. Therefore, many parents do not have access to easy-to-understand information regarding evidence-based practices for teaching their children with disabilities and challenging behaviors. Without such knowledge, parents are less likely to engage in parenting practices that are likely to increase positive behaviors and decrease inappropriate or challenging behaviors in their children. Evidence of success is critical for developing parental self-efficacy, and may reduce psychological issues such as depression (Bandura, 1997; Bandura, 1999; Coleman & Karraker, 1998, 2000).

For example, the primary researcher conducted a Google search using the terms disability, parents, and behavior. Some of the websites were out-of-date and had not been modified in at least one year or more. None of the websites offered online support to parents of children with disabilities. Nearly all the websites were specific to one topic or disability. The majority of the websites listed local resources, workshops, and networking. One website let me insert search terms for specific conditions, specific services/resources, specific events/conferences, for specific areas of the country. Many of the websites gave in-depth information concerning Special Education law/rights and the Individual Education Program (IEP) process.

One website, the Child Development Institute (CDI), was founded by Robert Myers, Ph.D., a Clinical Child Psychologist with 25 years of experience working with children, adolescents, families and parents. Realizing the unlimited potential of the Internet to provide useful information to parents, he decided to utilize this method to provide parent education that is current, relevant and easy to attain. This was the only website that contained researched-based practices for teaching children with disabilities, children with challenging behaviors, teenagers, parenting children with mental health disorders, and provides comprehensive information on child development, emotional growth, language development, and parenting guidelines from research studies related to various disorders found in children and adolescents. Dr. Myers' website is recommended by Psychology Today and the American Psychological Association (APA).

However, the CDI website is not aimed towards parents and families who are raising children with disabilities. There is no specific parenting information designed for helping parents and caregivers solve behavioral problems in children with disabilities. The website is also not interactive; there is no opportunity for parents to watch video demonstrations of other parents and caregivers successfully solving children's behavior problems. No modules or lessons that specifically teach skills on how to solve behavior problems. There is no location on the website where parents can interact with other parents who have dealt with similar behavior problems, either through a post or blog. There also is no place on the CDI website for parents and caregivers to make contact with professionals or other parents who have successfully solved specific behavior problems like theirs.

Statement of Purpose

The purpose of this study is to gain insight from parents of children with disabilities regarding what they would find helpful in solving their child's challenging behaviors. More specifically, this study will investigate what information parents of children with disabilities and problem behaviors would find useful on a website.

The Brigham Young University Family HOPE (Happiness, Optimism, Promise, and Excellence) Project is a program that works with families that have children with disabilities to help increase the family's quality of life through training the parents in a positive behavior support program in order to change problem behaviors. Results from this study will provide a foundation for understanding how the Family HOPE Project can help families increase quality of life through providing support and information through a website for families who cannot be served through the project.

Research Questions

This study investigates the following questions regarding what parents of children with disabilities would find helpful in solving their child's challenging behaviors on a website:

1. What behaviors are most challenging and persistent for parents of children with disabilities?
2. When parents are concerned about their child's behavior, where do they get support?
3. Where do parents of children with disabilities get the most helpful support in solving their child's behavior problems?
4. What do parents of children with disabilities want a website to provide to help them solve their child's behavior problems?

METHOD

Participants

The sample was selected from parents of children with disabilities in the state of Utah. Participants were recruited from the Utah Parent Center (UPC), a nonprofit parent-to-parent organization founded in 1984 by parents of children with disabilities. The UPC offers parents information to strengthen parent participation in helping their children live more productive lives in community settings. With their permission, the UPC included an announcement in their bi-monthly electronic newsletter regarding this study and request for parent participation. The announcement was included twice during a one month period. The UPC's electronic newsletter is offered two times per month and is distributed to approximately 2,500 Utah families. Participation was encouraged: Ten randomly selected participants who provide home addresses received a popular children's book featuring characters with disabilities. Mothers, fathers, and caregivers of children with disabilities were invited to participate.

The sample ($n = 26$) was composed of female participants (24 mothers and 1 female caregiver) primarily from Utah. Twenty four participants resided in Utah, 1 resided in Wyoming, and 1 participant did not complete the demographic section of the survey. Of the sample residing in Utah ($n = 24$), the majority ($n = 23$, 96%) resided in urban Utah; 1 participant reported living in rural Utah and 1 participant did not specify in what part of Utah she resided.

The sample was 92% Caucasian ($n = 24$), 8% African-American ($n = 2$). Of the participants who provided demographic information ($n = 25$), most ($n = 24$; 96%) had completed at least some college. In addition, 60% ($n = 15$) of the participants were stay-at-home mothers. Of the participants who were employed ($n = 12$), 50% were employed in the fields of Education

and Library. Most participants had high-speed Internet ($n = 24$, 96%) and 60% ($n = 15$) had more than one computer in their home.

Of the participants who provided demographic information ($n = 25$) on their child with a disability, most of the participants children had an intellectual disability/developmental delay ($n = 13$, 52%) or Autism ($n = 11$, 44%). One child had another health impairment. The mean age of the participants' children was 8 years (range 2 – 16 years). There were 2 outliers in the sample age 54 years and 31 years. The mean age of the participants' children at diagnosis was 2 years (range 0 – 9 years). The mean age of the adult participants was 41 years (range 27 – 76 years).

