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**Quality of Life For DeafBlind Individuals:
Comparing the Effect of Living With and Without Support Service Providers**

**By
Sheridan Lachney**

A thesis submitted to Western Oregon University
In partial fulfillment of the requirements for the degree of:
Master of Arts in Interpreting Studies

January 2018



WE, THE UNDERSIGNED MEMBERS OF THE GRADUATE FACULTY OF WESTERN OREGON UNIVERSITY HAVE EXAMINED

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- Thesis
Field Study
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Titled: Quality of Life for Deaf Blind Individuals: Comparing the Effect of Living with and without Support Service Providers

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ACKNOWLEDGEMENTS

I would like to thank the DeafBlind community for their willingness to share their thoughts and experiences in developing this research. Thank you to my fiancé, Tyler Whitworth, and my brother, Garrett Lachney, for helping with all of my technology needs. I would like to thank my teachers CM Hall, Amanda Smith, and Elisa Maroney for inspiring me to go further. Thank you to Jaime Wilson for introducing me to sign language and the Deaf community. I would like to give a special thanks to my mother, Ann Lachney, for editing not only this paper, but also every paper I have written throughout my educational career. I know I would not have made it this far without her and my father's support.

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ABSTRACT

**Quality of Life For DeafBlind Individuals:
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By

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Western Oregon University

December 2017

In this paper, the quality of life for DeafBlind individuals who have Support Service Providers (SSP) available will be compared to DeafBlind individuals who do not. SSPs are trained individuals who assist the DeafBlind population with tasks such as a communication support, environmental information, and mobility support; in addition, they typically possess at least some fluency in American Sign Language. The availability of SSP services varies between DeafBlind individuals depending on a variety of factors. This study explores possible differences in quality of life reported by DeafBlind individuals who currently have SSP services available and those who do not. In consideration to the responses provided by the DeafBlind community, a new discussion emerges attempting to identify ways to achieve an accessible world for these community members.

The 56 participants in this study are comprised of female and male individuals, 18 years or older, from a variety of ethnic and social groups across the United States who have a combination of hearing and visual loss. The methodology for this research is a quantitative survey. This study used KIDSCREEN Group's (2004) pre-existing survey. The survey respondents are divided into two groups: those with SSPs and those without SSPs. Each group had 28 respondents who filled out a similar survey. The group that had the higher percentage of positive responses was identified as possessing a higher quality of life. It was concluded that DeafBlind individuals with SSPs consistently had higher positive responses than the other group, DeafBlind individuals without SSPs.

Keywords: DeafBlind, SSP, independence, isolation, depression.

CHAPTER 1: INTRODUCTION

Background

I was first exposed to the DeafBlind community in my first year of the ASL/English Interpreting Program at Western Oregon University. I took both the DeafBlind interpreting introductory course and a practicum class that instructs students how to become a specialty paraprofessional for the DeafBlind called a Support Service Provider (SSP). The practicum class concluded with a week-long volunteer trip working as an SSP at Seabeck, a camp for DeafBlind individuals in Seattle, Washington. I was so moved by the DeafBlind community that I caught a flight to Minnesota to volunteer at another DeafBlind camp. Since then I have volunteered at the Seabeck DeafBlind camp twice, as well as at numerous DeafBlind events and meetings.

The best way to explain my background and drive for DeafBlind access and equality is to look back to my first time volunteering at a DeafBlind camp. I was paired with a young, low-vision Deaf camper during our afternoon free time at Camp Friendship in Annandale, Minnesota. My match decided he wanted to spend three hours fishing in the 100-degree Midwestern sun, so that is what we did. After fishing, he went to swim and cool off in the lake. After swimming in the lake, he decided he wanted to go back to the boys' cabin and shower. I guided him to his cabin and I told him I would be waiting outside. After waiting for a time I became worried as to why he was taking so long, and I entered his cabin to find him sleeping on his bunk in his swim trunks. I honestly left the cabin wanting to cry and had to sit down and reflect on what just happened. My match

had been so overwhelmed that he had access to all these activities. My belief is that he was so ecstatic to experience everything, to be in a world of “yes we can do whatever you want” for those four hours, that he simply became worn out. I realized that many of us who are hearing and sighted are remarkably privileged; we take for granted that we can go anywhere and do anything we want at any time of the day! We do not depend on another’s schedule; we do not have to face the numerous times each day that DeafBlind people have to hear “no you can’t.” This young camper taught me that one of the most fulfilling things you can do in life is to create a world of “yes” for someone who lives in a world of “no.”

Statement of the Problem

There are DeafBlind community members live without sufficient services to conduct day-to-day life. One of the biggest obstacles is the issue of 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 to fulfill these needs (Azenkot et al., 2011).

When planning a trip, DeafBlind individuals commonly use the transit agency website to obtain bus schedules, travel times, and bus stop locations (Azenkot et al., 2011). To add to the complexities, these websites are typically difficult to use because they do not fully load when accessing them through a screen reader (Azenkot et al., 2011). When all else fails and one cannot figure out the public transit website, the DeafBlind individual can request a Para-transit or an access van that provides shared door-to-door rides; however, these services must be often requested at least a week in

advance (Azenkot et al., 2011). I met a DeafBlind woman who described her process to get to the grocery store. She would wait at a bus stop with a note card saying “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.” She would then get on the bus and wait for a tap from the driver and then be escorted off at the correct location. Once she gets off the bus, she pulls out another note card saying, “Hi pedestrian, I am Deaf and Blind. Would you please guide me across the street and into the Fred Meyer? 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 (Anonymous, Personal communication, May, 2016). This process is very time consuming and requires a lot of research and planning in order to execute.

