



The Social Support
Research Program



Online Support for Adolescents with Cerebral Palsy and Spina Bifida

Final Report
August 2005

Online Support for Adolescents with CP and SB

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The full text (PDF) of this report is available at <http://www.ssrp.ualberta.ca>

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EXECUTIVE SUMMARY

Adolescents with a chronic condition are considered at risk for behavioural problems and poor social competence, particularly those with a functional disability. Studies of disabled adolescents, including those with spina bifida (SB) and cerebral palsy (CP), reveal deficits in social support and social skills. Social support has been demonstrated to be a resource for coping with stresses of chronic conditions. Yet, for adolescents with SB or CP, support interventions involving peers are virtually non-existent. Limitations in mobility and vocalization make it difficult for these adolescents to connect face-to-face or even by telephone with their disabled peers. Computers and internet technology can enhance access to peer support.

The purpose of this multi-site study was to determine the support needs of adolescents with disabilities and to design and test the impact of an accessible support intervention. The investigators sought to ascertain the effect of the computer-mediated intervention on support network size and composition, support needs, satisfaction with support, loneliness, coping with developmental and disability-related stress, sense of community, and self-esteem.

In a telephone survey, conducted prior to the development of the online support intervention, teens with SB or CP rated their parents as their primary source of support and indicated that peers provided the least support on a survey measure designed to elicit quantitative data. Although most did not currently use the Internet to communicate with disabled peers, when asked their preference for communicating with others for support, 64% wanted communication exclusively with teens, and of those most wanted to communicate with “teens that have the same disabilities.”

In Phase II, a six-month computer support intervention for youth with disabilities was designed and tested through a RCT. The communications environment was constructed from varied Internet technologies, including electronic mail, message boards, and chat rooms integrated under the Ability Online® interface. Adolescents and peer mentors met once per week in chat rooms for approximately 1-1.5 hours per session. Email and message board postings offered additional modes for communicating support. Adolescents in both the intervention and control conditions responded to interviews (mixed quantitative and qualitative methods) at pre-test, post-test (post-intervention) and delayed post-test (3 months later).

Analysis of the pre-test interviews (exclusively quantitative measures) showed that compared to teens with spina bifida, teens with cerebral palsy had fewer friends in their support network; reported more loneliness and lower perceived social acceptance; used more social support, particularly from their family, to cope. However, they had higher perceived self-worth.

Both groups of teens perceived their behavioural conduct more positively than typical peers and were aware of limitations in their physical competence.

The qualitative data from the post-intervention and delayed post-tests focused on: 1) intervention processes and satisfaction with intervention; 2) perceived intervention impacts; and, 3) recommendations for future interventions. The process data addressed positive and negative aspects of the online intervention. Five issues were discussed: qualities of the online environment that affected overall satisfaction and created a safe space to help adolescents develop a sense of connection, reciprocity of supportive exchanges, types of support provided (e.g. information, affirmation, emotional), technical barriers, and personal issues that made it difficult for the adolescents to follow through with the online sessions. Intra-personal impacts included changes in the adolescents' feelings about themselves resulting from participation in the online group. Inter-personal (i.e. family) and societal level impacts were also described. The majority of the teen participants perceived positive impacts (e.g. improved relationships with friends and family, social learning, reduced loneliness and stress) from the online support program (see page 18). They found the online environment to be non-judgmental, enjoyable, and a place to acquire information from peers in similar circumstances who shared common experiences.

Peer mentors speculated that the online support intervention could reduce feelings of loneliness and isolation. They also described the importance of providing positive role models for teens with disabilities and promoting interaction among different age groups to foster learning. Some peers described reciprocal support exchange, whereby they learned about their own health issues from teens online who had similar complications. They described the online environment as supportive and encouraging. Overall they expressed great satisfaction at having been part of a unique and potentially beneficial program.

Although no significant differences were found quantitatively between the control and intervention group with respect to the standardized measures (e.g. t-tests, repeated measures, ANOVAs), many lessons were learned that could guide the design of future online interventions (e.g. dose relationship, gender bias, support network composition, ceiling effects, a priori assumptions). The adolescent participants also provided suggestions and recommendations for future online support programs. Overall, the teens enjoyed their time online and recommended that the project be adapted and sustained in the future. The challenge that remains is to identify in advance which adolescents are most likely to accrue benefits, so that the intervention may be targeted effectively.

SIGNIFICANCE

Prevalence. Of the approximately 350, 000 children born in Canada each year, 2-3% will be born with a serious congenital anomaly (1). Advances in neonatal care have assured better survival rates for adolescents with congenital disability (2, 3). Activity limitations caused by chronic conditions affect roughly 101, 000 Canadian children 5-14 years (4). Over one half million Canadian children and youth under the age of 20 years have a disability that compromises their physical, social, and/or emotional health, and presents special challenges to families and to health, social and educational systems (5). Assessing prevalence rates of adolescents with disabilities is not straightforward. Children with disabilities are identified using a wide range of characteristics including activity limitations, chronic conditions (e.g. diabetes, muscular dystrophy), use of technical aids or crutches, and limitations in participating in age-appropriate activities (5). Of the 12.5% of Canadians living with a disability, 3.3 % represent the 0-14 year age group and 3.9% represent 15-24 year olds (4). Spina bifida (SB) and cerebral palsy (CP) are prevalent disabilities that limit the mobility and socialization of adolescents.

Neural tube defects, congenital malformations of the central nervous system, are among the most common and serious of all congenital anomalies (1). The prevalence of neural tube defects in Canada in 1999 was 4.0 per 10, 000 total births (1). SB is a defective closure of the neural tube in the vertebral column, affecting approximately one in 1000 children born in North America (6). Children with SB must cope with lifelong medical care. It typically results in hydrocephalus, paralysis of the lower limbs, bowel and bladder incontinence, lack of sensation below the lesion, dislocated hips, seizures and learning disabilities (7).

CP is an umbrella term to describe a complex, multi-dimensional group of non-progressive movement disorders resulting from damage to the brain prenatally, perinatally, or early in childhood (8). CP is one of the most frequent motor disabilities of childhood (9). The incidence has remained constant at 2.0 to 2.5 per 1000 live births (1). Significant abnormalities of growth and development are prevalent in children and adolescents with moderate to severe CP (10). Impairment of the upper limbs generates complications in almost all forms of human activity: self-care, school, work, play, and leisure activities (11).

Health Risks and Quality of Life. While medical advancements now allow children with physical disabilities to live well into adulthood, a longer lifespan puts them at an increased risk of secondary conditions including heart disease, stroke, respiratory problems, and emotional disorders (12).

Many of these secondary conditions are the result of unhealthy behaviours which may include tobacco, alcohol and drug use, unhealthy diets, and poor physical activity. Persons with disabilities are less likely than their non-disabled peers to rate their health as excellent.

The emotional and economic burden on the family and society is considerable. Adolescents with a chronic condition or disability are considered at risk for behavioural problems and poor social competence, particularly adolescents with a functional disability (13). Children with disability can be seen as less adaptive to their physical and social environments and less attractive, intelligent, and pleasant than able-bodied peers (7). Children with special needs were more likely than those with no special needs to report feeling "left out" or "bullied" at school. Thus children with special needs are more likely to face exclusion or disadvantage (5). Physical attributes continue to bar children from services (e.g. physical inaccessibility of facilities, lack of transportation) (14). Children and youth with special needs report a less positive experience socializing with their peers than do "normal" children (14).

There appears to be a close association between the physical mobility of adolescents with disability and social isolation. Moreover, many children with chronic illness experience depression due to loneliness which is likely magnified in adolescence (7). Children with SB and other neurological disorders have an elevated risk for psychiatric symptomatology (15).

Studies of disabled adolescents, including those with SB and CP, reveal deficits in social support and social skills. Adolescents with disability are also more likely to report insufficient emotional or informational support, affection, close friendships, and positive social interactions (16). Social support has been demonstrated to be a resource for coping with stresses of chronic conditions (17), a key protective factor in resilience, and a determinant of health status and health behaviour (18). Yet for adolescents with SB or CP, support interventions involving peers are virtually non-existent. Limitations in mobility and vocalization make it difficult for these adolescents to connect face-to-face or even by telephone with their disabled peers. Computers and internet technology can enhance access to peer support.