Procedures

Upon completion of IRB approval, the primary researcher worked with the Associate Director of Programs and Services at the Utah Parent Center to include a description of the research in their electronic newsletter, along with a link to the survey. Interested parents or caregivers had the opportunity to click on the hotlink and complete the survey via web-based survey software [www.qualtrics.com]. The survey's initial page included an informed consent detailing the study's purpose, risks and benefits (see Appendix A). It provided contact information for the primary investigator, thesis chair, and BYU's IRB Chair. After reviewing the informed consent, participants had the option of clicking an "I agree" button to access the survey login page. Appendix B contains the survey. The survey remained online for 30 days after the initial announcement.

The data were examined for response sets that may have come from the same individual (e.g., two consecutive surveys that provided the same age, location, and response pattern). None were identified.

Measures

Data were collected and analyzed using two assessment measures: a web-based survey and the Scales of Independent Behavior—Revised (SIB-R).

Survey. Data were collected from participants using a web-based survey using Qualtrics survey software (see Appendix B). Prior to finalizing the survey, the primary investigator did a talk-aloud interview with five parents to get their feedback on the survey. Next, an online pilot test was conducted with a convenience sample of five parent volunteers associated with the primary investigator. Volunteers were parents and caregivers of children with disabilities. Their feedback assisted in streamlining the survey and ensured understanding and ease of responding to the online survey. Following the completion of the survey, participants were asked questions concerning the survey: Did you have any difficulty completing the survey? Do you have suggestions to improve the survey? Were any questions hard to understand? Were any questions offensive? Please offer any other suggestions.

The final survey consisted of 20 questions. The first section has 8 Likert-type and open-ended questions. The second section of the survey is comprised of 12 demographic questions. Demographic questions include multiple choice response options or fill-in-the-blank. Questions included three areas of interest: adult-based questions, child-based questions, and computer and Internet information.

The adult questions included identity of the caregiver (mother, father, or male or female caregiver); age (fill in the blank); ethnicity (7 selections based on 2000 census ethnic descriptors); city, county and state of residence (fill in the blank); level of completed education (ranges of education were offered), current employment status (included unemployed, employed, student, and combinations of those descriptors; or other); and type of employment (17 selections

based on 2009 United States Department of Labor Statistics standard occupational classifications).

Child-based questions included ethnicity (7 selections based on 2000 U.S. Census ethnic descriptors); diagnosis (fill in the blank); age at time of diagnosis (fill in the blank); current age (fill in the blank); current age of child (fill in the blank). Computer and Internet information included questions regarding the number of computers in home (response options provided) and type of Internet connection (response options provided).

The Likert-type and open-ended questions included two areas of interest: (a) The nature of the child's challenging behavior, including when the caregiver was first concerned with their child's behavior, and where they obtained information and whether the information was helpful, and (b) What the caregiver would like to find on a website that would help them solve their child's behavior problem.

The first area of interest included a two-part research question asking parents and caregivers where they get support and to rate how helpful that support is from Not Helpful, Somewhat Helpful, Helpful, to Very Helpful. Respondents could choose from fourteen sources to obtain support including family, friends, doctor, district K-12 school, birth-to-3 provider, Internet, support group, and other. The second area of interest included a Likert-type research question asking parents what they want a website to provide to help them solve their child's behavior problems. Respondents were given eleven offered items to choose from and were asked to rank their top five choices in order from 1 being most preferred to 5 being least preferred. Choices included videos chats with professionals and/or parents, video demonstrations of parents successfully solving children's behavior problems, calendar with locally listed events, conferences and activities, and research summaries of strategies for solving behavior problems.

Scales of Independent Behavior-Revised. The Scales of Independent Behavior – Revised (SIB-R) is a caregiver survey that divides a child's behaviors into two sections, adaptive and problem behaviors. The adaptive behavior section gives a Broad Independence Scale score and is comprised of questions regarding motor skills, social interaction and communication, personal living, and community living. The Problem Behaviors section provides a maladaptive behavior score which considers eight categories of behavior: Hurtful to Self, Hurtful to Others, Destructive to Property, Disruptive Behavior, Unusual or Repetitive Habits, Socially Offensive Behavior, Withdrawal or Inattentive Behavior, and Uncooperative Behavior. The maladaptive behavior subscale in this study was used to investigate current behavior problems by categorizing respondent's problem behavior into the SIB-R's eight maladaptive behavior classifications (see Table 1).

Experts developed the Problem Behavior Scale of the SIB-R in order to assess both adaptive behavior and maladaptive behavior. This study looks specifically at problem behavior using the maladaptive behavior section. The maladaptive behavior subscale used in this study is given without a basal or ceiling and only investigates the current behavior problems. In order to ensure the validity of SIB-R test results, several studies were performed where individuals without disabilities were matched up by age, gender, and community of residence criteria. The results of the two groups (with disabilities and without disabilities) were then compared. On the Problem Behavior subscale, persons with moderate to severe retardation and those with behavior disorders showed significantly greater quantities of problem behavior than those individuals without disabilities. Therefore, social validity is within an acceptable numerical range according to the SIB-R Scales of Independent Behavior-Revised Comprehensive Manual (Bruininks, Woodcock, Weatherman, & Hill, 1996).

