

Disablity Related Issues and Constructing Online Communities

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Aaron J. Bond

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Department of Educational Psychology and Special Education
The University of British Columbia
Vancouver, Canada

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Abstract

In this study, two questionnaires were specifically developed to identify variables that may potentially effect participation in online communities. A total of seven organizations responsible for the design, development, and maintenance of online communities for or including children with disabilities or serious illnesses were involved with this study: Ability OnLine, Children With Diabetes, ConvoNation, KidSET, Project Do-IT, STARBRIGHT World, and Talk City. The information obtained from the seven system administrators and 151 participants provided information for future design and development of online communities, a first look at variables that potentially impact participation in online communities, and a better understanding of social experiences within online communities. Findings from this study indicated that adolescents with disabilities or serious illnesses perceive their peer group integration to be lower than their peers without disabilities or serious illnesses and that this isolation may increase with age. The provision of opportunities for students with disabilities to interact, develop relationships, and groups with others that share commonalties can diminish this isolation (Stainback et al., 1996). This study demonstrated the potential of online communities to provide opportunities for meaningful social experiences for adolescents with disabilities and serious illnesses.

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GLOSSARY

Technical Terms

The following definitions are based on definitions from Webopedia (1998).

Computer Mediated Communication (CMC)

CMC is used to describe various computer mediated environments that provide communication and/or collaboration between or among individuals. (e.g., E-mail, Newsgroups, Internet Relay Chat, Desktop Video Conferencing)

CU-SeeMe

CU-SeeMe is a real-time, multiparty video-conferencing system for the Internet.

Bulletin Board System (BBS)

A BBS is an electronic message center. Most bulletin boards serve specific interest groups. They allow a user to dial in with a modem, review messages left by others, and leave their own message if they want.

E-mail

E-mail allows a user to send message(s) to another user (or many users via mailing lists).

Internet.

The Internet is a world wide network of telecommunications that can link computers together to share information and provide communication.

Internet Relay Chat (IRC)

IRC provides real-time communication between two or more users via networked computers. Once a chat session has been initiated, either user can enter text by typing on the keyboard and the entered text will appear on the other user's monitor.

LISTSERV

LISTERV is a mailing-list program for group communication.

Multiple-User (MUs)

MUs are real-time interaction systems (usually text) traditionally used for social role-playing. MU = Multiple-User Dialogue/Domain/Dungeon and variants. Variants include MUD, MUCK, MUSH, MUSE, MOO.

MOO

A MOO is an object-oriented Multiple User Dialogue (MUD).

Newsgroups

Newsgroups are electronic discussion groups on a particular subject or theme utilizing e-mail to send and receive communications from the group and individuals through a network called USENET.

Special education terminology**Inclusion**

Inclusion refers to (1) the entitlement all students have to equitable access to learning, achievement and the pursuit of excellence in all aspects of their education, and (2) participation, friendship, and interaction (BC Ministry of Education, Special Education Services, 1995).

Integration

Integration involves (1) educating special needs students with peers who do not have special needs and (2) providing necessary accommodations and adaptations, determined on an individual basis, to enable them to be successful (BC Ministry of Education, Special Education Services, 1995).

Regular Class

A regular class includes students who receive the majority of their education program in a regular classroom and receive special education and related services outside the regular classroom. It includes children placed in a regular class and receiving special education within the regular class, as well as children placed in a regular class and receiving special education outside the regular class (U.S. Department of Education, 1995).

Resource Room

A resource room includes students who receive special education and related services outside the regular classroom. This may include students placed in resource rooms with part-time instruction in a regular class (U.S. Department of Education, 1995).

Separate Class

A separate class includes students who receive special education and related services outside the regular classroom. Students may be placed in self-contained special classrooms with part-time instruction in regular classes or placed in self-contained classes full-time on a regular school campus (U.S. Department of Education, 1995).

Separate School

A separate school includes students who receive special education and related services in separate day schools for students with disabilities (U.S. Department of Education, 1995).

Residential

A residential facility includes students who receive education in a public or private residential facility, at public expense. (U.S. Department of Education, 1995)

Homebound/hospital environment

Homebound/hospital environment includes students placed in and receiving special education in hospital or homebound programs (U.S. Department of Education, 1995).

PREFACE

The original intention of this study was to evaluate and compare existing online communities for children with disabilities or serious illness. The purpose of the two questionnaires, system administrator and participant, was to provide a balance in the data collected about the online communities. Since the majority of organizations (5) did not allow members to participate or did not have any responses from members, it was not possible to reliably compare the online communities. Comparison of the organizations was based solely on the descriptive data gathered through the system administrator questionnaire.

The participant population studied was specific to the Talk City community. However, the unexpected benefit of this single population was the ability to look for differences between the target population, youth between the ages of 12 to 18 with a disability or serious illness, and participants of the same age without a disability or serious illness.

The following thesis represents the evolution of the research project due to the unexpected obstacles encountered during the course of the research.

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CHAPTER I

Introduction

The idea of a community accessible only via my computer screen sounded cold to me at first, but I learned quickly that people can feel passionately about e-mail and computer conference. I've become one of them. I care about these people I met through my computer, and I care deeply about the future of the medium that enables us to assemble. I'm not alone in the emotional attachment to an apparently bloodless technological ritual. Millions of people on every continent also participate in the computer-mediated social groups know as virtual communities (Rheingold, 1993, p. 2).

History of Online Communities

The Internet is increasingly affecting how we work, socialize, and learn. The role virtual communities on the Internet will play in users lives is still uncertain. Online interactive communities have been a goal of the Internet since its inception in the 1970s. Licklider and Taylor, research directors for the Department of Defense's Advanced Research Projects Agency, created the first online community, ARPANET. They wrote in 1968: "In most fields they will consist of geographically separated members, sometimes grouped in small clusters and sometimes working individually. They will be communities not of common location, but of common interest..." (Rheingold, 1993, p. 21).

The great-great-grandmother of all virtual communities, Turoff's Electronic Information Exchange System, started in 1976. Turoff noted in 1976:

I think the ultimate possibility of computerized conferencing is to provide a way for human groups to exercise a "collective intelligence" capability. The computer as a device to allow a human group to exhibit collective intelligence is a rather new concept. In principle, a group, if successful, would exhibit an intelligence higher than any member. Over the next decades, attempts to design computerized conferencing structures that allow a group to treat a particular complex problem with a single collective brain may well promise more benefit for mankind than all the artificial intelligence work to date (as cited in Rhiengold, 1993, p. 36).

Although it is impossible to get a true count of the number of people currently accessing the Internet, it is estimated that 24 million people in the U.S. and 36 million worldwide access it regularly (eMarketer, 1998). The term "Information Superhighway" is widely used in the popular media to describe the Internet and the World Wide Web as the most valuable medium for information since the microprocessor (Schrage, 1997). The following description by Schrage (1997) shows how this view of these technologies is very limiting: "To say that the Internet is about "information" is a bit like saying that cooking is about oven temperatures; it's technically accurate but fundamentally untrue." (p.3) Schrage believes the so-called "information revolution" is more accurately a "relationship revolution" because the biggest impact these technologies have had, and will have, is on relationships between people and between organizations.

Recent research has begun to study the effects of computer mediated communication (CMC) on social experiences. Parks and Floyd (1996) and Ahern and Durrington (1996) have

found such media to be effective in developing social interactions and relationships. A survey by the Gallup Organization of 40,000 Internet users under 35 years old found that 45% used the Internet for socializing (Guly, 1998). Various CMC tools have been used by virtual communities to enable communication, collaboration, and construction.

One type of CMC tool is a Multi-User Domain (MUD) which affords real time, text-based communication and the construction of interactive virtual environments. Based on interviews with participants, Bruckman (1992) described MUDs as identity workshops. She found that many of the participants saw themselves as somehow different on a MUD than off, and this lead them to reflect on who they were in real life. These experiences may help people understand the concept of identity and the ways in which we construct ourselves. In virtual communities, a person can escape his or her physical body by creating images with lines of text. Social relationships become less threatening because at any time individuals can create new persona and start over (Bruckman, 1992).

Evidence from recent research suggests that CMC affords opportunities for social experiences and that Internet users are realizing the potential of various media to interact, develop relationships, and form communities. Before investigating and discussing how online communities can change our social experiences, we need to know who the people are that participate in these virtual places (Rhiengold, 1993). One group of individuals that have used the Internet to congregate and construct a community based on similar beliefs are adults with autism. A fundamental principle of this community is that autism is a way of being, not a defect or something to be cured (Dekker, Greer, Lally, Simpson, & Walker, 1998). Children

who are disabled or terminally ill have also started to experience and participate in online communities.

People with Disabilities and Online Communities

What is wonderful about a computer is being independent instead of being coddled all the time, like a baby in arms, because of my blindness. It feels like being coddled like a baby sometimes, because everybody wants to help.

[signed] Janice Ware, Student (Clarke, 1995).

For individuals with disabilities, the Internet has the ability to increase opportunities for accessing information and interacting with peers (Gold, 1997). Online communities for children with disabilities have been developing over the past several years, and are experiencing varying levels of success in terms of their overall use. Each virtual community has been designed and developed differently. Ability OnLine Support Network started in 1992 and uses a basic Bulletin Board System (BBS). Convomania was launched to the public on April 3, 1997, and uses a Web site with online chat, interactive games, a message board, and web pages for personal and group expression. Founded in 1992, Project DO-IT (Disabilities, Opportunities, Internet Working, and Technology) uses electronic mail to provide communication between high school students with disabilities who are interested in science, math, or engineering.

The number of participants in these communities range from 10 to 5,000; and the frequency of use, based on the number of postings, ranges from zero to two hundred communications daily (Burgstahler, 1997; Children with Diabetes, 1999; STARBRIGHT Foundation, 1998). A common goal of all the online communities is to develop a network of

peers for socialization and support. While a rationale for developing many of these online communities is not always explicitly communicated, one will be provided here.

A Rationale for Online Communities for Students with Disabilities.

The attributes and social skills necessary for social and emotional development for all children, as defined by the BC Ministry of Education (1990), involve providing children with experiences designed to: develop a positive, realistic self-concept; develop independence; set appropriate goals and feel satisfaction with their accomplishments and efforts; cope with change; share and cooperate; develop friendships; learn from others; and enjoy living. In a review of research on friendships, Bukowski, Parker, and Rubin (in press), found that the more a child is different from others in a group, the more difficult it is to form friendships. The premise that learning is socially constructed highlights the importance of meaningful social experiences within a student's learning environment. While students with disabilities are increasingly being integrated into the physical environment of their community schools, their inclusion in the social environment may be neglected (Kekelis, 1988b). Many students with disabilities do not finish high school and are less socially active than their peers without disabilities (Moccia, Schumaker, Hazel, Vernon, & Desher, 1989). The lack of meaningful social experiences may contribute to the isolation that many adults with disabilities experience. In a study of students with severe disabilities in a junior high school setting Chadsey-Rusch (1990) found that 99% of their interactions were with adults. A social environment devoid of meaningful peer interactions and relationships risks disruption of a child's overall development. During parent interviews, this same study found that school classmates had never visited nor been invited to the homes of students with disabilities after

school. These differences in social experiences for students with disabilities are alarming, given the important role peers play in a child's overall development. Based on a review of the research on social experiences, Bukowski et al. (in press) identified peers as powerful socialization "agents" who contribute to children's social and emotional well-being and adjustment beyond the influence of their families, school, and neighborhoods. Interviews by Chadsey-Rusch (1990) of parents of students with disabilities reported that their children did not have a lot of friends and rarely interacted with other students. The competence and self-esteem of children with disabilities can be positively effected by parents who provide opportunities to make choices, and interact with peers (Todis, Irvin, Singer, & Yovanoff, 1993). Many successful adults with disabilities identify opportunities to develop friendships with similar peers as critical to their development of a healthy self image that includes both their abilities and disabilities (Powers, Singer, & Todis, 1996). Online communities can provide students with disabilities access to mentors and peers who share similar life experiences. Across the spectrum of educational settings, full inclusion to residential, the Internet has the potential to provide a bridge that allows students with disabilities to communicate and congregate of their own accord.

A group of high school students with disabilities from all over the United States use the Internet for communication and collaboration as part of Project DO-IT, a federally funded project to support endeavors in science and technology. A recent study by Burgstahler, Baker, and Cronheim (1997) found that the largest percentage (61%) of Project DO-IT participants' communications were concerned with personal and social topics. This group of participants represented a wide range of disabilities including; physically disabilities,

deafness, blindness, health impairments and specific learning disabilities. This study indicates that students with disabilities may use CMC tools to interact with others who share similar life experiences as a person with disabilities.

Another benefit of using the Internet is the ease of access to the vast amount of information available on the World Wide Web (WWW). One Internet user describes the value of his experiences online as follows:

Apart from the freedom the net provides, it also carries a wealth of information on disability issues. There are newsgroups, e-mail lists, even IRC channels where you can discuss anything from deafness to bringing about equal rights. I have learned more about my own rare condition in 6 months on the Internet than in 23 years of visiting 'experts' (Egers, 1996, as cited in, Gold, 1997).

STARBRIGHT World is another online community specifically designed and developed for children with special needs. Steven Spielberg founded STARBRIGHT World, which, with support from leading technology corporations, represents an online community that utilizes many of the latest innovations in computer technologies. Two studies that have been done on STARBRIGHT World have investigated participant perspectives and patterns of use. During the beta testing of STARBRIGHT World, Holden (1997) noted that several children experienced technical problems with the Internet based programs and may have biased the observed use, 53% of the time, of the locally run game arcade programs. In the second study, participants highlighted the value of interacting with other children who have similar conditions and the need for additional features in the system (Bearison, 1997). Other

online communities for children with special needs use more basic CMC tools (e.g. BBS, E-mail) and have both flourished and floundered in terms of their overall number of active participants. Before studying the effect of participation in online communities, it would be valuable to know the variables that may effect participation in online communities. Current understanding of the design and development of online communities for children with special needs is very unclear. While there is evidence that suggests that CMC tools can provide a conduit for social experiences, there still remains a lot to be learned about how to best meet the needs of users that have disabilities.

Summary

The development of communities based on commonalties and shared ideas versus geographical location has long been a goal of the Internet. The view that the Internet is only about information misses the fact that information itself offers value only when presented in a social context (Schrage, 1997). People of all ages, both with and without disabilities, are participating in these virtual communities. Substantial research has investigated the social experiences of children with and without disabilities; however, it is unknown whether variables that effect social experiences that have been identified in "real life" settings will transfer to "virtual" settings. A few studies have begun to discover the potential of CMC tools to provide a medium for communication between children with special needs, but it is unclear how to best design and develop online communities that meet the needs of such participants. Rheingold (1993) highlights the point that technology will not in itself fulfill that potential; this latent technical power must be used intelligently and deliberately by an informed population.

The purpose of this investigation was to identify and understand issues that would inform the design and development of online communities that have the potential to provide students with disabilities a community for support and self-discovery. Through this investigation, variables were identified that may help develop effective applications of CMC tools and situate future research that seeks to understand participants' social experiences within online communities.

This study evaluated and compared existing online communities for children with disabilities. The field of user interface design provides insights into how to best understand or meet the needs of a target population. Nielsen and del Galdo (1996) recognized questionnaires as the best method for identifying variables because they allow for extensive coverage of diverse and dispersed users, which can lead to the discovery of differences between various groups of users and their specific needs.

To date, there is no questionnaire identifying variables that impact participation in online communities for members with disabilities. The survey used in this study was developed through a review of literature within two primary areas: (a) social experiences of children who have a disability and (b) social experiences within Internet based environments. Secondly, the survey tool was piloted with existing online communities of students with disabilities. The research question that guided the development of this survey tool was: What are the variables that impact the participation of students with disabilities in online communities?

To develop a rationale for the questions to be included in the survey, a review of the literature focused on the following questions:

1. What are the personal variables that effect the social experiences of students who have a disability?

2. What technology and design variables effect social experiences within computer mediated environments?

CHAPTER II

Literature Review

Introduction

In reviewing the literature on social experiences of students with disabilities the following topics appeared relevant: disability, gender, age, educational placement, communication, siblings, and non-school friends. These topics were used to organize the review of this literature and possible questions that are relevant to the survey. The second area of literature reviewed was computer mediated communication. The ACTIONS model, a framework developed by Bates (1995), was used to organize the review of CMC literature related to social experiences and people with disabilities. Again, questions that arose as a result of this review were applied to the development of the survey. The next section will provide an overview of the current online communities for children with disabilities and any research findings that exist. The last area will consider the need for a survey tool and the structure and questions for the pilot survey.

Variables That May Impact the Social Experiences of Students with Disabilities.

