Analysis:
Emotional Condition of Young Adults with Spina bifida

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INTRODUCTION

Relationships are vital to a healthy lifestyle. They are developed in various outlets of society: attending school, work, community groups, etc., not all individuals, however are allotted these opportunities. The National Spina bifida Association of America conducted studies in the year of 2001 to conclude how many individuals in the United States have Spina bifida; their results found:

There are approximately 70,000 people in the United States living with Spina bifida…
Sixty million women are at risk of having a child born with Spina bifida and each year approximately 4,000 pregnancies in this country are affected by Spina bifida, resulting in 2,500 births (SBAA, 2001, para. 1&2).

This is a significant number for social work practitioners to be aware of. The number of babies born with Spina bifida is growing every year, and this population needs encouragement and empowerment as they grow into young adulthood.

Living with a physical disability can often result in living in isolation – kept from society due to physical challenges or complications. The purpose of this paper is to assess the emotional and social needs of young adults living with Spina bifida.

CONDITION AND RESULTING PROBLEM

Condition of the Situation

After researching various local resources, and interviewing experts in the field, results found that there is a lack of community, relational building, and friendships within this population due to external factors such as transportation issues, inability to work or go to school, and medical challenges that often isolate individuals with disabilities.
Resulting Problem

The findings lead to the resulting problem: a lack of social and emotional support among young adults living with Spina bifida. This analysis will provide a historical context of the situation, valid information on local resources, expert statements on the condition, and stakeholder decisions, capacities and needs regarding the resulting problem. This analysis is important to the field of social work because of the obligation to “pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people,” (NASW, 2006) good rationale. This analysis works to provide social change on behalf of this population, in regards to their emotional and social needs being met on a continual basis. The paper will not cover any possible solutions. A future paper will focus on solution options and recommendations on how to build on the capacities and address the needs found in this assessment.

HISTORY OF CONDITION

Experts have found that through the use of technology, individuals with disabilities benefit a great deal. When asked if online counseling for individuals with disabilities is something he does often, E. Geraty replies: “Yes I have, sometimes disabled clients find this type of counseling to be even more beneficial... I have worked with clients who are terminally ill and bedridden and other types of disabilities which make it hard for them to attend onsite sessions” (E. Geraty, personal communication, March 25, 2008) Nice to quote the guest speaker. In Schoech’s scenario of a computer broadening the life of a young woman with cerebral palsy, we see that it provided, “a way to communicate with the outside world” and expert social work practitioners are of the opinion of technology benefiting those with disabilities (1999, p.13).
When assessing if the situation is changing, it is important to evaluate the current programs offered. There are few services offered for this population when working toward meeting their social and emotional needs, within the Dallas/Fort Worth, Texas area. Texas Scottish Rite Hospital for Children (TSRHC) is a non-profit pediatric hospital. They treat children born with orthopedic disabilities and who reside in Texas. Services are primarily medical, and children are discharged at the age of 18 (Texas Scottish Rite Hospital for Children, 2008).

Currently, The SBANT provides some social support to young adults with Spina bifida. SBANT offers an Adult Retreat every spring, which provides educational lectures and fun camp activities throughout the weekend (SBANT, 2008). The adult group also comes together a few times a year to do other fun activities (J. Cafeiro, personal communication, February 4, 2008). This F2F event is a great capacity to use as the center of a multifaceted social networking infrastructure for this population.

An expert interview with SBANT committee member, Joanne Cafeiro, RN, supports the need for a support group for people with Spina bifida. After being asked if she felt there was a need for a Spina Bifida support group, Joanne stated:

“I do feel that there is a need. As children, this group is cocooned in the pediatric care system and so are their parents. In many ways they are out of the loop as far as what their able bodied peers are doing and thinking. This serves to isolate them even more than their disability does. A “catch up” course is sorely needed so they can fit in as adults even if they didn’t as teens. Behaviors that are marginally acceptable as children and teens are not acceptable in the adult world. Taking responsibility helps with jobs and relationships. Learning to express yourself properly opens up new worlds and discussions on
relationships of all types builds confidence and avoids disasters all too common to those who didn’t learn this as children and teens” (J. Cafeiro, personal communication, February 4, 2008).

Joni and Friends Ministry located in Dallas provides some support throughout the year including “Special Delivery,” and “Family Retreat” (Joni and Friends, 2008). The Special Delivery program includes volunteers through Joni and Friends Ministry delivering packages to individuals with disabilities who may be in the hospital, or shut in their home for various reasons (Joni and Friends, 2008). Family Retreat occurs once a year within the span of two weeks; families, who have an individual with a disability within their family, attend a summer camp-like atmosphere for one week (Joni and Friends, 2008). Many activities take place for everyone in the family to have a good experience, and there are volunteers to assist the parents of severely disabled children (Joni and Friends, 2008). Again, another great capacity for building a social networking F2F and virtual infrastructure.