Table 1

Descriptions of Problem Behaviors on the SIB-R

Category	Description
Hurtful to Self	To injure his/her own body—for example, by hitting self, banging head, scratching, cutting or puncturing, biting, rubbing skin, pulling out hair, picking on skin, biting nails, or pinching self
Hurtful to Others	Cause physical pain to other people or to animals—for example, by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object
Destructive to Property	Deliberately break, deface, or destroy things—for example, by hitting, tearing or cutting, throwing, burning, or marking or scratching things
Disruptive Behavior	Interfere with the activities of others—for example, by clinging, pestering or teasing, arguing or complaining, picking fights, laughing or crying without reason, interrupting, or yelling or screaming
Unusual or Repetitive Habits	Unusual behaviors that he/she may do over and over—for example, pacing, rocking, twirling fingers, sucking hands or objects, twitching (nervous tics), talking to self, grinding teeth, eating dirt or other objects, eating too much or too little, staring at an object or into space, or making odd faces or noises
Socially Offensive Behavior	Behave in ways that are offensive to others—for example, talking too loudly, swearing or using vulgar language, lying, standing too close or touching others too much, threatening, talking nonsense, spitting at others, picking nose, belching, expelling gas, touching genitals, or urinating in inappropriate places
Withdrawal or Inattentive Behavior	Have difficulty being around others or paying attention—for example, keeping away from other people, expressing unusual fears, showing little interest in activities, appearing sad or worried, showing little concentration on a task, sleeping too much, or talking negatively about self
Uncooperative Behavior	Behavior that is uncooperative—for example, refusing to obey, do chores, or follow rules; acting defiantly or pouting; refusing to attend school or go to work; arriving late at school or work; refusing to take turns or share; cheating; stealing; or breaking laws

Reliability statistics used in the SIB-R were calculated for their intended use across all subscales. “The calculation of reliability statistics used data from the 2,182 individuals in the SIB-R norming sample. Reliabilities for all subscales were calculated using the split-half procedure and corrected by the Spearman-Brown formula” (Bruininks et al., 1996, p. 119). Test-retest reliability of Maladaptive Behavior Indexes range between .83 and .88 (Bruininks et al.).

Research Design

This research was initiated to investigate the needs of parents in regard to designing an educational website for parents/caregivers of children with disabilities, primarily to inform and improve the BYU Family HOPE Project’s website. This research provides a starting point from which to launch the initial groundwork of this website. This study was designed as an exploratory study (Creswell, 2003; Grinnell & Unrau, 2008), requiring quantitative and qualitative responses in order to gather an initial foundation for future research. Its responses are simply descriptive. Though the survey included open-ended questions, this study is not to be confused with qualitative research. Ultimately participants’ responses to survey questions were reduced, summarized, and categorized in a very simplistic manner, much more simplistic than would be prescribed by proponents of qualitative research.

Data Analysis

Research data were collected using a web-based survey. The primary investigator read, evaluated, and analyzed the participants’ survey responses. The demographic and Likert-scale questions were analyzed quantitatively and described with descriptive statistics, including percentages, means, standard deviations and ranges. To determine relationships between demographic variables and quantitative responses, descriptive statistics of frequencies were conducted.

The open-ended questions were analyzed for specific content. Common themes related to mothers' reports of their children's behavioral difficulties were coded and summarized. More specifically, caregivers provided information about their child's challenging behaviors, where they received information, the perceived helpfulness of that information, who provided support, and the perceived helpfulness of that support. Participants' open-ended responses were reviewed and coded by the primary investigator according to recurring topics. Mothers' perceptions of their child's problem behavior were categorized into the SIB-R's eight maladaptive behavior classifications (see Table 1). For example, when participants were asked which behaviors were most challenging and persistent for them as a parent of a child with disabilities, one caregiver responded, "scratching." The response "scratching" was coded under the SIB-R category of being Hurtful to Others because this category includes behaviors such as causing physical pain to other people by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object. Open-ended responses supported or elaborated upon the quantitative data. At least 30% of the open-ended responses were independently reviewed by a research assistant trained in summarizing responses based on the SIB-R's eight maladaptive behavior classifications. In order to achieve consensus on all items, any disagreements between the two reviewers were evaluated and resolved by a third trained rater.

In addition to describing the total sample's data, data were also described for two groups, rural and urban Utah. These groups were designated by the participants' response identifying their county and hometown. Counties outside of the U.S. Census Bureau Metropolitan Statistical Area (MSA) were described as rural. Those counties included in the U.S. Census Bureau MSA were described as urban. Those counties included in the U.S. Census Bureau MSA are Salt Lake, Davis, Weber, Morgan, Summit, Tooele, Utah, Juab, Washington, and Cache counties (U.S.

Census Bureau, 2007). This information defined specific needs of caregivers based on where they lived, identifying differences in perceived needs and support in urban MSA counties versus rural counties.

RESULTS

In this section, results are presented for each research question. First, the results will be presented regarding mothers' perceptions of their child's problem behavior; second, where they access support when they are concerned about their child's behavior; third, where they get the most helpful support in solving their child's behavior problem; and lastly, results will be presented regarding mothers' perceptions of what they want a website to provide to help them solve their child's behavior problems.

Problem Behaviors

Twenty-four respondents reported that their child with disabilities had problem behaviors while two reported that they did not have problem behaviors. The first research question asks what behaviors are most challenging and persistent for parents of children with disabilities. The most ($n = 6$) reported challenging behavior was coded under the SIB-R category of Uncooperative Behavior, which includes behaviors such as refusing to obey, do chores, or follow rules; acting defiantly or pouting; refusing to attend school; or refusing to take turns or share (see Table 1). Responses from participants for the SIB-R category of uncooperative behavior included statements like “non-compliance, being defiant, disobeys, and tantrums—dropping to the floor and flailing around.” One mother responded that her son is “rigid and temper tantrums when he doesn't get what he wants.”

The second most ($n = 5$) reported challenging behavior was coded under the SIB-R category of being Hurtful to Others, which includes behaviors such as causing physical pain to other people by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object (see Table 1). Responses from participants for the SIB-R category of being hurtful to others included statements like, “hits, tackles, kicks, punches, bites, pinches, and scratches.” One

mother responded, “My child is very aggressive towards adults and children. He will threaten to bite and sometimes will actually bite if he does not get his way.”

