THEORIZING INFORMATION AND COMMUNICATION TECHNOLOGIES FOR
PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

A Thesis in
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by

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ABSTRACT

Studying the challenges faced by families with children who have developmental disabilities has produced a considerable body of literature. Much of this literature focuses on the families’ needs for information and social support. Recent studies in the social sciences have explored how parents of disabled children use the Internet to fulfill those needs, research which has led to an opportunity for HCI researchers to address this unique domain of users and propose designs for them. This thesis explores an understanding of their needs to better inform the design of tools that are tailored for this group. A scenarios and claims analysis examines strategies for successful design and implementation of such tools. This analysis generates a design framework for online information and communication portals designed for parents of children with special needs. This framework is used to analyze the strengths and weaknesses of three existing web sites and produce recommendations for their improvement.
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For my family.
Chapter 1

The Unique Experience of Families of Disabled Children

Research has consistently demonstrated that families of children with developmental disabilities have a profound need for information and support. Information about education, government, caretaking, and medical resources is difficult to obtain. The caregiving responsibilities inherent to their family circumstances take a significant emotional toll, and, despite usually needing more support than parents of typically developing children, they often cannot rely on traditional support channels (such as extended family and friends) for help. They are chronically overwhelmed with daily challenges that do not abate. Because developmental disabilities are relatively low incidence, families are often geographically dispersed, especially in rural areas. Internet access has afforded new opportunities for information gathering to many of these parents. Online support groups can connect parents with other families whose children are affected by developmental disabilities. Professionals such as doctors, nurses, behavioral specialists, and educators can use the Internet as a means of disseminating information and communicating with families. This paper explores the experience of raising a developmentally disabled child, the information and support needs of parents, and the ways information and communication technologies can meet those needs. This exploration is followed by a scenarios and claims analysis that can advise the work of human-computer interaction (HCI) researchers and software development specialists who seek to create informative online communities for these parents, and a call for additional design research in this specific domain to better understand and accommodate their unique needs.
Terminology and Scope

Terminology changes rather rapidly and can vary by geographic area. In determining what is meant by “developmental disability,” this paper will refer to the scope defined by the Centers for Disease Control and Prevention (CDC). The CDC’s website lists several traits that characterize a developmental disability: it is a severe, chronic condition; it involves mental and/or physical impairments; it entails difficulties with activities such as language, mobility, learning, self-help, and independent living; it can manifest itself any time during development up until age 22; and it usually lasts a lifetime. The CDC website includes several examples of developmental disabilities, many of which were included in studies reviewed herein: autism spectrum disorder, cerebral palsy, hearing loss, mental retardation, and vision impairment (http://www.cdc.gov/ncbddd/dd/). Obviously, this definition allows for a great range of ability levels, challenges, prognoses, and treatment options. For the sake of simplicity, the term “disability” will sometimes be used throughout this review to refer to a developmental disability; the common term “special needs” will also be used.

Although the scope of developmental disabilities is considerable, families affected by them face similar struggles. Their personal experiences share much in common, and the complex array of government services administered through education, respite care, therapy, and medical insurance has classified them together for many years.

The Family Experience

It is important to recognize that parents of children with disabilities cannot be easily classified as “caregivers,” interchangeable with parents of children with serious illnesses. Although the two are similar in some respects, and some design ideas for one may be successfully
adapted for the other, a holistic consideration of the former’s circumstances and daily life experiences suggests that they would be better served if classified by HCI developers as a unique group. Lamb and Kling (2003) envisioned the reconceptualized notion of the “user” as a “social actor,” a construct which allows information specialists to define the people who utilize their developments not simply as IT users, but as people interacting in multiple social dimensions. These people are not primarily just users of ICT applications, but they do employ ICTs in a variety of contexts and roles during the course of their day for multiple purposes. Considering parents of children with disabilities as social actors within a complex social environment illustrates their unique needs.

**Challenges**

Although there are a range of challenges encountered among children with developmental disabilities and a variety of difficulties posed to their parents, their families have many experiences in common regardless of which disability the child may have. These similarities begin with the challenges parents face immediately after their child is diagnosed with that disability, which can occur before, immediately after, or up to several years after birth. One study found that parents generally go through a tripartite progression of emotions following their child’s diagnosis: first shock, denial, suffering and depression; then guilt, indecision, anger, and shame; and finally, acceptance and adaptation (Sen & Yurtsever, 2007). Kerr and McIntosh (2006) found that a diagnosis of a physical impairment was generally followed by feelings of isolation, concern about the future, and avoidance of others by the parents. Another study examined themes among the thinking of parents with newly diagnosed children, and found that parents went through phases of creating “future images” (adjusting their mental projections of how their child would progress), establishing possible actions, perceiving the child and not the
disability, communicating with health professionals, and implicitly expecting services from the health care system. This study’s researchers also found that parents’ experiences and coping were heavily influenced by the certainty of the diagnosis – uncertain diagnoses made their situations much worse (Graungaard & Skov, 2006). This relates to Osborne’s and Reed’s (2008) finding that the one positive feeling reported among parents after diagnosis was relief.

Frequently, parents suspect that their child has a disability, and the confirmation of their worries marks the end of wondering and the beginning of coping. Of course, for many parents, the preceding suspicion still does not mitigate the suffering they experience upon the initial discovery that their child definitively does have a disability.

Another common experience among parents of children with various developmental disabilities who have just been formally diagnosed is a perceived lack of support. Parents in one study of a physical disability that is apparent from birth reported that emotional support from midwives was lacking, information from doctors was inadequate, and that they personally experienced feelings of abandonment (Kerr & McIntosh, 2006). Osborne and Reed (2008) found that a high proportion of responses from their study’s participants reflected a perception that they had been given no help, support, or advice following the diagnosis of their child.

The coping process that parents (particularly mothers) undergo does not end soon after the diagnosis. Sen and Yurtsever (2007) conducted a study of children whose age ranged from 3 to 17 and found that 57.3% of their mothers experienced deep sadness, 54.4% were overwhelmed, and 36.9% felt anger. 35% of those same mothers reported that internal family relationships were affected because of their child’s disability. Mothers expressed a desire for counseling, home care, and psychological support, although their specific needs varied by disability.

One critical factor common among families of disabled children is the persistent, long-term nature of their daily challenges. The caretaking of children with developmental disabilities can be an imposing and intimidating task. Sen and Yurtsever (2007) found that families reported
difficulties in caring for their children. These challenges varied by disability. Children with physical impairments needed help eating, dressing and undressing, using the bathroom, and bathing. Children of parents with cognitive disabilities had difficulty communicating and required constant monitoring.

Social Capital Challenges

Social capital refers to how our lives are enriched and our productivity increased by social ties (Putnam, 2000). Parents (especially mothers) of children with developmental disabilities tend to experience social isolation, which limits their ability to acquire social capital. Sen and Yurtsever (2007) found that, within their sample, 76.7% of mothers experienced changes in their social life because of their child. Chenoweth and Stehlik (2004) reported that families of children with disabilities were socially isolated from extended family and other contacts. They also did not feel part of or welcomed by the local community. The authors noted that outsiders did not perceive that these family members were making voluntary contributions to the community. However, this was not the case: they joined advocacy groups and committees, and they spent a significant amount of time and energy in unpaid caring efforts. Although these contributions were substantial, they were generally not visible, and therefore not valued by others. Partington (2005) looked at how families of children with disabilities had trouble building social capital. They were typically unable to participate much in the community because they were focused on the tasks of day-to-day “survival” and had no extra energy or resources to build social capital. Others perceived it unlikely that special needs parents would be able to reciprocate support to families unaffected by disability. A sense of trust, another important component of social capital, was generally limited to immediate family and paid professionals. The atypical traits of disabled persons alienated them and challenged powerful social norms. Even the concept
of “inclusion,” which incorporates children with disabilities into “typical” settings such as regular classrooms, was implemented in a way that was not helpful – instead of a natural social process, it was seen as an outcome to be achieved through government-mandated policy.

Grant (2007) extended the idea of invisible contributions and explored why the actions of families affected by disability are not obvious to the outside world. He found that for many families, caregiving was intentionally concealed from the disabled person to maintain his or her sense of autonomy and dignity. Therefore, the monumental efforts that parents took to take care of their child’s physical and emotional needs were invisible and unapparent to people outside their homes.

The Task at Hand

Having a child with a developmental disability poses a unique challenge to parents. They are confronted with the constant realization that their child will never function “typically,” and will probably need monitoring and care throughout life. Meanwhile, daily life is difficult; children with disabilities generally require care and intervention far beyond that of a typical child. To compound matters, social capital tends to be a scarce commodity among these parents, which isolates them from social contacts and outlets that could provide much-needed relief. Unlike children who have considerable health problems but otherwise function typically, many children with developmental disabilities exhibit behaviors that are considered socially unacceptable and strange. Although exceptions do exist, prior research has demonstrated that parents in this situation face extraordinary daily challenges and fears without much support from the outside world. This holistic view of the experience of parents with developmentally disabled children illustrates their unique classification as social actors and their status as a unique group of users yet to be addressed by HCI researchers.
Given the currently unaddressed need for HCI research specific to this domain, this paper seeks to motivate a discussion in the HCI community about design possibilities for parents of disabled children. First, I will explore the support, information, and social needs of this particular population, and the ways that they typically try to address those needs. Next, I will report on how information and communication technologies are currently being used by these parents. I will follow that discussion with a section devoted to a scenario and claims analysis specific to the needs and circumstances of the population in question. Finally, I will apply the resulting framework generated by this design rationale analysis to three existing web sites, determining where this analysis has impact and suggesting the practical developments that may be undertaken to improve the designs of those sites.
Chapter 2

Information and Social Needs

Professional Services: A Complex Web

It is evident that the caregiving responsibilities inherent to raising a developmentally disabled child are both unusual and, commonly, much more demanding than the responsibilities of raising a typical child. Many families turn to public or private agencies for support in handling caretaking needs, and most rely on special education programs to educate their children.

Home and Community Based Care

Historically, public funding for the caretaking of individuals with disabilities was largely institutional, sometimes referred to as ICF/MR (immediate care facilities for the mentally retarded). However, the Omnibus Budget Reconciliation Act of 1981 authorized HCBS (home and community based services), which allows for home and community based support to be provided in lieu of ICF/MR institutional care. The HCBS services may include respite care and family support, case management, supported living, behavior management, and therapies (Braddock, 2007). HCBS has grown quickly, and the Deficit Reduction Act of 2005 authorized states to expand the program (Turnbull, Stowe, Agosta, Turnbull, Schrandt & Muller, 2007). HCBS funding is often called a “waiver option” because each family’s income and assets are “waived” in an effort to provide equal access among all income levels. Eligibility is instead determined by the severity of the child’s disability (i.e., the severity must be at or above a certain threshold for the child to qualify). The high demand for HCBS services has created long waiting
lists in many states, each of which has the authority to prioritize families as it sees fit. Prioritization mechanisms may be first-come-first-serve, urgency of need, time-limited supports, or a lottery system (Johnson et al, 2006). Upon gaining a funded slot, each child is assigned a case-manager who works collaboratively with the families and providers. Usually, gaining a slot also entitles the child to Medicaid eligibility (Johnson, Walker, Palomo-Gonzales, & Curry, 2006).