Ellen Dibler, a longstanding member of Spina Bifida Association of North Texas (SBANT), current member of the SBANT board, and who also served on the Spina Bifida Association National Board, attempted implementing an emotional support group in the year 2000 (E. Dibler, personal communication, February 5, 2008). Due to the lack of enthusiasm and involvement from participants, Ellen quickly moved her support to Joni and Friends Ministry, where she was able to offer emotional support to those who experienced the same disability as she, Spina bifida (E. Dibler, personal communication, February 5, 2008). No other support groups have been implemented since that time, but all leaders of the SBANT agree that it is a much needed program, especially for the young adult group.
Support groups have proven to be effective in uniting and empowering people who are undergoing similar circumstances both within and outside the medical community. Support groups such as the Depression and Bipolar Support Association and Gilda’s Club. Gilda’s Club North Texas is a support group in Dallas, Texas which helps people living with cancer find social and emotional support (Gilda’s Club North Texas, 2008). Support groups such as Alcoholics Anonymous and Narcotics Anonymous have also proven the power in uniting and educating people with similar circumstances.

A study of 32 participants who had participated in a support group was conducted by the CyberPsychology and Behavior Journal to evaluate the effectiveness of support groups. The study results reported “For many individuals, participation in the online support group served to reduce feelings of social isolation. The support group also helped people to feel better about themselves, thus improving their state of mind or how they dealt with things” (CyberPsychology and Behavior, p.146, 2007).

Also see


and

http://www.re-mission.net/

From the assessment of technology’s ability to improve the social and emotional well-being of individuals with disabilities, and assessing the current services offered in the Dallas/Fort Worth, Texas area, it is apparent that the situation is not changing for this population in
particular. While other online emotional support groups have proven to be successful, there have been no efforts made on behalf of this population as of yet. Excellent section.

STAKEHOLDERS OF CONDITION

Stakeholders of this condition include: young adults with Spina bifida, the family of young adults with Spina bifida, Spina bifida Association of North Texas (SBANT), social workers of this population and the health care system. Each stakeholder brings amenable knowledge, expertise and experience to the condition and resulting problem analyzed.

SYSTEM DEFINITION AND FUNCTIONING

The system of focus is young adults living with Spina bifida. The subsystems include: social, mental, emotional, and physical subsystems. The environment of the system is the local community the individual resides in.

There are various elements that make up each of these subsystems (Schoech, 1999). For the social subsystem the element would be the individual’s network of friends, or lack of; the daily activities they are involved in within the community (i.e. school, work, clubs, etc.); and their social charisma or capabilities to building relationships. Within the mental and emotional subsystems of the individual the elements would include: their cognitive functioning (whether or not they live with developmental delays, sometimes resulting from a common impairment within the realm of Spina bifida called hydrocephalus); and if the individual has ever dealt with any emotional challenges such as depression. Finally within the physical subsystem the elements would include physical capabilities (i.e. walking, use of mobility assistive devices, etc); and their current physical health (often Spina bifida results in many urological or neurological ailments).

“Another characteristic of systems is that they are dynamic; that is interaction occurs among the elements” (Schoech, 1999, p. 188). These interactions are defined as input, process
and output (Schoech, 1999). The input, process and output would be different within each of the subsystem’s elements as well. For the social subsystem the input would include the amount of effort the individual puts in when trying to develop relationships. It would also include the activities the individual involves themselves in (i.e. church, school, work, etc). Through these processes the output of the social subsystem would result in the amount of input that was worked toward. For example, if the individual heavily involved themselves in the community, then they are more apt to having relationships than not.

For the mental and emotional subsystems, the input might include whether or not they are seeking private training for a learning disability they may have, or seeking therapeutic treatment for their emotional challenges. Based on the input the individual puts in, will again determine the output – the ability to move forward in their learning, or the ability to cope with the emotional challenges.

Finally, for the physical subsystem the input would be exhibited in the form of how well they take care of their physical needs. If the individual regulates the common ailments of Spina bifida, then the output would be less hospitalization, resulting in less isolation.

As noted a moment ago, each subsystem can essentially affect the other. If one is not being properly cared for, then the other can suffer as well, which is exhibited in the concept of feedback and control. Feedback and control can also impact the inputs the individual makes within each subsystem (Schoech, 1999). For example, if the young adult makes the effort to involve themselves in the community, but receives negative feedback from peers, then they may control their next round of inputs in their social subsystem, which could often result in isolating themselves from society. This concept can be applied in every subsystem, and as long as the feedback is negative, less input may be given the next time around; however, if the feedback is
positive, than the individual may be more likely to continue increasing the amount of input in that particular subsystem.

It is evident when assessing the single and the specific condition studies, within this individual are many complex elements create a whole system of situations, circumstances and issues to address in the analysis.

Very good information. Since this is an open system, the environment is probably more important than any subsystem. You mention the environment, but do not discuss it. The environment was discussed somewhat in the history section and that discussion yielded many strong capacities.

Decisions of Stakeholders

Young adults with Spina bifida:

1. Young adults with Spina bifida often utilize internet sources such as Myspace or Facebook as a source to finding community and relational building.

2. Young adults with Spina bifida may communicate with friends via telephone, in order to find that sense of community.

3. Young adults with Spina bifida are also allotted the opportunity to attend the SBANT adult retreat annually. These would be better if worded as decisions.