Type of Disability

Children with disabilities do not represent a homogenous group. The range of disability types and the diverse nature of each child's abilities within a given disability group suggests that each child should be viewed as an individual. To gain a better understanding of a disability, it is helpful to group people with similar characteristics for the sake of making comparisons between and among them. However, it is important to remember the uniqueness of each individual. Since this is the first investigation across the spectrum of current online

communities for children with disabilities it is not possible to describe who the current participants of these communities are. As a result of this study, a better description will be possible. Following is an analysis of research on the social experiences of some of the more prevalent disability groups.

A review of research on peer relations by Hartup (1983) found that children who are labeled learning disabled, educable mentally retarded, "hyperactive," emotionally disturbed, physically disabled, or multiply disabled have considerably different socialization experiences. For example, Deaf children of hearing parents may not have had exposure to Deaf role models or Deaf culture and, due to educational integration, may not have any experiences with Deaf peers. This points to a need for exposure to Deaf peers and an understanding of the Deaf culture (Humphrey & Alcorn, 1994).

Over 6 years, Markides (1989) observed the social interactions of 108 hearing-impaired children and 192 hearing classmates, ages 13-15, in seven different high schools. The study found that the children with hearing impairments spent more time alone or with one or two other children during break times in comparison to the hearing children, who showed a greater range of interactions and interacted with their hearing-impaired classmates only 5% of the time. Cappelli, Daniels, Durieux-Smith, Mcgrath, and Neuss (1995) used peer evaluations of social preferences and likeability to assess the social interaction environment of 23 children with hearing impairments, who were matched on gender and classroom with 23 hearing children in grades 1-6. They found that students with hearing impairments were significantly more rejected by their peers and received lower likeability and social preference ratings.

Across both elementary and high school settings, research seems to clearly indicate that peer

interactions of deaf and hard of hearing students are significantly different than their hearing peers (Antia, 1982; Cappelli et al., 1995; Coyner, 1993; Markides, 1989). Whether or not the social experiences of students who are deaf or hard of hearing are significantly different in comparison to other disability groups is unknown.

A review of research on students with learning disabilities suggests that they may experience social isolation, social status difficulties with peers, and social skill deficits (Feigin & Meisgeier, 1987; La Greca & Stone, 1990). Wenz-Gross and Siperstein (1997) noted the value of this research in understanding the social environments of children with learning disabilities, but made the point that such research has often been conducted without the perspective of the child: "We believe it is important to investigate how the child with disabilities envisions his or her social world" (p. 184). These authors examined social networks by interviewing 106 children in grades 4 through 6, 40 of whom had learning disabilities and 66 of whom did not. They found that the social networks of children both with and without learning disabilities did not differ in size or composition, but that children with learning disabilities used their networks differently for support. Children with learning disabilities reported that they turned to peers less often for social support and experienced less positive features in their friendships in comparison to children without learning disabilities. Students with learning disabilities in this study were in separate classes for most academic subjects; which may have affected how they use their social networks. (The variable of educational placement is considered later in this review.) The risks of students with learning disabilities not developing adequate social relationships have been linked to loneliness (Margalit & Efrati, 1994), depression (Magg & Behrens, 1989), and suicide (Peck, 1985, as

cited in Bryan, 1997). A meta-analysis of sociometric studies found that students with learning disabilities had lower sociometric status than their non-disabled peers, regardless of their gender and grade level (Ochoa & Palmer, 1995).

Students who are blind or have low vision may also experience the social milieu differently. Through a social skills training program for students with disabilities, Jones and Chiba (1985) found that children with visual impairments were more socially isolated from classmates than groups of children with other disabilities (as cited in Kekelis, 1988b). This research suggests that students with visual impairments, as a group, have different social experiences than their peers without disabilities and peers with other disabilities. Students with visual impairments face considerable challenges in socializing with peers, due to diminished visual information that provides the contextual information that is critical to initiating and maintaining social interactions (Kekelis, 1988a). Children who are blind and visually impaired have been integrated into regular educational settings for over 50 years, but there is still concern that they may not have the ability to access social experiences with their peers (Sacks & Gaylord-Ross, 1988).

Students with developmental disabilities may also have difficulty entering into the social environments of their peers without disabilities. Researchers have found children with developmental disabilities experience limited success in developing and maintaining social relationships with peers without disabilities (Roberts & Zubrick, 1992; Saborine & Kauffman, 1987). However, a few studies have examined social experiences between children with developmental disabilities and found that they were successful at developing meaningful friendships (Siperstien & Bak, 1989) and social networks similar to children without

disabilities (Wenz-Gross & Siperstien, 1996). Siperstien, Leffert, and Widaman (1996) found that students with developmental disabilities who were able to engage in sustained social interactions experienced greater social acceptance from their peers with developmental disabilities. Understanding how these social experiences transfer to other social environments may be helpful in developing strategies that support the social development of children with developmental disabilities.

Sale and Carey (1995) compared the sociometric status of students from four different disability groups: Perceptual/Communicative Disorders (P/C), Significantly Identifiable Emotional Disability (SIED), Physical Disability, and other disabilities. The peer nomination technique was used in interviews with 524 students out of the 588 students in the elementary school studied. The interobserver reliability for nomination responses was 0.98 and the stability of responses was 0.59, based on interviews three weeks later with randomly selected students. Analysis of the data by disability group found a significant difference between groups on social preference scores. Students with SIED had the lowest social preference score, followed by students with other disabilities, P/C, and physical disabilities (Sale & Carey, 1995). The researchers noted that the findings should be interpreted carefully, since students identified as P/C represented almost 75% of the group.

These findings and resulting differences in socialization suggest that a student's disability does have an impact on their social experiences with peers inside and outside of school. However, it can not be assumed that the differences in social experiences that may exist between different disability groups will transfer to online communities. Other variables related to the type of disability that have been identified by research (Kekelis, 1988a) as

contributing factors are: age of onset, degree of the disability, and the presence of concomitant disabilities.

Gender

Gender, along with age, is one of two attributes that is most extensively shared by friends (Hartup, 1983). Relationships formed and maintained by females are thought to be qualitatively different from those of males, and norms for social behavior may be different for boys and girls (Bukowski et al., in press). The role gender plays in socialization may change according to a child's age. Same-sex friends account for an increasingly larger proportion of adolescents' perceived primary social network (Bukowski, et al., in press).

Socioeconomic Class and Ethnicity

Additional demographic variables that may effect social experiences include socioeconomic class and ethnicity. In a critique of the research on theoretical and methodological issues related to studying social experiences, the variables of socioeconomic class and ethnicity were found to be of importance (Hartup, 1983; Kekelis, 1988a). However, many of the students who choose to participate in this study may not have been able to accurately report either their socioeconomic class or ethnicity, mainly due to their age.

Age

Over the course of a child's development, social experiences show patterns of increasing diversity, complexity, and integration (Bukowski, et al., in press). Although social interactions and peer relationships with others continue to play critical roles throughout most of peoples' lives, the importance of social interactions, friendships and peer groups peak during the adolescent years, ages 12-18, and play a critical role in development (Burchard,

1996). While students with disabilities may not follow similar developmental timelines, the goal of promoting healthy social development for all students is assumed. Adolescents are faced with the challenges of incorporating the changes precipitated by puberty into a new identity and an increased need for autonomy from family and adults (Bee, 1992). Bee (1992) separated adolescence into two distinct periods: early adolescence, ages 12-14 years; and late adolescence, ages 15-18 years. During early adolescence, youth do not want to be different from peers in looks, behavior, or interests; and peer groups form cliques that provide security and support (Bee, 1992). Late adolescence is a time when youth have an increased need for autonomy and develop more individual identities (Bee, 1992). Most youth reach adult sexual identity, and sexual activity occurs for a large number of them. Friendships are commonly based on reciprocity, loyalty, and self-disclosure, and are a source of stability and support (Burchard, 1996). Having a person as a confidante for emotional support and having a meaningful role in schools, communities and homes are factors that can help meet the challenges of adolescence (Burchard, 1996). During the adolescent years, students typically prefer the company of their peers rather than adults. For students with disabilities who require ongoing assistance from an adult, this preference to hang out with peers may be disrupted.

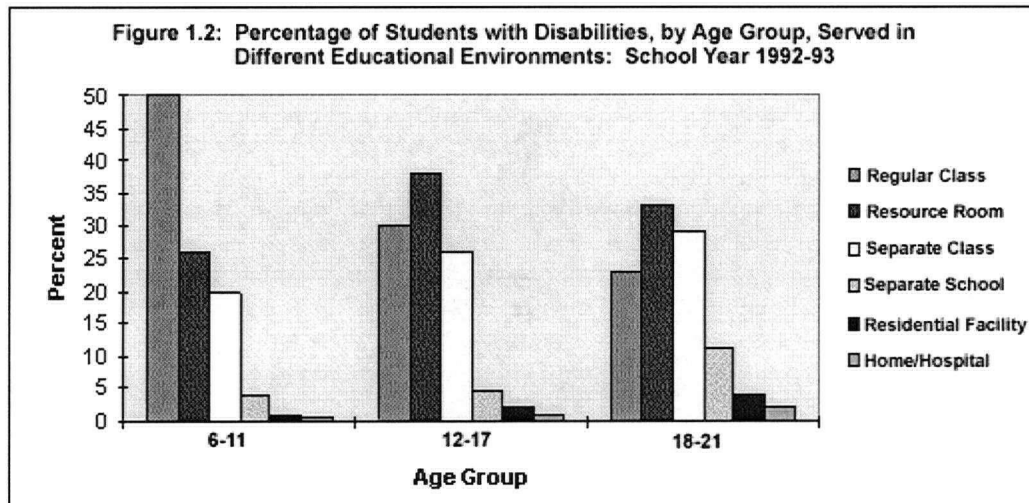
Caregivers

In a review of the research on barriers to social interaction between visually impaired children and non-handicapped peers, Kekelis (1988a) identified the role of caregivers and classroom teachers as potential determinants. Students with other disabilities may also require assistance for communication, educational, or medical needs. Antia (1982) observed

hearing impaired children in various school settings and found that they interacted less with peers and more with adults in comparison to hearing children. Students who are dependent on assistance from adults are at risk for having their social environments and experiences disrupted. Thus it appears from these studies that it would be valuable to know if a student requires the assistance of an aide for educational, communication, or medical needs.

Grade

Students with disabilities are not always placed in age appropriate classrooms, but in classes that are believed to be more developmentally appropriate. In the United States, students in special education can remain in high school until they are 21 years old. In the 1996 annual report to the U.S. Congress on the implementation of the Individuals with Disabilities Education Act (IDEA), significant differences in educational placement were found based on age and grade. The report found States have a tendency to serve a larger percentage of students with disabilities in elementary schools, ages 6-11, in regular classrooms. The percentage decreases for students in middle schools or high schools (see Figure 1.2 for the percentage in regular classrooms) (U.S. Department of Education, 1996).



Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

The relationship between a students' ages, grades and educational placements is evident.

Educational Placement: Full Inclusion to Residential Schools

Will educational placement effect their social experiences? The educational placement of students with disabilities has been the focus of much debate (e.g., Fuchs & Fuchs, 1991). The opportunity for social experiences with peers has been one of the center pieces of this debate. Advocates of inclusion stress the importance of opportunities to interact with non-disabled peers (e.g., Evans, Salisbury, Palombaro, Berryman, & Hollowood, 1992; Ferguson & Asch, 1989; Stainback & Stainback, 1991) while proponents of residential schools and separate special education programs believe in the value of a community of peers who share commonalties (e.g., Fuchs & Fuchs, 1994; Kauffman, Lyod, Baker, Riedel, 1995; Lieberman, 1996; Stinson, 1994). Studies that have examined the effect of educational placement and social interactions between disabled and non-disabled children have found that, without purposeful interventions, social proximity only is not effective and may be counter

productive (Asher, Oden & Gottman, 1977; Asher & Taylor, 1981; Gottlieb & Budoff, 1973). Kekelis (1988b) found that adolescents with visual impairments commonly fail to learn basic social skills and are socially rejected by non-disabled peers in integrated settings. There is a lack of research that clearly indicates how social skill interventions do or do not transfer across settings and over time (McMahon, Wacker, Sasso, Berg, & Newton, 1996). The social benefits of separate schools for students with disabilities has also been discussed by researchers.

Sacks & Reardon (1988) believe that residential schools for the blind provide a social network that provide lifelong support some people. Ferguson and Asch (1989) highlighted the need for children with disabilities to develop a sense of personal and social identity that incorporates their disability, but noted the difficulty of providing significant involvement with others who share similar disabilities within current practices of educational integration. However, a residential setting may restrict interactions to only those with disabilities. For example, although a residential school provides Deaf students with the opportunity to learn how to socialize with Deaf peers and adults, it subsequently limits opportunities to interact with hearing adults and peers (Leigh & Stinson, 1991). A recent report from the U.S. Department of Education (1996) suggests that educational placement may vary as a result of a student's disability. They found that the majority of students with speech and language impairments (87.5 %) are served in regular classes, and an additional 7.6 % are served in resource rooms. This report concluded that students with speech and language impairments are more likely than students with any other disability to spend the majority of their day with peers who do not have disabilities.

The majority of research on the social experiences of students with disabilities has focused on elementary settings and on interactions between disabled and non-disabled peers (e.g., Fryxell, & Kennedy, 1995; Hunt, Alwell, Farron-Davis, & Goetz 1996; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Janney, & Snell, 1996). The self-contained nature of elementary classrooms and the tendency of younger children to be more accepting of differences provides researchers with a more accessible and willing population of students than in post-elementary settings. Parents often report that non-disabled students in middle and high school are less accepting of students with disabilities than are those elementary school (U.S. Department of Education, 1996). Interventions that provide opportunities for social experiences between children with and without disabilities during the elementary years do not automatically transfer to social interactions and relationships in the adolescent years (Sommerstien & Wessels, 1996). The post-elementary setting traditionally does not have a self contained classroom structure, and the importance of social experiences with peers becomes a primary focus for most adolescents.

The few studies that have compared social experiences across different educational settings have not provided conclusive evidence that one setting is better than the other in regards to lasting social benefits. Antia (1982) compared the frequency of social interactions for hearing-impaired children in both integrated and special education classrooms and found no significant difference. In contrast, another study compared integrated and segregated settings and found that social skill development for students with severe disabilities in integrated sites improved while students in segregated sites regressed (Cole & Meyer, 1991).

The educational placement of students with students with disabilities invariably affects with whom they have interact, form relationships, and develop peer groups.

Communication Abilities and Modalities

For a time, the only way I could communicate was to spell out words letter by letter, by raising my eyebrows when someone pointed to the right letter on a spelling card. It is pretty difficult to carry on a conversation like that, let alone write a scientific paper. ...through the use of this system (Equalizer: a switch controlled word compiling program, a mobile computer, and a speech synthesizer), I have written a book, and dozens of scientific papers. I have also given many scientific and popular talks. They have all been well received. I think that is in a large part due to the quality of the speech synthesizer, which is made by Speech Plus. One's voice is very important (Hawking, 1995).

A central feature of developing social interactions and relationships is the ability to communicate. Difficulties with communication compound disruptions in social interactions experienced by individuals with disabilities (Musselwhite & St. Louis, 1982, as cited in Dethridge, 1997). Typically, communication is oral/aural or written; these modalities are often not accessible to students with disabilities (e.g. deaf, blind, learning disabled). Given the importance of interactions with significant others, it is not surprising that many research studies on the social interaction of students that are deaf or hard of hearing clearly identify communication as a major reason why some deaf students have higher levels of self-esteem and social development (Foster 1987; Mertens, 1989).

The effect of each student's disability on communication varies. For example, one student with cerebral palsy may use an assistive communication device for speech output while another student with cerebral palsy may use verbal communication. Augmentative and alternative communication (AAC) devices may present both opportunities for and obstacles to natural social experiences for students who rely on them for communication and interaction with peers. Dethridge (1997) found that AAC provides a means for students with profound and multiple learning disabilities to engage in social interactions, and that motivation to use AAC devices increased significantly when students were involved in social activities. In addition, Millar (as cited in Dethridge, 1997) warned of assistants who play too active a role in assisting children with communication which can encourage passivity and dependency.

Siblings and Non-School Friends

Another variable that has been identified in the research on social experiences is the role of siblings and non-school friends. East and Rook (1992) found that peer-isolated children have low support from school friends and that these children often derive some compensatory support from their favorite sibling. This study was unable to detect any support from non-school friends; however, this may be due to the method used of subject-only nomination of friendships and the limitation of only one nomination per child. The Loneliness and Social Dissatisfaction Questionnaire (Asher, Parkhurst, Hymel, & Williams, 1990) is a commonly used measurement instrument to examine children's self-perception of loneliness. This questionnaire was used in a study that found children with learning disabilities were more likely to report experiencing loneliness than children without disabilities (Margalit, 1994). However, a limitation of this loneliness measure is the exclusion

of possible social supports outside of school. To measure the full domain of a child's social experiences it is important that possible friends from outside of their classroom and school, such as on a sports team or in the neighborhood, be included (Bukowski, et al., in press). With this deeper understanding of a child's social environment, more accurate inferences can be made about a child's social experiences.