Beyond the fact that this process is time consuming and many things could go wrong, it is 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 a thief down.

This trend of soliciting aid from strangers is not a new phenomenon. Bourquin and Moon (2008) stated that this technique of communication by note cards has been used for at least 70 years. Bourquin and Moon (2008) referenced two other surveys, one by Sauerburger and Jones (1997) and the other by Lolli and Sauerburger (1997); both found that 27 out of 41 pedestrians who passed by did not notice the DeafBlind traveler

with their card soliciting aid. DeafBlindness is nothing new; ironically, we just have simply failed to see it.

Some might argue that it is such a small number of individuals who identify as DeafBlind, making the services cost prohibitive or unnecessary. However, Azenkot et al. (2011) counter this argument by stating that there are 1.3 million legally blind people in the United States who depend on public transportation, as well as roughly 50,000 DeafBlind individuals.

Bodsworth, Clare, Simblett, and Deafblind UK (2011) found that many DeafBlind individuals receive informal support from family members and unpaid caregivers. The DeafBlind individuals feel that the care provided to them has a positive impact on their life, but the recipient feels that he or she is a burden and that they must always be grateful for the services family members and friends selflessly provide (Bodsworth et al., 2011). Such feelings may themselves lead to increased anxiety, depression, and loss of self-esteem (Bodsworth et al., 2011). Bodsworth et al. cited the Department of Health stating that with this combination of impairments and increased dependence, it is not surprising that these individuals are at a higher risk of developing mental health problems as compared to their peers in the general population.

Having informal family support is a blessing and a curse for DeafBlind individuals. On one hand it is extraordinarily helpful to have a significant other who acts as their full-time taxi driver, chef, and caretaker. However, the feelings of guilt for the recipient can be crippling, and the burden placed on the caregiver can be detrimental to the relationship as well.

In a British study, Bodsworth et al. (2011) found that out of 366 DeafBlind individuals, 70% expressed a wish for a trained one-to-one support worker, and 73.1% reported that they receive any formal support (Bodsworth et al., 2011). Less than one-third (28.6%) reported that they were receiving specialist specific support, for example, from a communicator guide or service support provider. The overwhelming majority of respondents indicated that they wanted more formal support rather than informal family support (94.5%; Bodsworth et al., 2011).

Ideally DeafBlind individuals should be provided a specific amount of hours per week with a service support provider (SSP). SSPs are typically individuals who are fluent in signed language and trained in a variety of communication techniques such as tactile, close vision, and tracking, and can provide small brief exchanges by interpreting. They are trained in safely and effectively guiding a DeafBlind individual in a variety of environments. When a DeafBlind individual has time with their SSP, it provides respite for the family caregiver and allows the DeafBlind individual to feel less of a burden on the family and less dependent. The results of this study suggest that having SSPs positively impacts the DeafBlind individual's overall quality of life by reducing feelings of guilt, and providing safe and efficient travel to many destinations.

Purpose of the Study

The purpose of this study is to investigate if there is a difference in quality of life for DeafBlind individuals if an SSP is involved. This study is 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.

Theoretical Framework

The quality of life research conducted here 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 a Support Service Provider are outlined in connection to satisfying the hierarchy of needs for DeafBlind individuals.

Maslow's Hierarchy of Needs

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

The hierarchy of needs involves the following needs, ordered from bottom to top, the bottom having the most basic needs, and the top having the most elaborate. The first and most basic block is biological needs (e.g., food, water, oxygen, etc.). The second is needs regarding safety (e.g., psychological security and physical security). The third block is concerned with social needs (e.g., need for friendship, affiliation, to belong, etc.). The top and final block is regarding self-actualization, meaning the need to obtain achievement, self, expression, integrity, and self-fulfillment (Sirgy, 1986). Through the lens provided by Sirgy (1986) and Maslow, 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 and Sirgy's (1986) theories it can be argued that individuals in the DeafBlind community with limited support resources struggle to move up the hierarchy of needs and therefore struggle to obtain the highest quality of life possible. This paper is based in statements that DeafBlind individuals with limited access to support service providers frustratingly struggle to move up Maslow's pyramid because they are still working on obtaining the four bottom needs on the pyramid (i.e., biological needs, satisfaction needs, safety needs, social needs, esteem needs).

It must be noted that these statements are a generalization of the community. There are many DeafBlind individuals with support systems in place and live successful fulfilling lives. In this study, evidence is sought to show that there are many DeafBlind individuals living without supports and are therefore struggling to have basic needs met.