PROJECT SUMMARY

Purpose: To determine the 1) patterns of computer usage of adolescents with disabilities; 2) extent to which disabled adolescents use the computer-mediated intervention as a resource for social support; (3) effect of the intervention on (a) support network size and composition, support needs, and satisfaction with support, (b) loneliness/social isolation, (c) coping with developmental and disability-related stress, (d) sense of community, and (e) self-esteem; and (4) support intervention processes.

Hypotheses: Following the support intervention: (1) peers in social network and network size ↑; (2) satisfaction with support ↑; (3) support needs ↓; (4) support seeking (coping) ↑; (5) loneliness and social isolation ↓; (6) social competence ↑ (resilience).

Sites: Participants were obtained primarily from two urban centres in Alberta (Edmonton, Calgary) but were also recruited from towns across the province (e.g. Jasper, Grande Prairie, Medicine Hat, Rocky Mountain House, Evansburg).

Sample and Recruitment: Altogether, 54 teens participated in this study (CP=27, SB=27). Over the course of the project 5 teens withdrew. Three participants in the CP group and one adolescent in the SB group did not have complete sets of data. Three of these teens could not be contacted at the post-test stage due to change of address and one teen's father pulled him from the project at post-test due to time constraints and a distrust of computer technology. In addition, four intervention group members did not participate in a single online intervention session and were subsequently reclassified from the intervention to the control group for the delayed-post-test interviews and analysis. One additional teen with a complete data set was pulled from the CP sample when it was determined that he did not have either CP or SB. Therefore, 49 participants (I=22; C=27) remained at the conclusion of the project.

Table 1. Participation Summary

Test	Cerebral Palsy		Sub-total	Spinal Bifida		Sub-total	Total
	Control	Intervention		Control	Intervention		
Pre-test	13	14	27	13	14	27	54
Post-test	11	13	24	12	14	26	50
Delayed Post	11	12	23	12	14	26	49
Modified Delayed Post	12	11	23	15	11	26	49
Withdrew/Removed	2	2	4	1	0	1	5

There were no significant demographic differences between the control and intervention groups at pre-test. On average, participants were 15 years old (Control=15.60; Intervention=14.86), from English speaking homes, and living with three other family members. The gender split between participants was almost equally divided (males=51%; females=49%). Ninety-two percent of the sample were enrolled in public school (X=Grade Nine) while the remainder were private or home schooled.

Table 2. Demographics

Characteristic	Control		Intervention		Test Statistic
	Mean	SD	Mean	SD	
Age	15.60	1.78	14.86	1.74	T = 1.54; df = 51; p = .13
Grade	9.92	1.63	9.32	1.85	T = 1.24; df = 51; p = .22
Number of Co-habitants	4.08	1.0	4.32	1.16	T = -.81; df = 51; p = .42
Distance to Nearest Urban Centre (km)	9.72	16.11	13.32	39.42	T = -.43; df= 51; p= .67

Table 3. Demographics

Characteristic	Control		Intervention		Test Statistic
	N	%	N	%	
Gender of Participant					
<i>Male</i>	11	20.8	16	30.2	$\chi^2 = .91$; df= 1; p= .34
<i>Female</i>	14	26.4	12	22.6	
Disability					
<i>Cerebral Palsy</i>	12	22.7	14	26.4	$\chi^2 = .02$; df= 1; p= .88
<i>Spina Bifida</i>	13	24.5	14	26.4	
Language					
<i>English</i>	24	45.3	28	52.8	$\chi^2 = 1.14$; df= 1; p= .29
<i>Other</i>	1	1.9	0	0	
Type of School					
<i>Public</i>	23	43.4	26	49	$\chi^2 = .01$; df= 2; p= .99
<i>Private</i>	1	1.9	1	1.9	
<i>Home</i>	1	1.9	1	1.9	
Extra-curricular Activities	--	--	--	--	$\chi^2 = 53$; df= 52; p= .44
<i>Many different types</i>					
Co-habitants	--	--	--	--	$\chi^2 = 13.38$; df= 16; p= .65
<i>Many different combinations</i>					

Table 4. Diagnosis

Diagnosis		Percent (whole sample)	Percent (intervention)
SB	Myelomeningocele	84.6%	72.7%
	Meningocele	3.8%	9.1%
	Lipoma	7.7%	9.1%
	Thoracic Myelopathy	3.8%	9.1%
	Shunt	73.1%	72.7%
CP	Hemiplegia	27.3%	
	Diplegia	40.9%	
	Quadriplegia	22.7%	
	Athetosis	4.5%	
	Ataxic	4.5%	

Table 5. Mobility

Mobility		Walk	Wheelchair	Crawl	Combo
SB	At home (whole sample)	50.0	34.6	15.4	
	At home (intervention)	45.5	36.4	18.2	
	In community (whole sample)	30.8	61.5		7.7
	In community (intervention)	18.2	81.8		
CP	At home (whole sample)	87.0	8.7	4.3	
	At home (intervention)	90.9	9.1		
	In community (whole sample)	65.2	34.8		
	In community (intervention)	72.7	27.3		

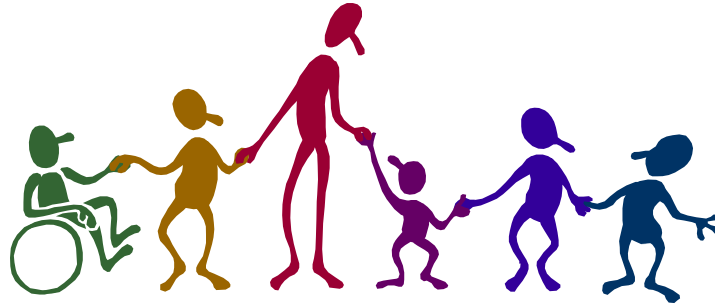
Intervention: This was a RCT of a six-month computer support intervention. All participants were identified at the research sites and then interviewed. Once all the pre-test interviews were complete, the participants were assigned to the intervention or control group by means of a computer generated random numbers table. Both the intervention and control condition included near equal numbers of adolescents with spina bifida and cerebral palsy. The Alberta Children’s Hospital in Calgary and the Glenrose Rehabilitative Hospital in Edmonton were the main partners in this study. The Northern and Southern Spina Bifida Associations, Alberta Cerebral Palsy Association, the Palliser Health Authority, and the Medicine Hat Regional Hospital played key roles in the recruitment of youth for the intervention phase.

Two health professionals and five peer mentors (2 CP; 3 SB), in Edmonton (n=3) and Calgary (n=2), acted as facilitators/resources for the adolescents participating in the intervention. The peers ranged in age from 22-39 years and included 3 females and 2 males. Peers were actively involved in community organizations serving people with disabilities and/or former adolescent clinic clients. Knowledgeable, skilled health professionals (clinical psychologists) were available to the peer mentors on an on-call basis to help manage challenging issues and to offer advice or feedback. Adolescents and peer mentors met once per week in chat rooms for approximately 1-1.5 hours per session for twenty-five sessions. The communications environment was constructed from varied Internet technologies, including electronic mail, message boards, and chat rooms integrated under the Ability Online® interface. Email and message board postings were ongoing for the duration of the intervention.

Research Capacity Building: Research assistants (n=5) were trained in both Edmonton and Calgary to administer qualitative and quantitative measures at three time points (pre/post/delayed post-test). One health professional (psychologist) in each site was trained to provide on-call support to peer helpers. Capacity building was emphasized through training and reinforcement. The peer and professional intervention agents jointly received intensive training by research team members. Peers and professionals were trained together. Ongoing monitoring and support were provided by the project staff through bi-monthly check-in sessions involving peers, professionals, and the project coordinator as well as periodic individual contact.

Evaluation: Adolescents in both the intervention and control conditions responded to interviews (mixed quantitative and qualitative methods) at pre-test, post-test (post-intervention) and delayed post-test (3 months later). The youth completed five standardized quantitative measures: *Loneliness and Social Dissatisfaction Scale*, *“Seeking social support” subscale from the Self-Report Coping Scale*, *Sense of Community Scale*, *What I am like: Self Perception Profile for Adolescents*, and *Children’s Inventory of Social Support*.