Summary

Similarities in age and gender strongly influence who children develop friendships with (Hartup, 1983). In addition to these general demographic variables, the type of disability, educational placement, and the communication style students experience may also effect their ability to access opportunities for social experiences with peers. Do the variables that have been identified as having a significant effect on the social experiences of school age children in "real life" transfer to "virtual life" in online communities? The current study, which included these variables, provided valuable information for future research and for informing the design and development of online communities for children and youth with disabilities.

The Internet and Social Experiences

As digital communications flash through the most heavily fortified borders, so can children, for the first time, reach past the suffocating boundaries of social convention, past their elders' rigid notions of what is good for them. Children will never be the same; nor will the rest of us (Katz, 1996, p. 120).

Over the course of history, technology has changed the way we get information, interact, communicate, and live. From pencil and paper to the copying machine, from the telegraph to the telephone, and from the radio to the television: everyone has been effected by the development of new technologies. Computer mediated communication has the potential to change how we interact, begin relationships, develop friendships, and form communities (Rheingold, 1993). The Internet provides opportunities for individuals with disabilities to interact with peers, gain access to current and diverse resources, and eliminate some of the physical constraints of communication (Gold, 1997). Both the convergence of existing technologies and the development of new technologies have occurred at unprecedented speeds, and the medium of the Internet is bringing these changes into our schools and homes. Both the Canadian and United States governments have made a commitment to have every public school on the Internet by the year 2000 (National Center for Education Statistics, 1998). Along with this rapid change, evaluation of the Internet's impact on students' lives is urgently required.

Cyberspace, a term originally used by the writer William Gibson, refers to networked multi-person computer mediated communication (Bruckman, 1992). Since the beginning of this new virtual space in the 1970s, interactive communities have been a goal of what is now

know as the Internet. Sherry Turkle, in her book "The Second Self" interviewed adolescents about their use of computers and the Internet. They described the computer as a kind of laboratory that is a safe place for testing their emerging adulthood and for escaping from the confusion of a contradictory real world that sometimes makes impossible demands on them (McCorduck, 1996). Turkle (1995) also sees the Internet as a social laboratory for experimenting with the constructions and reconstructions of self: "In this virtual reality, we self-fashion and self-create (p. 5)."

Many people fear that technology is leading society in the wrong direction, and see virtual communities as attempts to simulate the natural world (Rheingold, 1993). These critics often point to people who become so disconnected from real life that they prefer to socialize through a computer screen. Obsessive use of CMC is a legitimate concern, but it may limit opportunities for meaningful social experiences if over emphasized. Rheingold (1993) asked the question: "Who is to say that this preference for one mode of communication, informal written text, is somehow less authentically human than audible speech?" To ensure that virtual communities are used as an enhancement to real life experiences and not as substitutes for them, individuals need to be informed of their physical, social, and emotional advantages and limitations (Gold, 1997).

The Effectiveness of Computer Mediated Communication Related to Social Experiences and People with Disabilities

Bates (1995) developed a model for appropriate selection and application of technologies for distance learning that can be applied to any educational context. The model includes the issues of: access, cost, teaching objectives, interaction, organization, novelty, and

speed (ACTIONS). Since online communities do not have specific teaching and learning objectives, their purpose will be considered instead. The adapted ACTIONS model provides a framework for identifying external variables that may effect participation in online communities at the present time. Because of the lack of a clear rationale for the selection and use of specific technologies for designing and developing online communities, little information is available to guide evaluation, design, and development of online communities. Potential benefits and obstacles of online communities for people with disabilities will be considered within the ACTIONS framework.

Access. Research done during the development and implementation of the Jasper Series, a video laser disc series for teaching mathematical problem solving, focused on the development of learning communities (The Cognition and Technology Group at Vanderbilt, 1994). Teachers in the Jasper program were given e-mail accounts for communication with researchers and other teachers, but very few regularly used the accounts because they had no free time at school to access the Internet and home access was not provided (The Cognition and Technology Group at Vanderbilt, 1994). Salpeter and Milone (1996) found that students with disabilities usually have below-average access to computers, and that most of the equipment they do use is outdated or limited to assistive devices. While there are many benefits to using CMC, there are also limitations that need to be recognized (Berge & Collins, 1995).

The Autism and Asperger's Independent Living Association believes that assistive technology must be available throughout the lifespan of children and adults with disabilities as a vehicle for inclusion in the community (Dekker, Greer, Lally, Simpson, & Walker, 1998).

Access to the Internet for information, communication, and support can be viewed as an assistive technology for many people with disabilities (e.g., HTML 4.0 universal access specifications). However, the assistive technologies that enable students with disabilities to use computers may hinder access to online communities. For example, hardware and software are now available that translate written text into speech for people who are blind, convert speech into written text, and for people that use sign language to communicate visually over distance (Clarke, 1995). Some of these assistive technologies can be used with applications that provide access to online communities (e.g., web browsers). However, given the spectrum of technologies currently being used by online communities (from e-mail to 3-D graphical virtual reality) it is unclear which assistive technologies are of benefit or become obstacles to access. Banes & Walter (1996) recognized the need for research on new developments in Information Technology (IT), such as switch access to virtual worlds. A comparison between the existing online communities based on their technological requirements for participation and the current assistive devices and computers being used by students with disabilities would be valuable. Relevant questions include:

1. Where do students with disabilities access online communities?
2. What equipment is needed to access an online community?
3. What equipment do participants have access to?

Cost. The basic cost of access to the Internet includes the necessary hardware (computer, modem, and assistive devices) and an Internet service provider. The hardware and software specifications needed may vary, depending upon the technologies used by the online community. The total costs associated with participating in online communities should take

into account other associated uses of the technologies (e.g. word processing, CD-ROM's, Internet access for others). Since fees for Internet access can be per hour or a flat rate, costs may vary, depending on how much time participants spend online. Possible questions related to the issue of cost include:

1. Who pays for the cost of access to an online community?
2. Is equipment provided by the organization responsible for the online community?

Rationale and goal. The T in the ACTIONS model represents the importance of teaching objectives in relation to designing distributed learning environments. For evaluating online communities that are not intentionally designed for teaching and learning, we instead consider the rationale for and the goal of online communities for children with disabilities. Embedded within any decision about the use of technology for developing online communities should be a clear purpose for the use of each tool.

The marginalization of minorities in schools and communities is a major societal problem. Unlike ethnic minorities, children with disabilities most often do not have family members that share their experiences. The importance of relationships with family and friends is recognized as a critical factor in developing continuity, identity, and safety for a person with a disability (O'Brien, 1997). However, Perske (1997) warned that, while people with disabilities may have good family support and community programs, they still have a huge void in their lives because they may not have friends. Poor peer relationships have been found to be a primary cause of a variety of emotional and social problems (Hartup, 1983). Perspectives of many successful adults with disabilities identify friendships with typical

peers as a critical factor in their development of competence and a self-image that included being both “different” and “normal” (Powers, Singer, & Todis, 1996).

Students with disabilities in inclusive schools and communities are at risk of having limited opportunities for social experiences with other individuals who share similar experiences (Stainback et al., 1996). This isolation can create a problem in developing a positive self-identity that incorporates a child’s disability. The provision of opportunities for students with disabilities to interact and develop relationships, and groups with others who share commonalties can diminish this isolation (Stainback et al., 1996). The self advocacy movement has long realized the importance of developing communities of support for individuals to draw upon in their struggle to attain personal goals. Shoultz (1996) defines self advocacy as:

... independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us about our right, but along with learning about our rights we learn about our responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in (p. 25).

While the self advocacy movement has been developing in communities around the world for adults with disabilities, there is an apparent lack of this kind of support for adolescents with disabilities to be empowered in their schools and communities. Many people assume that only “higher ability” people with disabilities can advocate for themselves, but this is seen as an attempt to divide and ignore the disability community as a whole and as

a “put down” to those who have more severe disabilities (Kennedy & Shoultz, 1997).

Opportunities to learn from role models with similar characteristics provides students with a way to learn about self advocacy and determination (Field & Hoffman, 1996). Participation of adolescents with disabilities and mentors with similar disabilities in community activities has been shown to enhance self-efficacy and parents’ positive perceptions of the child’s capabilities (Powers, Sowers, & Stevens, 1993). For children who deal with similar ongoing health conditions, opportunities for socialization with each other are also very beneficial. Camps for children with chronic health conditions and disabilities have been shown to enhance self-concept, improve medical outcomes, and increase self-determination (Luckner, 1989; Moffat, 1983). The goal of current online communities for children with special needs, either explicitly or implicitly stated, is also to provide social experiences: interactions, relationships, peer groups, and support.

Interaction. How people interact with or through technology is an important aspect related to selection and use (Bates, 1995). Social experiences mediated through computer networks are inherently different. In face-to-face social experiences, we first meet people and then get to know them; while in CMC, we first get to know people and then decide whether or not we want to meet them. In a review of the research in the field of Computer Supported Collaborative Learning, (CSCL), two studies (Ahern & Durrington, 1996; Parks & Floyd, 1996) were identified that investigated social experiences in online environments. Ahern and Durrington (1996) studied the effect of anonymity and saliency on computer mediated group interactions. Through analysis of the structure and content of the communicative interactions, they found that anonymous groups had significantly longer communications and spent more

time within the computer mediated environments. However, the 15 participants in this study had known each other for over two years and, during this study, were classmates in “real life”. This may have effected the level of anonymity that was possible, as well as their motivation to interact in CMC discussions. Parks and Floyd (1996) studied the development and qualities of friendships formed in the “cyberspace” of newsgroups on the Internet. Of the 528 people who were randomly selected from 24 newsgroups, 178 responded to the e-mail survey. The study found that personal relationships were formed by 61% of newsgroup participants and that 55% of the dyads communicated weekly. The quality of the relationships assessed provided evidence that relationship development can occur within virtual communities. However, analysis of specific relationship domains were difficult to interpret, given the generality of the relationships identified through subject-only nomination. Various strategies can be used to help cultivate a social experiences in online communities. For example, Project DO-IT, at the University of Washington, brings new participants together for two weeks to meet in real life.

Members of virtual communities in Japan, England, France, and the United States all strongly agree that broadening their group of friends is one of the most significant benefits of computer conferencing (Rhiengold, 1993). At least two exploratory studies (Ahern & Durrington, 1996; Parks & Floyd, 1996) provided a “first look” at the potential of computer mediated environments to foster social experiences. Future research should plan valid measurement of the social experiences being analyzed and consider how the findings are situated within the overall framework of the interwoven levels of social interactions, relationships, and groups (e.g., Parker & Asher, 1993). Identification of the confounding

variables that effect participation in online communities will enable research to better evaluate the social experiences.

Organization. Online communities for people with disabilities have had varying levels of “success” in terms of the number of participants and frequency of use. One variable that may account for this difference is the amount of control the participants have to self-regulate and define the purpose and direction of the community. The Autism and Asperger's Independent Living Association believes that decisions regarding the design, provision, and use of assistive technology by individuals with disabilities must include the continuous recognition and enhancement of their abilities to exercise their rights of personal choice. Stainback, Stainback, and Forest (1989) noted that members of a group must be the ones who start and define the group in order to avoid violating their interests, needs, and basic rights. Opportunities for group formation can be facilitated by others, but decisions about who can join the group, how long they should participate, and their purpose should be the decision of the group members (Stainback, et al., 1996). Strully and Strully (1985) noted that, if parents and educators promote participation of children with disabilities only with others who have disabilities, it may perpetuate the segregation of years past. Groups that have self control can decide to allow others who may not share their commonalties but are interested in being their allies to participate. The ability of a group to remain self-determined, open, and flexible will help allay the concern that online communities will become the only “safe” place for people who have been marginalized and will thus intentionally hamper efforts to overcome segregation.

One example of a virtual community with self control is MediaMOO, a text based, networked, virtual reality environment designed at the Media Lab at M.I.T. The designers have found that letting the users build the virtual community themselves rather than interact within a pre-designed environment gives them opportunities for self expression, encourages diversity, and leads to a meaningful engagement and enhanced sense of community (Bruckman & Resnick, 1995). Group formation may be assisted by others outside of the group, but decisions related to the ongoing development of the community (e.g., participation, goals, restrictions) should be the responsibility of the members, if the goal is to enhance positive self-identity (Stainback, et al. 1996)

The issue of managing deviant behavior in virtual communities was a topic at a panel discussion presented at Computer Human Interaction 1994 annual conference. Behavior was defined as “deviant” if it was not in accordance with community standards. Some of the questions addressed were: How are these standards developed?, Should standards be established by system administrators and accepted as a condition of participation, or should they be developed by community members?, If a participant’s behavior is deemed unacceptable, what are the consequences?, and What is the appropriate balance between centralized and decentralized solutions? (Bruckman, 1994). Stainback et al. (1996) noted the need for research that seeks to understand how support groups are best developed and facilitated both in schools and the broader community (i.e., online communities).

Novelty. The novelty of a technology may be the reason for its selection and use by both the designers and participants of an online community. While some online communities use the “latest and greatest” technologies, (e.g., 3-D Virtual Reality in STARBRIGHT

World), and others use “older” technologies (e.g., text-based BBS in Ability Online), patterns of use by the participants may be prove to be very different. The following questions could help inform design issues in regards to novelty:

1. How long do participants stay involved in the online communities?
2. Does the frequency and duration of participation in the online communities vary over time?
3. What are the patterns of use for each CMC technology currently being used in online communities?

Speed. Technologies that can be implemented and updated quickly can respond to today’s rapid pace of technological change (Bates, 1995). Technologies that are flexible can also be more responsive to the needs of particular group of users. For example, a MUD is a text-based environment that allows participants to construct and reconstruct its contents based on their desires. However, the speed of learning how to use a MUD maybe slow in comparison to e-mail. Possible questions to address in reference to speed are:

1. How much time is required to learn how to effectively use a technology?
2. How long does it take to design and develop a technology?

Current Online Communities for People with Disabilities: Overview and Research

The University of Washington (UW) Program: DO-IT

Founded in 1992, DO-IT targets high school students with disabilities who are interested in careers in science, math or engineering. Each summer, participants spend two weeks at the UW attending labs and lectures to get a feel for college life, meet with faculty and student mentors, many with disabilities themselves,

to learn how new technology is making it easier for them to pursue degrees and careers in fields once thought out of reach. Throughout the year, DO-IT scholars use home computers and electronic mail to communicate with one another and with mentors from around the world. These cyber-relationships provide a sense of community and a source of encouragement to the students as they overcome common challenges to pursue their goals. Computers, modems and adaptive technology are provided for participants who don't have their own. DO-IT is sponsored primarily by the National Science Foundation and administered by the UW College of Engineering and UW Office of Computing and Communications (Burgstahler, 1997).

A recent study by Burgstahler, Baker, and Cronheim (1997) at Project DO-IT examined the social benefits of peer-to-peer computer mediated communication by collecting and coding electronic mail messages exchanged between participants over one year. The largest single category (61%) were personal messages. This shows the potential of e-mail for social interaction; however, this group of students had met face-to-face prior to their interactions online. The participants also completed a questionnaire about their interest in and use of computers, the Internet, and electronic mail. Ninety-two percent of participants responding to the survey used computers at least once per week, and 68% used them daily (Burgstahler et al., 1997). Project DO-IT provides Internet access to the participants at no cost; 87% of the participants "log-on" to their account once a week and 51% use it daily. The issue of who pays the cost of Internet access may effect participation in online communities. Sixty percent of the participants reported using e-mail daily and 95% said they enjoyed

exchanging e-mail. It is not clear in this study whether participants used e-mail within the Project DO-IT online environment and/or outside of the environment. How e-mail use compares to other technologies being used in online communities is not known.

SET-BC and "KidSET"

Over the past two years SET-BC, in partnership with the Vancouver Foundation, has sponsored KidSET and a Virtual Summer Camp. The goals are to:

1. Promote independence in the use of assistive technologies.
2. Promote a support group for users of these technologies.
3. Develop a core group of students who are familiar with the Internet, and who can act as mentors for other students.

During the camp, web pages are investigated and created. Students also become involved in a variety of other Internet and electronic activities, both on- and off-site. No research has been conducted on how KidSET is being used.