4. If this population is not able to make the above decisions based on lack of access to internet or phone service, and is not able to either financially or physically attend the SBANT adult retreat, many resort to living a very isolated life.

Family of young adults with Spina bifida

1. Family may utilize the internet as a resource to locate appropriate associations/groups for the young adult to belong to.
2. Family may encourage young adult’s involvement in individual/group counseling, or membership of an appropriate association in order to meet individuals who can relate to them, thus leading to social and emotional support for the young adult.

3. Based on physical limitations of the young adult, parents may seek out home health care systems in order to assist with their daily physical needs.

*Spina bifida Association of North Texas*

1. SBANT hosts the annual young adult retreat every spring, offering a time for young adult members to gather, learning of new research that may help regarding physical problems and participating in fun, camp-like activities.

2. SBANT hosts annual holiday parties for all members, non-specific to age.

3. SBANT provides valuable information and resources regarding issues surrounding Spina bifida via their homepage, which is available to all members. There is no information specific to young adults with Spina bifida, except the information regarding the adult retreat.

These do not sound like decisions and no mention is made of the IT needed or used in these decisions.

*Social Workers of this population:*

1. Social work practitioners whom work with this population may refer individual to face-to-face support groups, locating these groups via the internet.

2. Social work practitioners may utilize an agency database when searching for other outlets, such as sporting groups, specific activity groups, etc. for clients to participate in.
3. Social work practitioners may also facilitate individual counseling with this population, accessing appropriate information to solve emotional distresses via scholarly articles, books, or internet resources.

**Health Care System**

1. Medical professionals serve this population through the treatment of their physical challenges.

2. Doctors, nurses, physical therapists, etc. may also refer to emotional support groups via hospital social service resources.

*I think this section could be more powerful if it was stated as decisions and the resources including IT used and that could possibly be used to address this situation.*

**Capacities of Stakeholders**

*Young adults with Spina bifida*

1. When seeking out social and emotional support, one capacity of this population is to utilize the internet as a source to relational building (i.e. Myspace, Facebook, Email, etc.).

2. Another capacity this population owns is the ability to register for the young adult retreat through the SBANT.

3. **Does this population have the capacity to support and work with others with this disability?** Given the disabilities associated with Spina bifida seem diverse, do those with greater abilities have a special capacity to help and emotionally connect with those with fewer abilities. This is an important issue/capacity.

*Family of young adults with Spina bifida*

1. Parents have the capacity to be the adult caregiver for the young adult.
2. The natural bond between parent and child that exists lead to the family’s capacity of advocating on behalf of the young adult.

3. Families have the capacity to offer the care and emotional support the young adults are in need of.

**Spina bifida Association of North Texas**

1. The capacity of organizations such as the SBANT is their desire to be a key player in the linking of resources to this population, and advocating on behalf of them as well.

**Social Workers of this Population**

1. Social work practitioners have more access to community resources than the general population.

2. Social work practitioners are trained in therapeutic techniques regarding individuals with emotional challenges.

**Health Care System**

1. The capacity of the health care system would be their ability to offer the medical attention this population is in need of.

2. A second capacity would be the ability to refer to the hospital social services office, in order to seek out additional resources in providing emotional and social support to this population.

**Needs of Stakeholders**

**Young adults with Spina bifida**

1. The need for young adults with Spina bifida is to have a community source to turn to, that can meet their emotional needs, meaning a group of individuals who can relate to the common challenges this population faces on a daily basis.
Not only a resource that can meet their emotional needs, but their physical needs as well; one that can be easily accessed on a daily basis, without the constituents of driving abilities or inabilities, access to transportation, physical well-being to leave the home, etc.

**Family of young adults with Spina bifida**

1. Families of this population are in need of a resource to turn to that would meet the listed needs of this population.
2. If parents are primary caretakers of the young adult, then as the parents age the client will have to supplement the support received from the parent with a different resource.

**Spina bifida Association of North Texas**

1. This association is in need of an emotional resource to either implement through their current organization, or one to refer to when working with this population.

**Social Workers of this Population**

1. Social work practitioners are in need of an accessible resource to refer this population to.
2. Social work practitioners are in need of current information regarding the emotional needs of young adults with Spina bifida.
3. Social work practitioners are in need of an outlet, program or organization to implement group therapy through, regarding this specific population.

**Health Care System**

1. The health care system is in need of more emotional resources to provide medical professionals with more options when referring clients to get their social and emotional needs met in conjunction with their physical needs.
2. When referring to the historical context of this population in specific, it is also evident that there is a need for adult care within this population as well, especially medically.