The third most ($n = 3$) reported challenging behavior was coded under the SIB-R category of displaying Unusual or Repetitive Habits, which includes behaviors such as pacing, rocking, twirling fingers, sucking hands, talking to self, grinding teeth, eating objects, eating too much or too little, staring at an object or into space, or making odd faces or noises (see Table 1). Responses from participants for the SIB-R category of unusual or repetitive behavior included statements like, “He repeats questions over and over, even when given an answer; strange vocal sounds, *bruxism* (grinding teeth), echolalic behaviors, repetitive language, and stemming when agitated.” A communication or language limitation was also the third most reported challenging behavior. Responses from participants for communication or language limitations included statements like, “She is 2 and is only saying 2 words; poor communication, language limitations, lack of verbal skills to keep a conversation going with friends, and he has no words.”

The fourth most ($n = 2$) reported challenging behaviors were coded under the SIB-R categories of Disruptive Behavior, which includes behaviors such as interfering with the activities of others by pestering, teasing, arguing or complaining, laughing or crying without reason, interrupting, yelling or screaming and Socially Offensive Behavior, which includes behaviors such as talking too loudly, standing too close or touching others too much, talking nonsense, spitting at others, picking nose, belching, or expelling gas (see Table 1). Responses from participants for the SIB-R category of disruptive behavior included statements like, “[he] makes loud noises that scare other, physical acting out (yells, cries, growls), and he screams the minute he’s upset about something.” Responses from participants for the SIB-R category of socially offensive behavior included statements like, “The inappropriate comments are

challenging and embarrassing, especially for her brothers who have to ride her school bus; socially immature (recites movie scenes in conversation) and spiting.” One parent reported that her child makes inappropriate comments like, “Wow, you’re fat!” and invades others personal space by hugging, patting, and head rubbing her peers too much. Anger was also the fourth most reported challenging behavior.

When respondents were asked to report on any other challenging behaviors not listed, respondents reported their children had several behavioral problems: withdrawal or inattentive behavior by having a hard time focusing on any one thing at a given time, impulsivity, safety, eating, and sensory issues, physical limitations, losing abilities, poor social skills, and lack of toilet training.

Parental Support

The second research question asks parents where they get support when they are concerned about their child’s behavior. All 26 participants reported that they go the doctor for support; the second most reported places to seek support was from family ($n = 25$) and friends ($n = 25$). The third most reported avenue for seeking support was the Internet ($n = 22$). In other words, the majority of parents sought support from doctors, family and friends, and the Internet. Over half of participants reported seeking support from a support group ($n = 17$), parent center ($n = 16$), district K-12 school ($n = 15$), and district preschool ($n = 14$).

All 26 participants reported not seeking support from a charter preschool; 2 participants reported seeking support from a charter K-12 school, and only 1 participant reported seeking support from a private K-12 school. In regard to seeking support from school, logically those parents who did not enroll their children in charter schools and private schools would not have sought support from professionals employed in those settings.

Parental helpfulness. The third research question asks parents of children with disabilities where they get the most helpful support in solving their child's behavior problem. Tables 2, 3, and 4 summarize participants' responses. All 26 participants reported going to the doctor for support and 54% ($n = 14$) of them found the doctor to be helpful to very helpful. Of the 25 respondents who reported going to their family and 25 respondents who reported going to their friends for support, most ($n = 13$, 52%) found family and friends to be helpful to very helpful. Of the 22 respondents who reported using the Internet for support, most ($n = 8$, 36%) thought it was somewhat helpful. Of the 17 respondents who reported going to a support group for support, most ($n = 6$, 35%) thought it was not helpful. Of the 16 respondents who reported using a parent center for support, most ($n = 6$, 38%) thought it was only somewhat helpful. Of the 15 respondents who reported using their district K-12 school for support, most ($n = 10$, 67%) thought it was somewhat helpful to helpful. Of the 14 respondents who reported using their district preschool for support, most ($n = 9$, 64%) thought it was somewhat helpful to helpful also.

Eight respondents reported other avenues they use to obtain support. Most ($n = 6$) use therapists, including speech language pathologists, occupational therapists, and psychiatrists, and church support. Of the eight respondents who reported using other avenues to obtain support, most ($n = 6$, 75%) thought it was helpful to very helpful (see Table 2).

When respondents were given the opportunity to provide additional comments on where they obtain support and how helpful is that support, some commented that parent networking or support from parents of other children with disabilities was helpful. One respondent wrote, "Parent networking is invaluable." Two respondents commented on their school districts; one wrote, "During the school year the school district teachers and specialists are very helpful but I feel like they mostly deal with the behaviors they see at school and don't really help with

behaviors that happen during the summer or *after hours*.” One respondent commented on how she has no support group to turn to in her community.

Website helpfulness. The final research question asked what parents of children with disabilities want a website to provide to help them solve their child’s behavior problems. Respondents indicated what they want on a website to help them solve their child’s behavior problems on a scale of 1 (most preferred) to 5 (least preferred). Of the 22 respondents who ranked in the top five wanting “modules or lessons to teach how to solve behavior problems,” most ($n = 11$, 50%) rated this as being a preferred item on a website. Of the 20 respondents who ranked in the top five wanting “video demonstrations of parents successfully solving children’s behavior problems,” most ($n = 12$, 60%) also rated this as being a preferred item on a website. Of the 19 respondents who ranked in the top five wanting “information about how to solve behavior problems,” the same number of respondents rated it as being a preferred item on a website as respondents who rated it as not preferred on a website ($n = 7$, 37%). Also, of the 19 respondents who ranked in the top five wanting “blog/posts where parents can post questions and professionals and/or parents who have dealt with similar problems can post answers,” most ($n = 8$, 42%) preferred to have access to a blog/post on a website. Of the 13 respondents who ranked in the top five wanting “research summaries of strategies for solving behavior problems,” most ($n = 6$, 46.1%) rated it as their least preferred. Of the 12 respondents who ranked in the top five wanting “contacts with other parents and/or professionals through email,” most ($n = 4$, 33%) rated it as their least preferred.

