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Sheridan K. Whitworth
NA

Jaime Wilson
JADARA Subscribers

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Cover Page Footnote

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Quality of Life for DeafBlind Individuals: Comparing the Effects of Living with and Without Support Service Providers

Abstract

The current study examines the quality of life for DeafBlind individuals who have support service providers (SSPs) compared to those who do not have SSPs. A measure of quality of life (KIDSCREEN Survey, 2004) was administered to 56 DeafBlind individuals (N=58), ages 18 years and older. Half of the individuals (*n* = 28) participated in the group with SSPs, and the other half participated in the group without SSPs. Results from the quantitative survey indicate that DeafBlind individuals with SSPs have consistently higher positive responses than those without SSPs.

Authors:
Sheridan Whitworth
Jaime Wilson, Wilson Clinical Services, PLLC

Corresponding Author: Sheridan Whitworth MA, NIC; Phone: 253-548-7250; E-mail: sheridan.whitworth@gmail.com

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Quality of Life for DeafBlind Individuals: Comparing the Effects of Living with and Without Support Service Providers

Impact

- This study is the first to focus on the impact SSPs have on quality of life for DeafBlind individuals.
- This study uncovers the link between utilized social services and the individual's sense of independence and freedom.
- This study examines how lower levels of services correlate to decreased emotional health.

Definition

DeafBlindness is the condition of having little or no useful hearing and little or no useful sight (Kudlick, 2005). Similar to the Deaf culture and community that relies on American Sign Language (ASL) for communication, there exists a DeafBlind culture and community that relies on a visually modified or tactile form of ASL for communication (Macdonald, 1989). Although there are many individuals with residual sight that nevertheless culturally identify themselves as DeafBlind (Smith, 2002), there are also many who do not.

DeafBlindness has many etiologies that may have congenital or late-onset origins. Common etiologies (i.e., age, congenital rubella syndrome, CHARGE syndrome, Usher syndrome, Alport syndrome) result in varying severities of hearing and vision loss (Moller, 2003). Depending on the degree of severity, as well as the local resources available, individuals with hearing and vision loss may or may not encounter the DeafBlind community. Consequently, the term *DeafBlind* is a general term, and one will need to get to know the DeafBlind individual to know what degree of hearing or vision the person has and how it is useful to them in communication and daily living.

For the purposes of this paper, the term *DeafBlind* will be used to describe the community of individuals with hearing and vision loss who may or may not identify as a part of the DeafBlind community.

Statement of the Problem

Many DeafBlind individuals live without sufficient services to conduct day-to-day life. One of the biggest obstacles is commuting. Azenkot et al. (2011) described the importance of mobility: People need to travel to a variety of places (e.g., work, grocery stores, and doctors' offices) to live productive lives. Since people who are blind or DeafBlind cannot drive, they often rely on public transportation.

When planning a trip, DeafBlind individuals commonly use the transit agency website to obtain bus schedules, travel times, and bus stop locations. To add to the complexities, these websites are typically difficult to use because they do not fully load when accessed through a screen reader. Depending on local resources, an alternative to public transportation is an access van that provides shared door-to-door rides; however, these services often must be requested at least 1 week in advance (Azenkot et al., 2011).

One DeafBlind woman shared her process of getting to the grocery store (Anonymous, Personal communication, 2016), illustrating how a menial task that many of us may take for granted becomes a complex process requiring significant research, planning, and reliance on the goodwill of others to execute. She waits at a bus stop with a preprinted note card that states, “Hi bus driver, I am Deaf and Blind, would you please guide me onto the bus and tap me when we get to 72nd and Pacific? Tap me if you have read this.” After boarding the bus, she awaits a tap from the driver to be escorted off at the correct location. Once off the bus, she pulls out another pre-printed card that states, “Hi pedestrian, I am Deaf and Blind. Would you please guide me across the street and into the [grocery store]? Tap me if you have read this and are willing to help.” Once inside the grocery store, she pulls out another note card that says, “Hello employee, I am Deaf and Blind, would you please help me grocery shop? Tap me if you have read this and are willing to help.” She then pulls out a coupon book full of pictures of everything she wants to buy.

This process is time consuming, and given that many things could go wrong, it is also dangerous. There is not much literature available regarding the dangers facing DeafBlind individuals in soliciting aid, but it is not difficult to imagine the vulnerability one faces by carrying a purse full of money to shop or outwardly stating that they are DeafBlind and therefore unable to chase down a thief.

DeafBlind individuals soliciting aid from and relying on strangers is not a new phenomenon. Bourquin and Moon (2008) state that the technique of communication by note cards has been used for at least 70 years. Moreover, Bourquin and Moon referenced two surveys—one by Sauerburger and Jones (1997), and the other by Lolli and Sauerburger (1997)—that found approximately two thirds of pedestrians did not notice the DeafBlind traveler with their card soliciting aid.

Another study found that many DeafBlind individuals receive informal support from family members and unpaid caregivers (Bodsworth, Clare, Simblett, and Deafblind UK, 2011). Although such care can have a positive impact on the recipient’s life, the recipients may feel that he or she is a burden. Such feelings may lead to increased risk for mental health issues such as anxiety, depression, and loss of self-esteem. The feelings of guilt for the recipient can be crippling, and the burden placed on the caregiver can be detrimental to the relationship.