CONCLUSION

Analysis results indicate that a service providing the opportunity to build a social and emotional support network among this population would benefit the social and emotional condition of this population greatly. However, results also show that this type of service would need to be both beneficial emotionally and physically. In order to benefit this population the service will need to create opportunities for this population to relate well; this might result in an emotional social support group. For this service to benefit this population physically, the developed program must be physically feasible to attend and be apart of; this could possibly result in the support group being implemented via internet. These findings may result in a solution to the condition and resulting problem of meeting the social and emotional needs of young adults living with Spina bifida.
REFERENCES


Solution Design:

Friends Connects

Online Emotional & Social Support Group
For Young Adults with Spina Bifida

Developed for:
Spina Bifida Association of North Texas

By:
Holly R. Strother

Very good cover page
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Good.
EXECUTIVE SUMMARY

This paper examines the emotional and social well-being of young adults living with Spina bifida. A brief look at the historical background and current organizational efforts displays further needs for addressing this issue. After discussing needs and capacities of the condition, several information technology solutions are developed and discussed, resulting in one prominent solution in the end.

Brief Summary of Analysis

Condition:

A current lack of community, relational building and friendships exists within the community of young adults living with SB. This condition is a resultant of various external factors, such as: transportation issues and the inability to be actively involved in the community due to increasing health challenges.

Needs:

- Young adults with SB to have a community resource to meet emotional needs
- A supplement to family support, as parents age
- Emotional support resource to refer this population to

Capacities:

- Young adult utilization of the internet as source of community (i.e. Myspace or Facebook)

Local Organization Efforts:

- Joni and Friends Ministry
- Spina Bifida Association of North Texas
- Texas Scottish Rite Hospital for Children

Possible Information Technology Solutions

- Online Informational Database
- Email Pen Pal Program
- Online Emotional & Social Support Program

Evaluation

- A yearly program evaluation implemented through membership
• Good, but a conclusion is needed so that your readers get a view of the total paper from the executive summary.
INTRODUCTION

This report contains an analysis of the emotional and social condition of young adults living with Spina bifida (SB) in the North Texas region. Stakeholders, their decisions and capacities are thoroughly reviewed and discussed, leading to possible solutions to the current condition studied. In addition, local organizational efforts are reviewed and discussed, in order to further assess the need for a stronger solution for the situation addressed. Finally, possible solutions are analyzed, measuring advantages against disadvantages, leading to a final solution decision. Justification of the preferred solution will be presented, in addition to needed future proceedings to work toward in implementing this particular solution. The report will end by discussing evaluative measures to be taken after implementing the proposed solution.

ANALYSIS

Condition of the Situation

After researching various local resources, and interviewing field experts, results indicate that there is a lack of community, relational building and friendships within the community of young adults living with SB. This condition is a resultant of various external factors, such as: transportation issues and the inability to be actively involved in the community due to increasing health challenges.

Review of Literature

The National Spina bifida Association of America conducted studies in the year of 2001 to conclude how many individuals in the United States have SB; their results found:

There are approximately 70,000 people in the United States living with Spina Bifida… Sixty million women are at risk of having a child born with Spina Bifida and each year approximately 4,000 pregnancies in this country are affected by Spina Bifida, resulting in 2,500 births (SBAA, 2001, para. 1&2).

This is a significant number for social work practitioners to be aware of. The number of babies born with SB is growing every year, and this population needs encouragement and empowerment as they grow into young adulthood.

The National Institute of Neurological Disorders and Stroke (2007) defines Spina bifida as: “a type of neural tube defect, which is a problem with the spinal cord or its coverings. It happens if the fetal spinal column doesn't close completely during the first month of pregnancy” (¶ 1). There are many different types and levels of Spina bifida, but the typical repercussions of the disability include: some paralysis of the legs, learning difficulties, urinary and bowel problems and hydrocephalus (build up of spinal fluid on the brain) (National Institute of Neurological Disorders and Stroke, 2007).
Brief Assessment of Needs

From the literature, it is apparent that individuals with SB are growing in number every year. In the past there have been efforts to meet the emotional and social needs of this population. Ellen Dibler, a longstanding member of Spina Bifida Association of North Texas (SBANT), current member of the SBANT board, and who also served on the Spina Bifida Association National Board, attempted implementing an emotional support group in the year 2000 (E. Dibler, personal communication, February 5, 2008). Due to the lack of enthusiasm and involvement from participants, Ellen quickly moved her support to Joni and Friends Ministry, where she was able to offer emotional support to those who experienced the same disability as she, Spina bifida (E. Dibler, personal communication, February 5, 2008). No other support groups have been implemented since that time, but all leaders of the SBANT agree that it is a much needed program, especially for the young adult group Since this is a strong statement, you should give the source.

An expert interview with SBANT committee member, Joanne Cafeiro, RN, supports the need for a support group for people with Spina bifida. After being asked if she felt there was a need for a Spina Bifida support group, Joanne stated:

“I do feel that there is a need. As children, this group is cocooned in the pediatric care system and so are their parents. In many ways they are out of the loop as far as what their able bodied peers are doing and thinking. This serves to isolate them even more than their disability does. A “catch up” course is sorely needed so they can fit in as adults even if they didn’t as teens. Behaviors that are marginally acceptable as children and teens are not acceptable in the adult world. Taking responsibility helps with jobs and relationships. Learning to express yourself properly opens up new worlds and discussions on relationships of all types builds confidence and avoids disasters all too common to those who didn’t learn this as children and teens” (J. Cafeiro, personal communication, February 4, 2008). Good.