When respondents were asked for the names or links of websites they have found to be helpful in solving their child’s behavior problems, most reported on autism and other various websites. Some respondents knew the websites well enough to respond with the actual website

address. Only two respondents reported on website usage specifically related to behavior. One respondent wrote, “I was on a support group website which didn’t really help solve my child’s problems, but gave me some strength to keep going. I haven’t ever seen a problem-solving site.” Another respondent wrote, “I would love to have some [links of websites]. I don’t use the Internet much because it seems like the information I have found is often contradictory or there is just ‘too much’ to deal with.” When respondents were asked what was most helpful in these websites, most reported that written examples or specific applications of what they are searching for and parent, local, and/or national resources.

Table 2

Support for Parents of Children with Disabilities: Who Provides Support and How Helpful is that Support?

Source of Support	Total Responses		Not Helpful		Somewhat Helpful		Helpful		Very Helpful	
	<i>N</i>	% ^a	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Doctor	26	100	5	19	7	26	9	34	5	19
Family	25	96	3	12	9	36	5	20	8	32
Friends	25	96	2	8	10	40	9	36	4	16
Internet	22	84	3	13	8	36	6	27	5	22
Support Group	17	65	6	35	3	17	4	23	4	23
Parent Center	16	61	3	18	6	37	4	25	3	18
District School K-12	15	57	2	13	5	33	5	33	3	20
District Preschool	14	53	2	14	5	35	4	28	3	21
Birth-to-3 Provider	11	42	0	0	3	27	3	27	5	45
Other (list)	8	30	0	0	2	25	3	37	3	37
Private Preschool	5	19	0	0	2	40	1	20	2	40
Charter School K-12	2	7	0	0	1	50	1	50	0	0
Private School K-12	1	3	0	0	0	0	0	0	1	100
Charter Preschool	0	0	0	0	0	0	0	0	0	0

^a Percents listed in the Total Responses column are based on the total *N*, 26.

Percents listed in other columns are based on the number of participants responding, not to the total number of participants (26).

Table 3

Descriptive Statistics Summarizing Parents' Perceptions of Non School-Based Support

Source of Support	n^a	Mean ^b	SD
Doctor	26	2.54	1.03
Family	25	2.72	1.06
Friends	25	2.60	0.87
Internet	22	2.59	1.01
Support Group	17	2.35	1.22
Parent Center	16	2.44	1.03

^a $N = 26$.^bMean is based on scores ranging from 1 (*Not Helpful*) to 4 (*Very Helpful*).

Table 4

Descriptive Statistics Summarizing Parents' Perceptions of School-Based Support

Source of Support	n^a	M^b	SD
District School K-12	15	2.60	0.99
District Preschool	14	2.57	1.02
Birth-to-3 Provider	11	3.18	0.87
Other (list)	8	3.12	0.83
Private Preschool	5	3.00	1.00
Charter School K-12	2	2.50	0.71
Private School K-12	1	4.00	.00
Charter Preschool	0	NA	NA

^a $N = 26$.^bMean is based on scores ranging from 1 (*Not Helpful*) to 4 (*Very Helpful*).

DISCUSSION

The purpose of this study was to gain insight from parents of children with disabilities regarding what they find helpful in solving their child's challenging behaviors. Specifically, this research was initiated to investigate the needs of parents in regard to designing an educational website for parents/caregivers of children with disabilities. In regard to parents' preferences for website information on managing their children's behavior problems, results from this study indicated that most parents preferred modules or lessons related directly to teaching behavior management strategies, video demonstrations of parents successfully solving children's behavior problems, information on solving behavior problems, and blog/posts with parents posting questions and experienced professionals and/or parents who have dealt with similar problems posting answers. This study may provide incentive for practitioners, educators, and the human services field to design and make available training modules or video demonstrations for parents dealing with their children's problem behaviors at home. Due to the rise of computer networking via the Internet and advances in multimedia technology, there is now an opportunity open to provide services to families with limited access to traditional services (Feil et al., 2008).

Reflections on Parental Perceptions of Supports

Website. Results from this study also indicated what this group of parents ranked lowest or did not rank at all for what they would like to see on a website in helping them solve their child's problem behavior. Participants indicated what they want on a website on a scale of 1 (most preferred) to 5 (least preferred). Specifically, the same number of participants rated that information about how to solve behavior problems as a preferred item on a website as participants who rated it as not preferred on a website ($n = 7, 37\%$). In addition, research summaries of strategies for solving behavior problems was rated as participants least preferred,

and having contact with other parents and/or professionals through email was also rated as participants least preferred (range 1 – 5; $n = 5$). This suggests that this group of parents have little interest in looking for written summaries about research-based information relating to solving behavior problems. It has been suggested that the ability to review scientific literature critically, to identify major research flaws, and to interpret correctly the clinical implications of research findings, are skills acquired through training” (Ayonrinde, 1998, p. 449), rather than through gleaning information from the Internet. Consumers of information from the Internet may misjudge information, be inundated with so much information, they become overloaded, easily confused, and misinformed. Without consumers possessing the skills to discern and review scientific literature critically, consumers: “1. Fail to recognize that key information is missing, 2. Fail to distinguish between biased and unbiased information, 3. Fail to distinguish between evidence-based and non-evidence based claims, and 4. Misunderstand health information intended for health professionals” (Cline & Haynes, 2001, p. 680).