In their study conducted in Great Britain, Bodsworth et al. (2011) found that out of 366 DeafBlind individuals, 70% expressed a wish for a trained one-to-one support worker, and that only 73.1% received any formal support. Less than one third (28.6%) reported that they were receiving specialist specific support, such as a communicator guide or SSP. The overwhelming majority of respondents indicated that they wanted more formal support rather than informal family support (94.5%).

Ideally, DeafBlind individuals should be provided a specific number of hours per week with an SSP. SSPs are typically individuals who are fluent in a signed language and trained in a variety of communication techniques, such as tactile, close vision, and tracking, and can enable brief exchanges by interpreting. In addition, they are trained in safely and effectively guiding a DeafBlind individual in a variety of environments. When a DeafBlind individual has time with an SSP, it provides respite for the family caregiver and allows the DeafBlind individual to feel like less of a burden on the family. It can also foster feelings of independence while boosting self-esteem (Ehn, 2016).

Theoretical Framework

The quality-of-life research conducted for this study operates with the understanding that the human quality of life can be defined as the satisfaction of human developmental needs. In defining this satisfaction of basic/developmental needs, Maslow's Hierarchy of Needs is established as a reference point. Also, in this theoretical framework, the basic duties and impact of an SSP are outlined in connection to satisfying the hierarchy of needs for DeafBlind individuals.

Maslow's Hierarchy of Needs

As referenced in Sirgy's (1986) paper, Sirgy discussed Maslow's Hierarchy of Needs in related to obtaining a high quality of life. Maslow himself argued that an individual's fulfillment of one need, or block, of the hierarchy, allows the individual to move up the hierarchy to fulfill another block at a higher level. The individual is motivated to satisfy lower-order needs before moving to accomplish higher-order blocks.

Maslow's Hierarchy of Needs is ordered from bottom to top, where the bottom includes the most basic needs and the top the most elaborate. The first and most basic block according to Sirgy (1986) is biological needs (e.g., food, water, oxygen, etc.). The second block is safety needs (e.g., psychological security and physical security). The third block is social needs (e.g., friendship, affiliation, belonging, etc.). The fourth level consists of the person gaining confidence and the need to be an individual. The fifth and final block self-actualization needs, meaning the need to obtain achievement, self, expression, integrity, and self-fulfillment. By using Maslow's theories according to Sirgy (1986), the quality of life of an individual or community can be found in relation to the category in which they sit on the pyramid.

By using Maslow's theories through the lens of Sirgy's (1986), it can be argued that DeafBlind individuals with limited support resources struggle to move up the hierarchy of needs and, therefore, struggle to obtain the highest quality of life possible. The current study is based on the theoretical assumption that DeafBlind individuals with limited access to SSPs have difficulties moving up Maslow's pyramid because they are still working on securing basic-level needs (i.e., biological needs, safety needs, social needs, and esteem needs). This assumption can be construed as a generalization of the DeafBlind community, there are many DeafBlind individuals with support systems in place that allow them to live successful, fulfilling lives. However, the current study seeks to provide empirical data that there are also many DeafBlind individuals living without needed supports and are, therefore, struggling to have basic needs met.

Support Service Providers Duties and Impact

Nuccio and Smith (2010) described an SSP as a trained worker who is typically fluent in ASL and acts as a sighted guide to accompany a DeafBlind person while providing environmental information and communication support. Nuccio and Smith acknowledged that other resources, such as technology, can be helpful, but no amount of mechanical aid can replace the support provided an SSP.

Indeed, SSPs provide a foundational service. Without SSPs, DeafBlind individuals often face significant isolation that makes it difficult to meaningfully participate in society. Without SSP services, a great deal of background and contextual information can be overlooked, resulting in salient language and access being missed. Although the missed information can be retrospectively understood, in the moment, the gap of information becomes so great that even a skilled interpreter cannot fill in everything.

It is important to note that SSPs, like sign language interpreters, do not teach or tutor their DeafBlind clients (Smith, 2002). Moreover, SSPs do not make decisions for their DeafBlind clients. SSPs relay needed information and provide the DeafBlind individuals the autonomy to make their own decisions.

Danermark and Möller (2008) mentioned the importance of SSPs assisting in tackling barriers to meaningful and fulfilling social interaction. SSPs can aid this by driving clients to social events and by engaging in “light” interpreting. SSPs always provide visual and environmental information including, but not limited to, describing who is in a room and what the activity or mood is in the room, reading a menu or print if not legible to the client, and helping to locate items (Bourquin et al., 2006). Essentially, the modern SSP serves as the eyes and ears for the person who is DeafBlind.

The Current Study

Design

The current study was conducted with two online surveys utilizing SurveyMonkey. One survey was designed for DeafBlind individuals with SSPs, and the other survey was designed for DeafBlind individuals without SSPs. The two surveys asked similar questions in order to compare the results and identify which group had a larger number of positive responses. The group with the larger number of positive responses was equated with having a higher quality of life.