Support Service Providers Duties and Impact

A handbook by Nuccio and Smith (2010) described the concept of an SSP. Nuccio and Smith described them as a trained worker who is typically fluent in ASL, acts as a sighted guide to accompany a DeafBlind person while providing environmental information and communication support. Nuccio and Smith acknowledged that other resources like technology can be helpful, but no amount of mechanical aid can replace the human aid of an SSP. Nuccio and Smith explained that SSPs provide a foundational service. Without SSPs DeafBlind individuals often face isolation that make it difficult to participate in society in a meaningful way even when other services are provided (Nuccio & Smith, 2010). Without SSP services, a great deal of language and access is missed such as background or contextual information. Although the missed information later may be

understood, in the moment the gap of information becomes so great that even a skilled interpreter cannot fill everything in (Nuccio & Smith, 2010).

The existing literature has revealed the need for SSPs in order to improve DeafBlind quality of life. Current research has also revealed that there is a lack of implementation of services and understanding of the importance of SSPs. At the time, a publication by Bourquin et al. (2006) revealed that no coherent and consistent system existed for the funding of SSPs at the local, state, or national level. Locations that do have funding are sourced from diverse entities including donations, grants, private foundations, tax levies, fundraising event, and state agency contracts (Bourquin et al., 2006). Some of these programs are running on one-time funding while others receive annual contract funding (Bourquin et al., 2006). Bourquin et al. closed with a wise remark: “If the future expansion of SSP services is to succeed, greater and more consistent funding resources must be identified and secured” (p. 18).

In this study, Maslow’s hierarchy of needs will be used as a framework to show the importance of SSPs to achieve a high level of quality of life for DeafBlind individuals. In the next chapter, topics related to quality of life such as travel, mental health, and formal and information support will be discussed as these issues relate to DeafBlind individuals.

CHAPTER 2: LITERATURE REVIEW

Living as a DeafBlind individual presents unique challenges in society today. Reviewing the existing literature on this subject outlines that the lack of consistent support services impacts life in numerous ways including career choices, family dynamics, satisfying social interaction, and overall quality of life for DeafBlind individuals.

Involvement in Society

Hersh (2013) studied DeafBlind well-being and found that DeafBlind people throughout the countries she studied were interested in being involved and contributing to society and supporting one another. Most individuals imagine DeafBlind people as recipients of support rather than individuals who give and contribute to society (Hersh, 2013). Recalling Maslow's Hierarchy of Needs, DeafBlind individuals cannot move up the hierarchy until lower-level needs have been fulfilled. The most basic and vital of these is the need to fulfill "physiological self," after that "safety needs," then "belongingness and love," then "esteem needs" and "self-actualization" (McLeod, 2016). The "belongingness and love" category can be paralleled to the need for social interaction in society. DeafBlind individuals do indeed want to find their place in society and realize self-actualization; however, they are often near the base of the diagram, working to fulfill basic safety and belongingness needs.

A study by Brennan and Bally (2007) further discussed family stress when one loses their sight and hearing. They cite a study by Pray (1992) that found spouses and

close family experience grieving for the loss of their family member's hearing (as cited by Brennan & Bally, 2007). The individual's hearing loss caused difficulties in communication resulting in anxiety, stress, change in social activities, isolation, and negative self-image, which affected both the individual and the spouse (Brennan & Bally, 2007). A similar study conducted in Europe by Harris and Bamford (2011) resulted in similar findings for Deaf sighted individuals. They outlined the significant barriers that prevent fully participating in social roles of being a citizen, employee, parent and patient (Harris & Bamford, 2001).

Traveling

Sauerburger and Jones (1997) described more difficulty when traveling. They stated that the primary problem DeafBlind individuals face when trying to solicit aid is communication, as they are often asking for help from people who do not know signed language and who are untrained in guiding.

Wahlqvist, Moller, Moller, and Danermark (2016) indicated that the most common cause of DeafBlindness is Usher syndrome (USH), and that the three different types are all the result of problems in 13 different genes. This disease influences visual and hearing abilities and sometimes vestibular areflexia, which increases balance problems, light sensitivity, night blindness, visual field limitations, impaired visual acuity, and cataracts (Wahlqvist et al., 2016, p. 246). Combining balance problems and standing on the street waiting for a bus could potentially be dangerous.

Kappen (1993) also described that an issue for young DeafBlind individuals as they look into the future is the question of transportation. As a child, DeafBlind students have access to the school bus (Kappen, 1993). After they age out of the system their

dependable transportation disappears: “Accessing the community requires transportation and creative solutions to complex transportation needs” (Kappen, 1993, p. 239). Issues include: Communication while using the transportation system, the availability of public transportation (just because someone lives in a rural area should not mean that they are trapped), physical accessibility and safety (is the bus stop dangerous for a blind person to walk to?), personal assistance during traveling, and the cost for traveling (is it public or is it a taxi ride? Taxis are expensive and not a viable option). The government needs to keep in mind that if a DeafBlind individual requires a travel companion, additional financial support will be required: “If people who are deaf-blind are to have the same access as a typical citizen, arrangements need to be made for the travel companion to have a free or reduced fare” (Kappen, 1993, p. 240).

These are all unique issues faced by DeafBlind individuals. These unique needs can easily be overlooked unless consumers, family members, and advocates raise awareness and participate in planning efforts (Kappen, 1993). SSP services should be part of this community-based programming, as well as the other services SSPs provide. SSPs they can assist the DeafBlind individual in traveling to events in order to become a more involved member of the community. This issue of transportation relates back to Maslow’s Hierarchy of Needs in the fact that one cannot be involved in society if they cannot get out into it in the first place.