The qualitative data, collected at post-intervention and delayed post-test, were elicited from four sources. First, semi-structured interviews elicited participants' perceptions of the impact of the intervention, satisfaction with the intervention, and recommended changes to the intervention. Second, online discussions among youth with disabilities and the peer mentors were recorded in the computer transcripts (chat rooms & message board). Third, all peer mentors completed weekly fieldnotes to further document the intervention processes occurring online. Finally, exit interviews with peer mentors were administered following the intervention to describe perceived intervention impacts, intervention processes, benefits, challenges, and recommendations for improvements to the program. All qualitative data were transcribed and subjected to thematic content analysis.



FINDINGS

During the 6-month online intervention, participants posted an average of 21.5 messages, went on-line 68 times, spent 796 minutes on-line, and attended 3.36 chats. The CP teens posted more messages and attended a few more chats than SB teens, while SB teens were online a greater number of times. However, comparing the number of messages posted by group, there were no statistically significant differences ($X=16$ messages). Comparing minutes online by group, the difference approached statistical significance ($p= .06$). Comparing the number of chats attended by group, there were no statistically significant differences ($X=.96$ chats). Moreover, there were no statistically significant differences between the CP and the SB groups for message board postings, times online, minutes online, or chats attended. Peer mentors posted 109 messages on average, spent 1812 minutes on-line, and went on-line an average of 114 times.

Looking at the differences in participation by gender, there were no significant differences in the number of chats attended, number of minutes on-line, or number of times logged-on. Comparing the number of messages posted by gender, the difference was significant ($p= .03$); females posted 15.8 messages on average, while males posted 3.0 on average.

Table 6. Online Participation

Participation	Mean	Range
Number of messages posted	21.46	0 - 250
Number of times on	68	1 - 273
Number of minutes on-line	796.32	10 - 2833
Number of chats attended	3.36	0 -20

Qualitative Data Analysis

The qualitative analysis was based on telephone interviews with 27 participants; 13 adolescents with CP and 14 with SB. All qualitative data were transcribed verbatim and imported into FolioVIEWS™ software for data management (19). Most teens participated in both post-test and delayed post-test interviews (3 months following intervention). With the exception of declining recall at the delayed post-test interviews, the content of responses was very similar in the post-test and delayed post-test interviews. Consequently these two interview episodes were analyzed together for each participant. The themes are presented with an indication of the number of adolescents who spoke of that particular issue or concept. The adolescents varied markedly in the degree of detail provided on any issue. In particular, adolescents with cerebral palsy tended to be much more verbal and provided greater elaboration of their responses. Due to the uneven amount of detail in the CP and SB responses, weighting was considered inappropriate.

The data were partitioned into three broad sections: 1) intervention processes and satisfaction with intervention; 2) perceived intervention impacts; and, 3) recommendations for future interventions. The process data addressed both positive and negative aspects of the online intervention. Five issues were discussed: qualities of the online environment that affected overall satisfaction and created a safe space to help adolescents develop a sense of connection, reciprocity of supportive exchanges, types of support provided (e.g. information, affirmation, emotional supports), technical barriers, and factors that made it difficult for the adolescents to sustain participation in the online sessions.

The perceived intervention impacts were analyzed at three levels of abstraction: intra-personal, inter-personal (e.g. family, friends), and social impacts. Intra-personal impacts included primarily changes in the adolescents' feelings about themselves resulting from participation in the online support group. Inter-personal level impact focused on relationships within the adolescents' immediate home and school environment. The social level data centred on adolescents' insights into their place and connection with larger society.

Intervention Processes

A Safe Place to Talk with People Who Understand – Interpersonal Connections

For twenty-two adolescents, the online support environment created *a safe space* and fostered *interpersonal connections*. The adolescents appreciated having someone to talk to (n=20), a sense of belonging (n=12) because they shared the same disability (n=13), and an open and non-judgemental atmosphere (n=8). The following quotes summarize key qualities of the support group.

That it's got a sense of community to it, that everybody respects everybody; you have your own opinion, but at the same time, you don't try to shove it down people's throats to get it across. And just that it's great and you can talk about everything and anything, and nobody bashes you for it. Some people disagree with you, but they don't, like, bark at you for it. [CP-15]

I always felt that I couldn't talk to anybody about it 'cause I didn't know anybody else with a disability, really...Once I found this, it was just kind of like, "Oh, finally, I can let myself go and just" [pause] blab and, I don't know, uncensored. I always feel that I can never tell anybody 'cause they don't understand; they don't go through what I go through. They've never had to go through the kids calling you freaks and whatever else happens through the course of your school career. It was just, like, "Finally! I get to talk! They understand!" [CP-15]

Some participants noted that the virtual, non-visible environment provided an outlet to openly express opinions that they had not previously experienced with their visible disability. This format offered a degree of anonymity and/or escape from the “real world.” It was effective in “breaking down the barriers, like the barriers that you see when you look at a person ...That made it a lot easier for people to connect because we are all kind of vulnerable in that sense” [CP-19]. In summary, for the majority of participants who found the group effective, it provided a welcoming environment with “friendship, kindness and understanding” [CP-21].

If I were to have a bad day at school or something and there was a chat that night, then I could talk to somebody about it. [CP-09]

I don't know. It just helped me—I know it's going to sound cheesy and stuff, but just 'cause I had someone to talk to about this kind of stuff, it helped, yeah. [CP-21]

Three adolescents claimed they did not experience this sense of connection, in part because their disability was not a central issue in their lives.

I don't want to sound ungrateful or spiteful towards the group, I just [pause]. Like, you know what I mean, but some of the time, I just had better stuff to do because I assumed they would be talking about things that didn't apply to me. [CP-17]

Reciprocity

In exploring the process of reciprocity or social exchange, the adolescents were asked what they contributed to the online support group. Only four of the 23 responding said that they made no contribution.

[I gave] the same thing they were able to do for me...lend an ear, give them someone to talk to, try and share some of my experiences. [CP-15]

I talked to them the way I talked to my best friends, and I was just straight with them, and I just said what was on my mind, and I think that helped. People just got an impression what it was like to see a guy that, I don't know, is 16 and confident. [CP-17]

I was technically a leader because I was one of the older ones. I think I was the more talkative one in the group. I showed people that it was okay to talk. [SB-52]

Types of Support Provided

Information, affirmation, and emotional supports were present in many forms during the online chat sessions. Peer mentors offered information (e.g. career planning, transportation, independent living), affirmation (e.g. advice, feedback), and emotional (e.g. empathy, listening) support. Participants spoke briefly of the emotional and affirmation support they provided to other teens: listening to others (n=3); modeling confidence (n=4); offering friendship to those who felt alone (n=3); sharing their point of view on issues (n=2); providing practical advice (n=8); and, sharing experiences related to disability (n=2).

The peer mentors who provided this support received favourable comments in all interviews. They were described as supportive, encouraging and informative. They kept the discussion going and were able to answer questions. “They were always there, they were very open, and they had experienced a lot of the things that you would ask them” [CP-09]. “They had so much experience with the things, and they gave us different websites and people to contact in finding out these things” [CP-25].

Technical Challenges

Seventeen adolescents described various technical challenges. Accessing the website was a common problem early in the intervention, but this was remedied by a new navigator. Other technical issues identified by youth participants included: navigating the Ability Online website, problems with passwords, computers “freezing,” personal computer or internet access problems, and typing speed given the pace of the chat.

Constraints on Participation

Personal Factors Some adolescents faced personal barriers to participation in the weekly online discussions. A few participants held part-time work in addition to attending school classes (n=3); some engaged in a variety of extracurricular activities such as theatre, singing, riding, and hockey or were involved in school-related activities (e.g. tutoring, homework) (n=9). A few simply forgot (n=3).