The surveys used in this study were adapted from the KIDSCREEN group (2004) Child and Adolescent Health Survey. The original survey was developed as a standardized screening instrument for children’s quality of life. The survey has been used in representative U.S. and European health surveys (KIDSCREEN, 2004). The KIDSCREEN creators also state that their survey can be used as a generic instrument to assess quality of life in children and adolescents with a chronic illness. Nearly all the questions on both surveys had multiple-choice responses. The response choices for the majority of questions were “Never,” “Seldom,” “Quite often,” “Very often,” or “Always.” The response choices for the last two questions on both surveys were “Yes,” “No,” and “Other” with a text box for participants to specify.

The DeafBlind individuals surveyed were 18 years and older. The KIDSCREEN Child and Adolescent Health Screen Survey was chosen based on the patterns of language usage in the target population. Some deaf adults possess reading and writing skills that do not match the age and grade level of their hearing peers (Dyer, MacSweeney, Szczerbinski, Green, & Campbell, 2003). The current study is not concerned with the educational history of its respondents or their second language comprehension. As a previously standardized instrument, the KIDSCREEN Child and Adolescent Health Screen Survey was considered an appropriate and linguistically accessible survey for the purposes of the current study.

Data Analysis Procedures

The data were studied using SurveyMonkey’s analytics feature: each question was broken down showing what percentage of the participants marked which option. This study collected quantitative data. The participants read each question and chose the response that best fit their situation. The results were analyzed through the researcher’s lens, not a tested algorithm. For example, question number 18 asks, “Have you spent enough time with friends?” The researcher interpreted the response “Seldom” as a more negative response than the answer “Always.”

Results

Fifty-six DeafBlind individuals participated in the study. Twenty eighty filled out the survey for DeafBlind individuals with SSPs, and 28 filled out the survey for DeafBlind individuals without SSPs. In both surveys, some questions were not answered because a participant dropped out of the survey before completing it or preferred not to answer. However, for both surveys, at least 26 of the 28 individuals answered every question. The two surveys were identical with the exception questions 26 and 27, which asked the participants about their respective situations in living with or without SSPs.

The responses to all questions, except Questions 26 and 27, are categorized on three scales. In general, positive responses of “Always,” “Very often” and “Quite often” indicate a more favorable quality of life and negative responses of “Seldom” and “Never” indicate a less favorable quality of life. The positive responses were added to calculate the total positive percentage for each question; the overall negative responses were added to calculate the total negative percentage for each question. Question 4 has a different scale of “Extremely,” “Very,” “Moderately,” “Slightly,” and “Not at all.” Calculating the positive responses was done by totaling up the percentages of “Extremely” and “Very.” Questions, 7, 8 and 9 are formulated as negative questions. For example, “Have you felt sad?” and “Have you felt so bad that you didn’t want to do anything?” Therefore, the positive response for these questions were inversely calculated by adding up the total responses in the “Seldom” and “Never” categories. Question 1 has a different scale of “Excellent,” “Very good,” “Good,” “Fair,” and “Poor.” Positive responses in this scale consist of "Excellent," "Very good," and "Good." Negative responses in this scale consist of "Fair" and "Poor."

Emotional Health

The results for the variable of emotional health are summarized in Table 1 and Table 2. As discussed above, the selections of "Very" and "Extremely" have been combined to represent the overall positive rate of response. An overall negative rate of response for the "Slightly" and "Not at all" responses were also computed.

Table 1

Emotional Health KIDSCREEN Questions

	DeafBlind *With* SSPs		**DeafBlind *Without* SSPs**	
	% Positive Responses	**% Negative Responses**	**% Positive Responses**	**% Negative Responses**
Question 4: Has your life been enjoyable?	57%	43%	25%	75%
Question 10: Have you felt happy with the way you are?	93%	7%	61%	39%

Table 2

Emotional Health KIDSCREEN Question (Inverse Responses)

	DeafBlind *With* SSPs		**DeafBlind *Without* SSPs**	
	% Positive Responses	**% Negative Responses**	**% Positive Responses**	**% Negative Responses**
Question 7: Have you felt sad?	64%	36%	43%	57%
Question 8: Have you felt so bad you didn't want to do anything?	79%	21%	54%	46%

Table 1 shows that for Question 4—"Has your life been enjoyable?" —individuals with SSPs responded at a positive rate of 57%, whereas individuals without SSPs responded at less than half that rate at 25%. It must also be noted that 4% of individuals without SSPs responded that their life has "Not at all" been enjoyable, whereas no individuals with SSPs responded with "Not at all." For Question 10—"Have you been happy with the way you are?"—the two groups differ drastically. The most staggering difference is the negative rate for the response "Seldom": nearly one-third (32%) of individuals without SSPs responded "Seldom" compared to 7% of individuals with SSPs. The overall negative rate for both negative responses ("Seldom" and "Never") is also drastic: individuals with SSPs responded at a negative rate of a mere 7%, while individuals without SSPs responded at a negative rate of 39%. Individuals with SSPs responded at a positive rate of 93%, and individuals without SSPs responded at a positive rate of 61%.