Abbott, Watson, and Townsley (2005) looked at a multi-agency support system that specialized in home and community based care. They found that 16 of the 25 participating families felt their quality of life had improved since the agencies had begun supporting their caretaking needs. However, only 6 of those 25 families felt that their “keyworker,” the individual who coordinates those agencies’ services, was effective at doing so. Another study reported that families wanted a stronger link between supporting agencies (Osborne and Reed, 2008); for example, the diagnosis of autism occurs in a medical context, but almost all subsequent help is administered educationally. In an exploratory study of common features among successful support service models, Sloper (1998) found they shared a recognition of the importance of the parent-professional relationship, a focus on parents’ concerns, a philosophy of empowering parents, and a recognition of parents’ expertise.

**Education**

In addition to handling the daily stresses of caretaking, parents must attend to the schooling of their special needs child. In the United States, special education falls under the purview of the federal Individuals with Disabilities Education Act (IDEA), which was originally passed in 1975 (as The Education for All Handicapped Children Act) and reauthorized in 2004. IDEA provides federal funds to assist states and localities in the education of children with
disabilities, provided that all children with disabilities are provided a Free Appropriate Public
Education (FAPE) based upon the requirements determined in each qualifying child’s
Individualized Education Program (IEP) or Individualized Family Services Program (IFSP). By
law, parents have the right (and responsibility) to participate in every decision related to the
identification, evaluation, and placement of their disabled child, and are intended to play a major
role in the development of the IEP or IFSP (Horne, 1996; Silverstein, 2005). Whitaker (2007)
found that parental satisfaction with schooling depended primarily on two critical factors:
information flow and staff understanding. This study found that 80% of satisfied families felt the
schools kept them well-informed about progress and problems, but less than 33% of dissatisfied
families felt this way. Over 66% of satisfied parents agreed that school staff members understood
their child, whereas almost 75% of dissatisfied parents did not.

Professional Information Support

The information families need from professionals changes throughout the years. Obsorne
and Reed (2008) reported that parents of young children wanted information about early
intervention. They also wanted professionals to give them information about support groups.
Older children’s parents needed support from schools and teachers. The parents of older children
in this study felt they received no professional help and support, and wished they had more
information from professionals. Scorgie and Wilgosh (2008) found that parents of children who
were transitioning to adulthood needed information about adult placement and access. They
learned that, from the parents’ point of view, professionals were initially important for
collaboration, and then later to secure ongoing services. The constant need for services and the
drain on parents’ emotions and energy takes a financial toll on families, as several studies
reported that families of children with disabilities were likely to experience financial hardship (Chenoweth & Stehlik, 2004; Abbott et al., 2005; Sen & Yurstever, 2007).

**Information Needs and Information Seeking**

The complex array of services (and their requirements) available to families of children with special needs prompts a significant need for information. Pain (1999) found that such families use information for several specific purposes. Information was used by parents to enhance the management of their child, help the parents cope emotionally, and help the parents to access benefits and services for their child, and it also contributed to the acceptance process. Schaffer, Kuczynski, and Skinner (2008) learned that most mothers felt it was their responsibility to be well-informed. They felt that the inherent power dynamics in the doctor-patient relationships made their own scientific literacy necessary.

Parents’ information needs evolve as their child gets older. Immediately following the diagnosis, parents are looking for a “cure,” but as the years go on they desire information on how to “navigate the system” of education, health, and caretaking support resources (Scorgie & Wilgosh, 2008). Likewise, parents’ perspective on how much and when information should be administered tends to change over time. Osborne and Reed (2008) found that parents of younger children wanted all information pertaining to services throughout their child’s life to be given to them at the time of diagnosis, whereas parents of older children wanted information to be phased over time, given when it was needed. This likely reflects the realizations of parents of older children that they could not have handled knowing all they would need to know at the time of diagnosis, and could not have known what their child’s exact prognosis would be. Additionally, over time conditions evolve and information is updated, making older information no longer
relevant. However, it is easy to understand how parents of younger children would be frightened by the uncertainties ahead and would want to know “everything.”

The existence of information needs precedes the activity of information seeking. According to Wilson (2000), information seeking behavior is “the purposive seeking for information as a consequence of a need to satisfy some goal.” Within the context of this paper, parents must seek information with the goal of understanding how to effectively care for their child. Dervin’s Sense-Making approach (1983) describes this sphere in terms of a situation (the context of the information need, or problem), a gap between the current situation and the desired situation, an outcome, and a bridge linking the situation and outcome (closing the gap). In terms of the Sense-Making model, parents of children with disabilities often find themselves in situations where there is a gap between their knowledge and understanding of how to care for their children and possible better methods and solutions. There are a number of ways parents currently bridge that gap.

**Information Sources and Delivery**

Research has shown that parents of disabled children have a variety of information sources. Harger and Martin (2007) observed that agency staff members referred parents to online health information resources. Pain (1999) found that professionals were frequent sources of information, and that other parents of children with disabilities were seen as useful adjuncts to “official” information. This study also found that parents received information from voluntary organizations in the form of advice, leaflets, and services. Mackintosh, Myers, and Goin-Kochel (2006) found that on average, parents of children with autism spectrum disorder reported acquiring information from seven different sources. The most common personal source of information was other parents (72%), more than professional sources, family, or friends. The
most common written source of information was books (88%), followed closely by web pages and email listservs (86%). Jackson et al. (2007) found that parents sought information by searching the Internet, browsing leaflets, posing verbal questions to health professionals, and contacting condition-specific organizations, schools, and friends.

Parents have expressed preferences as to how information is delivered. One study found that personal communication was preferred, with written word as backup – leaflets alone were not sufficient (Pain, 1999). Another study affirmed that written sources were not enough, and that parents desired a professional practitioner working as a personal information advisor. Parents also preferred that written sources had attractive covers; featured a clear and accessible reference system, index, and contact details; were reassuring; gave insights into holistic support; discussed comprehensive issues; combined service information with advice; were up-to-date and easy to read; featured a variety and combination of formats; offered information at different levels and depths; were appropriate to the child’s period of life; could be found in everyday, nonthreatening places; and were personally delivered (Mitchell & Sloper, 2007). Many of these preferences could be applied, with slight adaptations, to the delivery of web-based resources.

**Inadequate Information**

Several studies found that the information parents receive does not adequately meet their needs. Families in one study reported that they did not have enough knowledge about their child’s condition (Sen & Yurtsever, 2007). Pain (1999) found that when parents did not actively seek information, it was because they didn’t know how or where to start looking. One research study found that parents’ primary complaints included the difficulty of learning about services (Sloper, 1999). Jackson et al. (2007) found that sometimes, information obtained by parents (particularly information from the Internet) was not comprehensible, satisfactory, or reassuring.
Mitchell and Sloper (2002) found that families were particularly confused about what services were available, the eligibility criteria were for those services, the various roles professionals played, and how to coordinate with and among various professionals.

Although many parents report difficulty acquiring information, this problem is even more pronounced among parents with low income or low education. Lower income parents used fewer information sources than middle and upper income parents. They were also less likely to obtain information from other parents, scientific journals, conferences, workshops, and group meetings (Mackintosh et al., 2006). Generally, attending informational venues is costly, and may present too great a burden for families with financial difficulties.

*The Insider-Outsider Phenomenon*

The finding that parents in similar situations were the most prominent information source, shared among many studies reviewed herein, can be considered an example of the Insider-Outsider phenomenon. Simply put, this is the notion that “it takes one to known one” – that, for people within a certain classification or strata, only others from that same group can truly understand their experiences (Merton, 1972). Chatman (1996) expounded upon the Insider-Outsider construct to explore how this mindset affects information acquisition. Chatman posited that due to the inherent social structure, which consists of many groups containing insiders (making everyone else outsiders), insiders actually shield themselves from information resources they need. Paradoxically, insiders believe that outsiders control these resources, yet they refuse to seek them from those outsiders. Hypothesizing about why this occurs, Chatman suggested that insiders who are information-poor desperately desire to keep their real state of need hidden, because they believe exposing this need would be too costly, and because outsiders have not shown themselves to be trustworthy. In our case here, families with developmentally disabled
children are insiders, and there is empirical evidence that they indeed trust primarily other insiders for information.

**Social Support Needs**

Besides their intensive information needs, parents of children with developmental disabilities have substantial and atypical needs for emotional and social support. Support networks for parents of children with developmental disabilities are different from typical family support networks. Mackintosh et al. (2006) found that the most common support source was other parents of children with disabilities (68%) — more than spouses, family members, friends, neighbors, and religious communities. Tsibidaki and Tsamparli (2007) found evidence that other parents of children with disabilities were the most prominent sources of support -- more than family, friends, or specialists. Mackintosh et al. (2006) further learned that many parents found written works to be sources of emotional support. The most prominent of these was web pages and listservs (43%), followed by newsletters and books (30% and 28%, respectively).

Many parents of special needs children struggle with a lack of help from extended family. It has been observed that many families of children with disabilities are not able to derive support from traditional support networks (Kerr & McIntosh, 2000). A study in Greece found that among parents with no disabled children, the family of origin was part of the support network for 73% of mothers, but among mothers of a child with a disability, the family of origin was part of the support network in only 30% of cases (Tsibidaki and Tsaparli, 2007). Sen and Yurtsever (2007) found that other nuclear family members were more supportive than extended family and friends. As noted previously, most of these parents lack social capital and are isolated from their communities (Chenoweth & Stehlik, 2004; Partington, 2005; Grant, 2007).
Professionals can play a significant role in providing emotional support to parents. Mackintosh et al. (2006) found that professional relationships were a source of support for some parents. Parents listed educators (48%), physicians (36%), and other professionals such as behavioral specialists (46%) as practitioners that provided support. Parents in another study expressed a desire for a person-centered approach from professionals, and they emphasized the importance of developing a good rapport and communicating with professionals (Jackson et al., 2007). Mandell and Salzer (2007) reported that providers played a critical role as referral sources to support groups.

**Bonding with Other Families and Support Groups**

Many studies found the importance of bonding with other families in similar situations. Chenoweth and Stehlik (2004) posited that these social contacts are considered easier because there is less risk of rejection, and they “know what it’s like.” Mandell and Salzer (2007) noted that there are benefits of peer support for families of children with autism. A study on a “Contact a Family” program in the UK reported that during a 5-year period in the early 2000s, 25,000 inquiries from families who desired to contact another family for emotional support were processed (Davies & Hall, 2005). Kerr and McIntosh (2000) observed that bonding with other families allowed parents to realize they were not alone, find someone who understood, and acquire a “glimpse into the future.” They noted that these opportunities provided parents with emotional support, practical advice, and an opportunity to reduce stress. Mandell and Salzer (2007) found that some families benefit from joining support groups. In their study, two-thirds of parents sampled had participated in a support group at some point. These families were more likely to have children with more severe disabilities and traits such as self-injurious behavior, sleep problems, and severe language deficits. Parents of older children were also more likely to
have been in a support group – probably because they had had more cumulative time to join one. Rural residents were significantly less likely to have been in a support group than to have not been in one.