When respondents were asked for the names or links of websites they have found to be helpful in solving their child’s behavior problems, most reported on Autism websites due to the large number of children with Autism in this study.

Other types of materials. When participants were asked where they go to get the most helpful support in solving their child’s behavior problem, a majority of respondents reported that they go to the doctor, family, friends, and the Internet for support and most found these avenues to be helpful in providing that support. Similar to related research conducted in the past, this study provides further evidence of the importance of parents and professionals working as a team in creating and implementing behavior support plans for the family. When professionals recognize, accept, and value the importance of the family in offering behavioral supports to

children with disabilities, they are more likely to work with families as partners and colleagues. In so doing, professionals and parents are more likely to participate in a reciprocal process of listening and learning about ways to best educate and support children with disabilities and problem behaviors (Lucyshyn et al., 2002).

When respondents were given the opportunity to provide additional comments on where they obtain support and how helpful is that support, eight participants reported other avenues they use to obtain support. Most ($n = 6$) reported using therapists, including speech language pathologists, occupational therapists, and psychiatrists, and church support. Of the eight respondents who reported using other avenues to obtain support, most ($n = 6, 75\%$) thought it was helpful to very helpful (see Table 2). Most respondents reported they seek support from family and friends, and most found family and friends to be helpful to very helpful. Similar to related research conducted in the past, this study provides further evidence of the importance of the family to the development, education, and behavioral support of a child with a disability (Erwin, 1996). Throughout the life of a child with a disability the family is the primary source of continuity, and is the most powerful influence on a child's development (Dunlap & Fox, 1996).

A large number of respondents also reported seeking support from the Internet and most found it to be somewhat helpful. This provides further evidence that parents access online medical health information by searching directly on web pages, participating in support groups and consulting with health professionals (Cline & Haynes, 2001). One respondent wrote that she does not use the Internet that often because the information she has found is often contradictory or there is too much information to sift through. This statement illustrates that "because the Internet is unregulated, accuracy, currency and bias vary; inaccurate information is disseminated widely" (Cline & Haynes, p. 679).

If families had the tools to solve problems of child behavior in a family context, then they may begin to overcome a myriad of care giving challenges; and in so doing, build a life with their child that is characterized by less stress, increased satisfaction, and greater success (Dyson, 1997; Floyd & Gallagher, 1997; Lucyshyn et al., 2002; Lustig & Akey, 1999).

The parental attitudes encountered in this study support other studies that explore the complexity of expectations concerning stress and coping. Isolation is a major factor for emotional distress and anxiety among parents of children with disabilities (Lainhart, 1999). Research demonstrates that the Internet is a new influential channel of communication that allows people in emotional distress to establish ties among themselves and remove them from isolation. Various parents of children with disabilities have praised the Internet as a tool that enables them to collect information, thereby enhancing their self-efficacy and assisting them in breaking out of the social isolation that parents of children with disabilities often face (Fleishmann, 2005).

One respondent commented that “parent networking is invaluable.” Studies have found that social support is important in preventing depression and stress (Fleishmann, 2005). The Internet is an avenue in which parents can create virtual support groups that enable them to free themselves from their isolation and actively combat lack of self-efficacy feelings, depression and stress that isolation can bring.

Limitations

There are several aspects of this study that may limit the ability of the data to accurately represent the population of parents of children with disabilities who have challenging behavior problems. First, the size of the sample group was not large enough to provide generalized results; therefore future studies should increase the number of respondents. Also, respondents were all

female, primarily Caucasian, and most had completed some college. Additionally, all of the respondent's children but one had some form of an intellectual disability or Autism. Finally, the instrument used to categorize problem behavior may not be sensitive enough for this particular study.

This research employed the use of a web-based survey. Web-based surveys are increasing and are not confined to higher education; the American Psychological Association has been associated with the implementation of more than 120 online research studies (Zimitat & Crebert, 2002). The major appeal of online surveys is the significant decrease in the time and cost of conducting the survey (Hmieleski, 2000). However, through the implementation of a web-based survey, coverage and sampling errors arise because the surveyed sample will most likely not represent the broader population. The sampled population that was targeted was parents of children with disabilities where level of access to a computer, web familiarity, Internet access, and a higher level of computer literacy are known.

The conclusions from this study are limited to the small, homogeneous sample collected for this study. Gender, socioeconomic status, ethnic and some cultural variables were considered, however, the relationships between the participant's responses and their demographic information were not investigated and warrant further investigation.

In future studies researchers may want to ask how frequently the participants use the avenue they chose for seeking out support. Researchers may also want to address why participants found their avenue of support to be most helpful. Is it because the avenue of support is more knowledgeable, reliable, or is other factors involved in parents' decisions regarding seeking support?

Implications for Research and Practice

Given that this study consisted of primarily female Caucasian participants, future studies could investigate what parents of children with disabilities want a website to provide to help them solve their child's behavior problems among non-Caucasian populations. Specifically, it could look at what parents of different cultural groups want a website to provide to help them solve their child's behavior problems. Future research could also investigate what fathers and/or male caregivers of children with disabilities want a website to provide to help them solve their child's behavior problem. To accomplish this, future Internet surveys could solicit specific ethnic, gender and/or cultural groups (e.g., African Americans, Latin Americans) through culture and/or gender-specific websites and/or even create culture and/or specific websites to unite these populations.