Table 2 shows that for Question 7—"Have you felt sad?"—individuals with SSPs responded at a positive rate of 64%, and individuals without SSPs responded at a lower rate of 43%. Even more telling is the negative response rate: individuals with SSPs had a negative response rate of 36%, and individuals without SSPs had a negative response rate of 57%. For Question 8— "Have you felt so bad that you didn't want to do anything?"—individuals with SSPs responded at a negative rate of 21%, and individuals without SSPs responded at a rate of 46%. Four percent of individuals without SSPs selected the most negative response that they have "Always" felt so bad that they didn't want to do anything. No individuals with SSPs selected "Always."

Health

The results for the variable of health are summarized in Table 3.

Table 3

Health KIDSCREEN Questions

	DeafBlind *With* SSPs		**DeafBlind *Without* SSPs**	
	% Positive Responses	**% Negative Responses**	**% Positive Responses**	**% Negative Responses**
Question 1: In general, how would you say your health is?	96%	4%	71%	29%
Question 2: Have you felt fit and well?	93%	7%	89%	11%
Question 3: Have you felt full of energy?	89%	11%	50%	50%

Table 3 shows that for Question 1—"In general, how would you say your health is?"—individuals with SSPs had a positive response rate of 96% compared to individuals without SSPs with a positive response rate of 71%. In the categorical breakdown, 0% of individuals with SSPs picked "Poor," compared to 7% of individuals without SSPs.

For Question 2—"Have you felt fit and well?"—responses were similar to Question 1. Individuals with SSPs responded that they felt "Extremely" fit and well at a rate of 15%, whereas no individuals without SSPs selected "Extremely." The overall positive and negative responses rates were similar for both groups.

For Question 3—"Have you felt full of energy?"—11% of individuals with SSPs responded with "Seldom," compared to 50% of individuals without SSPs. Thirty-nine percent of individuals with SSPs responded "Very often," compared to only 14% of individuals without SSPs. The overall positive rate came to 89% for individuals with SSPs came to 89% and 50% for individuals without SSPs.

Money

The results for the variable of Money are summarized in Table 4.

Table 4

Money KIDSCREEN Questions

	DeafBlind *With* SSPs		**DeafBlind *Without* SSPs**	
	% Positive Responses	**% Negative Responses**	**% Positive Responses**	**% Negative Responses**
Question 16: Have you had enough money to do the same things as your friends?	59%	41%	32%	68%
Question 17: Have you had enough money for your expenses?	69%	31%	54%	46%

The responses for Question 16—"Have you had enough money to do the same things as your friends?"—are thought provoking. The positive response rate totaled 59% for individuals with SSPs and 32% for individuals without SSPs. Conversely, the negative response rate elicited interesting statistics: 41% of individuals with SSPs felt they typically did not have enough money to do the same things as their friends, as compared to 68% of individuals without SSPs.

For Question 17—"Have you had enough money for your expenses?"—once again, the individuals with SSPs possessed a higher positive response rate in regard to finances. More than two-thirds (69%) of individuals with SSPs had a positive response of having enough money for their expenses, compared to 54% of individuals without SSPs.

SSP Services

Questions 26 and 27 relate to SSP services that the DeafBlind individuals do or do not receive and are different for each group. For individuals with SSPs, Question 26 asks, "Do you want more SSP hours?" and Question 27 asks, "Does having an SSP increase your feelings of independence and freedom?" For individuals without SSPs, Question 26 asks, "?" and Question 27 asks, "Do you know what an SSP is?"

Question 26 for DeafBlind Individuals with SSPs

Figure 1

Do you want more SSP hours?