Besides the obvious benefits, acquiring support from groups also encourages parents to later act in a supporting role. Scorgie and Wilgosh (2008) found that over time, emotional support was not as “essential,” and parents were able to become leaders instead of learners. Likewise, another set of researchers observed that bonding with other parents allowed families to eventually “come full circle” and offer support to others (Kerr & McIntosh, 2000). Klein and McCabe (2007) presented a study on mothers who went on to become disability professionals later in life. They found that these mothers were effective in their new roles for several reasons: they were able to listen to and share experiences, which was beneficial to both parent and client; they had personal experience that impacted their career choice and increased their credibility; their professional positions in early intervention and related areas promoted role change and tenacity; and their expertise as professional parents was acknowledged by colleagues. These mothers tended to agree that early intervention had a profound effect on their child’s progress. Schaffer et al. (2008) found that, as eHealth users, parents played an active role in the production and dissemination of genetic knowledge online. The mothers in their study, whose children had genetic-related disabilities, expressed conflicting emotions about their roles as disability advocates and the daily decisions they had to make in their own lives. This may suggest that an effective adoption of this role requires parents to recognize that they cannot be expected to give perfect or universally applicable advice all of the time.
Inadequate Social Support

Like information support, social support was found to be inadequate among families. Sen and Yurtsever (2007) found that 28.2% of mothers in their study had no emotional support. 43.6% of their sample reported that the support they received, if any, was insufficient. In another study, 36% of families reported that they had no emotional support whatsoever – not from services, family, or friends. This same study reported that there was very little emotional support for the children themselves (Abbott et al., 2005). Also, just as with information needs, the degree to which social support needs were addressed was related to income and education level. Mackintosh et al. (2006) found that low income parents were less likely to report support from other parents, friends, and neighbors. Mandell and Salzer (2007) reported that support group participants were more likely to be middle or high income, and have higher education.

Table 2-1 Summary of Needs and Sources for Addressing Them

<table>
<thead>
<tr>
<th>Need</th>
<th>Sources for Addressing Need</th>
</tr>
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</table>
| Information (Education, Caregiving, Health, etc.) | • Other Parents  
• Professionals  
• Voluntary Organizations  
• Books  
• Web Pages/List Servs  
• Online Health Information |
| Social Support                | • Other Parents  
• Family  
• Neighbors and Friends  
• Educators  
• Physicians  
• Other Professionals  
• Support Groups  
• Web Pages/List Servs  
• Newsletters  
• Books |
Chapter 3

ICTs for Information and Support

Internet health users are prevalent among the national population. In 2001, 40% of respondents with Internet access indicated in a national survey that they used the Internet to look up advice about health and health care (Baker, Wagner, Singer, & Bundorf, 2003). Just a year later, results of a national telephone survey found that 80% of adult Internet users (half the US population at the time) had searched online for health information (Fox & Fallows, 2003). Hardey (1999) found that users, rather than professionals or authors of Internet health information, decided what and how material was accessed and used. Cotton and Gupta (2004) reported that online health information seekers were likely younger and had higher income and higher education than “offline” health users.

Not surprisingly, parents actively use the Internet to learn about the health of their children. Bernhardt and Felter (2005) found that women were high Internet information seekers during pregnancy. After childbirth, mothers continued to use the Internet to learn about diagnoses, understand how to treat specific pediatric conditions, and seek out advice on parenting and development. Several studies found that it was generally mothers, not fathers, who used online health information and support resources (Skinner & Schaffer, 2006; Porter & Edirippulige, 2007; Bragadottir, 2008).

Parents of Disabled Children as Internet Health Users

Parents of children with disabilities commonly use the Internet for information purposes. One study found that 72% of parents who had Internet access used it for directly obtaining
information related to their role as parents of a child with a disability (Blackburn and Read, 2005). Skinner and Schaffer (2006) found that 83% of families had used the Internet for some purpose related to their child’s condition. This study found that most of them did not use it in this way until they had a definite diagnosis. Porter and Edirippulige (2007) found that parents search the Internet for purposes related to their child’s disability from the early years, throughout schooling, and beyond. The two most common searches in their study were for parent support groups (55%) and educational options (54%). Parents reported that they desired unbiased, evidence-based information so they could make informed choices. Schaffer et al. (2008) found that mothers reported that the best Internet information on treatment often came from other parents. They also discovered that parents reported knowledge growth as a result of their interaction in Internet communities. Online groups validated their caretaking decisions, increased their scientific literacy, and enhanced their perceived value of parental lay knowledge. One study found that information obtained on the Internet had a major influence on decisions made on the management of hearing loss (Porter & Edirippulige, 2007), while another study found that disability-related online communities were influential in parents’ treatment decisions (Skinner & Schaffer, 2006).

**Online Social Support**

Parents also benefit from cultivating emotional support online. Individuals who participated in an Internet-based support group experienced a significant increase in the availability of support relative to participants who had access to information only (Barrera, Glasgow, McKay, Boles, & Feil, 2002). Parents reported that having the right balance of information and emotional support was important (Baum, 2004).
Many parents participate in Internet-based and computer-mediated support groups, and they give several reasons for doing so. One study found that overall satisfaction with Internet-supported parent groups was high (93%). This same study found that parents indicated they participated to gain an increased access to current information and resources, and prevent misdiagnosis and mistreatment. Relatively low cost was also cited as an impetus for participation. Parents enjoyed the sense of safety and relaxation and appreciated the opportunity to engage in unfiltered “straight talk.” Participating in online groups gave parents a link to the outside world and improved their relationship with their child (Baum, 2004). Dunham et al. (1998) found that mothers reported that computer-mediated support groups gave them the opportunity to discuss daily stress and receive information and emotional support. Their participation reduced levels of parental stress (Bragadottir, 2008). A study of the messages exchanged in an online group focusing on disability found several themes (in descending order of frequency): support and empathy, information, problem solving, and expression of feelings (Finn, 1999). Another study of a similar group found comparable themes (in descending order of frequency): emotional support, information, esteem support, network support, and tangible assistance (Braithwaite, Waldron, & Finn, 2000). Huws, Jones, and Ingeldew (2001) looked at an email group for parents of children with autism. Their study found these email messages portrayed an overall theme of “making sense of autism.” Messages revealed that participants were searching for meaning, adjusting to changes, providing support and encouragement, and sharing experiences. Jones and Lewis (2001) performed a similar study on an online discussion group that was primarily used by parents of children with Down syndrome. They found that participants offered and obtained advice, shared trials and triumphs, gave and acquired information and support, and expressed opinions. They also looked for meta-themes among the messages, and discovered ones of celebration, perceiving the child before the handicap, hope and optimism, viewing parents as change agents, and validation and support. In a study of personal
web pages, one researcher found that information gained from other parents online changed parents’ self-perceptions for the better (Fleischmann, 2005). Zaidman-Zait and Jamieson (2007) recommended that parents for whom online discussion would be especially beneficial would be those living in rural areas, those whose children had a low incidence condition, or those for whom leaving home was challenging, whether that was a result of their child’s behavioral issues, the parents’ full-time jobs, or parental illness or disability.

**Sense of Virtual Community**

When parents interact in online groups, they can be said to be part of an online community – an entity that incorporates people, a shared purpose, policies, and computer systems (Preece, 2000). But do these parents actively experience a sense of that community? McMillan (1996) described “sense of community” (SOC) in terms of four dimensions: a spirit of being together, trust in an authority structure, a recognition that trade and mutual benefit arise from differences in the community, and the development of art as preserved shared experience. This idea was extended to online settings by Blanchard and Markus (2002), who coined the term “sense of virtual community” (SOVC). They separated the idea of virtual communities from virtual settlements, which are characterized by less engagement and a lack of relationships among members (e.g., an online store). SOVC was characterized by a recognition and identification of other members, support exchange, relationships, emotional attachment, and a feeling of obligation to the group. This was similar to SOC, but lacked a hierarchical command structure, and added the dimensions of individual identity and relationships (which may be assumed to exist in physical communities).

Research illustrates that parents do experience a “sense of community” when using these online groups – one that, as previously discussed, is sorely lacking in their “real” lives. In his
seminal book on social capital in America, Putnam (2000) wrote that “support groups substitute for other intimate ties that have been weakened in our fragmented society, serving people who are disconnected from more conventional social networks.” A study of young mothers showed that a sense of community was very much perceived in a computer-mediated support group (Dunham et al., 1998). Zaidman-Zait and Jamieson (2004) reported that parents were able to receive support, and subsequently provide support. They observed that this was crucial for their sense of community building, particularly when they lived in rural areas. One study found that 10% of parents remained “avid” users even after conducting online research, especially in the form of support and advocacy (Skinner & Schaffer, 2006). Fleischmann (2005) found that parents who were assisted by the Internet in finding information returned to help others. He noted that the Internet formed a structure for establishing mechanisms of assistance and support on a voluntary basis. Turner, Grube, and Meyers (2001) found when studying a listserv for cancer patients and survivors that participants tended to use the listserv more when their relationship with a face-to-face partner lacked support and depth.

**Success with Online Resources**

Despite their widespread use of online resources, parents exhibit varying degrees of confidence in how well they can determine the credibility of a web site. One study found that mothers in general used mostly commercial websites, followed by websites run by non-profit organizations and academic websites (Bernardt & Felter, 2004). Because their purpose is to generate profit and not to altruistically offer a service, some commercial websites may not best serve parents’ needs. Schaffer et al. (2008) found that mothers were skeptical about online resources’ credibility. They were afraid they would miss crucial information, and were concerned about their ability to evaluate and interpret websites. Another study found that the
information obtained over the Internet sometimes produced worry in parents because of its negative nature (Osborne & Reed, 2008). Bernhardt and Felter (2004) looked at how some parents determine the trustworthiness of Internet sources. Strategies employed included determining the website owners’ motives, and identifying and evaluating the source of information. Parents’ trust increased over time with website familiarity and information repetition and convergence. Their trust decreased when they observed disagreements among experts. They highly trusted other parents online in specific situations related to support, reassurance, and advice.

Professionals can and should play a critical role in helping parents to navigate the web. Zaidman-Zait and Jamieson (2004) posited that parents need support and guidance in the process of online information gathering and organizing information to make decisions. They also affirmed that professionals are needed to guide parents on how to use the Internet effectively, to promote awareness of its disadvantages, to discuss information found, and to refer parents to high-quality websites. They suggested that it would be helpful for professionals to use the web themselves to educate parents, provide information to them, and communicate with them.

Another study recommended that, for an online health group to achieve success, relevant professionals should know about it and be able to refer interested parties to it (Maloney-Krichmar & Preece, 2005). These suggestions respond to the finding that written information sources are not sufficient and that parents desire a human connection, too.