Ability OnLine

Ability OnLine is an electronic mail system that connects young people with disabilities or chronic illness to disabled and non-disabled peers and mentors. This easy-to-use network gives "wings" to thousands of children and adolescents by removing the social barriers that can come with having a disability and illness, and by providing opportunities to form friendships, build self-confidence, exchange information, and share hope and encouragement through e-mail messages.

Ability OnLine is also a valuable resource for families and friends anxious to know more about an illness and help manage it. The network provides disabled youngsters and their families with up-to-date information on medical treatments, educational strategies and employment opportunities through peer support. Access to the network is available through the use of a computer, modem and the telephone system, either by dialing directly into the system or by telnet via the Internet (Ability OnLine Support Network, 1998).

Ability OnLine is the only online community that has an open enrollment policy, and affords participants self control over content and participation. No information or data about the use of Ability Online are available.

Children With Diabetes

Children With Diabetes (CWD) is an online community for kids, families, and adults with diabetes. CWD was founded by Jeff Hitchcock, the father of a child with diabetes, in June of 1995. The goal of CWD is to empower everyone involved with diabetes with the information and support they need to care for themselves or their children. While CWD is not an online community specifically for children with disabilities it does reach out to the same general population of children with a special needs. Web site traffic is tracked based on the number of user sessions, defined as continued access from a single computer without more than a 15 minute span between page requests, and the number of web pages delivered. In 1998 there were 771,687 user sessions and 6,246,009 web pages delivered (Children with Diabetes, 1999). CWD does not track individual users because privacy is of paramount importance. No research has been conducted on how CDW is being used by the participants.

Convomania

In May, 1996, the Worldwide Disability Solutions Group (WDSG) at Apple Computer began Convomania, a 12-month pilot program designed to explore the effects of personal computer technology on children with serious illness and/or disability. Specifically, Apple was curious to learn how these children— whether in hospitals, rehabilitation facilities, or at home— would use the power of telecommunications to overcome experiences such as isolation, dependence, and boredom. Across the board, children (average ages 13-15) demonstrated strong enthusiasm for connecting to the Convomania website to be with others like themselves and to discuss all manner of subjects related to being sick or being different.

Formally launched to the public on April 3, 1997, Convomania provides seriously ill and disabled children with a place where it's OK to be not OK. The Convomania website provides children with a variety of ways to convene, to communicate, to question, and to express their candid opinions about living with illness and/or disability. The design and the attitude of the site was principally guided by the finding, during the pilot, that the community, itself, would be providing the bulk of Convomania's content, and practically all of its wisdom and insight.

Thirty kids from across the country are the life-blood of Convomania. They supply the energy, the humor, the wisdom, the attitude, the honesty, and the fearlessness. They do all this— and more— to ensure that

Convomania remains their kind of place, a community of enormous caring, untarnished by the efforts of well intentioned caregivers. "I don't need another place where I can be treated like a child," reported one Convomaniac. "I get treated like that too much anyway. What I need is a place where people know how to deal with me as I am. And that includes the cancer part of me."

(Convomania, 1998)

Convomania is one of the few online communities that put the participants at the center of the design and development of their online community. In the fall of 1998 Apple shut down Convomania as part of cost cutting measures and the people running the Worldwide Disability Solutions Group, and Convomania, were laid off. Seven of the participants worked together to find Internet freeware and hardware and a T1 host, and started building content for the new site know as ConvoNation.

STARBRIGHT World

STARBRIGHT World is an online virtual community designed to meet the specific needs of seriously ill children. Within STARBRIGHT World, hospitalized children access content that can help them address the psychosocial (the psychological and social aspects of illness) challenges that accompany prolonged illness, including pain, stress, fear, low self-esteem and isolation (Starbright Foundation, 1998).

STARBRIGHT World is the only online community specifically designed and developed for a specific group of children. This online community uses the largest spectrum

of technologies and many represent the latest innovations. The following is an excerpt from the Starbright website:

Activities: Kids can access a wide variety of activities within STARBRIGHT World, each chosen to address a specific health care challenge. Activities include single and multi-user games and areas for creative expression. Many games are fast-paced adventures which may distract a child from pain or from a painful procedure, while other areas allow children to use drawing, music, and creative writing to express their feelings.

Communication: More than anything, STARBRIGHT World is a community where seriously ill children can meet other kids who understand the challenges of illness. A variety of communication choices exist in STARBRIGHT World, including ProShare™ video conferencing, audio and text chat spaces, bulletin boards, and e-mail.

Information: Within the information section, children can learn about medical procedures and find easy-to-understand definitions of medical terms. Through secure Internet access, kids can find out about sports, school subjects, and their favorite interests. Every Internet site available to kids has been approved by STARBRIGHT and no inappropriate hot links are available.

Friends: Find a Friend was the number-one request of kids who used STARBRIGHT World during its beta test. Find-A-Friend enables children to locate friends online, and meet kids with similar interests and/or medical conditions. Cool Kid and Raxx guide children through STARBRIGHT World.

These characters have been created using Media Conveyor™, an interactive multimedia technology designed especially for the Internet. With Media Conveyor, Raxx and Cool Kid can interact with kids on STARBRIGHT World, personalizing each child's online experience (Starbright World, 1998).

Two research projects that have been done on STARBRIGHT World have investigated participant perspectives and patterns of use. Holden (1997) found that when children used STARBRIGHT World for communication, 68.9% of the time the topic was non-illness related; 2.9% of the time the topic was illness-related; 28.3% of the time there was either no communication or the topic was not discernible. Through observations they found that children used the game arcade 53% of the time, and the Tropical World (one of the five virtual worlds) 25% of the time. These observations were recorded during the beta testing of STARBRIGHT World. Holden (1997) noted that several children experienced technical problems with the Internet-based programs and this may have biased the use of the locally run game arcade programs. Another study used open-ended questionnaires to ascertain participants' perspectives on how they understood and utilized STARBRIGHT World (Bearison, 1997). Participants highlighted the value of interacting with other children with similar conditions and the need for additional features in the system: more games, medical information in language kids can understand, and a directory for locating kids with similar conditions that are online (Bearison, 1997).

Talk City

Talk City offers over 900 moderated chats a week and has over 60,000 participants under 18 years old. While Talk City is not specifically intended for youth with disabilities

and/or serious illness many of the chats are disability-related, such as "Living with Multiple Sclerosis" or "Special Needs Children". No research has been conducted on how Talk City is being used by participants with disabilities or serious illness.

Summary

These seven online communities provide people with disabilities or special needs (e.g., chronic illnesses) a social forum for support. Unlike the numerous web pages that just provide information about disability related topics, these online communities are developed for people with disabilities with the goal of providing opportunities to interact, form relationships, and construct communities of support. The method of designing, developing, and delivering each of these communities varies widely.

CHAPTER III

Method of Research

Introduction

The purpose of this study was to develop a survey designed to identify variables that effect participation in online communities for members with disabilities. The study consisted of three phases, each informed by the results of the previous phase. In the first phase, identification of potential variables were derived from a review of literature within two primary areas: (a) social experiences of children who have a disability and (b) social experiences within Internet based environments. The second phase consisted of generating questionnaire items for the variables identified in the literature review. Re-phrasing of the items was based on a pilot of the questionnaire, with relevant newsgroups and feedback from experts in field. In the third phase, the questionnaire was piloted with existing online communities of children with disabilities and/or illnesses. The information obtained from the development of this instrument will contribute to the construction of online communities for individuals with disabilities, and situate future research that seeks to understand the effects of CMC on social experiences.

The research question that guided the development of this survey tool was: What are the variables that impact the participation of students with disabilities in online communities?

Phase 1. Based on a review of the literature, 15 variables were identified that have been found to influence social experiences of children with disabilities and social experiences within computer mediated environments. Three additional variables were suggested by

experts in the fields of distance education and technology, special education, and social psychology:

1. Strategies used to encourage participation
2. Self-perception of loneliness
3. English as a first language

Phase 2. The 17 variables thought to influence participation in online communities for members with disabilities were organized into two main categories:

1. Personal Variables: The production and perception of children's social behaviors may be affected by their age, grade, gender, disability, educational placement, caregivers, communication abilities, siblings and non-school friends, English as a first language, and self-perception of loneliness.

2. Contextual Variables: The quantity and quality of social experiences may be affected by factors related to access, cost, purpose, interaction, strategies used to foster participation, organization, novelty, and speed.

Two semi-structured questionnaires were designed to gather information from the participants and system administrators of online communities. Questions for the surveys were generated to address the issues identified in phase one. It should be noted that portions of the surveys were modeled after Bates and Bartolic-Zlomislic's (1998) survey developed for course evaluation in the Department of Distance Education and Technology at the University of British Columbia. This instrument is currently being developed as part of a national research project to assess distance education and technology projects. Questions to measure self perception of loneliness are from Hayden's (1989) Relational Provision

Loneliness Questionnaire. This self-report measure consists of four subscales comprised of seven items each. The two subscales that assess personal intimacy and group integration with peers were used in the participant questionnaire. Hayden (1989) and Beaudion (1999) reported adequate reliabilities (via Cronbach's alpha) for each of the subscales. The items developed for each category are listed below for the participant questionnaire (see Appendix A):

1. Personal variables were addressed in questions 1-17. Question 13 was focused on peer social support and included 14 items. Questions 14-17 were concerned with computer experience.

2. Contextual variables were addressed in questions 18-27.

Seventeen items were developed for the system administrator questionnaire that addressed the other contextual variables (see Appendix B). The re-phrasing of items was based on a pilot of the questionnaire with relevant newsgroups, and on feedback from experts in the fields of distance education and technology, special education, and social psychology.

Phase 3. In the third phase, the questionnaire was piloted with participants of online communities for children with disabilities and/or illnesses. A description of the methodology used for this phase is provided below.

Participants

Participants were recruited from seven existing online communities for children with disabilities and other special needs. The online communities were identified through extensive searches on the WWW, consultation with professionals in the field, and postings to relevant newsgroups. The target population for this survey was participants with disabilities between

the ages of 12-18 who participate in an online community. The system administrator of each online community was also asked to participate in this study. The self-administration of this questionnaire allowed all members of the online communities to participate in this study which resulted in identification of participants that were not originally targeted.

Settings

Participants were from one of the seven online communities:

1. KidSET is an online community for students that receive services from Special Educational Technology of BC, (SETBC), and is in its third year of operation.

2. Ability OnLine has been in existence since 1992 and is an electronic mail system that connects young people with disabilities or chronic illness to disabled and non-disabled peers and mentors. This network provides thousands of children and adolescents opportunities to form friendships, build self-confidence, exchange information, and share hope and encouragement through e-mail messages (Ability OnLine Support Network, 1998).

3. Founded in 1992, DO-IT targets high school students with disabilities who are interested in careers in science, math or engineering. Throughout the year, DO-IT scholars use home computers and electronic mail to communicate with one another and mentors from around the world. These cyber-relationships provide a sense of community and a source of encouragement to the students as they overcome common challenges to pursue their goals. Computers, modems and adaptive technology are provided for participants who don't have their own (Burgstahler, 1997).

4. Convomania was a collaborative project between the Worldwide Disability Solutions Group (WDSG) and Apple Computer. In May, 1996 a 12-month pilot program

was designed to explore the effects of personal computer technology on children with serious illness and/or disability. During the implementation of this study Apple shut down Convomania as part of cost cutting measures and the people running the Worldwide Disability Solutions Group, and Convomania, were laid off. Seven of the participants worked together to find Internet freeware and hardware and a T1 host, and started building content for the new site know as ConvoNation. The system administrator of ConvoNation agreed to participate in the current study. Since Apple discontinued their support for Convomania and the resulting ConvoNation they have been directing people to Talk City and STARBRIGHT World.

5. Talk City offers over 900 moderated chats a week and has over 60,000 participants under 18 years old. Many of the chats are disability-related, such as "Living with Multiple Sclerosis" or "Special Needs Children". Subsequently Talk City was invited to participate in this research project and accepted the invitation.

6. STARBRIGHT World is an online community designed to meet the specific needs of seriously ill children. Within STARBRIGHT World, hospitalized children access content that can help them address the psychosocial and social challenges that accompany prolonged illness, including pain, stress, fear, low self-esteem and isolation (Starbright Foundation, 1998). STARBRIGHT World is not specifically intended for children with disabilities, however, many of the participants share similar barriers to social experiences with peers and may also have disabilities.

7. Children With Diabetes (CWD) is an online community for kids, families, and adults with diabetes. CWD was founded by Jeff Hitchcock, the father of a child with

diabetes, in June of 1995. The goal of CWD is to empower everyone involved with diabetes with the information and support they need to care for themselves or their children. While CWD is not an online community specifically for children with disabilities, it does reach out to the general population of children with a special needs.

Research Design

A cross-sectional design was used to examine participation in several online communities at one point in time. A recognized limitation of this design is that experiences of different participants can not be compared reliably (Mertens, 1998). However, the advantages are that a large amount of data can be collected in a short time and it allows for sampling across a spectrum of diverse groups. A general criticism of closed-ended survey research is that it oversimplifies issues by reducing them to a limited set of questions and responses (Mertens, 1998). The questionnaires were composed of both open and close ended questions. The purpose of this survey was not to reduce online communities to quantifiable data but rather to develop a general foundation of information from which future research can be situated.

Procedures

The questionnaires were web based and used HTML forms, Lasso programming, and server side FileMaker databases to collect and organize data. Web based data collection has been found to be both efficient and reliable (Slaughter, Harper, & Norman, 1998). The hope was that this method of survey would also be less invasive to the online community. First, a letter of request to participate was sent in November 1998 to each organization responsible for developing and maintaining an online community. An introductory notice was then sent

on e-mail to all participants in the online community, and the web site address for the survey was provided. If possible, an additional notification of the survey was included on the community's web site. The actual questionnaires were on a separate web site located on the web server used for this study. Participants and system administrators completed a questionnaire about their experiences with the technology and with other participants. Data collection took place over a period of eight weeks.

Method of Analysis

This study was descriptive and comparative. The exploratory nature of this study provided results that were anecdotal by nature and should be read as such. Data from the questionnaires were summarized with respect to means, standard deviations, ranges, and percentages. The data were grouped within and across the online communities where possible. A description of the analyses and the results are presented in Chapter 4.

CHAPTER IV

Results

As stated in Chapter 1, the overall goal of this investigation was to inform the design and development of online communities that have the potential to provide students with disabilities a community for support and self-discovery. In order to achieve this goal, two questionnaires were specifically developed to identify variables that may potentially effect participation in online communities. The results from the first implementation of these questionnaires are presented in the following order. First, a description of the online communities is presented from the results of the system administrator survey. Next, the results of the participant survey are reported across all respondents. Finally, specific information from respondents between the ages of 12 to 18 with a disability or serious illness are summarized.

System Administrator Responses

Online Community Demographics

A total of seven organizations responsible for the design, development, and maintenance of online communities for or including children with disabilities or serious illnesses were involved with this study; three (43%) of the organizations also provided the opportunity for their community members to participate in this study. One of the organizations, Talk City, is not specifically intended for youth with disabilities and/or serious illness, and these results are reported separately where appropriate.

The number of members in the seven online communities is described in Table 1. The mean number of total members in the online communities ($n=6$) (excluding Talk City), was

1425 (range = 10 to 3940); a mean of 1062 were under 19 years old (range =10 to 3495). Talk City has over one million registered members, with 60,000 under the age of 19.

Table 1

Number of Members in Each Online Community

Online Community	<i>n</i>	<i>n</i> (under 19 years old)
KidSET	10	10
ConvoNation	100	100
Project Do-IT	400	200 ^a
Ability OnLine	3000	1500 ^a
STARBRIGHT World	3940	3459
Children With Diabetes	10,000	1100
<u>Total</u>	<u>17,450</u>	<u>4559</u>
Talk City	1,500,000	60,000

Note. ^aNumbers based on system administrator estimates.

The system administrators were asked to describe the rationale and goal of their online community. Across all of the organizations the common goal, in general, was to provide a place where children with disabilities or serious illnesses could interact and communicate. From the five organizations that provided a rationale, the common theme was to overcome the isolation that can result from having a disability or serious illness. The other two organizations, Project Do-IT and KidSET, did not differentiate between goals and rationale.

The technical requirements for participating in an online community were reported to be cross-platform by five (71%) of the organizations. The other two organizations required a Windows operating system. Only one organization reported that there was a cost for members to use the online community. However, only four of the organizations reported supplying some computer equipment and Internet access for members. The most commonly available computer mediated communication (CMC) tools were e-mail (100%) followed by personal web pages for members (86%), text-based chat (71%), and listserves (71%).