Age of Participants While most adolescents were happy to have a range of ages present online, five believed that the group should be more age-specific (e.g. only grade 11 and 12’s in one group) so that there would be greater freedom to speak and all members would relate to the discussion. For example, one 16-year-old girl noted: “Well, a lot of them were really young. They were like 14” [SB-69]. Another 16-year-old explained:

Being 16, I’m into...going out and doing stuff, whereas the online support group kids tended to be more centred around—I don’t even know how to put it—like, wrestling and all that stuff. Because I go to high school, I’m experiencing a lot deeper things than that. [CP-17]

Online Experience While most adolescents welcomed the opportunity to connect with other teens with similar disabilities, a few found the experience impersonal (n=3), restrictive (n=3), and stressful (n=2). One teen did not appreciate the disability focus:

I personally don't like being grouped in specifically with people who have disabilities, 'cause it makes me think I'm not normal if I'm being stuck with other people who have disabilities, too It makes me focus on the fact that I'm different, and I don't really like that. [CP-04]

Satisfaction with Intervention Processes

Fourteen adolescents reported that they had *fun* being part of the online support intervention. At the outset, when selecting outcomes measures, the investigating team decided to ask the teens outright what (if anything) they enjoyed about the online group. They mentioned that the support intervention was “*enjoyable*”, “*humorous*”, and “*interesting*.” One said, “I got into a routine where I always wanted to be on the computer at a certain time” [CP-07]. Another reported:

It was fun, we had a lot of laughs, and we joked about stuff, and people actually cared about what you had to say, so that's why I found it fun. [SB-69]

Perceived Intervention Impacts

The adolescents were specifically asked about potential impacts of the intervention on their emotions and emotion focused coping, feelings of loneliness, pre-existing friendships, family dynamics, and continuing relationships with members of the online support group.

Intra-personal Impacts

Emotions and Emotion-Focused Coping Eleven adolescents reported that they were able to deal with negative feelings, or felt more positive, because of the online support group. They described being more patient or calm, less angry or depressed, and happier than prior to the intervention. Their descriptions included more positive perspectives and learning strategies to cope with negative feelings. For example, one youth reported learning to “vent” his feelings rather than bottling them inside. Another teen explained to the online group that she wrote poems, songs, and stories to channel her anger or sadness. When asked specifically about stress and coping, the term “stress” resonated differently with adolescents than adults. Two adolescents explained their viewpoints:

Well just talking with people, you know it takes the stress off you...Cause other people were aware of your problems and you didn't always have to keep it inside. Sometimes things are pretty hard to deal with. [SB-59]

Life, well, that's different than stress. Like—it helped me cope better with, like, loneliness and stuff, but I wasn't really stressed in the first place, so it didn't really have an effect on that. [CP-21].

Another major intra-personal impact involved gaining confidence (n=8); for some this was linked to being less shy and able to speak up more.

Just all the confidence that everyone had was just—it was amazing. It gave me confidence that this was going on and people were being successful. . . . just to have confidence in myself, and that confidence pays off. [CP-17]

They made me come out of my shell, because before this whole chat thing, I was very shy. Now I'm just a crazy machine. [SB-73]

These feelings of confidence were linked to the safe online environment and to the role modeling of other adolescents who were members of the support group. When one teen openly expressed an opinion or made a comment, others felt safe to do the same. These interactions boosted their confidence level.

Loneliness When asked if the online group had an effect on loneliness, 16 adolescents reported that the online support group had an effect on loneliness during at least the post- or delayed post-test interviews, attributing this to knowing there were other people with whom they could talk who had similar experiences. Little elaboration was provided. The following illustrates typical replies: “*It made me know somebody was there. It gave me another venue to talk to people*”; “*When I was doing the chats, I was involved with the conversation, and I wasn't thinking about [loneliness]*”; and, “*[The chats] made me realize that I'm not alone; like with my disability or whatever, there's lots of people out there that go through the exact same thing as I do.*”

Many teens reported that the effects on loneliness were moderate because the support was offered online without an opportunity for face-to-face contact. Still others liked the fact that if no one else was available, "*you could go on the computer and spill.*" Eight of the 24 (who replied consistently in both post-test and delayed post-tests) reported no effect on loneliness. Some contended that they were not lonely at the beginning of the intervention. This conclusion is supported by the quantitative measure of loneliness administered at pre and post test which revealed that 1) teens in the intervention group were not significantly lonely at pre-test, and 2) there were no differences in the loneliness scores of the intervention group over time.

Inter-personal Impacts

Family—Family Growth The adolescents were specifically asked if their participation in the support group had an effect on their relationship with their families and on family communication. Twelve of these adolescents claimed that they talked more with family following the intervention, but for seven the impact was qualified with statements such as:

Probably a bit more, I guess. Certain things that I've talked about in the peer group, I'm talking about it more in my family; I'm not keeping things to myself. [SB-51]

Adolescents were asked whether participation in the support group affected how they "got along with" their family. For those who identified specific links with the intervention, impacts stemmed from follow-up discussion of the online topics with family members (n=3), increased appreciation of their family (n=1), or improved ability to understand and connect with their parents (n=2) and siblings (n=2).

It just showed me how other people deal with their family members and kind of helps me make judgments in that way.[CP-09]

It helped me so I wouldn't get so mad all the time. [My brother] would say things and I would take it really seriously. I stopped taking stuff really seriously from him. [CP-07]

Most adolescents (n=17) denied any effect on their relationship with family. One explained that these were unrelated issues, so there was no reason to expect a change.

Friendship Fifteen adolescents described an impact of the intervention on their pre-existing friendships. They reported that the intervention enhanced their friendships in various ways as illustrated in these quotations, "*figure(ed) out who my true friends were,*" "*gave me some different things to discuss with my friends,*" and "*understood that they didn't exactly look at the big picture.*" Most adolescents struggled to explain the mechanisms of the effects on friendship. Three claimed that their increased confidence made it easier to "reach out" in discussions with able-bodied peers. One adolescent explained the impact derived from knowing that she was accepted in at least one group.

I just feel more accepted, 'cause I know that I have other people. I knew I had friends on the Internet. Especially in junior high, 'cause I was the only sort of one that was really "different," and now I know that I sort of have someone else. [SB-52]

By being successful in one friendship situation, success in other situations seemed more plausible. Eight adolescents reported no effect on friendship.

Continuing Contacts with Peers Eight participants reported ongoing contact with other members of the online support program after completion of the scheduled chat sessions. Communication occurred primarily through email, although some teens also exchanged MSN id's for instant messaging.

Societal—Social Learning

The adolescents described four impacts on learning: 1) strategies for dealing with people, 2) strategies for coping with disability, 3) knowledge about the disability, and 4) insights into other adolescents' perspectives. Strategies for dealing with able-bodied people centred on society's and healthy peers' insensitivity towards persons with disability. For the six adolescents who reported insensitivity, key challenges manifested as teasing and being "pushed around" or "babied." The strategies learned included ignoring people, avoiding arguments, practicing patience, and managing anger. The adolescents reported that they became consciously aware of situations that frustrated them prior to the intervention. Exemplar strategies included: "I try not to blow up at people", "try and talk calmly with people", "don't pick fights with friends", and "don't let things bother me as much."

Adolescent participants also learned to manage life with a disability. Of the twelve adolescents who reported this learning impact, half spoke generically about life with a disability and the other six spoke specifically about mobility, access and transportation issues. All participants had some mobility challenges. Their discussion varied by age and experience; younger adolescents were not yet responsible for "getting around in the outside world" [SB-76] independently, while older adolescents discussed vehicular adaptations for driving.

Eight participants with spina bifida reported learning about the nature of the disability. Two described their learning as follows: "There are different kinds of spina bifida, and I learned what CP was" [SB-69D], and "[I learned] more about my disability. Like, what caused it and stuff" [SB-74]. It is possible that the adolescents with spina bifida had less knowledge of their disability and other disabilities because of cognitive challenges.

Many participants observed that their social world did not previously include other individuals with disabilities. Consequently they had little prior exposure to disabled peers' views of the world. Seven participants described how the opportunity to hear other people's perspectives enhanced their self awareness through comparison. One eloquent adolescent explained: "They just showed me their perception of the world around them, and the truths and the myths that they took to heart, and just the interest about those things." [CP-17]. Another teen commented: "It gave me a different window into myself, not just into other people. It made me understand a bit more about myself and my limitations and my goals and the way that I can fit them." [CP-09]. Most explanations were more succinct; for example, the online chats "made me have a better attitude towards life, going through it and knowing that there was other people like me out there in the world" [CP-18] or "It gave me a different way of looking at life through other people's eyes." [CP-09] Three adolescents noted that the online support group taught them how to relate to other people who had disabilities.