Daily Functioning

Tolman, Kleinschmidt, and Gregg (2005) conducted a study of 144 outpatient participants from a vision clinic that specializes in the diagnosis and treatment of Age-Related Muscular Degeneration (ARMD). ARMD is an eye disease that occurs when the

cells of the macula deteriorate, causing loss of central vision (Tolman et al., 2005).

Tolman et al. (2005) described ARMD as a leading and irreversible eye disease that causes vision loss in older individuals. Of greater concern, 1.2 million people aged 65 and older are legally blind as a result of ARMD and the exact cause of the disease is unknown. There is no treatment that can reverse the damage caused to the eye from this disease (Tolman et al., 2005). Tolman et al. reiterated that although there is usually some remaining peripheral vision remaining, the ability to accomplish Instrumental Activities of Daily Living such as reading bank statements or medication labels, writing checks, paying bills, recognizing faces, is visually impossible. The inability to do such tasks can disrupt the person's sense of intrapersonal control and lead to depressive symptoms and social isolation (Tolman et al., 2005).

Brennan, Ya-ping, and Horowitz (2006) examined older individuals with dual sensory loss and the effects this has on daily functioning. Brennan et al. classified functioning in two categories: Instrumental Activities of Daily Living or "IADL" (e.g., managing money, preparing meals, shopping, using the telephone, housework) and "ADL" or Activities of Daily Living (e.g., indoor mobility, dressing, bathing).

Brennan et al. (2006) did an elaborate investigation on blindness and found that "research has found a strong relationship between visual impairment and functional disability among community-based older adults" (p. 778), highlighting the impact of blindness as a disability:

When compared with other physical impairments, visual impairment also has a more severe effect on everyday functioning and is as limiting as terminal cardiac disease in older adults For example, among nine common medical conditions

of older adults, Furner et al. found that visual impairment and stroke were the most pervasive in affecting IADL disability. (Brennan et al., 2006, p. 778)

They also found that self-reported visual impairment, but not hearing loss, was associated with higher levels of self-reported IADL functional disability. In a study of 1,191 Italian adults, ages 70-75, Brennan et al. (2006) cited that blindness affected functional performance, while deafness did not demonstrate such effects. However, when the individuals experienced dual sensory loss, the level of disability was increased in comparison with either single impairment alone.

These statistics sadly worsened following Brennan, Ya-ping, Horowitz (2006) citing that:

those reporting dual sensory loss had the lowest levels of education and were least likely to be college graduates compared with the other groups ... Older adults reporting dual impairment were the most likely to be at or below poverty level (23.1%), followed by those reporting visual impairment only (20.2%), and last, persons reporting hearing loss or no impairment (13.2% and 15.5%, respectively) ... In terms of self-reported cognitive status, older adults with self-reported dual sensory loss were the most likely to report frequent trouble with both memory and confusion (31.9% and 12.7% respectively). (p. 782)

Brennan et al. (2006) concluded that there is a general public unawareness of the unavailability of resources for these individuals: "Findings highlight the need for effective vision and aural rehabilitation and intervention services to help non-institutionalized older adults improve or maintain their functional independence" (p. 790).

Schneider et al. (2011) gave further support to the idea that visual impairment alone limits independence, increases reliance on services and supports, and overall reduces quality of life. They stated, “When two primary sense receptors are impacted, many individuals experience communication difficulties, psychosocial isolation, social isolation, depression, reduced independence, mortality, and cognitive impairment” (p. 1). Schneider et al. (2011) cite Capella-McDonnall (2005) and Chou and Chi (2004) in finding that there is an increased incidence of depression among individuals with dual sensory loss over those with hearing loss, but not statistically significantly greater risk over those with vision loss. Chou and Chi (2004) stated “similarly reported vision loss made a significant unique contribution to depression, but hearing loss did not add to the likelihood of depression when vision loss was already present” (as cited in Schneider et al., 2011, p. 7). The University of Minnesota Library (n.d.) outlined that one of the most vital elements in forming a society, community, and culture is a shared language. Individuals who become DeafBlind may lose their ability to have a driver’s license, but they may gain a community of individuals who share a common language, common struggles, and a common goal of independence and well-being. With consideration from the literature reviewed thus far, it is not unreasonable to state that the disabling factor in DeafBlindness is the loss of sight, not the loss of hearing.

Schneider et al. (2011) cited He, Sengupta, Velkoff, and Deborrow, (2005) reiterating that able-bodiedness is temporary. Schneider et al. suggested that a “longer life increases the risk of chronic disability. The proportion of the U.S. population aged 65 years and older will double between 2000 and 2030, from 35 to 72 million” (p. 2). It may be that the general population has been pushing DeafBlind individuals out of sight and

out of mind with the misconception that it is such a small population of individuals who are affected and need services such as SSPs.