Table 3-1 Summary of ICT Uses and Benefits

<table>
<thead>
<tr>
<th>Use</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Resources</td>
<td>• Support Groups</td>
</tr>
<tr>
<td></td>
<td>• Educational Options</td>
</tr>
<tr>
<td></td>
<td>• Evidence-Based Information</td>
</tr>
<tr>
<td></td>
<td>• Treatments</td>
</tr>
<tr>
<td></td>
<td>• Caretaking Decisions</td>
</tr>
<tr>
<td>Social Support/Support Groups</td>
<td>• Increased Access to Current Resources</td>
</tr>
<tr>
<td></td>
<td>• Prevention of Misdiagnoses</td>
</tr>
</tbody>
</table>
- “Straight Talk”
- Link to the Outside World
- Improved Relationship with Child
- Opportunity to Discuss Daily Stress
- Empathy
- Problem Solving
- Esteem Support
- Tangible Assistance
- Providing Support and Encouragement
- Sharing Experiences, Triumphs, and Trials
- Hope
- Validation
- Sense of Virtual Community
Chapter 4

The Role of HCI and a Scenario and Claims Analysis

The most significant contribution that HCI and computer-supported cooperative work (CSCW) can make to this field of study is research on the technological aspects of parents’ Internet use. Many of the articles reviewed in this paper are not especially specific about the technologies used by parents. This literature is quite attentive to the people using the technology, their purpose, and the information transferred, but it does not closely examine the technologies themselves, and in some cases does not even specify what they were (Zaidman-Zait, 2004; Porter & Edirippulige, 2007). Also, the available studies to date have not yet looked at the use of novel Web 2.0 tools such as social networking sites and mobile applications. Although the dearth of technology research is not surprising because this literature is published in venues that do not have a technology focus, it would be advantageous for researchers in this area to consider the findings of HCI and computer-supported cooperative work (CSCW) literature. It would be especially helpful if scholars in the HCI and CSCW communities conducted research on the specific design requirements in this field.

CSCW research and perspective can contribute to this area of study and offer practical recommendations through its findings on online community engagement and participation. These findings can provide a rich set of resources to guide the creation, design, and implementation of new online groups. For example, Millen and Patterson (2002) found that online communities that incorporate channeling mechanisms (to see general site activities) and notification services stimulated engagement. Participants were found to contribute more when they were shown personalized uniqueness information (Ludford, Cosley, Frankowski, & Terveen, 2004).
Literature in HCI and CSCW abounds with general guidelines for designing online communities. Some of the most pertinent guidelines for the domain of this paper pertain to actual and perceived credibility. Preece (2000) recommended that designers of health-based online communities take steps to ensure that information presented is cited and verified as accurate, and that members are protected from exploitation and promises of “miracle cures.” This point is crucial for parents of special needs children, whose frustration with daily difficulties makes them especially susceptible to bogus solutions. Sillence, Briggs, Fishwick, and Harris (2005) found that online health users were more likely to trust websites that had a clear purpose, allowed a personalized experience, and included markers of social identity.

Other important design objectives are those that facilitate the usability and sociability of online communities. Preece (1999) noted the difficulty of balancing emotional and factual communication in online communities. Given an evident preference for empathic communication in health-based communities, Preece proposed a short list of design solutions to facilitate such interactions while still maintaining information quality. These suggestions included making private communication easy, implementing better interaction protocols, skillful moderation, allowing personal bookmarking on bulletin boards, and providing techniques to support search. Preece (2000) provided further recommendations for the designers of health-based online communities, including providing citations for sources to verify accuracy, protection from exploitation and scams, and providing contact information. Maloney-Krichmar and Preece (2005) offered a list of suggestions for how to successfully implement a health-based message group. They recommended an early focus on supporting the development of strong group norms, a low profile for any moderators or management so as not to inhibit participation, prominent display of the message index, reliable and continuous service, strong community development, implementation of subgroups, branding and a statement of purpose, and information about the particular condition. Researchers or developers who seek to implement a new online tool for
parents would be wise to consult and extend this literature to increase their likelihood of being effective.

Additional findings could be used to develop guidelines for parents who are new to online communities and eager to begin interacting. Arguello et al. (2006) looked at online communities in general and examined strategies for individual engagement, which would be useful for parents who are desperately seeking information and support. Their study found that the rhetorical content of a person’s initial message in a listserv/discussion board environment has a large impact on whether they will get a response. They learned that testimonials, questions, and topical relevance increased the likelihood of a message yielding a response by 10%, 6%, and 10%, respectively. Using words that imply mental processes and words that portray positive or negative emotions increased the likelihood of gaining a response. Receiving a reply to an initial message improved the odds of a newcomer returning, especially if the reply contained positive emotions.

A Scenario and Claims Design Analysis

Here I will explore several possible design opportunities through the construction of scenarios and claims analysis (Carroll & Rosson, 1992). Simply put, a scenario is a narrative that describes actors engaged in some form of activity (Carroll, 2000; Rosson & Carroll, 2002). These scenarios are intended to illustrate the use of a technological system by representing its use with a set of narratives describing users’ interactions with it. All scenarios include the following elements: a setting or starting state, the behaviors and experiences of actors, task goals, plans, evaluation by the actor, actions, and events (Rosson & Carroll, 2002). In scenario-based design (SBD), these scenarios are envisioned in parallel with claims about the system’s affordances. While scenarios capture a holistic picture for designer analysis, claims provide the designer with
detailed, specific causal relationships between the artifact’s features and the consequences for actors and their activities (Carroll, 2000). The underlying assumption is that any decision made by a designer represents a trade-off. Use of scenarios and claims will give us the opportunity to develop a systematic analysis of a potential Internet-based tool for families of children with developmental disabilities. There are several types of design scenarios: activity, which describe system functionality; information, which look at how possible actions within a system are made understandable to the user; and interaction, which describe the mechanisms by which the user can access and manipulate functions of the system (Rosson & Carroll, 2002). For this exercise, I will use activity scenarios, which operate at the highest level of abstraction.

### Scenario 1

Lynn’s three-year-old son, Kyle, was just diagnosed with autism. Among the informational literature given to her at the doctor’s office was a pamphlet advertising a free online portal for parents of children with disabilities. Eager to find more information, Lynn typed in the URL for the web site to see what was offered. On the front page, she found links to various discussion threads, articles, and support groups. Also prominently displayed was a box urging her to either log in or create a personalized account. She clicked on a link to sign up for an account, and was given the opportunity to add a personal profile with pictures of her and her son. She was also able to add her location, interests, and information in an “about me” section. Once she was signed up, she noticed that the front page displayed a message welcoming her to the site and encouraging her to post on discussion boards. She navigated to a discussion thread for new users and introduced herself, describing her strong emotional response to her son’s diagnosis. When Lynn came back a few hours later, she found that several other parents had responded to her post with encouraging messages and stories of their own, and that one mother even mentioned that upon looking at Lynn’s profile she realized they lived about a half hour apart. Lynn felt very relieved to have already connected with some other parents. She felt safe confiding in them. That evening, she wrote a private message to the mother who lived close by, telling her more about Kyle and expressing a desire to meet sometime.

Figure 4-1: An activity design scenario emphasizing social interaction.
The first scenario examines the activity of a parent, Lynn, who has recently found out about her son’s disability, and who is presumably experiencing the range of negative emotions described in the work of Sen and Yurtsever (2007) and Kerr and McIntosh (2006). At this point, she is also in danger of experiencing a sense of abandonment (Osborne & Reed, 2008). Note that Lynn was informed about the online community by a health professional, which Maloney-Krichmar and Preece (2005) recommended for health community success. Although this scenario only describes Lynn’s initial two visits to the online community, we can observe that she has already garnered support from other members, simply by sharing her story. The design of the community web site has incorporated various elements to encourage participation, including personalization (Ludford et al., 2004; Sillence et al., 2005), and a message persuading new users to engage in discussion (Arguello et al., 2006).

Table 4-1 Claims for Scenario 1

| Making this interactive online community for parents of disabled children free… |
| Makes it accessible for anyone with Internet access, regardless of income level. |
| Makes it difficult to maintain without grant support. |
| Still does not make it available to parents who do not have Internet access. |

| Enabling and encouraging the creation of a personalized account… |
| Allows parents to feel welcomed to the web site. |
| Gives parents an opportunity to both share information about themselves and learn about others. |
| Allows users the freedom to express themselves not just as parents, but as people. |
| May put users at risk of revealing personal information about themselves or their families to inappropriate individuals. |

| The availability of discussion boards… |
| Gives parents the opportunity to talk about their lives with other people who understand their circumstances. |
| Encourages sense of community among participants. |
| Generates a sense of trust among participants. |
-Could result in hurt feelings among participants if their messages do not receive responses, or if responses are perceived as offensive.

<table>
<thead>
<tr>
<th>The availability of private messaging…</th>
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</thead>
<tbody>
<tr>
<td>+ Allows parents to have private conversations.</td>
</tr>
<tr>
<td>+ Generates a sense of trust among participants.</td>
</tr>
<tr>
<td>- May leave other users wondering why a discussion thread abruptly stops, and may prompt new users to believe that their discussion posts will not yield responses.</td>
</tr>
</tbody>
</table>

Parish and Cloud (2006) reported that children with disabilities were more likely to live in poverty than typically developing children, and Emerson and Hatton (2007) found that children with disabilities were at a greater risk to be socioeconomically disadvantaged. These findings only increase the relevance of the work of Mackintosh et al. (2006), which reported that lower income parents were even less successful than parents of average income at information and support acquisition. Many information resources, such as scientific journals, conferences, and workshops, are expensive, and parents who have difficulties making ends meet may even struggle to attend free workshops or support groups that meet during working hours, or require that they arrange for child care. The existence of a free, 24-hour information and support resource would be highly beneficial for parents who cannot afford costly resources. Of course, this does not solve anything for parents who are unable to afford Internet access.

The second claim explores personalization. Sillence et al. (2005) found that including a personalized experience in a health web site increased feelings of trust for users. Scenario 1 expounded upon that principle and showed that personalization could also foster community, as users are able to share information about themselves, and learn about other members in ways that may not be supported simply by discussion. The personalization described also allows parents to create profiles, as one would on a social networking site, giving them the opportunity to tailor it not only to their personalities as parents, but also as people. However, some parents may be
unwilling to use this feature because they fear that dangerous or predatory people could view their personal information – particularly since their very participation in this web community centers around their child. This claim suggests that privacy measures, whereby users can control who can see all or parts of their profiles, may appeal to parents – and the more obvious these mechanisms are, the better.

Scenario 1 also features the use of a discussion board. In this narrative, Lynn is pleased with the results of using this feature. She uses it to connect with other parents, building towards a sense of virtual community with fellow members (Blanchard & Marcus, 2002) and allowing them the opportunity to “come full circle” as they helped her through her journey as a mother (Kerr & McIntosh, 2000). Lynn’s feeling of “safety” in discussing issues with other parents demonstrates that their status as other “insiders” has earned them her trust (Chatman, 1996). However, what would have happened had no one replied to Lynn’s initial posting, or if someone had replied in an unkind fashion? It is likely that Lynn’s feelings would have been hurt and she would have discontinued using the site (Arguello et al., 2006), which would have excluded her not only from possible encouraging exchanges, but also from information resources. One measure that might be taken to avoid such situations is the incorporation of “veteran user” designation, whereby members who have been active for a given period of time would be given the option to participate in a “welcome wagon” outreach service to new members. If a member’s initial post received no responses within a period of a day or two, an automatic message could be generated and sent to members of the “welcome wagon” group encouraging them to respond if possible.