Graphical Internet Relay Chat, desktop video conferencing (e.g., CU-SeeMe), and MUDs were each reported only once as being available in an online community. Other CMC tools listed by organizations were: file storage, a searchable database of registered users, and a shared drawing board. The CMC tool used most frequently by members, as reported by the system administrators, was e-mail (n=3) followed by Internet Relay Chat (IRC) (n=2), video conferencing (n=1) and listserves (n=1). Listserves and personal web pages were both reported by two organizations as the least used CMC tool. The other three organizations reported a MUD, file storage, or text based IRC as the least used.

For Talk City, the online community was cross-platform, provided at no cost to members, and did not provide equipment or Internet access. The CMC tools included within Talk City were e-mail, listserv, newsgroups, personal and group web pages, text and graphical IRC, and online games. Talk City reported that IRC was the most used and listserv was the least used CMC tool. The technical background information for all of the organizations is summarized in Table 2.

Table 2

Selected Technical Variables for Online Communities (N=7)

Variable	Frequency	%
Technical Requirements		
Cross Platform	5 ^a	71
Windows OS	2	29
Total	7	100
Cost for Participants		
Yes	1	14
No	6 ^a	86
Total	7	100
Equipment Provided		
Yes	4	57
No	3 ^a	43
Total	7	100
CMC Tools		
E-mail	7 ^a	100
Listserv	5 ^a	71
Newsgroups	5 ^a	71
Web pages (Group)	4 ^a	57
Web pages (Personal)	6 ^a	86
BBS	2	29
MUD or MOO	1	14
IRC (text only)	5 ^a	71
IRC (graphical)	1 ^a	14
Video Conferencing	1	14
Online Games	2 ^a	29
Graphical Virtual Worlds	0	0
Other	2	29

(Table 2 Continued)

Variable	Frequency	%
CMC Tool Used Most		
E-mail	3	43
IRC	2 ^a	29
Video Conferencing	1	14
Listserv	1	14
Total	7	100
CMC Tool Used Least		
Listserv	2 ^a	29
Web Pages (Personal)	2	29
MUD	1	14
IRC (text only)	1	14
File Storage	1	14
Total	7	100

Note. ^aIncludes Talk City response.

All but one of the organizations provide some type of instruction on how to use the online community. Instructional strategies ranged from in-person training or phone-in help to online written instructions, tours, or animated help with audio narration. Specific strategies to encourage members to interact in the online community are used by all the organizations. Strategies include direct contact with staff, encouragement from community hosts and mentors, weekly e-mail newsletters, online promotions, and scheduled chat sessions with specific topics. Five of the organizations do not require members to provide any description of who they are. Four of the online communities are open to anyone, while the other three restrict access to individuals from a specific group (i.e., seriously ill children in hospitals). Rules and standards for participation in an online community are established by administration in three of the organizations, and by both members and administrators in the

other four. All of the organizations reported some type of consequence for unacceptable behavior in the online community. Most commonly this includes a process of warnings or discussions, then restricted access, and finally being completely logged off the system. The majority of organizations (n=5) described the primary control of the online community as centralized.

Talk City reported that they provide instructional support, use strategies to encourage participation, do not require members to describe themselves, and are open to anyone. In Talk City, the rules for participation are established by the administration, there are consequences for unacceptable behavior, and control of the community is centralized.

Table 3 summarizes the organizational variables for all of the online communities.

Table 3

Selected Organizational Variables for Online Communities (N=7)

Variable	Frequency	%
Instructional Support		
Yes	6 ^a	86
No	1	14
Strategies for Encouraging Participation		
Yes	7 ^a	100
No	0	0
Participants Descriptions Required		
Yes	2	29
No	5 ^a	71
Anyone Can Participate		
Yes	4 ^a	57
No	3	43

(Table 3 Continued)

Variable	Frequency	%
Who Establishes Rules		
Administration	3 ^a	43
Participants	0	0
Both	4	57
Consequences for Unacceptable Behavior		
Yes	7 ^a	100
No	0	0
Control of the Online Community		
Centralized (Administration)	5 ^a	71
Decentralized (Participants)	2	29

Note. ^aIncludes Talk City response.

Participant Responses

Personal Variables

Three of the seven online communities, Project Do-IT, KidSET, and Talk City, were able to provide members the opportunity to participate in this study. Because ConvoNation joined the study towards the end of the data collection period, time limitations did not allow members enough time to participate in this study. The other three organizations had policies to protect the sanctity of their online community and/or the privacy of the members, and did not allow members to be notified of the opportunity to participate.

A total of 158 questionnaires were returned from members in the three organizations whose administrators agreed to notify members of the survey. Seven questionnaires were excluded from the analysis because four of the responses were duplications and three

contained primarily irrelevant responses (i.e., “bite me”). Shown in Table 4 is the distribution of respondents by their geographic location.

Table 4

Geographical Location of Respondents (N=151)

Variables	<i>n</i>	%
USA	101	67
Canada	16	10
Australia	8	5
New Zealand	4	3
England	3	2
West Bengal	1	1
Philippines	1	1
Holland	1	1
No Answer Given	16	10
Total	151	100

The majority of the respondents were from Talk City ($n=150$) and one was from KidSET. The participants in the current study included 93 females (62%) and 58 males (38%) with a mean age of 15 and a standard deviation of 5.07 (range 3 - 52). The largest portion of respondents (41%) were in the 15 to 18 age group, 37% were between the ages 12 and 14, 13% were 11 or younger, and 9% were 19 or older. There were 35 respondents (23%) who described themselves as having a disability or chronic illness. Respondents from this group most commonly described themselves as learning disabled ($n=6$) and/or behaviorally disabled ($n=6$). Nine respondents from this group reported more than one condition and 11 of the respondents selected “other” to provide additional descriptions (e.g., ADHD, autism, asthma, or diabetes). Most commonly, participants attended regular schools (91%) and

reported grade levels within their age range (i.e., age 12 and grade 7). The mean number of siblings was 1.7 with a standard deviation of 1.4 (range = 0 to 10). A demographic description of the group of 151 participants in online communities is provided in Table 5.

Table 5

Selected Demographic Variables for Participants (N=151)

Variables	<i>n</i>	%
Gender		
Female	93	62
Male	58	38
Total	151	100
Age		
≤ 11	20	13
12-14	56	37
15-18	62	41
> 19	13	9
Total	151	100
Description		
Not Disabled	116	
Deaf	2	
Hard of Hearing	4	
Blind/Visually Impaired	4	
Learning Disabled	6	
Developmentally Disabled	1	
Speech or Language Disabled	4	
Physically Disabled	4	
Behaviorally Disabled	6	
Chronic Illness	4	
Other	8	

(Table 5 Continued)

Variables	<i>n</i>	%
School Setting		
Regular	137	91
Resource Room	2	1
Separate Room	1	0
Separate School	4	3
Home	7	5
Hospital	0	0
Total	151	100
Siblings		
0	22	14
1	62	41
2	37	25
3	17	11
4	6	4
5	4	3
≥ 7	3	2
Total	151	100

Note. Percentages were not calculated for type of disability because respondents were allowed to select more than one.

The target population for this study were youth with a disability or serious illness, between the ages of 12 to 18. There were 118 participants in the specified age range, and 22 of these had a disability or illness. The 22 participants consisted of 68% females and 32% males, with a mean age of 14.7. To determine if having a disability or serious illness was associated with selected demographic variables, a series of chi-square tests of independence were performed. The Pearson chi-square statistic did not reveal any significant associations ($p < .05$) as a function of age, gender, school setting, or siblings. In reporting the results of the present study, responses from the two groups (disabled or seriously ill and non-disabled participants) will be combined except where differences occurred.

Responses for the question about how many friends participants had outside of their school were not analyzed because answers were inconsistent (e.g., many, a lot, ??, 100+). The responses to the question about assistance from an adult at school were not recorded due to an error in the programming of the web based data collection.

Participants' communication abilities. The second section of the participant questionnaire addressed participants' communication abilities. There were 143 respondents (95%) who listed English as their first language. Spanish was spoken by 3% of the respondents (n=5) and French, Dutch, Korean, and Sign Language were each listed once. Similarly, 83% of the respondents (n=125) choose talking as their best method of communicating with peers and only 14% choose writing. Sign Language was chosen by one person and three people selected other (i.e., both writing and talking). As shown in Table 6, the majority of participants with or without a disability or serious illness choose talking as their best way of communicating with others. To determine if any of the communication variables were associated with the presence of a disability or serious illness a series of chi-square tests of independence were conducted. The only variable that was significantly associated with disability was preferred communication mode ($\chi^2 (3) = 9.51, p = .02$).

Table 6

Percentage of Participants by Their Preferred Communication Mode

Group	<i>n</i>	Communication Mode (%)			
		Talking	Writing	Sign Language	Other
All Participants	151	83	14	1	6
Non-disabled (12-18 yr.)	96	83	18	0	1
Disabled (12-18 yr.)	22	63	18	5	9

Difficulty with communication with peers, in general and through writing, was rated on a 1-5 scale where 1 = never, 3 = sometimes, and 5 = always. The mean ratings for all participants, and for participants between ages 12 to 18 both with and without a disability, are provided in Table 7.

Table 7

Mean Ratings for Communication Difficulty with Peers

Group	<i>n</i>	General		Writing	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
All Participants	151	2.03	.91	1.74	.9
Non-disabled (12-18 yr.)	96	2.00	1.0	1.61	.87
Disabled (12-18 yr.)	22	2.09	.88	1.73	.89

Peer personal intimacy and group integration. The next section of the participant questionnaire addressed participants' self-perception of personal intimacy and group integration with peers. Respondents used a 5-point scale to respond, on which lower scores indicate higher levels of perceived personal intimacy and group integration. Each subscale consisted of seven items, with scores ranging from 7 to 35 for each subscale. Means and standard deviations for participants with or without a disability or serious illness on the two social relational variables investigated in this study are presented in Table 8. Five of the participants did not complete this section of the questionnaire.

Table 8

Means and Standard Deviations of Peer Personal Intimacy and Group Integration

Group	<i>n</i>	Peer Group Integration		Peer Personal Intimacy	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
All Participants	146	15.94	5.94	13.80	6.63
Non-disabled	113	14.92	5.11	13.08	6.28
Disabled	33	19.42	7.22	16.27	7.30
Non-disabled (12-18 yr.)	93	15.00	4.98	12.80	5.96
12-14	43	14.30	4.28	12.84	5.67
15-18	40	15.60	5.48	12.76	6.25
Disabled (12-18 yr.)	21	17.90	7.17	14.62	6.94
12-14	11	16.18	7.33	14.09	8.09
15-18	10	19.80	6.84	15.20	5.79

A series of analyses of variance (ANOVAs) were conducted to determine group differences between participants with and without a disability on the variables of peer

personal intimacy and peer group integration. For all participants, ($n=146$) significant differences emerged between groups with respect to perceptions of peer group integration, [$F(1, 144) = 16.25, p < .00$], and peer personal intimacy [$F(1, 144) = 6.12, p < .01$].

Participants with a disability or serious illness had higher mean scores for peer group integration (19.42) and peer personal intimacy (16.27) than participants without a disability (14.92 and 13.08, respectively). Peer group integration also varied as a function of disability for participants between the ages of 12 to 18 [$F(1, 116) = 3.35, p < .05$]. Again the mean score on peer group integration was higher for participants with a disability or serious illness than participants without a disability (17.90 and 15.00, respectively).

Contextual Variables

Computer experience. In the fourth section of the survey participants were asked questions about how many years they used computers and approximately how often they used computers and Web browsers (e.g., Netscape, Explorer) each week. As shown in Table 9, almost half (48%) of the 151 respondents had been using a computer for 2-5 years. The largest percentage of participants used a computer 21 hours or more a week and a web browser 1-4 times a day. To determine if any of the computer background variables were associated with the presence of a disability or serious illness, a series of chi-square tests of independence were conducted. The Pearson chi-square statistic did not reveal any significant associations as a function of computer experience, average amount of computer use, or average amount of WWW use.

Table 9

Computer Experience Variables of Participants (N=151)

Variable	<i>n</i>	%
Computer Use		
Less than 1 year	19	13
2-5 years	73	48
Over 5 years	59	39
Total	151	100
Frequency of Computer Use		
1-4 hrs./week	31	21
5-10 hrs./week	41	27
11-20 hrs./week	36	24
≥ 21 hrs./week	43	28
Total	151	100
Web Browser Use		
Once a month	17	11
Once a week	14	9
2-4 times a week	32	22
1-4 times a day	48	32
5-8 times a day	17	11
≥ than 9 times a day	23	15
Total	151	100

The question about the use of assistive devices was either not understood (e.g., “what”, “??”) or not answered by the majority of participants (83%). Of the 25 participants (17%) who indicated that they did use an assistive device, 7 had a disability. However, the descriptions provided for the types of assistive devices used were generally in reference to peripherals for the computer (e.g., printer, scanner). Only one participant who was Deaf used a computer as an assistive device for communicating over a phone relay system.

The online community. The last section of the survey asked participants about their use of and opinions about their online community. It should be recalled that all of the respondents were members of the Talk City community, except for one from KidSET. A summary of participants' use of their online community is provided in Table 10.

Table 10

Participation in an Online Community (N=151)

Variable	<i>n</i>	%
Online Community Use		
Less than 6 months	57	38
6 months -1 year	44	29
1-2 years	38	25
> 2 years	12	8
Total	151	100
Frequency of Community Use		
Once a month	37	25
Once a week	21	14
2-4 times a week	32	21
1-4 times a day	24	16
5-8 times a day	15	10
≥ than 9 times a day	22	14
Total	151	100
Duration of Community Use		
< 15 min.	25	17
15-30 min.	16	11
30 min. - 1 hour	34	22
1-2 hours	38	25
> 2 hours	38	25
Total	151	100

As shown in Table 11, most of the 151 respondents (89%) accessed the online community mainly from home, 6% accessed it mainly from school, and only 3% accessed it mainly through community resources. The one participant from KidSET accessed the online community mainly from school and home. Nine participants listed other access points, such as work, Grandma's house, or a friend's house. There were 55 participants (36%) who were not sure of the speed at which they connected to their online community; however 56K modem connections were reported by the largest percentage of respondents (29%) who knew their connection speed.

Table 11

Access to the Online Community (N=151)

Variable	<i>n</i>	%
Access from home		
Never	7	5
Sometimes	9	6
Mainly	135	89
Not Applicable	0	0
Total	151	100
Access from school		
Never	69	46
Sometimes	61	40
Mainly	9	6
Not Applicable	12	8
Total	151	100
Access from community		
Never	105	70
Sometimes	20	13
Mainly	5	3
Not Applicable	21	14
Total	151	100

(Table 11 Continued)

Variable	<i>n</i>	%
Speed		
High speed connection (Ethernet, T1)	5	3
High-speed connection at home (Cable Modem)	16	11
56K Modem	44	29
33.6K Modem	16	11
28.8K Modem	12	8
14.4K Modem	3	2
Not Sure	55	36
Total	151	100

Participants were asked to rate the ease of learning for their online community by selecting a rating on a 1-5 scale where 1 = difficult, 3 = somewhat difficult, and 5 = easy. The mean rating for all 151 participants was 4.07, with a standard deviation of 1.20. For the 22 participants with a disability or serious illness, the mean rating was 4.32 with a standard deviation of 1.13.

To determine if any of the remaining online community variables were associated with the presence of a disability or serious illness, a series of chi-square tests of independence were conducted. The Pearson chi-square statistic did not reveal any significant associations as a function of duration of membership, frequency of use, duration of each use, ease of use, point of access, or speed of access.

To determine if any the variables were associated with the frequency of use of the online community, a series of chi-square tests of independence were conducted. The Pearson chi-square statistic did not reveal any significant associations with gender, disability, age group, English as a first language, communication ability, number of siblings, amount of

computer experience, point of access, or speed. Two communication variables that were significantly associated with frequency of use were preferred communication mode [$\chi^2 (15) = 27.12, p < .03$] and communication ability through text [$\chi^2 (20) = 34.19, p < .03$]. Frequency of use was also found to be significantly associated with the variables of amount of computer use per week [$\chi^2 (15) = 64.17, p < .001$] and amount of WWW use per week [$\chi^2 (25) = 73.83, p < .001$]. There was also a significant association between frequency of use and the length of time a participant had been a member of the online community [$\chi^2 (20) = 34.61, p < .003$], the duration of each use [$\chi^2 (20) = 36.84, p < .0001$], and ease of learning how to use the online community [$\chi^2 (20) = 31.99, p < .04$].