Recommendations

Thirteen participants recommended keeping the intervention program the same; they wanted to sustain the regular online chats. The most common recommendation for change was to add instant messaging features so that participants could break off into separate chat rooms for small group discussions rather than remain with the large group (n=9). Three adolescents would have preferred face-to-face interaction (see above). Another three found the topics were too structured and the conversation felt forced.

Varied ideas for new features were offered. For example, three suggested webcams, other individual suggestions included: photo albums, guest books, surveys, personalized font colours, greater log-in security, a shout box, and games. One creative participant imagined an unlimited budget and the ability to include: a web cam with headphones and subtitles for the deaf, voice activation for those with poor hand motor skills, and multilingual translation so that the chat could be worldwide.

Two participants thought the peer mentors should be younger and better able to understand the adolescents' online slang and current trends. The most common recommendation was for the peer mentors to share more of their perspectives. Some adolescents wondered if the mentors had been told to not talk too much.

Quantitative Data Analysis

Table 7. Summary of Perceived Intervention Impacts

Impacts	Frequency of Impacts
Impact of Online Support	35.7% reported a large or very large impact (n= 10)
Experience Participating	60.7% (n= 17) reported that their experience was good or excellent
Satisfaction with Peer Mentors	64.2% (n= 18) reported that they were either quite satisfied or very satisfied
Relationships with Family	17.9% (n= 5) reported a large or very large effect on how they got along with family members
Relationships with Friends	14.3% (n= 4) reported a large or very large effect on how they got along with friends
Social Learning	46.4% (n= 13) reported that they learned a lot or quite a bit
Effects on Loneliness	25% (n=7) reported a large or very large effect in reduced feelings of loneliness
Effects on Level of Stress	17.8% (n= 5) reported a large or very large effect on diminishing level of stress
N= 28; but N= 6 missing data	

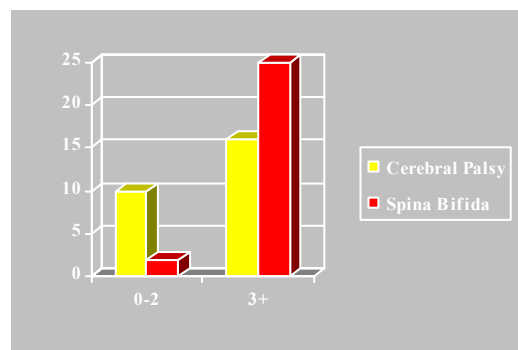
Children's Inventory of Social Support

(Wolchik, Sandler, Braver, 1984; adapted from Barrera's Arizona Social Support Inventory Schedule; to assess support as a multidimensional construct).

Wolchik, S.A., Sandler, I.N., Braver, S.L. (1984). The Social Support Networks of Children of Divorce. Poster presented at the annual meeting of the American Psychological Association, Toronto.

At pre-test the adolescent's network size ranged from 4 to 27 people with a mean of 13.5. There was a mix of family and non-family members. There was nothing significant by group other than males had significantly fewer contacts overall than females (previously reported). There is very little to go on but there are some unusual things in the contact types etc. For example, there were no significant differences by group on any of the CISS variables with the exception of negative interaction. The intervention group had significantly less negative interactions than the control group and over time was more likely to drop negative interactions with classmates versus individuals named as friends. They were also less likely to have negative interactions with teachers.

Unique Findings: Females ($X=31.04$; $SD=8.83$) had significantly larger networks than males ($X=25.00$, $SD=11.00$; $T= -2.14$, $df = 48$, $p=.04$). The difference in network size between the control group and intervention group failed to reach significance but is of note (Control = 29.71, $SD=9.68$ vs. Intervention = 25.55, $SD=11.00$; $t = 1.42$, $df = 48$, $p=.16$). The intervention group did have a smaller network, which included less contacts of a negative nature. Size of network did not differ by type of disability overall, however the network size for the SB intervention group was significantly lower than all other groups ($X= 22.4$ contacts). There was a significant interaction between type of disability and group membership. Network size was lowest among males in the SB Intervention group ($X=18.17$, $SD = 7.19$).



The control group had a higher number of negative interactions overall but there were no significant differences across time in reduction of negative contacts by group membership. Both groups reported a reduction in the number of negative interactions over time. Females had slightly more negative interactions than males; however, the difference was not significant. Both males and females had a reduction in negative contacts over time. SB teens had more negative interactions than CP teens. Although both groups had a reduction in negative contacts the reductions was much greater for CP teens (67.4%) than SB teens (4.8%).

Loneliness and Social Dissatisfaction Scale

(24 items [8 fillers]; Maximum possible score is 80; higher score = more loneliness)

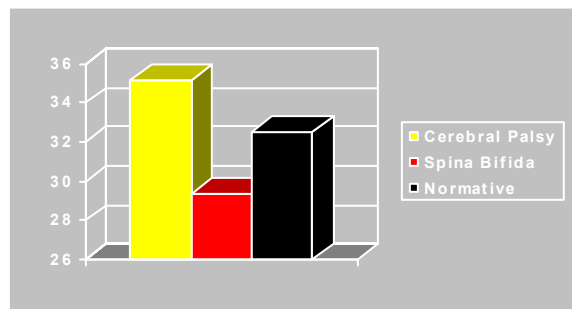
In the original sample, loneliness scores ranged from 16-79 with a mean score of 32.51 and a std. dev. of 11.82 (moderate loneliness=46)

Ahser, S., Hymel, S., Renshaw, R. (1984). Loneliness in children. *Child Development*, 55, 1456-1464.

At both post and delayed post-test, no statistically significant differences between intervention and control means (t-tests) were found. Prior to the intervention neither the intervention or control group would have been considered lonely. The intervention group mean score was 34 (SD=10) and the control group mean score was 31 (SD=8). The groups were not significantly different at pre-test. There are no normative values for the teens on this scale. For a large sample of children in Grade 3 to 6 the mean was 32.5 (SD= 11.8).

Repeated measures revealed no statistically significant differences between intervention and control groups. Both groups displayed means similar to the previous study involving children in Grades 3-6. These means were in the average range for loneliness. In other words, these particular teens were not considered to be lonely from the outset. Thus there is little reason to believe that their reported loneliness would decrease significantly as a result of this intervention.

Unique Findings: CP teens reported significantly more loneliness at pre-test than did teens with SB ($p= .019$). This finding held at post-test where CP teens continued to report more loneliness ($p=.045$).



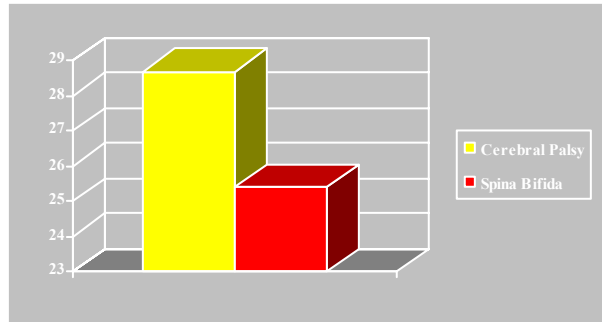
Self-Report Coping Scale

(Maximum possible score is 40; Higher score = better coping)

Causey, D., & Dubow, E. (1992). Development of a self-report coping measure for elementary school children. *Journal of Clinical Child Psychology*, 21, 47-59.

At both post and delayed post-test, no statistically significant differences between intervention and control means (t-tests) were found. Repeated measures also revealed no statistically significant differences between intervention and control groups. The intervention and control groups had a mean score of 27 (SD=6) at pre-test suggesting a willingness and ability to seek social support. However, there are no reported norms for an adolescent sample. Further, this subscale is actually derived from a measure composed of 5 subscales. Our study only utilized the *seeking social support subscale*. The findings in previous studies compared correlations in each of the subscales but did not report norms for the individual subscales. Thus there is no way to compare our teen participants to other samples.

Unique Findings: At pre-test, teens with CP were significantly more likely to use social support for coping ($p = .026$) and used family support to a greater extent than did persons with spina bifida. In this study, a mean score of 29 (SD=4) was reported for the CP teens while the mean for the SB sample was 25 (SD=6). Both scores are much higher than those previously reported for males ($M=17$) and females ($M=20$) in grades four to six.