The research from this study may have several implications for practitioners, educators, and the human services field in general. Because parents in this study perceived physicians to be supportive and helpful, parents of children with disabilities may find it easier to manage problem behaviors simply because they have access to a doctor they can ask questions or talk to. When given the opportunity to give any additional feedback, several respondents stated that having a professional available would be helpful. One respondent wrote, "Sometimes I just wish a professional could come in my home for a day, observe interactions and behavior, and then teach skills." Another respondent wrote, "Classes are helpful especially if respite care is available, so online classes would be great since sometimes you can't find respite (actually respite is really HARD to find)." Technology and specifically the Internet can make these interactions more accessible.

Since parents in this study perceived schools to only be somewhat helpful to helpful, school professionals need to enhance their relationship of support with parents of children with disabilities. Parents of children with disabilities may find it easier to manage problem behaviors simply because of the attention they feel from school professionals regardless of the level of support and instruction they receive. School professionals often have many responsibilities and work with many families with various needs. Something as simple as taking time to listen and understand the parent's story may be a good investment in enhancing their perceived level of support from the school. It is possible that this may be all they need to feel as though someone knows and cares about their child and family, and now they feel more empowered to manage their child successfully because they know someone understands them. Research has suggested that support (e.g., family, community, or professional) is one of the factors contributing to minimize a crisis situation (McCubbin & Patterson, 1983). Professionals can help families decrease their stress and increase their quality of life by providing support, resources and expertise, and allowing the locus of control to lie within the family (Bennett & DeLuca, 1996).

Again, the human services field has been slower to adopt technology in important areas, such as behavioral assessment, prevention/intervention work with families, and disseminating evidence-based practices (Self-Brown & Whitaker, 2008). Despite the hesitance, "it is clear that people are becoming more and more dependent on technology in their everyday lives, especially for interpersonal interactions and knowledge seeking" (Self-Brown & Whitaker, p. 319). The human services field must be open to exploring how technology can enhance their clinical work. It is critical that empirically supported interventions be adapted for a nontraditional delivery system, such as the Internet.

Research shows that a model of good practice for disseminating user-friendly information shows that written information is not enough by itself (Mitchell & Sloper, 2000). When providing an information-giving service, parents emphasized the role of having a personal information advisor, ideally, a designated person that the parents know how and where to contact. Many families reported this was reassuring. In Mitchell and Sloper's research, parents emphasized that written and audio-visual information must be viewed in conjunction with a personal information advisor.

Parents also commented on the importance of providing information on different level and using a range of media to disseminate information. The information must be eye-catching and interesting, referencing made easy through well presented and referenced guides, and information whether spoken or written should be clear 'jargon-free' information. One parent in this study called it 'highfaluting' language. Parents felt this information to be both confusing and potentially isolating. Similarly, how information was presented was also perceived as important. Parents looked for an informal and reassuring tone, that is, "one which made them feel more comfortable and confident about seeking support, sending out the message 'that it is okay to ask for help'" (Mitchell & Sloper, 2000, p. 26).

Research by Feil et al. (2008) shows that when delivering services through a technology medium, attention must be paid to the message being delivered; transferring to Internet delivery must only be made when the effectiveness of the program in its original format has been demonstrated. Also, scaffolding may need to be provided via immediate feedback on use of the webpage or program through contact with a designated individual that can provide this assistance (Feil et al.).

Conclusion

The impetus for conducting this study was to gain insight and feedback to inform the BYU Family Hope Project's website. This research provides a starting point from which to launch the initial groundwork of this website. Results from this study indicated that parents want modules or lessons to teach how to solve behavior problems, video demonstrations of parents successfully solving children's behavior problems, and blog/posts where parents can post questions and professionals and/or parents who have dealt with similar problems can post answers. Website designers must use the information gathered from this study with caution as this research is preliminary.

It is possible that results may not reliably be generalized to most families, as further research is needed regarding what information parents of children with disabilities and problem behaviors would find useful on a website. Practitioners and researchers are encouraged to use the information gathered from this study to improve research and practice in the area of positive behavior support and technology for families with children with a disability.

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APPENDIX A

Participation and Consent to be a Research Subject

Background

This research study is being conducted by Heather Collins, a graduate student at Brigham Young University, to gain insight from parents of children with disabilities regarding what they would find helpful in solving their child's challenging behaviors. More specifically, this study will investigate what information parents of children with disabilities and problem behaviors would find useful on a website. You were asked to participate because you are a parent or caregiver of a child with disabilities.

The Brigham Young University's Family HOPE (Happiness, Optimism, Promise, and Excellence) Project is a program that works with families that have children with disabilities to help increase the family's quality of life through training the parents in a positive behavior support program in order to change problem behaviors. Results from this study will provide a foundation for understanding how this program can help families increase quality of life through providing support and information through a website for families who cannot be served through the project.

Study Procedure

After consenting to participate, you will be lead to a questionnaire which will take approximately 30 minutes to complete. Questions will include details about your demographics, your personal views concerning the nature of your child's challenging behavior, including when you were first concerned with your child's behavior, and where you obtained information and whether that information was helpful. Lastly, you will be asked what you would like to find on a website that would help you solve your child's behavior problems.

Risks/Discomforts

There are few risks associated with the study. Sometimes when family members answer questions regarding various aspects of family life, unpleasant memories or frustrations may be recalled.

Benefits

There are no direct benefits to subjects. However, it is hoped that through your participation researchers will learn more about what parents of children with disabilities would find helpful in solving their child's challenging behaviors. More specifically, to assist the Family HOPE Project in providing a foundation for understanding how this program can help families increase quality of life through providing support and information through a website for families raising children with disabilities.