In response to the question: "Have you made new friends on your online community?" most of the participants (84%) answered yes. Similarly, 70% of the participants said they interacted with others on a regular basis in their online community. The mean number of people with whom participants ($n=83$) interacted regularly with in their online community was 10.93, with a standard deviation of 9.75 (range = 1 - 30). The mean for participants ($n=22$) between the ages of 12 to 18 with a disability or serious illness was 10.35, with a standard deviation of 10.17 (range = 1 - 30). A chi-square test of independence was conducted to evaluate whether participants with friends with whom they interacted with on a regular basis in their online community were frequent users of the online community. Frequent use and interacting regularly with friends online were found to be significantly related [$\chi^2 (5) = 40.03, p < .0001$].

A series of three open ended questions was asked to determine what participants liked most, used most, and liked least about their online community. The responses were examined for common words and then organized into themes. A total of 119 participants responded to the question about what they liked most about their online community. Some of the responses included more than one idea and others provided very general comments (e.g., everything, fun). The most common theme among the responses was the comment that friendships were what participants liked most about their online community. Comments about friends ranged from very simple responses such as, "Great friends" and "There is friends that I know cre bout [care about] me :-)" to longer responses such as, "I love that you can get to know people online that you can share things with people that like you for who you are not by what you look like or even what you have." and "I meet people who have the same interests as I do. I then become friends with those people and talk to them almost every day." This theme of friendships was also mentioned by participants with a disability or serious illness; for example, one participant said, "I have a large group of friends in NewsTalk [a specific group within Talk City] where I chat 99% of the time. In addition to life-long friendships having been formed, there is always great discussion....". The friendship theme was further illustrated by another participant who made the following comment about what was liked most, "...I can even talk to friends about real life things that I have a hard time talking to my RL [real life] friends."

The following are other themes that were mentioned by five or more participants (listed in order of occurrence): (a) safe and supervised, (b) chat, (IRC) (c) participants with similar interests, (d) easy to learn and use, (e) diversity, (f) social interaction, (g) e-mail, (h)

games, and (i) web pages. The following are some examples of comments related to some of the themes mentioned previously:

Safe and supervised: "I like Talk City because they constantly have a watch and if someone is bothering you can easily get help..."; "They are the best place on the net for young people like myself to go and talk and not have to worry about perverts bothering us."

Chat: "Chat rooms," "Talking with other people," and "Chatting with friends."

Participants with similar interests: "...meeting people with similar interests all over the world," "I meet people who have the same interests as I do," and "...people of all ages come together and share things in common with each other."

Easy to learn and use: "Fast and easy," "Easier to use than AOL," and "It's easy and fun."

Diversity: "...folks from around the world," "talking over problems with people of various ages," and "The feeling of interaction with people on another side of the planet...it's all a jumble and can suit almost anyone."

A total of 114 participants responded to the question about what they used most of the time on their online community. The majority of responses identified a specific technology. Chat (IRC) was mentioned the most by participants (n=45) followed by e-mail, web pages, a specific chat room, the world wide web, and hosting chats (12, 10, 8, 7, and 5 respectively). Chatting with friends was specifically mentioned in six of the responses that identified Chat as being used most. For example one participant responded, "I usually chat with my friends, I mean my true friends are online. They can keep secrets and I trust them, becuz who are they going to tell?"

For the question about what participants liked least about their online community, 119 participants responded. Many of the participants (n=21) responded that there was nothing that they liked least. Abusive users were mentioned in 20 of the responses; for example, one participant commented: "The people who just want to make life a living hell who don't like the server or its rules and the fact that they just don't go away." Another participant said, "The thing I like least are the troublemakers that attempt to ruin the chat for others." A variety of technical problems were mentioned as the part liked least by 16 participants, such as: server shut downs, slow access and the long time it takes to move around or get into a chat room, and incompatibility with a computer system. No other themes occurred more than two times among the other responses.

Some of the responses to the three open ended questions from participants with a disability or serious illness provided a unique perspective on being a member of the online community. A participant with a physical disability said, "TalkCity is a level playing field for me--I can do all I am not able to do in "real" life (run, skip, jump, etc.)". A participant who was Deaf had this to say, "It's where all deaf people and even hearing people come together and simply just have fun, relate to others and all kinds of things." In response to what they liked best about the online community a participant with a learning disability said, "I get to talk with other people and to draw pictures with symbols. Coloring from the keyboard, too." Another participant with a learning disability said, "I like to play sounds". Art was also mentioned in the following response to the question about what participants did most in the online community, "The Graffiti Kidswall". The importance of shared interests

was highlighted by a participant who said, "it's always interesting to find people of shared interests."

The last section of the questionnaire allowed for any additional comments. The majority of the 75 responses praised Talk City for how great it was (i.e., "It Rocks!", and "Great Community!!!! Best place on the net."). The high praise for Talk City was also mentioned by a participant with a disability who said,

Talk City has to be one of the best online networks I've ever seen. In 6 years online I've used Efnets, Freenet, DalNet, Undernet, MUDs, BBB's and Prodigy. When I found Talk City's chat network, though, I stopped looking. That was a little over a year ago, and I haven't left since.

Some of the more in depth comments were among the 23 responses from participants with a disability or serious illness. For example one participant said, "TalkCity has become MY city--no longer am I housebound and alone---someone is always there!!" and another participant said, "I am a proud volunteer worker for TeenTalk and Local channel which I simply love to work at. The people there are just simply the best!" The theme of friends occurred again in the following comments; "TalkCity is the best thing that has ever happened to me. I have made so many friends--over 30 of which I've had the pleasure of meeting in real life. They're always there for me and very supportive and understanding." and another participant said,

Talk City...has taught me a lot about people things. life in general. Thanks to Talk City I met 2 new best friends. They mean a lot to me. Talk City in my

eyes, just doesn't supply a place to just hang out but while you are chatting and "hanging out" you don't know it but you've learned a lot.

Summary

The Typical Online Community for Members with a Disability or Serious Illness

The typical online community represented in this study had an average of 1425 members, provided a free service, was cross platform, and provided equipment on a limited basis. The typical online community used e-mail, Chat (IRC), newsgroups, listserves, and personal web pages. The CMC tool most frequently used was e-mail and the tools least used were listserves and personal web pages. Instructional support and strategies for encouraging participation were used by the typical online community. The typical online community allowed anyone to participate, did not require participants to describe themselves, was centrally controlled, had consequences for unacceptable behavior, and allowed both participants and administrators to establish rules.

Demographic Characteristics

The typical participant in this study was a nondisabled female from the United States of America is 15 years of age with 1-2 siblings, and attended a regular school. The typical participant spoke English as a first language, preferred talking as a method of communication, and rarely found it difficult to communicate with peers in general and through writing. The typical participant rated the level of peer personal intimacy and peer group integration as high. The typical participant had used a computer for 2 - 5 years between 5 - 20 hours a week, and used a web browser (on average) 1 to 4 times a day. The typical participant was a member of an online community for less than 6 months, and used the online community once

a week, for two or more hours each time. The typical participant accessed the online community from home, used a 56K modem, and found it easy to learn how to use the online community. It should be recalled that there was a significant association between the frequency of use and preferred communication mode, communication ability, computer experience, and online community experience. The typical participant identified friends as the thing liked most about the online community, used Chat (IRC) the most, disliked abusive users the most, and made new friends and interacted with them regularly in the online community.

Participants with a Disability or Serious Illness

The typical participant with a disability or serious illness in an online community was similar to participants without a disability except for lower levels of perceived peer personal intimacy and peer group integration.

CHAPTER V

Discussion

The current spectrum of online communities designed for children with disabilities and serious illnesses provided a diverse source of information that could inform future design and development of existing and new communities. Neilsen and del Galdo (1996) recognized the questionnaire as the best method for identifying variables related to design because it allows for extensive coverage of diverse and dispersed users, which can lead to the discovery of differences between various groups of users and their specific needs. The questionnaires designed for this study were piloted with seven online communities. The information obtained from the seven system administrators and 151 participants provides a first look at variables that potentially impact participation in online communities and a better understanding of the social experiences within online communities. The main findings from this survey will be discussed in the following order: (a) online community data, (b) access, (c) computer mediated communication tools, (d) participant data, (e) communication abilities, (f) contextual variables, (g) social experiences in online communities, (h) limitations, and (i) future research.

Online Community Data

Six system administrators of online communities specifically for youth with disabilities or serious illness were contacted for this study (a) Ability OnLine, (b) Children With Diabetes, (c) ConvoNation, (d) KidSET, (e) Project Do-IT, and (f) STARBRIGHT World. Another online community, Talk City, included in this study is not specifically intended for youth with disabilities but has the largest (60,000 members) community of

youth that include youth with disabilities or serious illness. Three of the seven online communities, Project Do-IT, KidSET, and Talk City, were able to provide members the opportunity to participate in this study. Because ConvoNation joined the study towards the end of the data collection period, time limitations did not allow members enough time to participate in this study. The other three organizations had policies to protect the sanctity of their online community and/or the privacy of the members, and did not allow members to be notified of the opportunity to participate. While it is understandable that these groups should not be seen as captive audiences for research the hope was that research, that sought to improve present and future online communities would be considered of importance to both members and administrators. In addition to the goals of this research being of potential benefit to the online communities themselves, the study was designed to be the least intrusive to the members. Members were only notified of the study and could choose to participate or abandon participation at any time.

The total number of members in the online communities studied ranged from 10 - 1.5 million, and from 10 - 60,000 for members under the age of 19. Two of the organizations could only estimate the number of members under the age of 19 because these data were not specifically tracked. Ability OnLine based their estimate, 1500 or 50% of the total, on the median age, 24, of their members. The estimate from Project Do-IT was based on the following communication from the system administrator: "That 400 number I provided is not solely DO-IT Scholars -- it also includes mentors, campers from other programs, staff, members of DO-IT interest lists, and DO-IT Pals. I'll guess about half are students with disabilities. Age range 12-18." The system administrator questionnaire did not request

enough specific information about members (e.g., age range, disability) and required follow-up questions to be asked of the system administrators.

The purpose of the system administrator questionnaire was to collect data about the online communities that would balance the data collected from the participant questionnaire. Since the majority of organizations (5) did not have any responses from members then it was not possible to balance the data from system administrators. Any comparison of the organizations based solely on the descriptive data gathered through the system administrator questionnaire is very limited and based on conjecture. For example, it is difficult to know how effective different instructional strategies were without feedback from participants on how easy it was to learn how to use the online community. Without more information about the participants, their preferences, and their patterns of use, the best that can be provided is a descriptive analysis of the online communities. The results of the system administrator's questionnaire were grouped together to provide an overall picture of current practice in online communities for children with disabilities or serious illnesses. Specific attention will be given to Talk City where the system administrator's responses can be compared and contrasted with the participant's responses.

Access

The ACTIONS framework developed by Bates (1995) provides a model for appropriate selection and application of technologies for distance learning and was used in the present study to help identify external variables that effect participation in online communities. From the participants' perspectives, all of the issues raised within the ACTIONS model ultimately effect their ability to access an online community. According to

Gupta (1995), convenience of access is at the core of the adoption of any technological application and determines its ultimate success. The issues decided upon mainly by the organizations will be discussed first.

Technical requirements. The system administrator's questionnaire first addressed the issue of technical requirements for access. The basic technical requirements for using an online community were Internet access and a web browser. Two of the online communities required a Windows operating system to access all parts of the community. In addition, two of the systems were built on BBS software and required users to install software (e.g., First Class, and Wildcat) to access the online community. Given the cross platform nature of the Internet, it is surprising that systems are being developed that will only function on a specific operating system. While there may be some elements of a system that only run locally (e.g., Games), the elements of a system that allow participants to communicate and interact should be accessible to all computers that can access the Internet. Only STARBRIGHT World required what might be considered a high end computer (i.e., Pentium 166, with 64 megabytes of RAM) to access all of the functions available in the online community. STARBRIGHT does provide all computer equipment for participating hospitals, but will need to consider issues of access if they extend the community to children with serious illnesses at home. The issue of being accessible to a range of computers should be addressed by organizations that have equitable access as a goal. This does not mean that online communities should lower their technical standards to the lowest common denominator but that alternative solutions should be considered. These might include various levels of technical access to an online community, and community-based access terminals in, for example, libraries, schools, and

hospitals. Designers and developers of online communities should follow the accessibility guidelines set forth by the World Wide Web Consortium (W3C) to promote a high degree of usability for people with disabilities. The Web Accessibility Initiative (WAI), in coordination with organizations around the world, is pursuing accessibility of the Web through five primary areas of work: technology, guidelines, tools, education & outreach, and research & development (W3C, 1999).

Cost. There was no fee charged for using any of the online communities, but only one organization recognized the cost of hardware and Internet access that participants needed to purchase to use the online community. Three of the organizations provided donated equipment (e.g., modems and computers) to some of the participants and one organization, STARBRIGHT World, provided all of the equipment for each participating hospital. Cost is another variable that organizations need to carefully consider if they want to provide equitable access to all participants. The recent commercial success of computers priced below \$1,000 and the development of inexpensive devices that enable Internet access over the television are trends that will help overcome the barrier of cost and computer access (Hoffman & Novak, 1998).

Rationale and goals. The rationale for the majority of the online communities was to overcome the social isolation that can accompany the presence of a disability or serious illness. The goals of the online communities were to provide a place for interaction, communication, and building communities of support. Talk City's rationale was more general, "To foster community through the use of online technologies." and the goals were similar but without the focus on disability, "... to be integrated into places in which people have common

interests and shared experiences.” While the rationale and goals of the organizations share similarities, the differences may account for who can participate in the online community. For example, STARBRIGHT World’s goal, “to use technology to provide interaction, communication, information and play opportunities for children who have reduced access to (or increased need for) these opportunities because of a serious illness” specifically focuses on meeting the needs of children with a serious illness; thus this online community is open only to this population. In contrast, Ability OnLine’s goal is, “For children with disabilities to exchange messages with their peers with similar disabilities or conditions” but the online community is open to anyone. The target population is commonly identified in the mission statement of the organization responsible for the design and development of an online community. The majority of the online communities surveyed were open to anyone and the suggestion is not that online communities should be closed to specific user groups, but that the majority of resources should benefit the intended target population.

Community control. Research suggests that the amount of control participants have to self-regulate and define the purpose and direction of the community will effect the success of a group’s ability to reach its goals (Stainback, Stainback, & Forest, 1989; Stainback et al., 1996). Five of the organizations have centralized control over the online community and the rules and consequences are determined by the administration in four of these organizations. The two organizations that reported a decentralized control of the online community (i.e., participants have access to a server to change the environment) also involved both participants and administrators in establishing the rules and consequences of participation. One example of an online community with self control is MediaMOO, a text based,

networked, virtual reality environment designed at the Media Lab at M.I.T.. They have found that letting users build the virtual community rather than merely interact with a pre-designed environment gives participants opportunities for self expression, encourages diversity, and leads to a meaningful engagement of participants and enhanced sense of community (Bruckman & Resnick, 1995). The question of what is the appropriate balance between centralized and decentralized solutions should be answered by everyone involved in a community.

Instructional support. A variety of instructional strategies were used by the organizations to help participants learn how to use the online community. Three of the organizations provided face-to-face training for some of the participants in the online community. Evaluating the effectiveness of the different strategies was not possible without participant feedback on the usability of each online community. Talk City uses web based tours and tutorials to familiarize new participants with the environment and provide instructions on how to use various parts of the community. Both participants with and without disabilities thought Talk City was easy to learn to use. Comments from some of the participants did indicate difficulty with learning how to make their personal web pages on Talk City. Literature in the area of distance education has highlighted the importance of instructional support for increasing student success (Bates, 1995; Brindley, 1995) but to date no research that has evaluated the effectiveness of various instructional strategies in distance education or online communities. Hoffman, Novak, and Chatterjee (1995) identified ease of use as a potential barrier to access, and suggested that attempts to develop technology that is user-friendly are as important as the development of the technology itself.

Strategies to encourage participation. All of the organizations reported using strategies to encourage participation, but without any feedback from participants on how often and long they participate in the online community it is not possible to determine the effectiveness of the different strategies. This study failed to ask what strategies were used to attract potential participants to the online community. The need for a certain critical mass of participants to increase communication and participation was recognized by four of the system administrators. Talk City obviously has the advantage of a very large user base which helps to ensure that a critical mass and diversity always exist. Talk City has formed strategic partnerships with industry (e.g., CISCO and USWest), content providers (e.g., ZD Books and TV Guide), and broadcast companies (e.g., NBC) that have allowed them to inform a very large population of who they are and what they have to offer. While Talk City represents the only for-profit organization in the present study, other organizations could still learn from the success of their marketing and partnership strategies. STARBRIGHT World is an example of a non-profit organization that has also been very successful at developing partnerships with other companies and increasing awareness of their endeavors by being part of events such as the Super Bowl and working with celebrities and community leaders. Professionals in advertising and marketing have long since realized the benefit of strategic partnerships for increasing brand exposure. Strategic partnerships, community development, and marketing have been identified as the ingredients of success for iVillage, the leading online community for professional women (FastCompany, 1998). Because the attention of Internet users is fragmented across millions of Web sites, sites must compete intensely for even a small share of user visits (Meeker, 1997). Markus (1987) believes that

critical mass for interactive technologies is an "all-or-none" proposition, which suggests that an online community may not be successful as a social medium until it achieves critical mass.