Blindness is a prevalent disability that affects many more individuals than most realize. Bagley (1995) stated that the incidence and prevalence of vision loss increases with age, and visual impairment is among the top 10 most frequent physical impairments among people over the age of 65 (p. 46). Bagley also suggested that individuals who have spent the majority of their lives sighted and hearing acquire sensory loss later in life can also benefit from services. Sadly, frequently these individuals' needs are dismissed because they are labeled as a normal part of aging (Bagley, 1995). Individuals who acquire an age-related disability often learn to cope with the disability the best they can by using their existing senses to compensate. For example, when a person's sight diminishes and they can no longer read books or see their cellphone screen, they might turn to audiobooks and voice command usage on their cell phone to text. These coping strategies become complicated when a person possesses a severe hearing loss and then is faced with a loss of vision. For these older adults the additional loss occurs late in life, after many years of successfully living with a single sensory loss (Bagley, 1995, p. 47). Having the support of an SSP could ease this transition into dual sensory loss by working with the individual in finding the best communication method. Bagley (1995) stated that support systems are important to all older adults, particularly those with hearing and vision loss, but not everyone is fortunate enough to have a reliable support system. This is another reason why SSPs are vital to the DeafBlind community: They are dependable individuals who are available to practice a variety of communication techniques with the DeafBlind individual before they have to rely on it completely.

Vision impairment is no new phenomenon. Bazargan, Baker, and Bazargan (2001) cited the U.S. Department of Health in stating that vision impairment is identified as the second most prevalent physical impairment within the elderly population, and that these rates sharply increase with growing age. The authors estimate that there are as many as 2.7 million older people in the United States with a sensory impairment, and reported rates show that occurrence is significantly higher in predominantly African American areas than in predominantly White populations (Bazargan et al., 2001).

As stated by the U.S. Department of Health and Human Services, hearing loss is also a major chronic condition for advanced age in the United States (Bazargan et al., 2001). Bazargan et al. cited Strawbridge et al. (2000) in stating that hearing loss among the elderly has doubled over the past 30 years, and that the National Academy on an Aging Society (1999) stated more than four million Americans age 65 and older are affected by hearing loss (Bazargan et al., 2001). A survey conducted in Alameda County showed that over 21% of those age 60 and older reported that hearing loss affected their understanding of words in conversation, over the telephone, and the ability to effectively carry on a conversation in a noisy room (Strawbridge et al., 2000, as cited in Bazargan et al., 2001). Nondahl et al. (1998, as cited in Bazargan et al., 2001) declared that although these individuals could greatly benefit from support, there is a popular belief that since hearing loss is part of a normal aging process it doesn't deserve to be qualified as a health problem or deserve special attention or service. For individuals who do get intervention services and obtain hearing aids, many studies have documented significant reductions of psychotic activity and improvement in mood, self-sufficiency, and social relationships after the fitting of hearing aids (Bazargan et al., 2001). This thought also applies to those

who are Deaf as well as blind. If there was a Service Support Provider available to talk to the DeafBlind individual and escort and interpret social activities, it is easy to imagine that similar positive results would be present.

Various reports have claimed that dual sensory loss appears to have a significant relationship to overall functioning in the elderly, regardless of income (Lee & colleagues, 1999, as cited in Bazargan et al., 2011). Another study found that women aged 75 and older with dual sensory loss have a strong relationship to physical dependency (Dargent-Molina & colleagues, 1996, as cited in Bazargan et al., 2011).

The Bazargan et al. (2001) research followed the trend in finding that individuals with more severe vision impairment were likely to report higher numbers of limitations in daily activities and lower levels of self-rated health status, the combined effects of which lead to a lower level of psychological well-being. Well-being was found to be directly affected by the limitation of daily activities, and self-rated health status, whereas hearing loss showed only indirect impact on well-being only in relation to functional status (Bazargan et al., 2001).

Bazargan et al., (2001) cites Burak-Weiss (1995) noting that a loss of sensory and motor abilities contributes to a sense of vulnerability, dependence on others, and fear of additional loss. Some elderly persons feel helpless and hopeless, and a decrease in mobility may precipitate social withdrawal and isolation. Burak-Weiss (1995) reported a visually impaired older person saying, "I could handle the pain of arthritis, I even got to the point that I could inject the insulin. But now that my sight is fading, I don't know how I can go on" (p. 29 as cited in Bazargan et al., 2001). Would this fear of hopelessness and

loneliness be reduced if the DeafBlind individual knew they would have assistance from a Service Support Provider to assist with all the things they miss?

This issue of daily functioning relates back to Maslow's Hierarchy of Needs in a variety of categories. One major category DeafBlind individuals without supports struggle to achieve is a level of the hierarchy of "Social Needs" (the need for friendship, affiliation, to belong). Achieving the fulfillment of "Social Needs" is difficult if the individual is struggling in effective daily functioning.

Falling

As might be expected, there is a definite connection between visual impairment and falling with the result of a hip fracture. Ivers, Norton, Cumming, Butler, and Campbell (2000) set out to demonstrate this connection by conducting a study in Auckland measuring the occurrence of hip fractures with vision impairment. The study found that over two-and-a-half years of surveillance of the Auckland region, there were 1,832 hip fractures in 1,774 older individuals (Ivers et al., 2000). The interesting part of this study found that subjects who usually didn't wear their glasses were not significantly more likely to have had a fracture than those who reported usually wearing glasses (Ivers et al., 2000). With this information it could be suggested that the tunnel vision that many DeafBlind individuals experience from Glaucoma or Retinitis Pigmentosa can pose a different danger than what individuals with distance glasses experience. People who wear glasses can still see the general shape of objects, but with tunnel vision the peripherals are completely cut out to varying degrees, which means that they are not seeing obstacles on the ground unless they are looking directly at it.