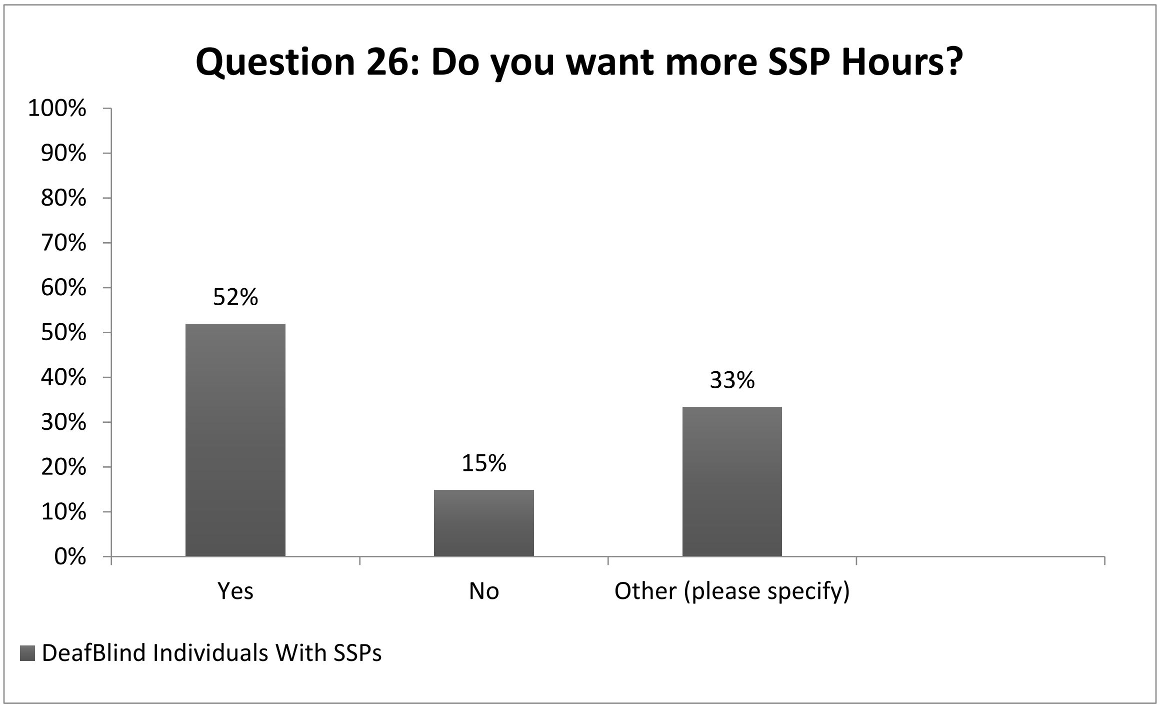


Figure 1 shows that for Question 26—"Do you want more SSP hours?"—52% of the individuals with SSPs responded "Yes," 15% responded "No," and 33% responded "Other, please specify." One respondent typed the following comment about the hours and services available:

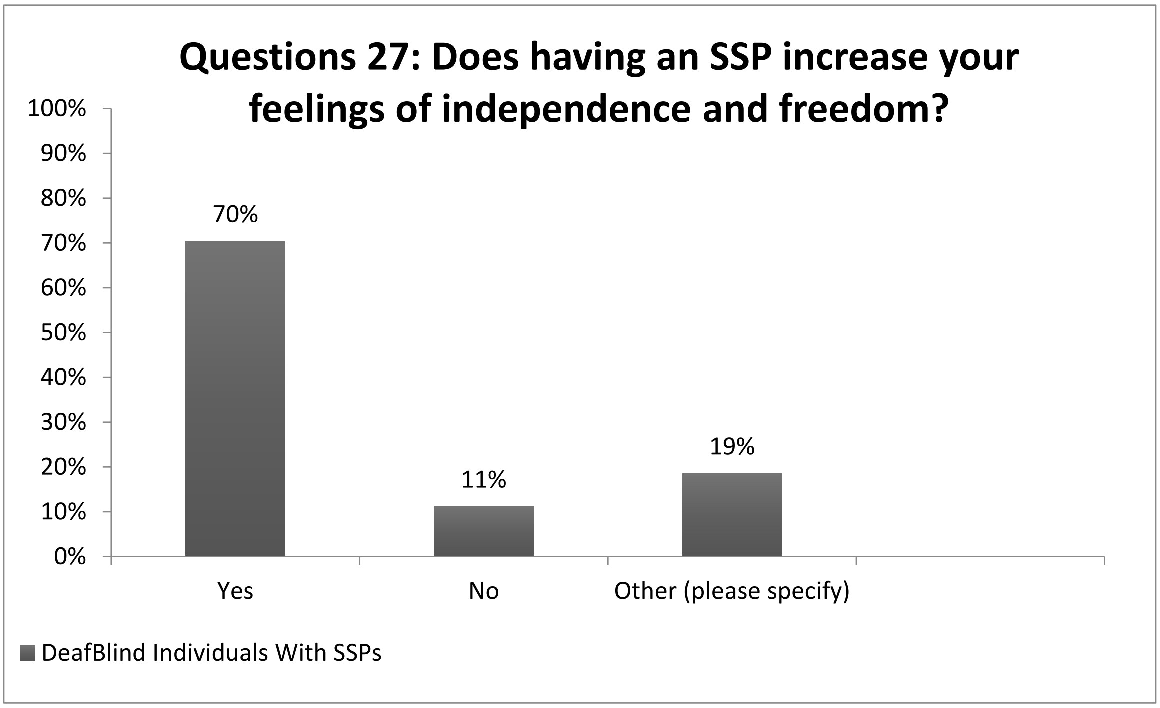
> The legislature took away bus routes, as I own my home, I am not able to find other place to live, as what I paid for the home, it has not equaled out do to market crash. Thus, I live alone, am very stranded. I only get out of the house when my caregiver is here, only [sixteen] hours per week. This means [groceries], medical appointment, etc. Not enough hours to get out and do [something] enjoyable for me. On the bright side, I am learning to walk down a no [side walked], highway for one mile to catch a bus if necessary. This will only be available in the summer months, but at least an option. I do have a deaf/blind mobility instructor to help, this will give me a few more freedoms.