In Scenario 1, Lynn sends a private message to another user who has identified herself as living close by. Parents who are accustomed to email and other services that allow for private messages, including social networking tools, will most likely expect that they will be able to communicate with other members privately. This would allow parents to have conversations that they do not want to be publicly viewable. However, it may leave other users, particularly new
and inexperienced ones, wondering what happened to a discussion thread, should another member decide to shift modes and reply to a post privately instead of publicly.

Scenario 2
Mike, a single father, was about to move to a new state with his fourteen-year-old daughter, Jaime, who has Down Syndrome. Mike had to change locations due to a job transfer, but he was concerned about how Jaime would adapt and what resources would be available for her there. He had been a member of an online service for parents of children with disabilities for a couple of years, but thus far he had only used it to discuss the challenges of daily life with other parents.

One evening, he sat down with his laptop and began using the site’s search capabilities to find out more about the schooling and home-based care options available for Jaime in the state to which they were moving. He was happy to find a detailed explanation of the process for obtaining a waiver for caretaking services and Medicare within the state. He was also able to find information about various school systems in the county where they planned to find a home. He noted that both of these resources had both email and phone contact information for the necessary parties. Realizing that he would want to look at this information again later, he bookmarked both pages.

Unlike the first scenario, this narrative does not involve a novice parent, but rather an experienced one who, because of a major change he needs to make in his life, must re-learn the “system” he has already been navigating. In the scenario, Mike breaks from his habit of simply using the parent web site for social support, and instead uses it to look for formal supports (Johnson et al., 2005). Here, we can imagine the effects of incorporating a search function, including contact information for needed professionals, and allowing users to bookmark content that they will want to revisit (Preece, 1999; Preece, 2000).

Table 4-2 Claims for Scenario 2

<table>
<thead>
<tr>
<th>Providing a search capability…</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Allows users to find information tailored to their specific question.</td>
</tr>
<tr>
<td>- May be frustrating for users who are not adept at structuring search queries.</td>
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</tbody>
</table>
Providing search capability was one of several key suggestions made by Preece (1999) for the development of a health-based community that effectively balances information and communication. In Scenario 2, we observe how this functionality helps Mike to quickly find resources specific to schooling and caretaking support – a common information need for a parent of an older child (Scorgie & Wilgosh, 2005). However, if his search terms had been inadequate, would he have continued to try searching until he found what he needed? If the information he needed was not contained within the web site, what would he have done? The web site administrators may want to consider partnering with Google or another engine with a highly-developed, intuitive search algorithm. Another design element worthy of consideration would be allowing the user to include search results from the entire Web, particularly during the site’s early stages when its databases may not be as comprehensive.

In this scenario, it is evident that there is a vast quantity of schooling and HCBS-related information available to parents on the web site. Would it be possible to assemble such a large repository? How could this be properly maintained, particularly considering the great variety of laws that are often updated which so profoundly affect the administration of such programs? This is a particularly crucial area, as many parents have reported difficulty in finding out about services (Sloper, 1999; Mitchell & Sloper, 2002; Jackson et al., 2007). Having a well-developed search capability that indexed a thorough, up-to-date, and understandable repository of service-
related information would give parents a viable information seeking option when they don’t know how or where to even begin (Pain, 1999). Although assembling and maintaining such a database centrally would be too formidable a goal, delegating this authority to groups representing states or local areas would potentially be quite feasible.

Preece (1999) also suggested the inclusion of personal bookmarking for bulletin boards. Scenario 2 does involve personal bookmarking, but instead of referring to a discussion post, it is used for bookmarking information. The benefits of being able to quickly navigate back to an important page are evident, but trouble may arise if users become too bookmark-happy, or if they do not use a bookmark organization structure if it is provided. The availability of discussion bookmarks would be very useful for parents who want to be able to refer back quickly to a particular post, but it could potentially add a great many bookmarks to their collection. This potential problem could be solved by a mechanism that would organize and sort bookmarks within the site.

**Scenario 3**

Debbie wanted to learn more about possible interventions for her five-year-old son, Ben, who has Asperger’s Syndrome. She had watched several television specials on various treatments, both medical and behavioral, but she didn’t feel adequately well-versed in current research to discriminate between credible claims and fraudulent ones. So she logged into the web site that housed the online community she had joined recently for parents of children with disabilities. She started a new discussion thread in the channel for families of children with Asperger’s asking if anyone was familiar with the treatments. Another parent, Jim, soon responded, providing a link to the “treatments” section of the web site. This page contained multiple postings by medical professionals and behavioral specialists describing treatments that were grounded in extensive research. There were also links to other evidence-based information resources. At the top of the page was a written guarantee from the web site administrators that anyone posting to this area of the site had passed a screening process to ensure that they were actually a professional, and that any external sites that were linked only contained scientifically sound content. Debbie felt reassured to know that the information she was reading was trustworthy, and she was encouraged
This scenario introduces a parent who is afraid of being exploited by fraudulent treatments programs marketed to her and other parents eager to do anything to help their child. Debbie’s experience with the web site is reassuring, because it includes information from knowledgeable professionals regarding verified treatment options (Preece, 2000). Her fear that she will not be able to judge the credibility of a treatment claim herself is not uncommon (Schaffer et al., 2008), and the web site’s stringent requirements for contributors to this section make her more willing to trust the information presented there (Berhardt & Felter, 2004).

Table 4-3 Claims for Scenario 3

| A section of content on treatments that is updated exclusively by professionals… | +Gives parents the reassurance that this content can be trusted.  
-May inadvertently give parents the impression that all content on the web site is filtered for accuracy, which is impractical. |
|---|---|
| Including links to other credible information repositories… | +Gives parents access to resources beyond the web site itself.  
-May cause potential members to navigate away from the site and never return. |
| The availability of discussion boards… | +Allows parents of older children to “give back” by assisting others.  
-May put parents at risk of accepting inappropriate or erroneous advice. |
| Pushing email alerts when new content is posted… | +Allows parents to keep up-to-date without constantly checking the site.  
-May be irritating if too many emails are received, especially if they pertain to a medical or behavioral issue that is uncommon. |
In Scenario 3, Debbie finds information about treatments that has been posted by various health professionals. The credibility of such content, while reassuring to parents (and, presumably, safe for them and their children), could possibly result in parents mistakenly thinking that all of the content on the web site can be trusted, particularly since they are already inclined to believe what other parents say (Bernhardt & Felter, 2004). Just as the web site administrators have posted a message on the “Treatments” page asserting that its content is regulated, they may be wise to post another message on the discussion pages noting that its content is not.

Partnering with other credible information repositories will lighten the amount of information that must be included on the web site itself. However, linking to external sites could lead users away from the web site permanently. To reduce this possibility, these links could be set to automatically open in another tab or another browser window.

Like Lynn in Scenario 1, Debbie makes use of the discussion boards. Her purpose is to ask about treatments options; this is certainly possible, as parents have shown an inclination to trust other parents for advice (Bernhardt & Felter, 2004). In this scenario, Debbie receives an appropriate response that directed her to a credible place. Supposing she had received a response that was inappropriate or inaccurate – would she have trusted it? If not, how would that affect her future use of the site? Such a possibility emphasizes the importance of making a very obvious distinction between credible areas of the site and potentially less-than-credible areas, such as the discussion boards.

This scenario also incorporates email notifications of updates. These would be especially helpful for parents who are not online every day, or who check a particular area of the site only once and then never return again. However, it is possible that some users could become annoyed with the volume of email generated by such a system. If it were possible to tailor the notifications so that a parent could sign up for alerts about a specific disability or symptom only, and/or they could specify how frequently they wished to receive such alerts, this would not only
reduce the number of emails pushed to each user, but would also contribute to the personalized feel of the web site.

Scenario 4
Dennis, a behavioral therapist, found out from a colleague about a new web community for parents of children with disabilities. He wanted to learn more so that he could recommend it to his clients, so he navigated to the web site and clicked on the FAQ section. In the FAQ, he read about the site’s dual purpose — as an information repository and a virtual community for parents. He then noticed a link to another FAQ for professionals interested in contributing to the site. His curiosity piqued, he clicked on the link and read that doctors, lawyers, educators, therapists, and other professionals could apply to be official contributors to the site. He filled out a brief online application, which included a request for state certifications and questions about his expertise and location. When he finished, a thank-you message appeared indicating that he would be contacted by a regional web site administrator within a few days. Three days later, a local administrator sent Dennis an email welcoming him as a contributor to the therapy section of the web site. He was given log-in information so he could add content to that portion of the site. When he logged in, he noted that his profile indicated his area of expertise, applied behavioral analysis.

In our fourth scenario, we observe a professional using the web site. This scenario explores the mechanism by which a professional could become an official, trusted contributor to the information portion of the web site. This is a critical process, as credible material for this online tool will not be produced out of thin air. It also features the use of a frequently asked questions (FAQ) section, a common component of multifaceted online resources.

Table 4-4 Claims for Scenario 4

<table>
<thead>
<tr>
<th>Having an FAQ for both parents and professional members…</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Provides a quick resource explaining the purpose, design, and features of the web site.</td>
</tr>
<tr>
<td>+ Affords members of various backgrounds the opportunity to learn about why they should use the site.</td>
</tr>
<tr>
<td>- May not be the most obvious channel for professionals to find the application to become an official contributor.</td>
</tr>
</tbody>
</table>
Including an application to screen potential contributors that includes a request for state certifications…
+ Will help protect parents from potential contributors who lack the needed expertise.
- May be rather laborious for the professionals being screened.

Allowing professionals to sign on as contributors…
+ Provides more resources for parents.
+ Lends credibility to the web site.
- May prove difficult, as it is hard to recruit volunteers.

In Scenario 4, Dennis immediately visits the FAQ page when he first examines the web site. This feature, common among web sites, would be helpful for any person interested in the web site, regardless of their purpose. It is a resource familiar to many. It could include explanations of each portion of the site, and it could emphasize the sources of each content area – which would reiterate the messages suggested earlier, such as the disclaimer on the discussion board that its content is not moderated by an administrator. Including an FAQ for potential (and current) professional contributors would certainly be helpful – and including a link to the application would be fine – but, it would be best to also include a more prominent link on the site’s homepage for potential contributors in case they do not click on the FAQ first.

As this source seeks to be as comprehensive as possible, it would be extremely helpful to allow professionals who are not part of the administrative team to add content. This is in keeping with the commitment to providing credible resources. However, it is always difficult to recruit volunteers. This effort could be spearheaded by the initial team members, who could contact colleagues from other geographic areas to encourage them to participate – and spread the word further.