Crews and Campbell (2004) examined the health, activity, and social participation of people aged 70 years or older with vision impairment, hearing loss, or a combination of both. Crews and Campbell (2004) stated that there is a definite relationship between dual sensory loss and prevalence of a decreased quality of life, hip fractures from falls, depression, hospitalizations, and family stress. They found:

Older people with both vision and hearing loss were 3.0 times more likely to have fallen in the past 12 months than were people without vision or hearing problems, and 2.1 times more likely to have broken a hip. They were 1.5 times more likely to report hypertension, 2.4 times more likely to report heart disease, and 3.6 times more likely to have had a stroke.... They were 4.3 times more likely to report difficulty walking, 4.7 times more likely to report difficulty getting outside, and 3.8 times more likely to report difficulty getting into or out of a bed or chair. In addition, this group was 4.7 times more likely to report difficulty preparing meals and 4.0 times more likely to report difficulty managing medication. (p. 825)

Crews and Campbell closed their research with suggestions on how to make the environments friendlier for DeafBlind individuals. For example, the presence of sidewalks is always helpful when walking, and larger print on medicine bottles could make a world of a difference in the general health of DeafBlind individuals. Also imagine if DeafBlind individuals had SSP services to help navigate through the environmental barriers when there are not sidewalks and when the medicine bottle print is too small to read. Even a few hours per month may help older DeafBlind individuals maintain their independence and refrain from being institutionalized.

The risk of falling issue relates to the second category in Maslow's Hierarchy of Needs regarding psychological and physical safety. DeafBlind individuals without these visual supports struggle to move up to ultimately achieve self-actualization when the individual is still struggling to obtain physical safety. SSPs can aid in this mission by providing communication support and orienting the DeafBlind individual to the surroundings so they can safely enjoy their social time and ultimately move up the hierarchy.

Ontological Security and Independence

Ontological insecurity is Danermark and Möller's (2008) top concern for DeafBlind individuals. One DeafBlind individual stated that he cannot just go through life without relying on somebody; it's a frightening world and the environment is hostile to DeafBlind people (p. S120). Danermark and Möller concluded that "persons with deafblindness have to rely on other people to such an extent that the relations between the person with deafblindness and those helping him or her are especially vulnerable on the dimension of trustworthiness" (p. S121). People assisting DeafBlind individuals may sometimes do it as a favor that will need to be repaid. When a family member or friend provides care, it can add to feelings of guilt for the DeafBlind individual. This is another reason why it is important to have trained and background-checked SSPs, as the fear and guilt DeafBlind individuals face can be crippling. The Deaf-Blind Service Center Training (2009) handbook acknowledges this fear by stating that as an individual's vision and hearing decreases, simple tasks such as shopping, reading mail, and managing finances become more difficult. An SSP can make a huge difference in the independence for DeafBlind individuals by providing aid in these tasks when necessary (Deaf-Blind

Service Center Training, 2009). The world could be a little less intimidating for DeafBlind individuals if there were trained and empowering SSPs there to assist them when needed. Danermark and Möller (2008) concluded their research suggesting that obtaining information is one of the top challenges for DeafBlind individuals:

Since reduction of the two most important senses, hearing and vision, heavily impede the possibilities to receive and produce information and therefore to communicate, it is of utmost importance that the health care systems develop support systems that ensures this for each person with deafblindness. (p. S 122)

DeafBlind individuals do not have the luxury of being able to spontaneously live their lives; they must rely on critical planning (Bagley, 1995). When a DeafBlind individual has access to an SSP for a certain number of hours per month, they are given the freedom to live more spontaneously for that allotted amount of time. They can go anywhere and do anything without living in the restriction of bus schedules or interpreter availability. As Bagely (1995) suggested:

Just as with parents and siblings, caregiving often falls to spouses or children. Children often live far away from parents and find themselves divided between caring for their parents and for their own children. In some cases, the spouse is the caregiver who must deal with his or her own sensory loss or other chronic physical condition at the same time. (p. 47)

This is another reason why SSP services are advocated for among the DeafBlind community and their families. The children of DeafBlind parents should not have to choose between caring for their parents or their own children. Even more significantly, “older adults with developmental disabilities may not have spouses or children to provide

support. Individuals who do not have families need a broader variety of support options” (Bagley, 1995, p. 47). Basic support should not depend on biologically reproducing in order to receive care later in life. In conclusion, Bagley (1995) declared:

The challenge to independence that severe vision and hearing losses bring is one that older adults must not be left to face alone. It is a challenge that has not been adequately addressed. It nonetheless is one that we can no longer afford to ignore. The alternatives, needless loss of independence, inappropriate institutionalization, unnecessary loss of quality of life, and the unmanageable burden placed on families, will worsen as the older population grows older. (p. 49)

Brennan, Horowitz, and Su (2005) did a longitudinal study examining a total of 5,151 people at the age of 70 and older. They also found the general claim to be true that advanced age increases the likelihood of sensory disability, stating that “sensory impairment is one of the most common chronic conditions of later life; visual impairment affects between 9% and 18% of older adults, and hearing loss affects 24% to 33%” (p. 337). Unfortunately, “much less attention has been paid to dual sensory loss. Between 5% and 9% of older adults are estimated to have dual sensory loss” (p. 337).