This comment provides valuable feedback that links previously asked questions regarding transportation and safety. This DeafBlind individual stated that they own their own home and are financially unable to pick up and move to another location that would better serve their needs. Individuals who are hearing and sighted are privileged in that they may not have to choose a home based on the availability of the public transportation system or based on an area that has preexisting services available. The frustration with bus services suddenly becoming unavailable is a fear expressed by the individual's response above. This individual's comment implies that their "caregiver" provides similar services that SSPs do. It is not, however, mentioned if this caregiver is fluent in the DeafBlind individual's language preferences or if they have training in DeafBlind culture, guiding, visual description, and communication support.

Question 27 for DeafBlind Individuals with SSPs

Figure 2

Does having an SSP increase your feelings of independence and freedom?



The responses for Question 27 for individuals with SSPs demonstrated that specifically trained SSPs have a positive impact in providing assistance. Figure 2 shows that for Question 27—"Does having an SSP increase your feelings of independence and freedom?"—70% of the individuals responded "Yes," 11% responded "No," and 19% responded "Other, please specify." Five respondents typed comments. One respondent says:

> YES! YES! With her help, and especially when she is with me, I feel like I can conquer the world. I [believe] this is due to her personality; [when I need to be] independent, and [she] is just there if I need her, but she jumps in when she sees me struggle, or a look on face that I am not hearing. Because she is not trying to "control" me, but be there for me in a time of need, she gives me a lot of confidence. I try more things when she is [around], and I am more independent when I know she is there to rescue me if needed. My other family and friends are taking away my [independence] [and] freedom by not allowing me to explore and find things on my own. I feel I can accomplish so much if I can be left alone for just a moment! :)

A second respondent comments, “As [I] deteriorate, [I] need SSPs more and more. They [help me] maintain my independence.” A third respondent writes, “[I] am still using my residual vision so I do not think of getting SSPs.” Residual sight is something that could skew the results in analyzing the need for DeafBlind individuals to obtain SSP services.

Question 27 for DeafBlind Individuals Without SSPs

Figure 3.

Do you know what an SSP is?

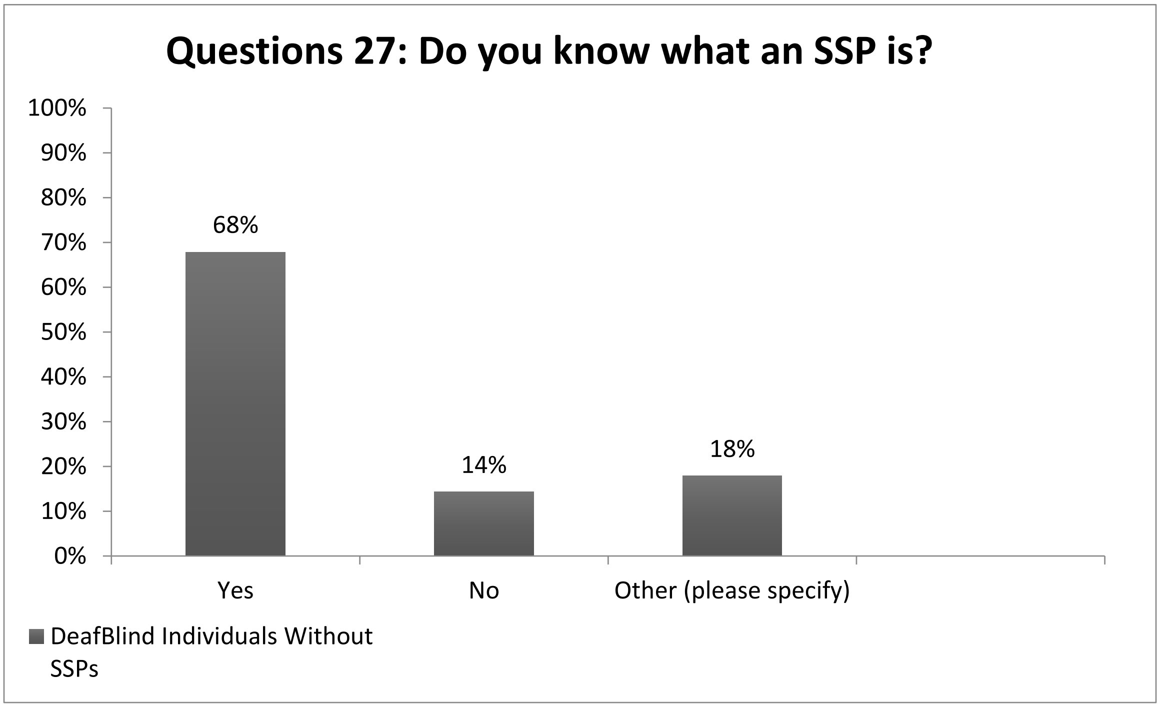


Figure 3 shows that for Question 27—“Do you know what an SSP is?”—about two-thirds (68%) of the individuals without SSPs responded “Yes,” 14% responded “No,” and 18% responded “Other, please specify.” Responses in the comment box varied quite a bit. One respondent said, “I just looked it up”; another said, “Yes, [it’s] my wife and family” and “Depend on spouse.” One response elaborated by saying, “I know of the SSP service but have no information or even if it’s provided where I live. I am very interested though.”