Confidentiality

All information provided will remain confidential and will only be reported as group data with no identifying information. All data reported on the questionnaire will be kept in a locked storage cabinet and only those directly involved with the research will have access to them. After the research is completed, individual questionnaire data will be destroyed.

Compensation

Ten randomly selected participants who provide home addresses will receive a popular children's book featuring characters with disabilities.

Voluntary Participation

Participation in this research study is voluntary without penalty or loss of benefits. Also, participation will not affect your participation with the Utah Parent Center. You have the right to withdraw at anytime or refuse to participate entirely without consequence.

Questions about the Research

If you have questions regarding this study, you may contact the primary investigator, Heather Collins at (307) 370-0172, heathercpsc@hotmail.com. or the thesis chair, Dr. Tina T. Dyches, EdD at (801) 422-5045.

Questions about your Rights as Research Participants

If you have questions you do not feel comfortable asking the researcher, you may contact Christopher Dromey, PhD, IRB Chair, 422-6461, 133 TLRB, Brigham Young University, Provo, UT 84602, Christopher_Dromey@byu.edu.

1. You must agree to the below statement in order to take this survey.

I have read and understood the above consent and desire of my own free will to participate in this study. I am at least 18 years old.

APPENDIX B

SURVEY

Parent Perceptions of Website Helpfulness for Solving Behavior Problems of Children with Disabilities

Please answer the questions as thoroughly as you can. Thank you for your participation! If you have more than one child with a disability, please complete a separate questionnaire for each child. You will need to log out and log in again to complete each questionnaire.

Today's Date: _____

Survey Questions

1. Please list the behaviors your child exhibits which impede his/her social, emotional, educational, physical, or intellectual development.
2. Which of these behaviors is the most persistent or challenging for your family to deal with?
3. When you became aware of your child's disability, which challenging behavior was your first concern?
4. When you are concerned about your child's behavior, where do you obtain support? How helpful is this support?

		Not Helpful	Somewhat Helpful	Very Helpful	Very Helpful	Comments
Family	Yes or No	N/A 1	2	3	4	
Friends	Yes or No	N/A 1	2	3	4	
Doctor	Yes or No	N/A 1	2	3	4	
Birth-to-3 Provider	Yes or No	N/A 1	2	3	4	
District Preschool	Yes or No	N/A 1	2	3	4	
Charter Preschool	Yes or No	N/A 1	2	3	4	
Private Preschool	Yes or No	N/A 1	2	3	4	
District School K-12	Yes or No	N/A 1	2	3	4	
Charter School K-12	Yes or No	N/A 1	2	3	4	
Private School K-12	Yes or No	N/A 1	2	3	4	
Support Group	Yes or No	N/A 1	2	3	4	
Parent Center	Yes or No	N/A 1	2	3	4	
Internet	Yes or No	N/A 1	2	3	4	
Other (list) _____	Yes or No	N/A 1	2	3	4	

5. What are the names or links of the websites you have found to be helpful in solving your child's behavior problems?
6. What is included on these websites that makes them helpful?
7. What would you like to find on a website that would help you solve your child's behavior problems? (Please rank your top five in order from 1 being most preferred to 5 being least preferred.)

Information about how to solve behavior problems

Modules or lessons to teach how to solve behavior problems

Research summaries of strategies for solving behavior problems

Video demonstrations of parents successfully solving children's behavior problems

Blog/posts where parents can post questions and professionals and/or parents who have dealt with similar problems can post answers

Podcasts of parents and/or professionals who have successfully solved specific behavior problems

Video chats with professionals and/or parents

Text-based chats with professionals and/or parents

Contacts with other parents and/or professionals through email

Calendar with locally listed events, conferences and activities

Other (list) _____

8. Other feedback:

Demographic Questions

Information about adult caregiver of child with disability:

1. Are you the Mother? _____ Father? _____ Male Caregiver: _____ Female Caregiver: _____

2. Your Age: _____

3. Your ethnicity:

A. White; B. Black or African-American; C. Asian; D. American Indian and Alaska Native;

E. Native Hawaiian and Other Pacific Islander; F. Hispanic or Latino; G. Other race

4. Where do you live? (Please include city, county, and state.)

City

County

State

5. What is your level of completed education?

- Did not graduate from high school
- Graduated high school
- Some college
- Bachelor's degree
- Graduate degree
- Other (please specify) _____

6. What is your current employment status?

- Unemployed
- Student, not working
- Student, working part-time
- Student, working full-time
- Part-time employment
- Full-time employment
- Other (please specify) _____

7. Type of employment:

- Business and Financial
- Computer and Mathematical
- Architecture and Engineering
- Life, Physical and Social Sciences
- Healthcare
- Legal
- Community and Social Service
- Education and Library
- Art, Design, Entertainment, Media and Sports
- Sales
- Office and Administrative
- Protective Occupations and Military
- Food Preparation and Serving
- Maintenance, Construction, Installation and Repair
- Farming, Fishing and Forestry
- Production Occupations
- Transportation

Information about your child with a disability:

1. Child's diagnosis?

Primary medical diagnosis: _____

Primary school disability (found on your child's IEP): _____

Autism

Deaf/Blindness
Developmental Delay
Emotional Disturbance
Hearing Impairment/Deafness
Intellectual Disability
Multiple Disabilities
Orthopedic Impairment
Other Health Impairment
Specific Learning Disabilities
Speech/Language Impairment
Traumatic Brain Injury
Visual Impairment (Including Blindness)

2. Child's age at time of diagnosis? _____

3. How old is your child now? _____

Computer information:

1. How many computers are in your home?

0 1 2 3 4 or more

2. Do you have high-speed Internet?

yes no