Stakeholders

- Young adults living with SB
- Family of this population
- Spina Bifida Association of North Texas (SBANT)
- Social workers of this population
- Health Care System

Stakeholder Decisions:

- Young Adults with SB
Decisions that young adults with SB make regarding the current condition include: utilizing internet sources such as Myspace or Facebook as a resource to finding community and relational building; communicating with friends via telephone; attending the annual young adult retreat implemented through the SBANT; and finally, living an isolated life if unable to make the above decisions based on lack of access to internet or phone services, and financial or physical inability to attend adult retreat.

- **Families of this Population**

  Families may utilize the internet as a resource to locate appropriate associations/groups for the young adult to belong to. Families may also encourage young adult’s involvement in individual/group counseling, or membership of an appropriate association in order to meet others who can relate to them. Finally, based on physical limitations of the young adult, parents may seek out home health care systems in order to assist with their daily physical needs.

- **Spina Bifida Association of North Texas**

  The SBANT hosts the annual young adult retreat every spring, offering a time for young adult members to gather, learning of new research that may help regarding physical challenges that may arise in adulthood and participating in fun, camp-like activities. The adult group leaders of the SBANT market the adult retreat via internet (Myspace) or on the internet homepage. SBANT also hosts holiday parties for all members, non-specific to age. Finally, the SBANT provides valuable information and resources regarding issues surrounding Spina bifida via their internet homepage site. There is no information specific to young adults with Spina bifida, except the information regarding the adult retreat details.

- **Social Workers of this Population**

  Social work practitioners working with this population may refer individuals to face-to-face support groups, locating these groups via internet. They may also utilize an agency database when searching for other social and emotional support outlets. Finally, practitioners may also facilitate individual counseling with this population, accessing appropriate information to solve emotional distresses via scholarly article searches, books, or internet resources.

- **Health Care System**

  Medical professionals serve this population through the treatment of their physical challenges. This population suffers from many physical complications due to the resulting challenges that Spina bifida often brings on. The health care
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system is trained to meet these needs, and therefore services this population through providing the specialized medical attention they are in need of. Medical professionals also provide referrals to the social service division of the health care system, in order to locate additional resources that would help meet the emotional and social needs of the young adult. **Probably the medical care system is unprepared to assess client’s emotional and socialization needs and provide ways to ameliorate any issues identified.**

**Needs and Capacities**

**Needs:**
- Young adults with SB to have a community resource to meet emotional needs
- A supplement to family support, as parents age
- Emotional support resource to refer this population to
  - SBANT
  - Social workers
  - Health Care System

**Capacities:**
- Young adult utilization of the internet as source of community (i.e. Myspace or Facebook)
- Registration and attendance of SBANT Young Adult Retreat
- Parents’ capacity to be caregiver
- Natural bond between parent and child which leads to advocacy on their behalf
- Families have the capacity of offering emotional and social support
- SBANT’s desire to be key player in linking of resources to this population
- Social workers access to more community resources than the general population
- Social workers being trained in therapeutic techniques regarding individuals with emotional challenges
- Health care system to offer medical attention this population is in need of
- Health care system’s ability to refer to social services for additional emotional and social support resources

**LOCAL ORGANIZATION EFFORTS**

**Texas Scottish Rite Hospital for Children**

Texas Scottish Rite Hospital for Children (TSRHC) is a non-profit pediatric hospital. They treat children born with orthopedic disabilities and who reside in Texas. Services are primarily medical, and children are discharged at the age of 18 (Texas Scottish Rite Hospital
for Children, 2008). TSRHC does offer a Transitional Group for patients of the hospital between 15 and 18 years of age, educating them on services they will need for the future (H. Strother, personal communication, February 1, 2008).

**Spina Bifida Association of North Texas**

Currently, The SBANT provides some social support to young adults with Spina bifida. SBANT offers an Adult Retreat every spring, which provides educational lectures and fun camp activities throughout the weekend (SBANT, 2008). The adult group also comes together a few times a year to do other fun activities (J. Cafeiro, personal communication, February 4, 2008).

**Joni and Friends Ministry**

Joni and Friends Ministry located in Dallas provides some support throughout the year including “Special Delivery,” and “Family Retreat” (Joni and Friends, 2008). The Special Delivery program includes volunteers through Joni and Friends Ministry delivering packages to individuals with disabilities who may be in the hospital, or shut in their home for various reasons (Joni and Friends, 2008). Family Retreat occurs once a year within the span of two weeks; families, who have an individual with a disability within their family, attend a summer camp-like atmosphere for one week (Joni and Friends, 2008). Many activities take place for everyone in the family to have a good experience, and there are volunteers to assist the parents of severely disabled children (Joni and Friends, 2008).

**POSSIBLE INFORMATION TECHNOLOGY (IT) SOLUTIONS**

The following section provides three possible information technology solutions to the discussed condition: Online Information Database, Email Pen Pal Program and Online Emotional & Social Support Group. Under each description, advantages and disadvantages will be discussed regarding IT issues and other various opportunities or barriers.