In 1993, Monmouth, Oregon hosted a national symposium on children and youth who are DeafBlind. O’Donnell, Warner, Caudill, and Fredericks (1993) described the journey of a parent whose child is DeafBlind: “It has been a long and difficult road to travel through infancy, childhood, and adolescence, only to find that adult services are an even bigger challenge to develop and access” (p. 87). A parent of a DeafBlind individual gave a personal account at a symposium and shared the following:

I will never forget the doctor who diagnosed her visual disability. I was in shock when the bad news was presented to me. I said to the doctor, “What do we do now?” His reply was, “Go home and pray.” Can you imagine the hopelessness I felt?” (Caudill, 1993, p. 99)

Caudill echoed the countless claims that family support during this initial phase of learning about the child’s disabilities is staggeringly important. However, in many cases Caudill (1993) highlighted that not all families have support, and the diagnosis of a disability can cause strains in familial relationships, causing alienation and tension for family members and spouses. Once a child reaches adulthood, it is a common notion that the child will not live at home indefinitely. Caudill (1993) stated that she frequently observed adult DeafBlind children staying long after schooling is completed. This may be due to many reasons, one of which being that parents frequently have to continue being advocates for their children (Caudill, 1993). Caudill has a painfully honest moment stating that she has never met a parent of a child who is DeafBlind who doesn’t have some sort of fear for the future. Where will the child seek support after they pass away? Imagine the parent’s relief if there were government-funded Service Support Provider services that will help their child live independently in their adult life. Caudill’s (1993) wish was for more person-centered services from the beginning of the education system, throughout the vocational rehabilitation, to whatever is needed in the future for the individual. Some of these services are provided flawlessly to the family of the DeafBlind individual, but the truth is that it is only happening for some, and never on a consistent basis (Caudill, 1993).

Vadasy and Fewell (1986) surveyed 41 families of DeafBlind children. When the authors asked participants where they expected their child to live as an adult, most indicated that they would live in the parent's home, six indicated the child would go to a group home, five thought their child would live in an institution and one thought their child would live in a foster home (Vadasy & Fewell, 1986, as cited by Fredericks, 1993). None indicated that they thought their child could be independent. This survey also asked parents if they thought their child's needs could be met in programs that serve people with other types of disabling conditions. Twenty-six parents felt that their children needed services that were specifically planned for DeafBlind individuals. Not all individuals with DeafBlindness are otherwise disabled, so providing them with services meant for mentally disabled individuals for example is simply insufficient. Another survey inquired 28 Vermont parents of DeafBlind children about their future. The participants indicated that they were uncomfortable with long-term planning regarding their child because "it's too big of an unknown" (Giangreco & associates, as cited in Fredericks, 2005, p. 110). If parents knew that their child could live an independent adult life because of SSP services, this could change not only quality of life for the DeafBlind individuals but also give peace of mind for the families.

Ontological security issues relates to the second category in Maslow's Hierarchy of Needs regarding psychological safety. In thinking about the future and wanting to obtain independence (self-actualization) is also related to psychological security for the DeafBlind individual and the parent of the DeafBlind individual alike.

Depression and Social Isolation

A vital piece that contributes to a DeafBlind person's well-being is social life (Kappen, 1993). Kappen explained that regardless of disability, a person's quality of life is enhanced by recreational experiences, which:

provide opportunities for self-esteem, self expression, social interactions, and relaxation. Children and adults who are deaf-blind are entitled to satisfying recreation experiences. However, individuals who are deaf-blind have long been systematically excluded from actively participating in normalized recreation activities in community settings (Certo, Schlein, & Hunter, 1983). Starting with young children, recreation should provide opportunities for relationships with peers. The real goal should be to develop friendships. (p. 235)

A study by Capella-McDonnall (2005) sought to uncover the prevalence of depressive symptoms among elderly individuals with dual sensory loss. Capella-McDonnall (2005) cited Blazer (2003) unsurprisingly stating that depression among older individuals is common and can significantly decrease quality of life. Capella-McDonnall (2005) described confirmed variables that are known to be related to causing depression: functional disability, older age, being female, being in poor health, low socioeconomic status, and lack of actual or perceived social support. Persons with dual sensory loss tend to be a part of a lower socioeconomic class, specifically in areas of health, poverty, education level, and social activities (Capella-McDonnall, 2005). As one may expect, these categories are known to be related to symptoms of depression (Capella-McDonnall, 2005). The prevalence of sensory loss linked to depression is an issue that should not be ignored, because as the population grows, the prevalence of depression is only going to

increase. In the United States people are living longer, and with longer life the incidence of hearing loss and vision loss increases (Capella-McDonnall, 2005). As Capella-McDonnall further suggested:

Current estimates, taken from the 2001 National Health Interview Survey, of the number of people aged 55 and older in the United States who experience some level of dual sensory loss is 4.4 million. This represents 7.8% of the community-dwelling population (Capella-McDonnall, unpublished analysis of raw data). If looking at the entire population, these numbers would likely be much higher because many elderly persons with hearing and/or vision loss are institutionalized. (p. 856)