Requiring state certifications would add considerable overhead to the project, but the site administrators must have some method of verifying the credibility of potential contributors. A web site administrator would likely be unequipped to assess a professional’s credentials. Relying
on an external authority to provide a “stamp of approval” for a potential contributor would remove the burden of this responsibility from the site administrators. Simplifying the application as much as possible would perhaps ameliorate the burden of furnishing these certifications. A brief statement explaining just why such verification is so important would most likely appeal to a potential contributor’s sense of pride in his or her expert status.

### Scenario 5

Jeni logged into the online community and opened up her chat list. She was very thankful that Carol, her friend from several states away, was online. An upsetting incident had occurred at her son Chris’s school, and she needed to vent her frustrations. Like Chris, Carol’s son Philip was permanently disabled after a traumatic brain injury. When Jeni described the unfortunate incident at school – Chris had been excluded from a field trip at the last minute because no aide was able to accompany him on the bus – Carol responded in an empathic and emotional way. Jeni reflected on how, without this online community, she never could have known the support and friendship of Carol – a woman she had never met in person! Several months earlier, Carol had responded to Jeni’s first discussion post about the challenges she face raising Chris, and the friendship had quickly blossomed.

**Figure 4-5:** An activity design scenario emphasizing synchronous communication.

In our final scenario, Jeni seeks immediate support after a distressing situation. She finds it in her friend Carol, another parent whom she knows exclusively online. Jeni and Carol “met” through the discussion boards, but now their relationship has progressed to the point that they enjoy synchronous communication.

### Table 4-5 Claims for Scenario 5

- Including a chat mechanism...
  - Allows for synchronous interaction.
  - Increases sense of community among participants.
  - May lure parents away from the asynchronous discussion board.
According to Blanchard and Markus (2002), among the key features of sense of virtual community are exchange of support, relationships, and emotional attachment. The synchronous online discussion – made possible through the chat feature – between Jeni and Carol clearly demonstrates these qualities. Although geographically dispersed, the web community has afforded them the opportunity to develop a relationship with each other. They have been able to find common ground through their experiences as parents. Given that their circumstances are statistically rare, it is not surprising that they do not live close to each other – but in many ways, online communication has rendered that unnecessary.

Of course, it is possible that users such as Jeni and Carol may eventually prefer synchronous chat exclusively over asynchronous communication, such as the discussion board. Because the discussion board has been leveraged as the primary communication portal, it is important to maintain reasonably high levels of activity there so new members can be assimilated into the virtual community. Displaying the discussion boards prominently – on the front page after members log in – will make it the centerpiece of the communication portion of the web site and will keep it relevant for veteran users. Tagging is another possible mechanism by which interest in the discussion boards could be maintained: the site could provide a predetermined list of tags, such as names of individual disabilities, or terms like “school” or “caregivers,” for discussion posters to choose among, and members could sign up to receive alerts whenever posts with a particular tag or tags are created.

Summary of Findings

The claims analysis generated from our three scenarios of use imply a number of design strategies for the consideration of software designers and other interested parties. The following
is a summary of those strategies and their rationale; our final chapter will explore their implications for design.

Table 4-6 Summary of Strategies

<table>
<thead>
<tr>
<th>Claims</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making this interactive online community for parents of disabled children free… make it accessible for anyone with Internet access, regardless of income level.</td>
<td>Provide the web portal at no cost to members.</td>
</tr>
<tr>
<td>+Makes it difficult to maintain without grant support.</td>
<td></td>
</tr>
<tr>
<td>-Still does not make it available to parents who do not have Internet access.</td>
<td></td>
</tr>
<tr>
<td>Enabling and encouraging the creation of a personalized account on an interactive web site for parents of disabled children…</td>
<td>Give members the opportunity to create a personalized profile, and allow them to place privacy controls on the content if they wish.</td>
</tr>
<tr>
<td>+Allows parents to feel welcomed to the web site.</td>
<td></td>
</tr>
<tr>
<td>+Gives parents an opportunity to both share information about themselves and learn about others.</td>
<td></td>
</tr>
<tr>
<td>+Allows users the freedom to express themselves not just as parents, but as people.</td>
<td></td>
</tr>
<tr>
<td>-May put users at risk of revealing personal information about themselves or their families to inappropriate individuals.</td>
<td></td>
</tr>
<tr>
<td>The availability of discussion boards…</td>
<td>Incorporate discussion boards into the web site. Encourage veteran users to join a “welcome wagon” group that would be alerted if a new member’s first post did not receive a reply within a couple of days.</td>
</tr>
<tr>
<td>+Gives parents the opportunity to talk about their lives with other people who understand their circumstances.</td>
<td></td>
</tr>
<tr>
<td>+Encourages sense of community among</td>
<td></td>
</tr>
<tr>
<td>The availability of private messaging…</td>
<td>Incorporate private messaging into the system, and have the option to send a private message prominently displayed so new users are aware of the capability.</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>+Allows parents to have private conversations.</td>
<td></td>
</tr>
<tr>
<td>+Generates a sense of trust among participants.</td>
<td></td>
</tr>
<tr>
<td>-May leave other users wondering why a discussion thread abruptly stops, and may prompt new users to believe that their discussion posts will not yield responses.</td>
<td></td>
</tr>
<tr>
<td>Providing a search capability…</td>
<td>Partner with a highly-developed search engine, such as Google, which does not require advanced search techniques for successful results. Allow users to search the entire Web from within the site so that more resources are available to them.</td>
</tr>
<tr>
<td>+Allows users to find information tailored to their specific question.</td>
<td></td>
</tr>
<tr>
<td>-May be frustrating for users who are not adept at structuring search queries.</td>
<td></td>
</tr>
<tr>
<td>Providing information on specific school systems and state-specific waiver programs…</td>
<td>Delegate control of this database so that it can be administered locally. Distribute the responsibility to specialists who are familiar with the resources available in their area.</td>
</tr>
<tr>
<td>+Helps parents learn about resources in their specific area.</td>
<td></td>
</tr>
<tr>
<td>+Gives parents a way to navigate through an often complex system.</td>
<td></td>
</tr>
<tr>
<td>-May be too difficult to integrate into such a website, given the quantity of information.</td>
<td></td>
</tr>
<tr>
<td>The availability of an integrated bookmarking resource…</td>
<td>Integrate a bookmarking resource for both discussion and information pages, and include</td>
</tr>
</tbody>
</table>
| +Makes it easy for users to find relevant information later.  
- May create a lot of overhead if there is no way to manage them (i.e. categorize them into folders) and users have accumulated many of them. | an easy-to-use folder system for bookmarks. |
| A section of content on treatments that is updated exclusively by professionals... +Gives parents the reassurance that this content can be trusted.  
- May inadvertently give parents the impression that all content on the web site is filtered for accuracy, which is impossible. | Prominently display messages at the top of each page that indicate the source of the content so that users are better able to evaluate the credibility of the information presented. |
| Including links to other credible information repositories... +Gives parents access to resources beyond the web site itself.  
- May cause potential members to navigate away from the site and never return. | Partner with other credible information sources and link to them, but set up these links so their pages open in another tab or another browser window. |
| The availability of discussion boards... +Allows parents of older children to “give back” by assisting others.  
- May put parents at risk of accepting inappropriate or erroneous advice. | Post a message at the top of each discussion thread explaining that the content of the thread is not moderated by site administrators. |
| Pushing email alerts when new content is posted... +Allows parents to keep up-to-date without constantly checking the site.  
- May be irritating if too many emails are received, especially if they pertain to a medical or behavioral issue that is uncommon. | Allow users to customize the frequency and content of email alerts. |
<p>| Having an FAQ for both parents and | Include an FAQ for both parent and |</p>
<table>
<thead>
<tr>
<th>professional members…</th>
<th>professional members. Display an obvious link for potential contributors on the main page.</th>
</tr>
</thead>
<tbody>
<tr>
<td>+Provides a quick resource explaining the purpose, design, and features of the web site.</td>
<td></td>
</tr>
<tr>
<td>+Affords members of various backgrounds the opportunity to learn about why they should use the site.</td>
<td></td>
</tr>
<tr>
<td>-May not be the most obvious channel for professionals to find the application to become an official contributor.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Allowing professionals to sign on as contributors…</th>
<th>Use the pilot group of clinicians as a professional base that encourages colleagues, both local and geographically dispersed, to sign up as contributors.</th>
</tr>
</thead>
<tbody>
<tr>
<td>+Provides more resources for parents.</td>
<td></td>
</tr>
<tr>
<td>+Lends credibility to the web site.</td>
<td></td>
</tr>
<tr>
<td>-May prove difficult, as it is hard to recruit volunteers.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Including an application to screen potential contributors that includes a request for state certifications…</th>
<th>Incorporate the application, including the request for state certifications, into the screening process for new contributors. Make the application process as simple as possible, and explain the need for credible resources so that parents are not led astray.</th>
</tr>
</thead>
<tbody>
<tr>
<td>+Will help protect parents from potential contributors who lack the needed expertise.</td>
<td></td>
</tr>
<tr>
<td>-May be rather laborious for the professionals being screened.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Including a chat mechanism…</th>
<th>Include a chat mechanism so that participants can enjoy real-time interaction. To maintain an interest in the discussion boards, display them prominently, and encourage participants to sign up to be alerted if members post about topics of interest to them.</th>
</tr>
</thead>
<tbody>
<tr>
<td>+Allows for synchronous interaction.</td>
<td></td>
</tr>
<tr>
<td>+Increases sense of community among participants.</td>
<td></td>
</tr>
<tr>
<td>-May lure parents away from the asynchronous discussion board.</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 5

Implications for Design

The current understanding of health-related online communities offers an excellent starting point for researchers as they seek to better support parents of developmentally disabled children. However, the best systems will require research specific to these families as an individual domain. Although many of their struggles may be similar to other groups, such as families of children with cancer or diabetes, they cannot be assimilated into a generalized category of “families of children with health care needs” any more than can those with children who have the aforementioned illnesses. The challenges inherent to parents of children with developmental disabilities are unique. The fact that their circumstances are statistically uncommon is only the beginning of why they feel isolated. Children with developmental disabilities require persistent attention and care, throughout the day, every day. Depending on their disability and its severity, they may engage in behaviors that are considered socially unacceptable or even dangerous. The “official” channels of support, such as education, various therapies, and medical interventions, are fragmented, making the “system” very difficult to navigate. Although the child’s condition is usually expected to last his or her entire life, treatment options, government assistance, and educational policies vary greatly over time, and information about improvements and alterations is often not communicated to parents in a timely manner, if at all. The unique composition of these parents’ experiences makes them a unique category of users whose specific needs are yet unexplored by software designers -- who in this era of ubiquitous connectivity could make a significant contribution towards improved information and social support.
The analysis presented herein prompts a framework for a free, dual-purposed web site for parents of children with special needs. The scenarios and their resulting claims have suggested a good many design possibilities for achieving both purposes: the dissemination of much-needed information, and the opportunity for increased social engagement and sense of community. If implemented, such a web site would offer a comprehensive solution to a largely invisible but pervasive problem.