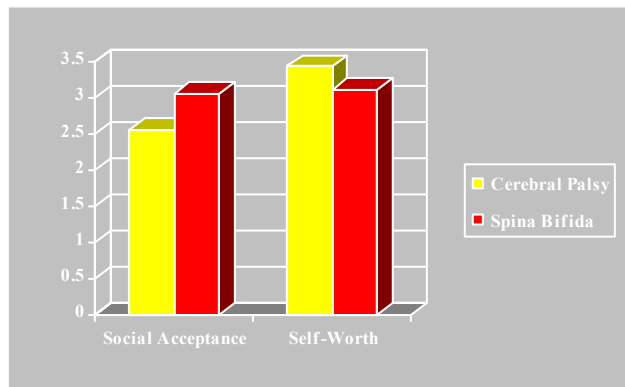


Adolescent Self-Perception Profile (Harter Scale)

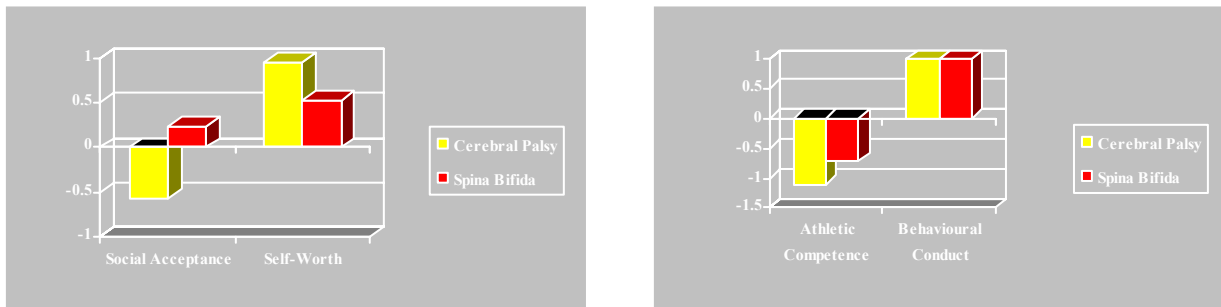
(Maximum possible score is 25 for each subscale; taps domain-specific judgments of competence or adequacy in five separate areas.)

These measures illustrated how adolescents perceive their own functioning in 9 subscales (45 items). The subscales included scholastic competence, athletic competence, job competence, social acceptance, physical acceptance, romantic appeal, behavioral conduct, close friendships, and self-worth. A MANOVA test revealed a $p = .04$ difference between CP and SB teens in the following subscales: athletic performance, behavioral conduct, social acceptance, and self-worth.

At pre-test there were significant differences between the teens on two subscales. Teens with CP reported lower social acceptance scores ($x=12.58$; $SD=4.6$), however, they had significantly higher general self-worth scores ($x=17.4$; $SD=2.6$). Providing normative values is difficult as the means vary depending on the grade level and gender of the person. Therefore we calculated z-scores to examine how each individual's scores compared to the normative sample.



Relative to the normative sample, the mean score for teens with CP was a little over half a standard deviation below the mean for social acceptance. So while the differences between the groups were significant, both groups are within the range expected for typical teens. Teens with CP have mean self-worth scores almost one standard deviation above the mean. Both groups are on the positive side of the typical range.



Generally the scores of both groups of teens fell within one standard deviation of the normative mean. However, there were two exceptions. Not surprisingly, teens with CP rated themselves greater than one standard deviation below the norm for athletic competence. Both groups of teens rated themselves well above the mean for behavioural conduct. These adolescents weren't getting into trouble. Perhaps the youth who were getting into trouble did not volunteer for this study.

Our sample also had slightly lower alphas for scholastic, athletic, romance, conduct, and self-worth than Harter's reported alphas for each sub-scale. At both post and delayed post-test no statistically significant differences between intervention and control means (t-tests) were found. Missing variables for the Romance and Job sub-scales of this instrument are interesting: 14 CP teens had missing values (9 males; 5 females); 8 SB teens had missing values (3 males; 5 females). There was a temporal effect of age in ability to provide answers to questions from the Job and Romance sub-scales. The sample was well within the normative range of responses at pre-test. Thus great differences as the result of an intervention could not be expected.

Sense of Community Scale

(Maximum possible score is 35; Higher score = more sense of community)

Dunham, P. et al (1998). Computer-mediated social support. *American Journal of Community Psychology*, 26, 281-306.

Pre-test scores did not reflect any significant differences between the intervention and control group. At post-test a statistically significant ($p = .02$) difference in means was detected between intervention and control groups (t-tests). However, the control group had the higher mean, which does not support the hypothesis. At delayed-post test no statistically significant differences between intervention and control means were observed (t-tests). Repeated measures revealed the same findings as the t-test. This scale was adapted from an original assessment of environmental risk. Dunham et al modified the scale for use with single young mothers. Our dose relationship was investigated as Dunham found that the more the mothers used the online support, the greater their SOC scores. Their online access was available 24/7. Unlike Dunham, we did not find higher scores for those who participated more in the intervention. Hosting the intervention once a week may not have been enough to create an impact.

Additional Findings: Comparing Means

- SB teens (intervention and control) had higher means for *Sense of Community Scale* at pre & post test
- Intervention males had lower *Sense of Community Scale* scores at post and delayed post-test
- CP teens had a higher mean for *Loneliness and Social Dissatisfaction Scale* at pre, post, & delayed-post test
- Male teens (intervention and control) had higher means for *Loneliness and Social Dissatisfaction Scale* at pre, post, & delayed post-test
- Intervention group had slightly higher means for *Loneliness and Social Dissatisfaction Scale* than control at pre and post, but slightly lower at delayed post test
- Rural teens had lower means on *Loneliness and Social Dissatisfaction Scale* at pre-test
- Rural control had much lower *Loneliness and Social Dissatisfaction Scale* scores
- Urban teens (control and intervention) had higher means for *Loneliness and Social Dissatisfaction Scale*; however, at post-test and delayed-post the control group had a lower *Loneliness and Social Dissatisfaction Scale* mean score than the intervention group
- Both intervention and control participants living in rural areas had higher means for the *Self Report Coping Scale* at pre, post, & delayed-post test



Internet Use Survey

Few significant differences were observed between the intervention and control groups on the survey. Differences, where apparent, cannot be attributed to the intervention alone. Descriptive statistics are listed below.

- **Who provided you with the most support?** No significant differences were reported between the intervention and control groups. However, over the course of the project, there was a significant increase in the number of teens overall who reported receiving support from their parents (76% up from 66%). Conversely, support decreased from siblings, friends, health professionals and others.
- **Use of support groups.** Outside of this intervention 94% of teen participants were not part of an organized support group. Many were involved with local SB and CP organizations such as sports associations and teen camps.
- **Health information & the Internet.** No significant differences were reported between intervention and control groups with respect to seeking health information using the internet. Overall there was a 10% increase in use of the internet to find health information. This may be reflected by a general increase in computer use (described later).
- **Email use.** No change in email usage (80% use email)
- **Effects of the internet on personal relationships.** The intervention group reported meeting new people through online connections ($p=.031$) and that the internet had an effect on the way they relate to others ($p=.026$). This is a time and group effect in that over time teens in the intervention group were less likely to say that the internet had no effect on their relationships with others.
- **Internet communication.** As predicted, the intervention group reported an increase in online contacts with teens with the same ($p=.03$) and different ($p=.01$) disabilities. There was no significant increase in relationships with other teens or adults in either the intervention or control groups.
- **Time online.** There were no significant differences between the intervention or control groups. Overall, the teens increased the number of times they logged on to the internet but spent less time online once they were there. 76% of participants at post-test indicated they go on the internet at least once if not more each day compared to 62% at pre-test. Once online 22% of teens stayed online for 2 or more hours (compared to 24% at pre-test) and 38% were online less than 1 hour (compared to 34% at pre-test).
- **Internet activities.** Teens in both the intervention and control group reported being involved in a number of online activities. The use of MSN messenger, chat, and online gaming skyrocketed for both the intervention and control groups.

Table 8. Internet Use

Activity	Whole Sample	
	Pre-test (%)	Post-test (%)
Email	80	80
Chat	56	70
Web-surfing	92	86
Games	36	66
Messenger	6	38

PEER MENTOR EXPERIENCES

The participation of young adult peer mentors as intervention agents was innovative and important. All peer mentors completed exit interviews at the conclusion of the intervention. Most wished this intervention had been available when they were teens. They highlighted the value of having access to an “understanding ear” or words of advice from someone who “had walked in their shoes.” One peer mentioned that she “wouldn’t have felt so alone or isolated” if she had had access to this type of support. They described the “importance of providing positive role models” for teens with disabilities. One peer commented that she only met other teens with a disability at clinic when “meeting friends was the last thing on your mind.”