**Online Information Database**

A development of an information database implemented via internet would be beneficial to the resulting problem. It could either be implemented as its own entity or through an existing organization that services this population. The database could include: medical information regarding Spina bifida, organization/agencies that service population, support groups (either F2F or online), and articles that address the social and emotional needs of this population.

This solution builds on the capacities of all stakeholders, because of their current utilization of the internet when seeking out either emotional and social support or referral information on behalf of this population. It would meet the needs of the stakeholders through providing needed information on already existing field-related studies and
organizations that exist to service this population. A final need the online database meets of stakeholders is the easy utilization of the database, through being accessed via internet.

The IT infrastructure required would be utilizing database software and internet hardware and software. The database of information would include both medical and social/emotional resources and scholarly articles; these subjects would be considered entities, while the actual information on the referral or article would be the attributes. Good Shows you are reading the text. (Schoech, 1999). All of this information would be compiled onto the internet located through a HyperText Transfer Protocol (HTTP), where computers automatically exchange protocols (Schoech, 1999). The methods of separating and reconstructing the stream of bits during data transmission will be used in asynchronous transmission, users interacting on their own schedule (Schoech, 1999).

**Advantages**

An advantage to this IT solution is the physical accessibility of the database. As discussed previously, often times this population is unable to transport themselves due to the physical complications that come with the disability. Through implementing the database via internet, the young adults would be able to utilize the solution from their home, or any place they happen to be that has access to the internet. Another advantage to this solution is the availability of both medical, social and emotional information to the population. The database would be careful to cover all concerns of the population, and work toward providing agency/organization demographic information, existing support groups, and articles that address the social and emotional needs of this population.

**Disadvantages**

While this database would educate and inform the population of what already exists, it would fail to provide emotional and social support through its personal site. It would also be impossible to utilize without the access to a computer and the internet. A wiki front end on the database may be useful to make maintenance less of a chore.

**Email Pen Pal Program**

An email pen pal program could possibly be implemented through the SBANT or another agency/organization that services this population. Specifically, the SBANT would be able to compile a listserv of young adult members to market the email pen pal program. Then, the organization could develop a survey – seeking out: pen pal preferences, individual interests, hobbies, current involvements, disability specifics, and basic information such as age and gender. Through these surveys, workers could then assess pen pals that would be appropriate for one another.

The email pen pal program builds on the capacities of the stakeholders through being implemented via a common communicational device: email. Young adults mentioned utilizing the internet as a resource (Myspace or Facebook) often times when seeking solutions to the condition, so it can be presumed that most own a personal email address.
The IT infrastructure required would be utilizing internet software, located through many user HTTP locations, based on what email provider they are subscribed under (Schoech, 1999). The system would again operate asynchronously, for pen pals would correspond at their own leisure (Schoech, 1999).

**What about building on what Facebook or Myspace now offer by maintaining a specialty section on these sites?**

**Advantages**

The advantage of an email pen pal program would be presenting the members with an opportunity to meet a new person, and possibly develop a friendship. Also, again, with the physical limitations of this population, the email pen pal program would be easily accessible to individuals who have a hard time getting out into society.

**Disadvantages**

A major disadvantage to this program is it being solely utilized through the access to the internet. If members have no means of getting to a computer with the internet, then they would be unable to participate in this program. Another disadvantage to this type of program is the opportunity to meet one new person, opposed to many people.

**Online Emotional & Social Support Program**

An online emotional and social support program would include all details of the previous IT solutions presented. First and foremost, the program would be implemented via internet, accessed through an online site. At this site, individuals would be able to navigate through various medical informational pages (including links to scholarly medical articles), emotional and social informational pages (including links to various entities that provide this support and to scholarly articles addressing these issues/concerns), links to online community opportunities (volunteer or job-related), individual blogs and finally continual weekly online discussion forum opportunities to be a part of (via Windows Live Messenger or AOL Instant Messenger).

An online emotional and social support program build on the existing capacity of most stakeholders utilizing the internet when seeking support resources and information on existing agencies/organizations that service this population. The program would meet the specific physical, emotional and social needs of the young adults. It would be easily accessible to those whom face health condition challenges that often to isolation in the home or hospital. It would also serve to meet their emotional and social needs through providing links to online community opportunities, individual blogs and online discussion forum opportunities.

The program would meet the awareness and educational needs of all other stakeholders with providing the medical, social and emotional information within the different pages of the homepage website. Finally, the program would meet the needs of all
The online emotional and social support program would include a vast array of technological applications within the program. First, it would be based within a home page, the initial page that users see when visiting a site (Schoech, 1999). Within this homepage would include a vast array of other technological characteristics such as: external links to resources (community opportunities), information and articles (medical & social/emotional), threaded discussion forums (implemented through a feature such as Windows Live Messenger) and bulletin board systems (implemented through the individual blogging feature) (Schoech, 1999). Again, the homepage, including all other internal applications, would be used through an HTTP location (Schoech, 1999). An example of the homepage screen shot can be found in Appendix A.