Computer Mediated Communication (CMC) Tools

The two most commonly available CMC tools were e-mail and personal web pages. It was not clear whether or not organizations provided unique e-mail addresses for participants or if participants were using their own e-mail addresses when communicating with others in the online community. Talk City does not provide unique e-mail addresses for participants; however, six participants reported using e-mail in Talk City. Talk City also reported providing personal web pages. Participants did identify personal web pages as what they liked most and what they do most. However, they also voiced frustration in not being able to learn how to fix their web pages and that others did not use them. For example, one participant responded, "I think it is hard to make a homepage that people like when you don't know HTML. So I think there should be an online tutor...and they should have a way to check to see whose really working on their pages..." Software that allows users to create web pages continues to improve and will reduce the barrier of a steep learning curve for many of the participants. How online communities can take advantage of this tool for participants to provide a representation of themselves is an area that deserves more attention. A recent study on the design and implementation of a system for computer-supported distance art therapy found the presence of graphical art images compensates somewhat for the lack of a physical dimension in online social experiences, making the interaction more concrete (Cubranic, 1998).

STARBRIGHT World reported using three unique tools: desktop video conferencing, a searchable database of users, and a shared drawing board. They also identified video conferencing as the tool used most by participants. While many would argue that this type of technology is only accessible to participants with high speed lines and high end computers, this barrier is quickly disappearing as computers become cheaper and faster and high speed access becomes ubiquitous. In contrast to Talk City, who identified chat as the most used tool, STARBRIGHT World identified text-based chat as the least used tool. Whether or not this is due to the presence of video conferencing is not clear, but could indicate a possible preference for face-to-face communication over text-based communication. Woodruff and Mosby (1996) have found video conferencing improves interaction among participants, enhances understanding, and helps participants feel connected to each other. They believe this goes a long way toward building relationships in a way that e-mail, telephone, or online chat systems cannot.

Project DO-IT was the only online community that reported using a MUD, but it also reported it as being the least used tool. The reason for this is not apparent; however, Bruckman (1997) suggested that most existing MUDs are difficult to learn how to use due to the poor quality of software tools available. Since MUDs are one of the few technologies that afford both synchronous and asynchronous communication and the ability for participants to collaboratively construct the environment, it is surprising that more of these online communities have not attempted to use them. Bruckman (1997) developed an easier user interface for a MUD called Moose Crossing and has successfully used this with over 1000 children under the age of 12. Designers of online communities should consider how

environments like Moose Crossing can be integrated into a set of networking tools for participants to communicate and co-construct their online community. A participant in Talk City recognized the value of the kind of role playing that is possible in MUDs when s/he stated, "I like the fantasy forum because I can talk to people being someone I am not and enjoy myself. I talk to friends about things that I have a hard time talking to my RL [real life] friends." A few participants with disabilities in Talk City indicated a preference for additional modes of communication and expression through drawing pictures, symbols, and playing sounds. Designers of online communities should consider tools that provide opportunities for creative expression and multiple modes of communication. Previous research has indicated that systems with graphical interfaces and multichannel interactions encourage individuals to participate (Ahern & Durrington, 1996).

As mentioned previously, the intention of the two questionnaires was to provide two perspectives in order to balance the data. This was true of the system administrator questions about the CMC tools available, most used, and least used and the participant questions about what they liked most, used most, and liked least about their online community. While it was not possible to compare these responses across the online communities, the findings may be applicable to other online communities since the majority of responses were in the nature of social commentary and did not pertain to specific technologies. The expected responses to the three questions posed to the participants were ones that identified specific technologies or tools that they used in the online community (i.e., E-mail, Chat, Web Pages). While these responses did occur, the main theme that reoccurred across all of the questions was friendship. That the majority of participants focused on friendships versus the technologies

themselves strengthens Schrage's (1997) assertion that the so-called "information revolution" is more accurately a "relationship revolution." If friendships are the element of the most importance to participants, then designers and developers of online communities need to carefully consider the tools that support the development of meaningful relationships. The novelty of new technologies that are entertaining in and of themselves may not appeal to many and ultimately the novelty may wear off, while those technologies that afford meaningful social experiences may be more widely adopted and become transparent to the experience of making new friends. The importance of friendships will be discussed further with other findings relevant to social experiences.

Another re-occurring response from the participants was the importance of safe and supervised environments. For adolescents who tend to prefer the company of their peers (Bee, 1992), this response was surprising at first, but that was based on the assumption that the chat rooms were always monitored by adults. To find out more details on the supervision of chat rooms in Talk City, I followed up with the system administrator. The system administrator responded;

Our monitors range in age from 10-70. The younger hosts are paired with adult hosts. Not every chat room in Talk City is monitored, because users can create their own rooms. But in Talk City all our "official" rooms for kids are only open when they are hosted by our trained staff. We also have 24/7 assistance called CSA (City Standards Advisors) that users can call at any time, from any chat room to get help if there is a problem.

The strategies used by Talk City to provide a safe environment are appreciated by the participants and may serve to empower them to be responsible members of the community. The “dangers” of the Internet are a concern held by many parents and youth and safety and supervision strategies should be considered in the development of online communities.

Participant Data

Demographics

Who are the people that participate in online communities? The majority of the 151 respondents were female (62%) with a mean age of 15. These results are in contrast to recent estimates that 39% of total net users are female with an average age of 38 (eMarketer, 1998). Bruckman (1997) also observed a higher percentage of females in the online community, MOOSE Crossing, in comparison to current estimates of females on the net in general. The higher percentage of females found in online communities could be attributed to the social nature of the environments. However, designers of online communities should avoid the gender-stereotyped design that is the dominant view in gaming research and software design for girls (de Castell & Bryson, 1998). The higher percentage of responses from females in this study cannot be explained and could be due to a response bias. The lower average age of the participants can partially be attributed to the fact that the questionnaire and invitation was directed to children. However, it should be remembered that the age range of the respondents was 3 - 52 and that almost half of the total population in Talk City is under the age of 19. A recent survey by eMarketer (1998) reports that less than 13% of the total net users are under the age of 18. The larger percentage of youth found in online communities may point to a different trend in how this new generation will use the Internet for their own purposes.

The global reach of online communities is evident from the diversity of countries in which the participants resided. The majority of participants were from North America and other English-speaking countries (e.g., Australia, England, New Zealand). Since the questionnaire was written in English it was not surprising to have 95% of the participants list English as their first language. The cultural and linguistic implications of English-only communication in online communities can be alienating to those who are non-native or non-English speakers and their needs should be carefully considered in the design and development of online communities. For example, the Media Lab at M.I.T. has successfully used online language translation software to mediate communication between children from over 100 countries who collaboratively define and achieve the goals of a project called JR Summit (Massachusetts Institute of Technology, 1999).

The sample population studied was specific to the Talk City community and makes generalizations difficult. However, the unexpected benefit of this single population was the ability to look for differences between the target population, youth between the ages of 12 to 18 with a disability or serious illness, and participants of the same age without a disability or serious illness. Participants with a disability or serious illness were not significantly different demographically from participants without a disability. As might be expected, there was a significant relationship between having a disability and preferred communication mode since only participants who were deaf choose Sign Language.

Communication Abilities

Previous research had suggested that communication difficulties may disrupt social experiences for individuals with disabilities (Dethridge, 1997; Foster, 1987). However the

two groups of participants in this study did not differ significantly on their ratings for communication difficulty with peers. It was expected that participants with disabilities may find it more difficult to communicate in written text which would have an influence on the text based communication tools used in an online community.

While there was no difference between the two groups of participants on their rating of written communication, the variable in general was significantly associated with frequency of use of an online community. For the total population of participants, the distribution of percentages suggests that those who found written communication with peers difficult tend to use online communities less frequently. There was also a significant association between preferred communication mode and frequency of use of an online community. The distribution of percentages suggest that those who used online communities the least preferred talking as their mode of communication over writing, sign language, or other modes. The association between written communication and frequency of use may be due to the heavy reliance of text based communication tools (i.e., e-mail, chat, listserv, newsgroups) in most online communities. Future development of online communities should try to incorporate multiple modes of communication, similar to STARBRIGHT World's use of video conferencing.

Contextual Variables

Computer and online community experience. The majority of participants had 2-5 years of computer experience, used a computer between 5-21 hours a week, and used a web browser 1-4 times a day. These results are similar to those in a recent survey by the Graphic, Visualization, and Usability Center (GVU) that found the largest percentage of Internet users

have 1-3 years of experience and access the web 1-4 times per day (Georgia Tech Research Corporation, 1998). The Gvu survey also found that the majority of respondents access the web exclusively or primarily from home and use modems with a speed of 28k or more. Similarly, the majority of participants in this study reported using modems with speeds from 28k to 56K and accessed the online community primarily from home. The frequency of participants' use of the online community was significantly associated with both computer experience and use of the web. Because the survey was done online and involved participants of online communities, these findings are not surprising. In the present study there were no significant differences between participants with or without a disability or a serious illness for the variables related to computer and online community experience. With regard to point of access, Hoffman and Novak (1998) found that individuals who have access to a computer at home and work or school are much more likely than others to use the Internet. President Clinton's "Call to Action for American Education" will likely guarantee access at school with the objective to wire every classroom and library in the country by the year 2000 (Clinton, 1997). However, Harmon (1997) has found that, while almost 70% of the schools in the U.S. have at least one computer connected to the Internet, less than 15% of classrooms have Internet access. Organizations with a goal of developing online communities for special populations should consider ways to ensure access is available at home and in school or the community since, as Hoffman and Novak (1998) believe, access may translate into usage.

The other variables related to how the participants used online communities indicate certain patterns. There was a significant association between frequency of use and how long a participant had been a member of the online community. The largest percentage of

participants had been members of the online community for less than six months and used the online community one to four times a week. The most frequent users, one to four times a day, had been members of the online community for one to two years. The novelty of new technologies and online communities themselves was an area of concern identified in the literature review during the development of this survey (Bates, 1995). These findings suggest that the novelty of participating in the online community, (in this case, Talk City), does not lead to a decrease in use after initial exposure; instead, use tends to increase over time. Some may think online communities and the Internet on which they are built are just “fads” or only of interest to a few. Similar views were held about automobiles, telephones, and television. Along with the introduction of a new technology (i.e., printing press, radio, telephone, and television) comes inevitable “hype” and criticism. Online communities have been a goal of the Internet since its inception in the 1970’s (Rheingold, 1993) and are continuing to develop to this day.

Another variable significantly associated with the frequency of use was the duration of each use. The largest percentage of participants who reported using the online community for 1 – 2 hours or more each time they entered the online community were also the most frequent users. Similarly, Bruckman (1992) found that some participants who used MUDs did so for 20 hours a week, on average. Do people who spend this amount of time in online communities have a problem? What one person may see as waste of time can be seen by another person as a preference for spending leisure time. Ultimately, these distinctions are a matter of value judgments. As Bruckman noted, “It is tempting but dangerous to impose value judgments on MUD players who are happy with how they are spending their

time”(Bruckman, 1992, p. 36). It should be remembered that these patterns of use are based on self-reports of the participants and that, without a method for validating the data, these results are tenuous.

As reported previously, participants found the online community to be easy to learn how to use, in general. How easy participants thought the online community was to learn was significantly associated with how frequently they used it. The largest percentage of participants who reported that the online community was not easy to learn were also the least frequent users of the online community, and the largest percentage of the most frequent users reported that the online community was easy to learn. These findings could either indicate that active participants will learn how to use an online community regardless of how difficult it is to use or that effective instructional strategies and support are important for fostering active participants in online communities. Previous research supports the idea that strategies that make technologies easier to use and more user-friendly will lead to wider adoption and more use (Hoffman, Novak, & Chatterjee, 1995; Seaman, 1995).

Social Experiences in Online Communities

Through a review of the research literature, a series of variables were identified that may effect an individual’s ability to access opportunities for social experiences with peers in “real life” these included; age, grade, gender, type of disability, educational placement, caregivers, communication, and siblings. The majority of these variables did not seem to transfer to the ability to access online communities, with the exception of ones identified previously; preferred communication mode, and communication ability through. If individuals

are able to access online communities, will they experience social interactions, develop relationships, and form social groups?

The view of people who use computers for socializing with others may conjure up images of social misfits or computer geeks who seek out the social contacts that are missing in real life. The adventitious findings of this study suggest otherwise. The average ratings for all of the participants for peer personal intimacy and peer group integration were consistent with average ratings from previous research utilizing the same measure with children of the same age (Hayden, 1989; Beaudoin, 1999). These results may indicate that participants in ✓ online communities do not perceive their level of peer personal intimacy and group integration differently than others.

The findings from the present study support the hypothesis that children with a disability or serious illness feel more isolated from their peer group than children without a disability or serious illness. The statistically significant results from the ANOVA suggest that participants between the ages of 12 to 18 with a disability or serious illness perceive their peer group integration to be less than that of participants without a disability or serious illness. For all of the participants, regardless of age, the difference between the mean scores for the two groups on both peer group integration and peer personal intimacy was even larger. The statistically significant results from the ANOVA suggest that participants with a disability or serious illness perceive their peer group integration and peer personal intimacy to be less than that of participants without a disability or serious illness. These findings may suggest that individuals with disabilities increasingly feel more socially isolated from peers as they get older. The research literature recognizes the importance of relationships with family

and friends for individuals with disabilities and warns that, while people with disabilities may have good family support and community programs, they still are at risk of feeling socially isolated because they don't have any friends (O'Brien, 1997; Perske, 1997). Feedback from participants in this study indicate that this sense of isolation does not seem to transfer to social experiences within online communities.

Peers are powerful socialization "agents" who contribute to an individual's social and emotional well-being and adjustment beyond the influence of their families, school, and neighborhoods (Bukowski, et al., in press). Many successful adults with disabilities identify opportunities to develop friendships with similar peers as critical to their development of a healthy self image that included both their abilities and disabilities (Todis, Irvin, Singer & Yovanoff, 1993). The results of this study suggest that online communities provide opportunities for participants to interact and develop relationships with peers.

The majority of participants responded that they had made new friends in the online community and that they interacted regularly with these friends. This method of subject-only nomination of friends provides a very limited view, and reciprocal nomination of friendships should be used to ensure the validity of the nominations (Bukowski, et al., in press). However, these initial findings do indicate that participants believe they are forming friendships with other members of the online community. The fact that the participants who interact with friends online regularly are also the most frequent users of the online community provides more evidence that these friendships actually exist. Research by Parks and Floyd (1996) and by Ahern and Durrington (1996) also found CMC tools to be effective in developing social interactions and relationships.

Participants' responses to the four open-ended questions in this survey provide further evidence that meaningful social experiences occur within online communities. One of the participant's responses suggested a natural progression of social experiences; "I meet people who have the same interests as I do. I then become friends with those people and talk to them almost every day." Ahern and Durrington (1996) studied the effect of anonymity and saliency on computer-mediated group interactions and found that anonymous groups had significantly longer communications and spent more time within the computer mediated environments. A response from one of the participants provides an example of the effect of anonymity: "I love that you can get to know people online that you can share things with people that like you for who you are not by what you look like or even what you have." Bruckman (1992), who designed Moose Crossing for children under 12 years old, describes online communities as identity workshops where participants can see themselves as somehow different in the online community than out, leading them to reflect on who they are in real life. These experiences help people understand the concept of identity and the ways in which we construct ourselves (Bruckman, 1992). A participant in this study explained how the online community is like an identity workshop: "I mainly like the fantasy forum because I can talk to people being someone I am not and enjoy myself, I can even talk to friends about real life things that I have a hard time talking to my RL [real life] friends." In online communities, a person can escape his/her physical body by creating any image with a line of text. A participant with a physical disability suggested how this escape is possible: "TalkCity is a level playing field for me--I can do all I am not able to do in "real" life (run, skip, jump, etc.)." With the opportunity to experiment in online communities social

relationships can become less threatening because at any time participants can always create new persona and start over (Bruckman, 1992).

Limitations

This study required the development of a survey designed to inform the design and development of online communities for individuals with disabilities or serious illnesses. However, there are limitations to be considered when the questionnaires are employed for practical purposes (Mertens, 1998). The majority of the questions were understood and were answered accurately by the respondents; however, there were concerns about some items, as mentioned previously. The self-reporting method of data collection used threatens the reliability of the data and should be balanced with other sources of data (i.e., system administrator, observation).