**Designing for Information Needs**

For the information end of the site, prior research has indicated a profound need for credible resources. Therefore, I recommend that this web site be designed by a team that incorporates the knowledge of a clinicians and specialists from various backgrounds. This pilot group could spearhead a grassroots effort to recruit professional participation from throughout the United States. As participation grows, areas of the web site could be administered regionally, so that the responsibility of gathering information specific to various states or cities is delegated to professionals who are experts in each geographic region. Professionals from the medical, educational, legal, and therapeutic fields could apply to be contributors to this information repository directly through the web site, and could be screened to ensure that their credentials are valid.

In an effort to expand the availability of resources, the web site could partner with other trustworthy information sources and provide links to their sites. These links could open in new tabs or browser windows so that users could easily navigate back to the original page. To facilitate the information seeking process, this web site could have a domain-specific search function, provided by a high-quality engine such as Google. This search function could also be used to search the whole web, if a user should wish. Members would be able to bookmark from
within the site so that they might return to pertinent pages at a later time, and they would be able to organize those bookmarks to the level of specificity they desired. Users could sign up for periodic email alerts when new information is posted – with content that they specify if of interest to them, at frequencies that are suitable for their needs. Each page could have an indication of what information source is producing the content, so that parents gain confidence in their ability to discriminate between credible and questionable information. A prominently displayed FAQ for both information seekers (parents) and information sources (professional contributors) could be provided to explain the purpose, design, and navigation of the web site.

Designing for Social Needs

The second goal of this web site is to facilitate social support and bolster sense of community among parents of children with disabilities. To this end, it should also allow them to interact with each other both publicly and privately. Parents should be able to create detailed personal profiles, giving them the opportunity to have an “identity” all their own in the community. Members should be able to maintain privacy controls on these profiles so they can feel safe. Discussion boards could act as the gateway to communication and social connection, and the primary vehicle for achieving a sense of virtual community among participants. To encourage activity on the boards, especially among new members, a “welcome wagon” team could be assembled by recruiting veteran members as volunteers to respond to first-time posters if their posts do not receive a reply within a few days. Also, discussion tagging could be incorporated so that posters would be able to use tags to indicate the content of their posts – much like bloggers do. Other members could sign up to receive notifications if new posts were submitted concerning topics of interest to them. Private interactions could consist of both
asynchronous (private messaging) and synchronous (chat) features, giving members the opportunity to socialize in a one-on-one fashion and build closer relationships.

**Analysis: Applying the Framework**

Now that a framework for developing an effective web site for parents of developmentally disabled children has been established, I will apply that framework to three existing web sites to explore where the results of this thesis may have impact. All of these web sites currently provide information and communication opportunities to families of children with disabilities.

**First Analysis: New Horizons Un-Limited**

The first web site to be examined is New Horizons Un-Limited, which can be accessed at [www.new-horizons.org](http://www.new-horizons.org). New Horizons is a 501(c)3 non-profit institution with a mission to “make information and life experiences accessible to individuals with lifelong disabilities and their families.” Is it based in Milwaukee, Wisconsin, and provides technology-related services to the greater Milwaukee area in addition to maintaining a web site for national outreach. New Horizons’ commitment to building community is evident through its motto: “You are not alone!”

All services provided through the New Horizons web site are free. Their web site includes links to support New Horizons financially by donating funds, providing equipment for their office and outreach programs, or by participating in fundraising activities. These requests speak to the advantage of organizing as a non-profit – there are opportunities to support a free service through volunteer donations and fundraising.
New Horizons does reasonably well at overall site management. I recommended that resource development be delegated and distributed. New Horizons expresses interest in recruiting volunteers nationwide for the purpose of site testing and sharing resources. One of the scenarios demonstrated the usefulness of including an FAQ for both potential parent members and potential contributors. Here, New Horizons is not as effective: the site has an FAQ for the discussion boards, but not for explaining the site’s overall purpose and use. There is another large FAQ linked from the front page, but it is comprised of disability-related questions, not questions about the web site itself.

New Horizons provides an impressive quantity of information. My recommendation was that a pilot group (in this case, based in Milwaukee) could expand the network of contributors by calling on colleagues from their professional network. It appears that this has been done to some extent. However, most of the resources in every section are applicable to the entire United States or are specific to Wisconsin. Information specific to other states does appear sporadically, but a typical information category will contain resources for the US, Wisconsin, and another seemingly random selection of one to five states.

There are two methods of sharing expertise with New Horizons. Both are linked off the front page of the site, although not as prominently as they could be. The first is to “Share Your Knowledge and Experiences,” which seems to primarily target veteran families of children with disabilities. Here, one can fill out a brief form to submit a narrative of a personal experience, which the site administrators may choose to add to the “Experiences” section of the web site. One could also submit a review of an online or print resource; the site administrators can add all or parts of these reviews to multiple areas of the web site that point to external resources. The other primary way of sharing expertise with New Horizons is to sign up as a volunteer through the “Contribute” link on the web site. From here, a user can access a volunteer application form. New Horizons lists a variety of volunteer opportunities, most of which are location-specific and
require availability in the Milwaukee area. However, “website research and writing” and “newsletter writing” are also listed as volunteer opportunities, and New Horizons encourages Internet-only volunteers to apply. The volunteer application is fairly simple and includes fields for two non-family references. It does not, however, explain the importance of providing these references. There is no emphasis whatsoever on recruiting state-certified professionals. (See Figure 5-1.)

![Image of New Horizons Un-Limited Inc. Volunteer Application](image)

**Figure 5-1:** New Horizons’ volunteer application. While the application does request references, it does not ask for any state certifications.

Remarkably, despite the impressive repository of information available through the New Horizons web site, there is no search tool for the content portion of the site (the discussion board has a built-in search feature). Links advertising “search” in fact only allow the user to browse
through the site directory. New Horizons does, however, partner with many credible information sources, and there are a prodigious number of links throughout the site to external sources. These links do not follow my recommendation to open in another browser window or tab, so a user could easily navigate away from New Horizons for good. In terms of information organization, there is no bookmarking tool, and no method of receiving email alerts when new content is posted.

New Horizons is notably effective at expressing the source of information content on each page. One area of the web site is devoted to editorials, and each one is designated as such. There is no message on the discussion boards themselves noting that they are not moderated; however, when a new user signs up for an account, he or she must agree to terms which acknowledge that New Horizons does not warrant the accuracy of the content posted to the forum.

In addition to providing a vast quantity of information, New Horizons’ web site also encourages sociability. Users can create personalized profiles with information about their interests, a picture, and alternative methods of contacting them. However, there are no social networking privacy controls built into this personalization. A user can limit the information provided in his or her profile, but cannot provide additional information to other trusted members as there is no “friending” tool. The discussion boards are the primary communications portal, although they are not displayed prominently on the front page of the site – one of New Horizons’ few major shortcomings. There appears to perhaps be a rather informal “welcome wagon” team in place, as some posts have received responses from moderators. However, this does not appear to be of great importance currently, as the vast majority of existing posts were written by moderators. A type of discussion alerts is built in to the New Horizons forum: one cannot sign up for posts in a particular thread or of a certain topic, but one can sign up to receive email alerts if
his or her post receives a response, and/or if an “announcement” (a general informative post submitted by an administrator) is posted.

Private sociability is supported currently by asynchronous private messaging (termed “instant messaging” by the New Horizons site, a potentially misleading term as it evokes real-time interaction for most users) and email. Although there is no synchronous chat feature available currently, this is listed as a future goal.

New Horizons: Impressions and Impact

Analysis of the New Horizons web site through the lens of our new framework demonstrates that it does a fairly good job already of balancing information and sociability. The site’s motto immediately speaks to its commitment to building sense of virtual community: “You are not alone!” The site adheres to several of the information-related recommendations generated by the scenario and claims analysis: the administrators seek volunteers distributed throughout the United States (Scenario 2), the pilot group of professionals appears to have expanded with moderate success (Scenario 2), volunteer recruits are required to furnish references (Scenario 4), the sources of information content are displayed (Scenario 3), and new discussion board members must agree to terms acknowledging that posts are not moderated for validity (Scenario 3). New Horizons also performs reasonably well in terms of supporting communication, as it allows for some personalization (Scenario 1), demonstrates a “welcome-wagon” approach to new discussion posters (Scenario 1), provides some discussion alerts (Scenario 5), enables private messaging (Scenario 1), and indicates movement toward synchronous chat support (Scenario 5).

Although they may not be readily apparent, the shortcomings inherent to New Horizons’ web site design are illuminated by our framework-driven analysis. There is no general FAQ for the site (Scenario 4) – only the discussion boards have one, so users who want to learn more
about the information portion of the web site have no resource for this. Although volunteers are required to provide references, there is no effort on New Horizons’ part to recruit professional, credential-bearing contributors (Scenario 4). There is an impressive quantity of information available on the site, but it can be very difficult to sort through because of the absence of a search tool (Scenario 2). The many external links do not open in a new browser window or tab, creating a possibility that a user may navigate away permanently from New Horizons (Scenario 3). Information management is also in need of improvement, as there is no bookmarking tool (Scenario 2) or method of receiving email alerts when new content is generated (Scenario 3).

New Horizons exhibits a goal of supporting sociability, but several inadequacies limit its success with this objective. Most significantly, the link to the discussion boards is not displayed prominently on the main page of the site (Scenario 5). It would be very easy to miss, and the relatively low traffic on the discussion boards suggests that perhaps it has been overlooked by visitors. Other limitations are less problematic, but still indicate possibilities for improvement: users are not able to customize privacy controls or perform advanced social networking functions such as establishing “friend” ties with other users to grant them greater access to their profiles (Scenario 1), and there are no topic-specific discussion alerts available on the forum (Scenario 5).

The following table summarizes my recommendations for the New Horizons site, based upon the framework developed in this paper.

Table 5-1 Recommendations for New Horizons

<table>
<thead>
<tr>
<th>Information-Related Recommendations</th>
<th>Social Support-Related Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Add FAQ for both parents and contributors</td>
<td>• Display discussion link prominently on the homepage</td>
</tr>
<tr>
<td>• Add mechanism for recruiting professional contributors</td>
<td>• Add privacy controls for profiles</td>
</tr>
<tr>
<td>• Add search tool</td>
<td>• Add topic-specific discussion tagging and alerts</td>
</tr>
</tbody>
</table>
• Set up links to external sites so they open in a separate window/tab
• Add bookmarking tool
• Add content-specific email alerts

Second Analysis: Children’s Disabilities Information

Our second sample web site is Children’s Disabilities Information, which resides at http://childrensdisabilities.info. Children’s Disabilities Information seeks to provide “articles and resources empowering parents of children with disabilities and special needs.” It is run by a mother whose son, now a young adult, has multiple disabilities. All resources are provided for free. The site includes advertising links to various online stores that sell disability-related products and some Google ads on the sidebar, but these appear to be its only revenue source, as no solicitation for charitable contributions can be found on the web site.

In sharp contrast to the model developed in this paper, Children’s Disabilities Information is run centrally by one person. Despite this constraint, there is an impressive quantity of information gathered, and the web site owner encourages authors to contribute articles and books for review. However, there is no FAQ for either parents or contributors; the “About Us” page includes a bit of information for potential contributors, but there is no obvious link for them to follow on the front page of the site.