Advantages

The online emotional and social support program has a great number of advantages. First is the opportunity it allots to this population in meeting new individuals whom live with Spina bifida as well. It also provides medical, emotional and social information, that many young adults may have concerns about. Through providing links to online community opportunities, it promotes and encourages other social involvements. Finally, the program would also be easily accessible to those young adults who have a difficult time getting out into society.

Disadvantages

The one disadvantage to this type of program is again, the ability to utilize the program solely through the internet. If young adults do not have access to the internet, then this is a portion of the population it would not be able to reach.

I think another disadvantage, if not carefully designed, is that it can keep the community isolated rather than expand the community’s horizons. That is, it could encourage those with Spina bifida to socialize with others with the disability and not with the general population if not designed properly. This was pointed out in class and I think can be a big issue. For many reasons, those without Spina bifida may want to learn more about this community and to socialize with it.

I think you should call this an online community, as it seems to be what you are describing. There are some good articles on online communities and their functions.

PREFERRED SOLUTION & JUSTIFICATION FOR SELECTION

Preferred Solution
Based on the capacities utilized and needs met of the stakeholders, the preferred solution to the current condition would be implementing an online emotional and social support program. Justification for this decision lies in the many stakeholder needs it would meet, and serving the ultimate purpose of providing emotional and social support to young adults with Spina bifida. The program would entail all other solution opportunities within its one entity, utilizing an internet homepage website for being a sort of gatekeeper for all information and relational connection opportunities discussed previously.

This type of program would meet the emotional needs of the most important stakeholder, young adults living with Spina bifida. It would meet these needs through developing the homepage to include individual blogs and scheduled online discussion forums. Ideally, co-members would add comments to blogs, stimulating discussion and leading to the young adults getting to know one another. The online discussion forums could take place weekly, around a previously mentioned topic/concern and implemented by a Licensed Master Social Worker or Licensed Professional Counselor. Good idea.

The program would also meet the social needs of the young adult population through providing information on various online community opportunities. As Jayne Cravens mentioned this semester, there are many online volunteer opportunities available to individuals internationally (J.Cravens, personal communication, February 26, 2008). The homepage website could provide a link directly to websites that promote and provide these opportunities. Entities that provide online job opportunities could also be provided on the homepage website as well. Very good.

Finally, the informational articles surrounding emotional and social concerns of this population, would educate all users on specific challenges this population faces. Each of these opportunities would promote sociality within this population, encouraging community involvement on whatever capacity they are able.

**Justification for Preference**

Experts have found that through the use of technology, individuals with disabilities benefit a great deal. When asked if online counseling for individuals with disabilities is something he does often, E. Geraty replies: “Yes I have, sometimes disabled clients find this type of counseling to be even more beneficial... I have worked with clients who are terminally ill and bedridden and other types of disabilities which make it hard for them to attend onsite sessions” (E.Geraty, personal communication, March 25, 2008) In Schoech’s scenario of a computer broadening the life of a young woman with cerebral palsy, we see that it provided, “a way to communicate with the outside world” and expert social work practitioners are of the opinion of technology benefiting those with disabilities (1999, p.13).

A study of 32 participants who had participated in a support group was conducted by the CyberPsychology and Behavior Journal to evaluate the effectiveness of support groups. The study results reported “For many individuals, participation in the online support group served to reduce feelings of social isolation. The support group also helped people to feel
better about themselves, thus improving their state of mind or how they dealt with things”
(CyberPsychology and Behavior, p.146, 2007). **Very good to cite the literature.**

**FUTURE PROCEEDINGS**

**Steps to Take**

There are many steps to take when working toward implementation of this type of program. The proposal is to attempt implementing the program through the SBANT in Plano, Texas; however, developers are open to implementing program/IT application through any interested, field-related entity.

First, the decision must be made to implement it through an existing field-related agency/organization or as its own entity. If deciding to implement through an existing agency/organization, then a program presentation must be made to the board of directors, seeking the permission to proceed with the program plan. If the entity approves the program, then request for proposals must be searched and applied for, in hopes of receiving funding to develop the online emotional and social support program.

After hypothetically receiving funding, then developers must hire an IT Professional to develop, implement and maintain the homepage website of the support program. Developers must also either research themselves, or hire professionals to research the medical, social and emotional informational articles and online community opportunities, in order to provide external links via the homepage website. These steps would lead to the ultimate implementation of the program. The same steps would be made if choosing to create an individual entity opposed to implementing through an existing agency/organization. An example of a Logic Model can be found in Appendix B.

**Issues to Consider**

Agency/organization collaborations will need to be made in order to provide thorough and accurate information within the program homepage website. This could take more presenting to and convincing these entities that this is indeed a need within the young adults with Spina bifida community. Also, developers should take into consideration those young adults who do not have access to the internet and develop new and creative ways to involve them in the program as well. Finally, developers should consider having to seek out permissions of all agencies/organizations linked to via the homepage website. All of these issues could lead to time setbacks in implementing and even developing the ideal program.