Discussion

Questions 4, 5, 6, 7, 8, 9, and 10 all inquire about emotional aspects of the DeafBlind individual’s life. Question 7—“Have you felt sad?”—elicited a consistently higher negative rate with individuals without SSPs. Smith (2002) described how engrained society is in disregarding the needs of DeafBlind individuals, which could contribute to feelings of sadness. As Smith stated:

> Privilege decides how money and time are spent. Typically, budgets start with outlining "the basics." The basics like rent or building overhead, phones, and supplies are based on things that we all need for any program. When we ask ourselves what is basic, we must ask "Who is 'we'?"
>
> If we begin from a Hearing/Sighted perspective and then consider the needs of Deaf-Blind people to be add-ons we will consider things such as reader software for the computers, interpreters, and CCTVs to be add-ons. For Deaf-Blind people, however, such communication tools are basic in the way phones and computer networks are for Hearing/Sighted people. (p. 207)

It stands to reason that considering accessibility as an "add-on" to a budget insinuates that a DeafBlind individual's participation in society is unwanted and at best unplanned. It is not unreasonable to surmise that feelings of sadness may be associated with feelings of inadequacy, being disregarded, and not feeling like one's basic needs are met. In a perfect world, funding sources would see that SSPs as well as establishing programs with endowments focused on providing essential services were essential to improving a DeafBlind individual's quality of life.

Responses to Questions 16 ("Have you had enough money to do the same things as your friends?") and 17 ("Have you had enough money for your expenses?") suggest that individuals with SSPs have more money to do the same things as friends and to cover expenses than individuals without SSPs. These results start an interesting discussion of the connection between disability and poverty. The response to this question implies that DeafBlind individuals who live in an area with stronger governmental support for public aid are wealthier than DeafBlind individuals who do not live in those areas. It also could be suggested that when there are no SSPs, it causes further expense to the DeafBlind individual. Without SSP services, DeafBlind individuals may need to pay out-of-pocket for services that are provided for free to others in a different geographical area.

Question 27 for individuals with SSPs—"Does having an SSP increase your feelings of independence and freedom?"—evoked the largest majority response in one answer with 70% of individuals responding "Yes." One respondent typed into the comment box that as their hearing and vision abilities deteriorate, they depend on SSPs more in order to maintain independence.

Independence among the DeafBlind is valued. One of the largest community clusters of DeafBlind individuals in the United States is Seattle, WA. This is due to the combination of access to services, transportation infrastructure, and opportunity for employment at the Seattle Lighthouse for the Blind (Cronin, 1999). Such prominence in the DeafBlind world led to the creation of an SSP Policy Handbook (2012), which was largely written based on input from the Seattle Deafblind community. The SSP Policy Handbook outlines important elements of a successful SSP services model and is an excellent reference for those wanting to learn the essentials of an SSP's role.

The handbook emphasizes the importance of independence in a DeafBlind individual's life. Independence is a cornerstone value for the duties of an SSP. The SSP Policy handbook elaborates:

> The…SSP Program is intended to support the independence of Deaf-Blind people by contracting with qualified vendors to act as a sighted guide, provide visual information, and to facilitate communication for deaf-blind people. (p. 1)

Prominently underlined in the handbook is the statement, "<u>The deaf-blind person decides</u> where to go and what to do" (p. 2). This important element is one of the first things that SSPs in training learn: that the SSP is there to do tasks WITH the DeafBlind person, not FOR them. When an SSP supports a DeafBlind person properly, it empowers the DeafBlind person to make their own independent decisions. These specifics from the handbook that was written by DeafBlind Service Center (DBSC) lend insight into why a significant majority (70%) of DeafBlind individuals responded in the affirmative to the question, "Does having an SSP increase your feelings of independence and freedom?"

In terms of successful implementation of an SSP program, the SSP Policy Handbook states that each DeafBlind individual's SSP hours are decided on a case-by-case basis. Procedures for the intake process may prove useful to those looking to establish an SSP referral program:

> Deaf-blind people wishing [for] SSP service will meet with [their] Deaf-Blind Service Center Case Manager to discuss how DBSC can best meet their needs. The Case Manager will describe all the services DBSC offers, as well as, relevant services offered by other agencies, and make any appropriate referrals… If SSP services are appropriate, the deaf-blind person will be referred to the SSP Coordinator for an appointment. (p. 4)

Given the varying degrees of hearing and vision loss, a triage source to screen for the needs of a given DeafBlind individual is an important element to successful implementation of services.

Limitations of the Study and Suggestions for Future Research

It must be noted that KIDSCREEN Group (2004) has a coding system available to aid researchers in interpreting their results. To prevent a skewed frame of reference, the coding system was not implemented in the current study. As previously noted, the KIDSCREEN survey's target population is for children, and the researchers were concerned that further coding could override the intention of using the survey with DeafBlind adults, individuals struggling and working toward a higher quality of life. The current study is meant to be a starting place for future research in examining quality of life for DeafBlind individuals. The current study is thought to be the first available on this topic.