The population in this study only represented youth who currently use online communities and did not include youth who may no longer participate in these communities. The methodology of using an online survey may tend to involve respondents who spend a substantial amount of time on the online community. For this reason, the results may show a bias toward more active participants.

Portions of this study were correlational, and although chi-square tests of independence can show associations between specified variables, causation cannot be inferred. Until further studies are conducted with full participation of members and the system administrators of other online communities, it is difficult to determine the validity, reliability, and generalizability of the questionnaires to other online communities.

Future Research

Future research and design of online communities should consider how decisions regarding technical requirements, cost, intended target population, community control, instructional support, and strategies to increase participation will effect equitable access and meaningful engagement of participants. The cultural and linguistic implications of English-only communication in online communities can be alienating to those who are non-native or non-English speakers, and need to be carefully considered in the future design and development of online communities. Future online research should also consider research methods that are multi-lingual to avoid any possible exclusion of participants who do not speak English as a first language.

The survey methodology used in the present study was recognized as the best method for identifying variables related to design because it allowed for extensive coverage of diverse and dispersed users (Nielsen & del Galdo, 1996). Future studies that seek to better understand the development and quality of social experiences within online communities should consider research methodologies that are more sensitive to each individual's experience. Justine Cassell suggested that a composite methodology of ethnography and quantitative measures can lead to a deeper understanding of phenomena experienced in online communities (Bruckman, 1997). Future research should carefully consider alternative strategies to encourage organizations to afford members of online communities the opportunity to decide for themselves if participation in a study is worthy of their time.

What effect various modes of computer mediated communication will have on the development of social experiences in online communities is an area for future investigations.

A future research study should also consider a usability study with a group of individuals with various abilities using a variety of augmentative and alternative communication devices.

The findings from this study emphasized the importance of friendships to participants in online communities. Future research that further investigates the quality and importance of friendships in online communities needs to be situated within an overall framework of the interrelated levels and complexity of social experiences (Bukowski, Rubin, & Parker, in press). The concept of friendship is bound both philosophically and culturally, and could be an issue of much debate. The basic elements of friendship that are agreed upon by most researchers are as follows: (1) friendships are reciprocal, meaning the friendship is mutually acknowledged by both individuals in the relationship; (2) friendships are voluntary, not assigned or an obligation; and (3) friendships require the interdependence of two individuals based on reciprocal affection: in other words, the two people who like each other (Bukowski, Newcomb, & Hartup, 1996). The present study used subject-only nomination of friendships and future studies should use reciprocal nomination to better understand friendships in online communities.

This evaluation of the current spectrum of online communities for or with participants with disabilities or serious illnesses did not identify one best method of designing or developing a community. The preferred method of design and development of online communities should use a framework for building the community that is flexible and responsive to the needs of its members. The issues identified in this study provide some directions for developing this framework and are further supported by similarities to a set of

guidelines developed by recognized experts (e.g., Amy Jo Kim, Amy Bruckman, and Mitchel Resnick) in strategic design of online communities (Glaser, 1997).

Mission statement. The rationale and goals of a community should be clearly communicated in a mission statement that identifies the intended membership. Kim also believes the mission statement is very important and that the founders should explain the rationale for starting the community and how they plan to be involved in the community (Glaser, 1997). The mission statement will help people understand the community and serve as a measure of accountability.

Strategies to attract and retain members. Form strategic partnerships with other organizations that can help fulfill the mission and increase awareness of the community. Strategies to increase access to computers and the Internet at home and the community need to be supported in order for use of online communities to follow. The emphasis should not simply be to attract people to the community, but to also preserve the quality of the experience once they are there.

All of the organizations in this study used strategies to foster participation similar to ones offered by Kim; such as providing hosted or focused discussions and holding regularly scheduled events (Campbell, 1997).

Instructional support. Kim's views agree with the issues raised in this study that suggest effective instructional strategies and support are important for guiding new members and fostering active participation.

Community control. The appropriate balance between centralized and decentralized control should be determined by membership of the community. Similar to Talk City's

practice of having members volunteer as monitors and hosts, Kim suggests giving responsibility to members who want to get more involved (Glaser, 1997). Both Bruckman (1994) and Kim (Glaser, 1997) agree that while there is no one right way to handle conflict that how conflicts are handled will effect the culture of the online community. Bruckman and Resnick (1995) contend that a decentralized model that allows servers to be distributed has both technological and creative advantages. A distributed model was not used by any of the communities in the present study.

CMC tools. Synchronous and asynchronous text-based communication, e-mail, and chat were the most commonly available and most used tools in the online communities studied. Personal web pages for members of the community were available in six of the seven online communities studied; however, this tool was not reported to be used often and in two communities was the least used tool. A more effective use of web pages would meet two other recommendations from Kim, namely, to provide tools that allow members to learn about and find others who are in the community and to create spaces that combine information with socialization (Glaser, 1997). Bearison (1997), in a study of STARBRIGHT World, found that participants highly valued the searchable directory for locating kids with similar conditions. A searchable directory that allows members to find others with similar interests who may be online at the same time could be incorporated with the use of personal web pages. Since MUDs and MOOs are one of the few technologies that afford synchronous and asynchronous communication and the ability for participants to collaboratively construct the environment, it was surprising that they were not used successfully by any of the online

communities studied. For any tools used in an online community the issues of ease of use and interoperability or seamless movement within the community are important.

Future online communities should consider a constructivist approach to design and development that has been previously advocated for by Bruckman (1997) because it can help make the community more responsive to the needs of the participants and a more valuable experience for everyone involved. Bruckman (1997) identified the elements of a constructivist approach to the design of online communities as one which:

1. seeks to maximize each individual's opportunities for creative expression and active participation;
2. provides well-designed software tools which have a low initial barrier to use, and a high ceiling for what can be accomplished with them;
3. encourages users to be creators of content, maintaining overall quality by enforcing a minimal set of community standards and establishing a distinction between private space and public space; and
4. provides an opportunity for individuals with disabilities to communicate and congregate of their own accord.

Conclusion

Students with disabilities in inclusive schools and communities are at risk of having limited opportunities for social experiences with other individuals who share similar experiences (Stainback et al., 1996). This isolation can create a problem in developing a positive self-identity that incorporates a child's disability. The premise that learning is socially constructed highlights the importance of meaningful social experiences within a

students learning environment. Findings from this study indicate that adolescents with disabilities or serious illnesses perceive their peer group integration to be lower than their peers without disabilities or serious illnesses and that this isolation may increase with age. The provision of opportunities for students with disabilities to interact, develop relationships, and groups with others that share commonalties can diminish this isolation (Stainback et al., 1996). This study has shown the potential of online communities to provide opportunities for meaningful social experiences for adolescents with disabilities and serious illnesses.

While this study was not able to describe the best way to construct online communities for adolescents with disabilities and serious illnesses, the findings do provide a general description of the typical online community for adolescents with disabilities and serious illnesses. The typical online community represented in this study had an average of 1425 members, provided a free service, was cross platform, and provided equipment on a limited basis. The majority of online communities used e-mail, Chat (IRC), newsgroups, listserves, and personal web pages. The CMC tool most frequently used was e-mail and the tools least used were listserves and personal web pages. Instructional support and strategies for encouraging participation were used by all of the online communities. The typical online community allowed anyone to participate, did not require participants to describe themselves, was centrally controlled, had consequences for unacceptable behavior, and allowed both participants and administrators to establish rules.

Social experiences in online communities. The variables that were related to participation in online social experiences were communication abilities, technical experience,

length of membership in the online community, duration of use of the online community, and ease of use of the online community. The findings from this study suggest that all levels of social experiences, interactions, relationships, and groups, occur in online communities. The majority of participants in this study indicated that they made new friends in their online community and that they interact regularly. Evidence from this study suggests that the stereotype of individuals who participate in an online community as social misfits or loners may be erroneous and that, in fact the opposite may be true. For members of an online community with a disability or serious illness, the value of their experiences is best described in their own words:

“TalkCity has become MY city--no longer am I housebound and alone---someone is always there!!”

“TalkCity is the best thing that has ever happened to me. I have made so many friends--over 30 of which I’ve had the pleasure of meeting in real life. They’re always there for me and very supportive and understanding.”

“Talk City...has taught me a lot about people things. life in general. thanks to Talk City I met 2 new best friends. they mean a lot to me. Talk City in my eyes, just doesn’t supply a place to just hang out but while you are chatting and “hanging out” you don’t know it but you’ve learned a lot.”

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<http://www.kn.pacbell.com/wired/vidconf/description.html#what>.

2. ☒ Male ☐ Female

3. Do you describe yourself as: (check all that apply)

☐ Not disabled

☐ Deaf

☐ Hard of Hearing

☐ Blind/Visual Impaired

☐ Learning Disabled

☐ Developmentally Disabled

☐ Speech or Language Disabled

☐ Physically Disabled

☐ Behaviorally Disabled

☐ Chronic Illness

☐ Other (please describe)

4. What school grade are you in?

5. Please select the best description of where you go to school now?

☒ Regular School

☐ Resource Room

☐ Separate Room

☐ Separate School

☐ Home

☐ Hospital

6. How many brothers and sisters do you have?

7. How many friends do you have who are not from school?

8. How often do you require the assistance from an adult at school?

Never 1 ☒ Sometimes 3 ☒ Always 5 ☒
2 ☒ 4 ☒

II. Communication

9. What is your first language? (For example; English, Spanish, etc...)

10. How do you communicate best with others your age?

☒ Talking

☐ Writing (with a computer or other electronic device)

☐ Sign Language

☐ Other (please describe)

11. Do you find it difficult to communicate with other people your age?

Never 1 ☒ Sometimes 3 ☒ Always 5 ☒
2 ☒ 4 ☒

12. Do you find it difficult to communicate with others through writing?

Never 1 ☒ Sometimes 3 ☒ Always 5 ☒
2 ☒ 4 ☒

III. Peer Social Support

Please use the following scale:

1 =		3 =		
Always	2 = True Most of	Sometime	4 = Hardly	5 = Not At
s True	the Time	s True	Ever True	all True

13. a) I feel part of a group of friends that do things together.

Always 1 ☒ 2 ☒ Sometimes True 3 ☒ 4 ☒ Not at all True 5 ☒
True

b) There is someone my age I can turn to.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

c) I have a lot in common with other children.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

d) There is someone my age I could go to if I were feeling down.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

e) I feel in tune with other children.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

f) I have at least one really good friend I can talk to when something is bothering me.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

g) I feel like other children want to be with me.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

h) I have a friend who is really interested in hearing about my thoughts and feelings.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

i) I feel that I usually fit in with other children around me.

Always

True

1 ☒

2

☐

Sometimes True

3 ☒

4

☐

Not at all True

5 ☒

j) I have a friend I can tell everything to.

Always

True

1 ☐

2

☐

Sometimes True

3 ☐

4

☐

Not at all True

5 ☐

k) When I want to do something for fun, I can usually find friends to join me.

Always

True

1 ☐

2

☐

Sometimes True

3 ☐

4

☐

Not at all True

5 ☐

l) There is somebody my age who really understands me.

Always

True

1 ☐

2

☐

Sometimes True

3 ☐

4

☐

Not at all True

5 ☐

m) When I am with other children, I feel like I belong.

Always

True

1 ☐

2

☐

Sometimes True

3 ☐

4

☐

Not at all True

5 ☐

n) There is a friend I feel close to.

Always

True

1 ☐

2

☐

Sometimes True

3 ☐

4

☐

Not at all True

5 ☐

IV. Information About Your Computer Experience

14. How long have you been using computers?

☒ Less than 1 year ☐ 2-5 years ☐ Over 5 years

15. What is the average amount of time you use your computer each week (for any purpose)?

☒ 1-4 Hours per week ☐ 5-10 Hours per week ☐ 11-20 Hours per week ☐ More than 21 Hours per week

16. Do you use any assistive devices with a computer?

☒ YES (please describe)

☐ NO

17. a) On average, how often do you use a WWW browser (Netscape or Explorer) for any purpose?

- ☒ Once a month ☐ Once a week ☐ 2-4 times/week ☐ 1-4 times/day ☐ 5-8 times/day
☐ More than 9 times per day

b) On average, how often do you use your Online Community?

- ☒ Once a month ☐ Once a week ☐ 2-4 times/week ☐ 1-4 times/day ☐ 5-8 times/day
☐ More than 9 times per day

V. Information About your Online Community

18. How long have you been a participant in your Online Community?

- ☒ Less than 6 Months
☐ 6 Months - 1 Year
☐ 1-2 Years
☐ More than 2 Years

19. How are you usually connecting to (name of online community)?

- ☒ High-speed connection at school(Ethernet, T1)
☐ High-speed connection at home(Cable Modem)
☐ 56K Modem
☐ 33.6 K Modem
☐ 28.8 K Modem
☐ 14.4 K Modem
☐ Not Sure

20. Where do you use a computer for (name of online community): (please check all locations)

a) Home

Never 1 ☒ Sometimes 2 ☐ Mainly 3 ☐ Not Applicable N/A ☐

b) School

Never Sometimes Mainly Not Applicable

1 2 3 N/A

c) Community

Never Sometimes Mainly Not Applicable

1 ☒ 2 ☐ 3 ☐ N/A ☐

d) Other (please specify)

21. On average, how long do you use (name of online community) each time you go online?

☐ Less than 15 minutes

⌚ 15-30 min.

⌚ 30 min. - 1 hour







 1-2 hours

☒ More than 2 hours







22. What do you like most about (name of online community)?

/TEXTAREA		▲
		≡
		▼

23. What do you use most of the time on (name of online community)?

/TEXTAREA		
		
		
		

24. What do you like least about (name of online community)?

/TEXTAREA		
		
		
		

25. Have you made new friends on (name of online community)?

26. Are there people you interact with regularly on your Online Community?



How Many

The map shows the northern Adriatic coastline of Italy. Sampling stations are indicated by numbers 1 to 15. Station 1 is near the Gulf of Genoa, and station 15 is near the Gulf of Trieste. The map includes latitude coordinates (44° 30' N, 45° 00' N, 45° 30' N, 46° 00' N) and longitude coordinates (10° 00' E, 11° 00' E, 12° 00' E, 13° 00' E).

27. Is using your Online Community easy to learn?

NO

10

20

Somewhat

30

40

YES


50

28. Please list any additional comments that you would like to make about your Online Community.

Submit

Thanks for taking the time to participate in this survey!

By completing this questionnaire, you will influence the quality of future development of online communities you may participate in. Your co-operation is important and greatly appreciated.

Online Community: 

Position: [REDACTED]

Email address:

I. BACKGROUND INFORMATION

1. How many participants are in the online community? 100

2. What are the minimum hardware and software requirements for participating in the online community?

3. Do participants pay any cost?

☒ YES (please describe) YES (please describe)



4. What equipment and or service is provided to the participants by the organization?

/TEXTAREA		▲
		≡
		□
		▼
◀	≡	▶

5. What is the goal of Ability Online?

/TEXTAREA

6. What is the rationale for providing (name of online community)?

/TEXTAREA

7. What computer mediated communication (CMC) tools are currently available? (check all that apply)

☐ Email

☐ LISTSERV

☐ Newsgroup

☐ Web Site (Community)

☐ Web Pages (Participants)

☐ BBS

☐ MUD or MOO

☐ Internet Relay Chat (text only)

☐ Internet Relay Chat (graphical)

☐ Cu-SeeMe

☐ Online Games

☐ Graphical Virtual Worlds (avatars)

☐ Other (please describe)

8. What CMC tool is used most often? (based on your best estimate)

/TEXTAREA

9.What CMC tool is used least often? (based on your best estimate)

/TEXTAREA

II. ORGANIZATIONAL INFORMATION

10. Is any instruction on how to use (name of online communitiy) provided?

- ☒ YES (please describe)
☐ NO

11. Are any strategies specifically used to encourage participants to interact in the online community?

- ☒ YES (please describe)
☐ NO

12. Are participants required to describe who they are?

- ☒ YES
☐ NO

13. Who can participate in the online community?

/TEXTAREA

14. Are standards established by system administrators or developed by members of the online community?

☒ Administration

☐ Participants

☐ Both

☐ N/A (No standards established)

15. What are the consequences of unacceptable behavior and who enforces them?

/TEXTAREA

16. Would you describe the primary control of the online community as centralized or decentralized? (For example, do participants have access to the server to change the environment.)

☒ Centralized (Administrative control)

☐ Decentralized (Participant control)

17. Please list any additional comments that you would like to make about Ability Online.

/TEXTAREA

Submit

Thanks for taking the time to participate in this survey!