Children’s Disabilities Information falls short of many of the information-gathering requirements developed in this thesis’s framework. There is no “pilot group” of clinicians or professionals ready to tap into a network of colleagues, as the site is run exclusively by one parent. There is no clear application process to become a contributor to the site. Instead, the web site owner requests that interested parties send her an email. Despite these shortcomings, it is
obvious that the web site owner has developed a considerable network of relevant authors who provide information for the site.

In accordance with the suggestions I have developed, Children’s Disabilities Information does have an internal search function provided by Google. However, a user can only search the site itself, not the entire web. The site has partnered with many external resources, and links to their sites open in a new browser window (or tab, depending on the browser being used). However, no bookmarking system or content update email alerts are provided.

Information quality assurance is implemented well on the Children’s Disabilities Information site. The author of each article is provided, and most articles feature detailed biographical information about the author at the bottom.

Children Disabilities Information’s major shortfall is its limited sociability support. The site allows for no personalization, discussion, or synchronous communication, rendering it a “virtual settlement” instead of a true virtual community. Its only support for social interaction is a lengthy list of links to disability-specific list servs. (See Figure 5-2.) While this is certainly helpful and better than no reference to communication at all, it completely removes any possibility of sociability from within the Children’s Disabilities Information site. Of course, given the site’s name and mission, it is not surprising that information resources are almost exclusively emphasized.
Children with Disabilities Information: Impressions and Impact

While Children’s Disabilities Information does not perform as well as New Horizons when examined through our framework’s lens, it still has its strengths, especially considering that it is run by a single person. The website author encourages authors to contribute their expertise to the website (Scenario 3), and she has obviously assembled a formidable network of contributors. Users can find information with relative ease through the Google internal search (Scenario 2), and can quickly navigate back to the site if they click on external links since they...
open in a separate window (Scenario 3). The site administrator seems to take information quality assurance quite seriously, as author names and biographies are prominently displayed on articles (Scenario 3).

Children’s Disabilities Information’s content-related weaknesses are many. It is run centrally by one person, so all updates depend on her (Scenario 2). There is no FAQ available (Scenario 4), and although some information for contributors is provided on the “About Us” page, this is not an obvious channel for this purpose. There is no application process for contributors (Scenario 4), so the web site owner’s method for assessing their credibility is a mystery. Users are not able to search beyond the web site itself (Scenario 2), nor can they bookmark (Scenario 2) or sign up for email alerts when new content is added (Scenario 3).

Of course, Children Disabilities Information’s most prominent flaw is its limited sociability support. The web site does provide a long list of disability-specific email list servs with links that allow users to sign up for them, but there is no communication functionality housed within the site (Scenario 1, Scenario 3, Scenario 5). One could argue that supporting sociability is simply not a goal of the Children Disabilities Information site – after all, its name does not suggest otherwise. However, this one-sided approach gives the site a “virtual settlement” quality with no sense of virtual community. Also, its mission is to provide “articles and resources empowering parents”; the literature reviewed herein has provided an abundance of evidence that social support contributes substantially to a parent’s sense of empowerment.

The following table summarizes my recommendations for Children’s Disabilities Information, driven by the results of the scenarios and claims analysis.
Table 5-2 Recommendations for Children’s Disabilities Information

<table>
<thead>
<tr>
<th>Information-Related Recommendations</th>
<th>Social Support-Related Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Leverage the web site owner’s current network to recruit more moderators and delegate responsibility</td>
<td>• Provide within-site socialization to complement the socialization opportunities available outside the web site (list servs) – could use a free discussion forum service and build from there</td>
</tr>
<tr>
<td>• Add FAQ for both parents and contributors</td>
<td></td>
</tr>
<tr>
<td>• Incorporate screening application for potential contributors</td>
<td></td>
</tr>
<tr>
<td>• Allow for external search</td>
<td></td>
</tr>
<tr>
<td>• Add a bookmarking tool</td>
<td></td>
</tr>
<tr>
<td>• Add content-specific email alerts</td>
<td></td>
</tr>
</tbody>
</table>

Third Analysis: Family Village

The final web site to be analyzed using the new framework is The Family Village, a site hosted by the University of Wisconsin-Madison that bills itself as “a global community of disability-related resources.” All its services are provided for free, and management of the site is funded by Mary Claire Phipps, the Charles H. Phipps Family Foundation, and the Waisman Center at UW-Madison.

There is no evidence that authority over content is delegated to other groups and professionals, as it appears that all the work of assembling and disseminating content has been done by the team at UW-Madison. There is no overall FAQ for the website. The discussion area has its own FAQ, while the site’s main page links to an “About Us” that is set up in a question-answer format. This “About Us” section includes information on having resources added to the site, and links to a “Suggestions” area (which is also linked on the front page). This “Suggestions” area links to several forms for adding links and other resources. There is no
application process, but those who make suggestions are encouraged to provide contact information. It is not apparent whether or not the UW-Madison team has networked with other colleagues for input, but it is at least possible, as the Family Village is affiliated with the Waisman Center, described as “one of nine national facilities that includes a Mental Retardation Developmental Disabilities Research Center and a University Center for Excellence in Developmental Disabilities.”

The Family Village site provides multiple search capabilities, both for the discussion forum and the rest of the site. Searching the site navigates away from the Family Village domain and does not open up a new tab or browser window. (See Figure 5-3.) Linking to credible resources is probably its most significant function: all of the information resources are links to other web sites. However, none of the links are specific to states or other regional interests. The links do not open in a separate tab or window. Although a “What’s New” page does list all content updates for each month, there is no way of pushing this information through email alerts, and there is no bookmarking system.

Figure 5-3: The Family Village search page. The web site supports both internal and external search, but search results do not open in a new window or tab, and searching navigates away from the Family Village domain.
Since none of the content is actually stored within the web site, the identification of source content is instead given in the text of each link. Most links are to official agencies or advocacy groups, and these sites provide their own credentials. At the very bottom of the main page of Family Village is a link to a disclaimer indicating that the content on the site is “for educational purposes only” and that the inclusion of a link does not necessarily imply Family Village’s endorsement of its content. When a new member signs up for the discussion boards, he or she must agree to a set of terms that includes an acknowledgement that individual posters, not Family Village, are responsible for the content on the forum.

Sociability is also promoted on the Family Village site. There is a link to discussion boards on the main page. Members are able to create personalized profiles with the same features as those on the New Horizons forum. There are no advanced social networking capabilities, such as “friending” or privacy control settings. There does not appear to be any “welcome wagon” team, as many of the posts have received no response, and there is no way to sign up for discussion alerts. Users may communicate privately using private messaging (although this option is not displayed prominently). There are no synchronous chat opportunities available through Family Village.

**Family Village: Impressions and Impact**

Like New Horizons, the Family Village web site is reasonably adept at providing both information and social support resources. Their site’s description, “a global *community* of disability-related *resources*” (emphasis mine), evokes the dual nature of its goals. Distributed information gathering is supported (Scenario 2), as the site administrators have created an understandable mechanism for contributing suggestions to the Family Village by placing a link
on the front page. The project is within the purview of the Waisman Center at UW-Madison, which gives its administrators access to the network already established by members of this center through collaborations with professionals around the country. Site navigation is simplified by the incorporation of a search tool (Scenario 2), and the sources of content are consistently identified (Scenario 3).

Family Village has also taken steps to promote communication opportunities through its site. The link to discussion is more prominently displayed on the site’s main page than its counterpart on New Horizons’ homepage (Scenario 5). Members can create personalized profiles (Scenario 1), and private messaging is available (Scenario 1), though not as prominently displayed as it could be.

Like the other sites reviewed herein, Family Village has a variety of areas needing improvement. The information portion of the site has multiple shortcomings: the central assembly of content has resulted in a lack of any state- or region-specific resources (Scenario 2), there is no general FAQ for the site (Scenario 4), and there is no application process for potential contributors (Scenario 4). Information acquisition is hindered by a search tool that navigates away from the Family Village web site and links that do not open in a new window (Scenario 3). Information management is also limited by a lack of bookmarking (Scenario 2) and email alerts (Scenario 3). Although the sources of information are identified, Family Village’s disclaimer indicating a lack of responsibility or endorsement of content on external links is buried at the bottom of its homepage, and could be easily overlooked (Scenario 3). Although sociability is supported at Family Village, it has its limitations, including a lack of privacy controls (Scenario 1), an absence of a “welcome wagon” team (Scenario 1) and discussion tagging (Scenario 5), and no method of communicating synchronously (Scenario 5).

The following table summarizes my recommendations for Family Village, generated by the framework developed herein.
<table>
<thead>
<tr>
<th>Information-Related Recommendations</th>
<th>Social Support-Related Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Network with other centers to provide regional and local information</td>
<td>• Add privacy controls for profiles</td>
</tr>
<tr>
<td>• Add FAQ for both parents and contributors</td>
<td>• Add “Welcome Wagon” team</td>
</tr>
<tr>
<td>• Incorporate screening application for potential contributors</td>
<td>• Add topic-specific discussion tagging and alerts</td>
</tr>
<tr>
<td>• Change search so it does not navigate away from Family Village</td>
<td>• Enable real-time chat interaction</td>
</tr>
<tr>
<td>• Set up links to external sites so they open in a separate window/tab</td>
<td></td>
</tr>
<tr>
<td>• Add a bookmarking tool</td>
<td></td>
</tr>
<tr>
<td>• Add content-specific email alerts</td>
<td></td>
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</tbody>
</table>

**Conclusions**

Parents of children with developmental disabilities face many challenges as they care for their children. They report great needs for information and emotional support, yet their experience shows that these needs are not adequately met. A review of current research illustrates that various Internet resources can help to meet parents’ needs for information, emotional support, and a sense of community. Parents report a high level of satisfaction with these tools. They are particularly useful for families who are located in remote areas, who have children with uncommon disabilities, who have difficulty leaving home, or who experience financial difficulties (a relatively common struggle).
The findings of this thesis should be of interest to software developers who are interested in designing and deploying new tools (or improving existing tools) for parents of children with special needs. The preferences expressed by parents as to how they desire written information to be delivered could be adapted to the web interface. An obvious need for credible information should inform the development of any information portal or repository. Parents have consistently stressed the importance of communication for support, whether it is from other parents or from professionals. Facilitating such connections should be a primary objective in the design of a new online tool.

Although the research directly pertaining to online use among parents of disabled children is not currently published in information science and technology venues, it would benefit from the integrated perspective of this field. In this case, such a perspective gives a rich view of the entire context – the people involved (parents, other family members, practitioners, etc.), the information required (and likewise, that which is not required – i.e. erroneous, misleading, or confusing information), and the technology that mediates communication and information exchange. This integrated approach affords researchers a better and more complete understanding of the situation, but also allows for a greater opportunity to assess needs, misunderstandings, and knowledge gaps among parents and professionals that may be addressed through practice and implementation.


References


Dervin, B. (1983) An overview of sense-making research: concepts, methods and results to date. Paper presented at the International Communications Association Annual Meeting, Dallas, TX.