That would have been helpful to me, but that wasn't available when I was growing up (Peer Mentor #3).

Just being able to vocalize some of the things and maybe having it reinforced that, "Yeah, its okay. I went through that too." It would have been nice to have an adult with the disability tell me, "Yes, this is normal for you, and yes, you will get through this" (Peer mentor #2).

Peer mentors emphasized the difference between their experience as teens and their new insight into the world for teens with disabilities today. Two peer mentors with SB, in their late 30's, mentioned that they were the first generation of children who survived to live productive, independent lives, with minimal parental involvement. One mentor clearly remembered the expectation that he would not live past 20 years of age. They described teens today as being “more focused”, “less victimized”, “more adapted”, “busy”, “proactive”, and “quite educated about their disabilities.” They noted teens to be “secure”, “assimilated”, “accepted”, and “open to talking about their disability.” These adolescents were “not afraid to socialize with other kids” and thus demonstrated “more self-confidence” than they remembered having at that age.

It almost seems that these kids were remarkably normal teenagers. I don't know why that surprised me as a peer mentor, but I'm, like, "wow!" Maybe a different world now or at least a radically different experience on my end. (Peer Mentor #4).

Many of the [teen participants] honestly seemed to believe that if they tried, they were successful, which enlightened me, because I know at their age, unless I was 100% successful, I was not successful (Peer Mentor #3).

These teenagers were far more educated and secure regarding their disability than I was, and they were far more, assimilated in their communities and more open regarding their disabilities than I was at their age (Peer mentor #2).

Impacts and Benefits for Peer Mentors

Peers described the impact/benefit of the program for themselves as mentors. Peers enjoyed meeting young people with the same disability. They reported that it was rare to have an opportunity to interact with the “next generation.” Peers found it valuable to share personal experiences, provide options, and assist others in need. Some peers described reciprocal support exchange, whereby they learned more about their own health issues from teens online who had similar complications. Most peers believed the online support intervention helped sharpen their own computer skills and improved their message board and chat familiarity.

A couple of peer mentors practiced the “social work” and “facilitation” skills that they learned in postsecondary school. Peers enjoyed the opportunity to meet and interact with other peer mentors and project staff. They received feedback, new ideas, and advice from each other as well as the project coordinator. They described the online environment as supportive and encouraging. Overall they expressed great satisfaction at having been part of a unique and potentially beneficial program.

I think it was actually really cool for me to interact with disabled youth. I came away with the sense that sometimes I was genuinely helpful to these kids, and that gave me a very deep satisfaction, that I appeared to have impacted somebody positively by the way they were reacting to me. So I thought that was pretty cool (Peer Mentor #4).

It sounds kind of corny, but just the overall satisfaction of reaching out to people younger than me (Peer Mentor #5).

I would really like to state emphatically that I really enjoyed working with the peer mentors particularly, and the whole process for me was overwhelmingly positive (Peer Mentor #4).

My only overall comment was that it was actually a pleasure to really be involved in it [online intervention]. It was awesome; it was a great experience overall (Peer Mentor #3).

Impact and Benefits for Adolescents

The peer mentors reported varied impacts and benefits of the intervention for teen participants. They indicated that teens found “many more people out there with the same disability” who shared common interests. Through the intervention a few teens appeared to make new friendships, although it was difficult to confirm whether some knew each other before the intervention started. They thought that the online intervention offered a “shoulder to turn to,” and instilled confidence that people were available who “understand or get me.” Teens heard about each others’ experience and knew that others had gone through similar experiences.

Teens also had an opportunity to share coping strategies. Peers believed the online environment provided an opportunity for small talk. Even though some discussions “went off-topic,” there was no shortage of conversation. Thus communication and networking opportunities were definite benefits.

I think some of the kids were pleasantly surprised that there were so many people they could kind of plug in with (Peer Mentor #4).

Teens were offered a unique, “cool” online venue in which they could develop their computer and typing skills. Moreover, the website-based intervention offered a safe, accessible, and protected environment. Teens were free to discuss issues of importance to them; no subject was taboo. One peer wondered whether involvement in an online support intervention might exacerbate isolation by decreasing contact outside the home. “Would online support become a substitute for real-life interaction? Or would any interaction regardless of modality, be beneficial?”

Challenges for Peers and Teens (From the Peer Mentors' Perspective)

According to the intervention agents, all online participants faced a number of challenges, yet they offered thoughtful recommendations to offer the research team.

When it works well, it works REALLY well, just so you know, and when it works poorly, it works really poorly. I think it was a challenge for some of these teens to almost fit the study into their lives, if that makes any sense, 'cause of prior commitments' (Peer Mentor #4).

One common source of frustration involved technology problems. This included an unstable platform which periodically froze or booted people from the system. Personal technology problems included one's physical abilities with respect to the online environment (e.g. typing speed, reading comprehension, rapid conversation). Communicating online added a new dimension. Many participants found it hard to "speak" over chat room "noise." There were multiple strings of text to read and a limited opportunity for clarification and response.

Peer mentors were often frustrated with the teens' random attendance and participation patterns. The teen participants rarely logged on at the scheduled start time, did not remain online for the full hour, frequently deviated from the weekly topic, missed a number of chats, and didn't make full use of all the online activities (e.g. message board, emails). The mentors recognized that the teens had busy schedules (e.g. extracurricular activities, homework, paid work) and struggled to find a day and time to accommodate the majority.

Some of the peers wondered how they could have effectively supported the teens to "talk openly about issues," "get personal," or "say something meaningful." One peer mentor thought that chat rooms may not be conducive to a "support" intervention. From an early age children are told by their parents and teachers *not* to share personal information online. He proposed that chat rooms may be more useful as a social interaction tool. Many peers suggested that a face-to-face meeting before the online sessions could have helped to break the ice. Everyone remarked how difficult communication became when they could not read the "non-verbals." Another challenge faced by the peer mentors included organizing their own schedules more efficiently. In addition to facilitating weekly chats, mentors were responsible for preparing the weekly chat topics and attending to the message board. Two peer mentors believed the project allowed them to work on their own "follow-through" issues.

One peer wondered what made the project a success. Was it consistent attendance? Was it a packed chat room week after week? Was it a "juicy" discussion on career planning or independence? Is the online environment more conducive to support provision or socialization and would both be better served by face-to-face meetings? If social exchange was the goal then the project was a success for those individuals who regularly attended. Yet, it seemed like the most secure people (e.g. outgoing, chatty) were the ones who came out week after week. What happened to the quiet, shy types?

Types of Supports Offered

One peer contended that he offered support based on personal experience. The peers identified varied types of support provided during the online sessions. While some peers believed they offered emotional support, others did not think that the online environment was conducive to that level of exchange. Examples of emotional support included addressing fears of driving, being alone, and not making friends. Humor was classified as a form of emotional support. Peers also offered inspiration and hope.

The most frequently reported types of support functions discussed were affirmation (advice, feedback) and information. Information support included discussions on post-secondary options and adjustments to a vehicle to accommodate a disability. Coping and problem-solving strategies were shared. Most group discussions could have been classified as information-sharing (e.g. career planning, school, accessibility). Affirmation was offered through sharing common experience. Peer mentors were able to “authenticate” stories from teens as they had experienced similar situations. They believed they could play this role better than parents, friends, or doctors who had not “walked in those shoes.”

I'm older, so I've been there. Whenever we had our chats, especially with the girls, regarding relationships, sexuality, I could support them on how they felt, and reassure them that things would be better. Just support them in being who they were, and be accepting (Peer mentor #2)

Some peers reflected reciprocity in reports of gaining information and receiving feedback from teen participants. Social comparison was evident as peers compared teen experience today and their own experiences 10-20 years ago.

Training and Monitoring of Peer Mentors

All peer mentors valued the presence of a strong coordinator for the project. The peers thought they were supported by the project team and were grateful that someone could assist them and answer their questions. Peers also appreciated having access to the health professionals. In fact, they wanted more opportunity to interact with and learn from their psychologist co-facilitators.