The current findings reveal that there is a difference in the type and number of services needed between DeafBlind individuals with no vision and DeafBlind individuals with residual vision. If and when SSP and related services become widespread, it should be noted that they should be established on a case-by-case basis. This study has high external validity in regard to the DeafBlind community across America as a general group. The limitation in studying DeafBlind individuals as one encompassing group is that the extent of sensory loss was not noted. As stated by one of the survey respondents, SSP services are not used on a 24/7 basis, and residual vision can allow for added independence. Residual vision could be a vital factor in pinpointing the needs of DeafBlind individuals depending on the severity of sensory loss. Further research is needed to denote which types of DeafBlindness sensory loss requires more services.

This study did not examine the effects of marital status on quality of life for DeafBlind individuals. In a prior section of this article, we referenced the idea that caregiving relationships can be helpful but could lead to feelings of guilt that might be detrimental to the relationship. An in-depth examination regarding the influence of marital status on the quality of life for DeafBlind individuals is an avenue worth considering for future research.

As noted, the geographic location of residence can be a pivotal factor in access to transportation. Further research is needed to study location of residence and its effect on social interaction and as well as access to employment.

Another limitation of the study is that the results are analyzed through the researcher's lens, not a tested algorithm. For example, Question 18 asks, "Have you spent enough time with friends?" The researcher interpreted the response "Seldom" as a more negative response than the answer "Always." It is recommended that for future research an algorithm is developed for coding these responses so that the writer's personal opinions are disassociated from the results.

Conclusion

The purpose of this study was to investigate if there is a difference in quality of life for DeafBlind individuals if an SSP is involved. Findings indicate that by and large, SSPs are critical to enhancing the quality of life for DeafBlind individuals. The current study is also meant to provide a foundation for further research investigating the impacts SSPs have on the independence and overall quality of life for individuals who are DeafBlind.

For those with late-onset hearing and vision loss, the transition to DeafBlindness can cause grieving in a variety of areas: feelings of loss, sense of identity in a changing self, unwanted change, freedom of mobility, friends and lovers, sensory deprivation, lack of intellectual stimulation, dependency and boundaries, feelings of control over one's life, and access to authority (Smith 1993). The feeling of loss is a prominent feature during this transition process because hearing and vision are powerful tools, critical to the ability to drive, read print, and have access to countless career options. Further losses include loss of easy participation in group conversations or the loss in the ability hear or see one's native language.

One major element unveiled in both the literature review and the current study was the negative effects of isolation and lack of social interaction. Difficulties in communication can cause anxiety, stress, change in social activities, and negative self-image (Brennan & Bally, 2007). It is also vital to note that vision impairment, but not hearing loss, is associated with higher levels of self-reported functional disability (Brennan et al., 2006). The cultural bond that forms among individuals who speak the same language may be the reason behind the higher reported functional disability. This is why providing DeafBlind individuals with SSPs can be vital.

Another critical piece that contributes to a DeafBlind person's well-being is social life (Kappen, 1993). Capella-McDonnall (2005) explains that depressive symptoms for individuals with dual sensory loss is complicated by the point that most in the DeafBlind community have difficulty with communication and transportation, which makes obtaining treatment services more difficult. SSPs may be the solution to the social isolation, transportation barriers, and lack of access to services that many DeafBlind individuals face. Having the support of an SSP can allow a DeafBlind individual to participate in various life activities that, in turn, can affect quality of life in a positive way.

Interestingly, Tolman et al. (2005) found a relationship indicating that the fewer services a DeafBlind individual utilized, the greater their depressive symptoms. They also found that the "acceptance-of-vision-loss factor" was the strongest predictor of depression being present. The more a person with vision loss denied their disability, the farther they pushed away from obtaining assistance. This is clearly a vicious cycle. These findings highlight the serious need for providing rehabilitation services and SSPs for the DeafBlind community.

The current research has also highlighted that there is a lack of knowledge regarding the duties, definition, role, and impact an SSP can have on the quality of life for a DeafBlind individual. Such lack of knowledge can lead to a dearth of SSP programs and services.

Another interesting element uncovered in the current research is the suggestion that DeafBlind individuals without SSPs are further economically disadvantaged compared to DeafBlind individuals with SSPs. Individuals with SSPs consistently reported a higher positive response to the current study's monetary questions (Questions 16 and 17) than individuals without SSPs. Further research is needed to confirm the relationship of location, services, and economic disadvantage that DeafBlind individuals without SSPs face. Further research is also needed to identify exactly where services exist and to what extent funding is available. Establishing a knowledge base regarding the kinds of funding that are available for SSP programs and services can also be beneficial.

In the absence of SSPs, the world is ever-changing and can be daunting (Miner, 1997; Danermark & Möller, 2008). There is clearly a need for further SSP resources in the United States. Smith (1993) recognized that "Deaf-Blindness can be an incredibly isolating and dehumanizing experience. But it does not have to be" (p.141). SSPs can be a fundamental service resource to reduce the barriers to participating in life that many hearing and sighted individuals can take for granted. Without resolving issues of depression and social isolation, the movement up Maslow's hierarchy toward self-actualization is very difficult for any individual.

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