**EVALUATION**

**Program Evaluation**

Evaluators of the program would include solely the young adults with Spina bifida. At the end of each program year, online surveys will be administered (by program manger,
hypothetically through the SBANT) for each member to complete. The survey will measure member reactions, through use of a Likert scale, to the different functions of the program such as: quality of information provided via homepage, quality of facilitation during discussion forums, quality of technological applications such as online discussion forums and blog entries. In addition to these responses, the evaluation would ask how the program might be improved to meet the needs of the member. Member answers will be assessed and suggested changes made for the following program year. An example of the administered survey is found in Appendix C. This could be done with SurveyMonkey or Zoomerang to lower cost and effort.

Technology Application Evaluation

Based on Schoech’s (1999) Guidelines for IT Success, there are many possible dimension measures to assess when evaluating the technological application implemented. The program manager, program developer (hypothetically within the SBANT) and IT specialist would be those to evaluate the technology application of the program. First, the program plan would be measured, what type of long-range plan is established within the agency for each application and whether each application has written, up-to-date, clear purposes, goals, objectives, system requirements and mechanisms for evaluation and revision (Schoech, 1999).

Next, the characteristics of the application would be evaluated, including: “month of operation, sources of application, application scope, application size, accessibility, flexibility, primary orientation, privacy protected, documentation and reflection of agency operations” (Schoech, 1999, p.357). For the purposes of evaluating the online emotional and social support program, the most important characteristic to evaluate would be the accessibility for users.

Finally, user involvement would be evaluated, looking at the steering committee, open communication and involvement in implementation of the program (Schoech, 1999). The program developer and program managers would be those whom this portion of the evaluation would consider. An example Table of IT evaluation can be found in Appendix D.

**CONCLUSION**

Analysis results indicate that a service providing the opportunity to build a social and emotional support network among this population would benefit the social and emotional condition of this population greatly. However, results also show that this type of service would need to be both beneficial emotionally and physically. In order to benefit this population, the service will need to create opportunities for this population to relate well. The best possible solution would be to implement an online emotional social support group for young adults with SB. The assessment of the three different IT solutions indicate that a collaboration of all three ideas would best service these young adults in meeting both their emotional and social needs. *Very good.*
REFERENCES


Welcome to Friends Connect! We hope you find the community you are looking for within our program.

We are a FREE online emotional support program for young adults living with Spina bifida. Offered are a vast array of services ranging from: online community opportunities to weekly online discussion forum opportunities.

Take a look around, and feel free to contact for further membership information. Thank you for stopping by!

To contact us:
Spina Bifida Association of North Texas
Plano, Texas
Phone: 682-559-1378
E-mail: hollystrother@gmail.com
APPENDIX B

LOGIC MODEL  Very good. Again, the point made in class is that an outcome is that the larger society could be educated about and socialize with those with Spina bifida.

Need to mention the processes. I think your items in Outputs after the word including: are processes.
APPENDIX C

Yearly Evaluation of *Friends Connect*

1. Information provided via homepage
   1  2  3  4  5

2. Facilitation during discussion forums
   1  2  3  4  5

3. Technological applications
   a. Discussion forums
      1  2  3  4  5
   b. Blog entries
      1  2  3  4  5

4. How can this program be improved to better meet *(split infinitive identified by grammar checker)* your needs?
## APPENDIX D

<table>
<thead>
<tr>
<th>Factor/Dimension</th>
<th>Possible Dimension Measurements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Planning</strong></td>
<td></td>
</tr>
<tr>
<td>Types of plans</td>
<td>Agency long-range plan for IT application</td>
</tr>
<tr>
<td>Written specificity of plans</td>
<td>Application includes written, up-to-date, clear purposes, goals, objectives, system requirements and mechanisms for evaluation and revision</td>
</tr>
<tr>
<td><strong>Application Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Month of operation</td>
<td>Months since IT application was developed</td>
</tr>
<tr>
<td>Sources of application</td>
<td>Developed in-house vs. purchased</td>
</tr>
<tr>
<td>Application scope</td>
<td># of agency departments</td>
</tr>
<tr>
<td>Application size</td>
<td># of subsystems developed and type; # of intended users</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Ratio of input/output devices targeted to users</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Estimate of time &amp; cost to change database structure or add a new form or report to application</td>
</tr>
<tr>
<td>Primary Orientation</td>
<td>Application designed to meet needs of administration, direct service personnel, or support personnel</td>
</tr>
<tr>
<td>Privacy Protected</td>
<td>Formal written procedures used to ensure security and privacy</td>
</tr>
<tr>
<td>Documentation</td>
<td>Whether formal documentation exists on each application for users, developers and managers</td>
</tr>
<tr>
<td>Reflection of Agency operations</td>
<td>Extent that application is an information model of the operations it supports</td>
</tr>
<tr>
<td><strong>User involvement</strong></td>
<td></td>
</tr>
<tr>
<td>Steering committee</td>
<td>Existence and inclusion of key decision makers</td>
</tr>
<tr>
<td>Open communication</td>
<td># of written communications, oriented meetings</td>
</tr>
<tr>
<td>Involvement in implementation</td>
<td>Estimated # of hours spent by administrators and support in each stage of development</td>
</tr>
</tbody>
</table>

Formatted by guidance of Table 12.6 (Schoech, 1999, p.357-358)
APPENDIX E

PowerPoint Presentation