That was actually the strength [of the training] that I can recall, was just having one-to-one access to the professionals (Peer Mentor #4).

The face-to-face training session was rated very highly. Peers believed that meeting in person before working online introduced them to partner intervention agents and established camaraderie. Although the training session was teleconferenced to involve the intervention agents in Calgary, it would have been beneficial to have everyone together in the same venue. Some peers would have liked more preparation for facilitating in an online environment and additional information on dealing with teenagers (e.g. tools to keep conversations on track, options for discipline, dealing with side conversations, technology problems). Peers believed the training sessions provided an opportunity for practicing real situations (e.g. role playing activities).

Monitoring was seen as a very useful supplement to the training sessions. The bi-monthly teleconferences encouraged brainstorming, checking objectives, offering feedback, and socializing with fellow peer mentors and project staff. These sessions offered opportunities to “share stories”, “seek advice, guidance, and affirmation from staff and professionals”, and “plan ahead.” Check-in discussions were “reinforcing”, “validating”, and provided a chance to “strategize.” Finally, the teleconferences offered a safe place to “vent”, “laugh” and share common frustrations. The only drawback to the monitoring sessions was an inability to get all intervention agents attending at the same time due to conflicting schedules.

Peers wanted to know more about the anticipated outcomes of the study and constructive feedback on whether they were accomplishing the goals set out by the project team. The mentors believed that they were online to facilitate the discussions and to keep the teens on track. When this task was difficult, they wondered if their performance was considered unsatisfactory. They wanted to know “what success would look like.” Some mentors contended

that the message board monitoring and fieldnotes were an added burden. However, these same peers believed these responsibilities enabled them to follow-through and “multitask.”

Table 9. Peer Satisfaction with Training and Monitoring

Training	Agreement
Information provided during training	60% strongly agreed and 40% agreed that the information in training sessions was adequate to assist adolescents
Support skills learned during training	60% agreed and 40% were neutral for the online conversations
Strategies to address teen issues/concerns developed during training	80% agreed and 20% disagreed
Monitoring	
Bi-monthly teleconferences with project staff	Responses ranged from neutral (20%) to strongly agree (40%).
N= 5	

Recommendations for Change in Future Interventions

Can the project be sustained? Peers raised the ethical dilemma of conducting research with over-studied populations and then terminating services once the research team has collected their data. They thought the best possible outcome would be for the teens to take over the online chat room and continue to meet independently from the facilitators. Other suggestions included:

- Choose a more stable platform for the chat groups (e.g. MSN)
- Meet face-to-face before onset of the intervention to initiate rapport building
- Age group divisions—separate the older teens from the younger ones
 - Topics could be modified to be appropriate for younger age groups
- Offer face-to-face support groups, online is too impersonal, no body language
- Offer more range and flexibility in scheduling
 - Multiple chats per week
 - Different days and times

Final Comments

It was successful because I think we were doing what we were supposed to do, and that was to discuss experiences and lend support and get their feedback and their feelings and how they feel about self-image (Peer Mentor #3).

The fact that they [teen participants] have a disability doesn't make their dreams any smaller (Peer Mentor #4).

LIMITATIONS AND LESSONS LEARNED

Dose relationship

Attendance at the chat sessions was not uniform. The range in attendance was 1 session to 20 sessions. With a small sample size we could not determine the critical number of chats needed to produce a desirable change. It would be important in future studies to set a realistic minimum attendance standard.

Optimal target population

Age differences among participants are important. Adolescents attending Junior High school lead different lives than those who attend High School. Issues such as dating and relationships or independence are not on the minds of thirteen year olds. Subsequent studies could place age boundaries on the chat sessions. Our experience was that 12-15 year olds are not fully compatible with 16-18 year olds. As stated by a 16-year-old female participant: "Well, a lot of them were really young. They were, like, 14!"

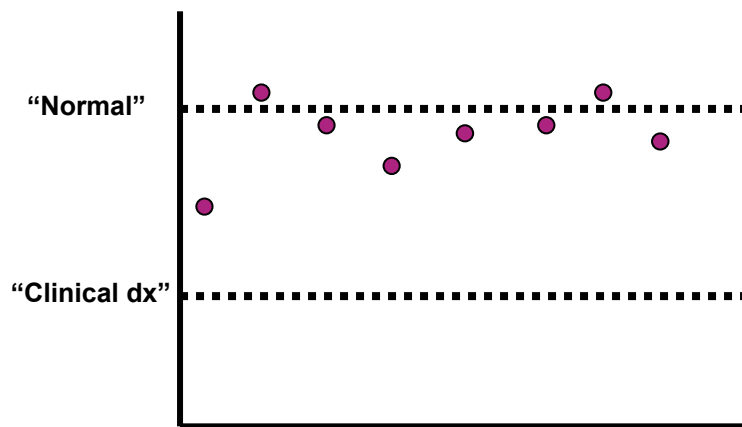
Gender differences also played a role in this intervention. Girls posted significantly more messages ($x = 15.8$) than boys ($x = 3.0$) ($p = .03$).

Despite pre-screening (IQ > 80, read > grade 6, able to use keyboard), cognitive & motor capacity affected some teen's ability to keep up with the discussion and respond to questions.

Adolescents' need for additional support should be ascertained prior to enrollment in the support intervention. Some teens may well be socially adjusted without a need for new connections. One teen reported: "I wasn't really in need of companionship. I was doing a lot of stuff, and I was around a lot of people."

Ceiling effects and A priori assumptions

It cannot be assumed that adolescents with disabilities will fare poorly on standardized measures of psychosocial wellbeing. In fact, in this group of young people most of the participants scored well within the "normal" range of responses. Many of the teens commented that they "weren't that stressed to begin with" or they "didn't feel lonely" when they joined this support group. For this reason, the hypothesized impacts of the intervention were tempered by these "ceiling effects". If teens were scoring in the normal range at pre-test then the intervention could not be expected to make them less lonely or improve their self perception.



SUMMARY

The online support intervention was clearly enjoyed and considered helpful by most participants. For these participants, "it was a learning experience, and a way to meet people with the same disability, and to share the knowledge that they possess with you, for you to share what you know with them, as well as, in time, making friends with people that have the same interests as you" [CP-17]. For a few participants, the online intervention did not resonate in the same way. These tended to fall into two groups: (1) adolescents who were minimally affected by their disability and did not perceive a need for a disability-focused intervention, and (2) adolescents whose disability was sufficiently severe that it was difficult to participate fully. For this group it is much more difficult to assess the true impact.

The challenge that remains is to identify in advance which adolescents are most likely to accrue benefits, so that the intervention may be targeted effectively. However, when the intervention was deemed effective by adolescents, the impact was described in varied ways such as the quote below.

Before I did the support group, I thought there were only a few people like me out in the world, but when I went on the online support network, it was, like, "Whoa, there's, like, 30 people here that are basically going through the same thing I am." And it was absolutely wonderful because it made my whole vision of how many people are disabled in the world or in Alberta, just for an example, is extremely large, and they're all out there, and they're all suffering from a common thing. You know. I mean, they couldn't do things physically—some of them can't, some of them don't have very many friends. So it was basically just a common bond in-between all of us, even the peer mentors. [CP-18]

DISSEMINATION

To date, investigators and research staff have presented findings at the following conferences:

- (1) Campus Computing Symposium, University of Alberta, Edmonton, AB June 21, 2005,
- (2) 10th International Paediatric Nursing Research Symposium, Montreal, PQ, November 10-12, 2004,
- (3) Margaret Scott Wright Research Day, Faculty of Nursing, University of Alberta, Edmonton, AB, October 29, 2004,
- (4) Canadian Association of Occupational Therapists Conference, Charlottetown, PEI, June 24-27, 2004,
- (5) Society of Research on Adolescence Biennial Meeting, Baltimore, MD, March 12-14, 2004,
- (6) Canadian Association of Occupational Therapists Conference, Winnipeg, MB, May 23, 2003,
- (7) Campus Computing Symposium, University of Alberta, Edmonton, AB June 24, 2003.

Plans for future dissemination include distribution for this report to partner agencies, posting the findings on the Social Support Research Program website (www.ssrp.ualberta.ca), and publication in peer reviewed journals.

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