Capella-McDonnall's findings are similar to previously discussed research finding "a definite relationship between all types of sensory loss and symptoms of depression.... Those with dual sensory loss have the greatest odds of experiencing symptoms, followed by those with vision loss only and those with hearing loss only" (p. 858). There is a concern that there are not enough service providers who are familiar with dual sensory loss and how to work with such persons and that rehabilitation for sensory loss usually focus on one loss or the other (Capella-McDonnall, 2005). Capella-McDonnall further explained that depressive symptoms for individuals with dual sensory loss is complicated by the fact that most in this community have difficulty with communication and transportation, which makes circumstances for obtaining treatment more difficult. This rings true for many DeafBlind individuals as they struggle with obtaining transportation and fight feelings of isolation. Service Support Providers are trained to work with individuals who have a variety of hearing and sight abilities as well as providing

transportation services. Could the solution to social isolation and depression be more interaction and aid from Service Support Providers?

Tolman et al. (2005) were not the first to recognize the importance of a support system. They cited Jose's (1983) conclusion that people with visual impairments may report benefiting from the support of family members, friends, and helping professionals that reframe negative self-perceptions regarding their blindness and that the availability of external help resources was related to positive effects. Unfortunately, as individual's visual impairment worsens, there is a tendency to subside participation in enjoyable activities, which further perpetuates feelings of depression (Tolman et al., 2005). If these blind individuals have the support of a Service Support Provider, they could continue to participate in these activities that would affect their quality of life in a positive way. Even worse, Tolman et al. (2005) found a relationship indicating that the fewer services a DeafBlind individual utilized, the greater depressive symptoms were found to be. 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. The people who are depressed aren't getting the services they need in order to relieve their stress. Tolman et al. (2005) also found that legally blind older adults who report poor adaptation to vision loss experience more depressive symptoms than do older adults who have accepted their current state of vision loss. This is further evidence that adaptation to the current situation is possible, and it highlights the serious need for providing rehabilitation services and SSPs for this community.

Resnick, Fries, and Verbrugge (1997) collected data from 18,873 nursing home residents regarding their hearing and visual abilities and related effects on social engagement. Hearing, vision, and communication abilities play important roles in older adults' capacity to develop and maintain relationships, to participate in activities, and to preserve a healthy sense of self and well-being. Resnick et al. (1997) also found that increasing levels of visual impairments and hearing loss is associated with low levels of social activities. In the nursing home setting, opportunities for social interaction are already limited; impairments in sensory and communication abilities can affect residents' quality of life by causing isolation (Resnick et al., 1997). Sensory loss can also affect nursing home residents in other ways such as interfering with the ability of staff to obtain medical information from the resident; and if a hearing loss is combined with cognitive impairment, a resident may be identified as more disabled than he or she truly is (Resnick et al., 1997).

Severe hearing loss is associated with low social engagement and low amount of time engaged in activities (Resnick et al., 1997). Interestingly enough, Resnick et al. cited Rudberg and colleagues' (1993) finding that hearing loss's association with ADL disability (Activities of Daily Living) dramatically decreases after four years to non-significance as a result of adjustment to the chronic condition. As an interpreter I can't help but wonder: could this positive adjustment to Deafness include learning sign language? Could it include using an interpreter to provide immediate repetition into the ear of the client so they too can participate?

Resnick et al. (1997) provided some pointers to disassembling barriers in an effort to include residents in social activities in hope of improving their social wellbeing. They

suggested “establishing a wax-removal protocol, assignment of a trained nurse as a hearing specialist, and environmental modifications such as carpeting and sound-absorptive window, wall, and ceiling treatments” (p. S143). Adding SSPs to this list of adaptations could dramatically increase these residents’ quality of life by assisting in socializing and activities that are so drastically important to the aging population.

For people with Ushers Syndrome, the transition to DeafBlindness can cause grieving in the following areas: feelings of loss, sense of identity in a changing self, adjusting to 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 vision and hearing are powerful tools. Vision and hearing provides information about the world and they are critical to the ability to drive, read print, countless career options (Smith 1993). Further losses include loss of easy participation in group conversations or the loss in pleasure to hear one’s native language being used (Smith, 1993). It could be argued that an SSP could soften this grieving time and transition by providing in these areas.

Identity is another obvious challenge during the transition period. People with Usher Type II in particular have a difficult time giving up the image of themselves as “normal” (Smith, 1993). While individuals with Usher Type I have to move their identities from one group to the other, from Deaf to DeafBlind. For them it is not so much a loss but really, a change of identity.

Adjusting to unwanted change is never an easy thing to do. Some teenagers with Ushers who live in rural areas risk driving with their deteriorating vision to avoid being

stuck at home; their only other option is to depend on family or friends for transportation (Smith, 1993). The young DeafBlind in city areas with a good public transportation system must constantly deal with the danger of crossing the street and traffic (Smith, 1993).

Dependency, intimacy, and boundaries are a sticky situation for DeafBlind individuals. Smith (1993) suggested that people who are DeafBlind cannot continue to live independently in the way they were before they were losing their vision. They must now redefine independence. The inability to drive and the need for interpreters, readers, and other expensive equipment can create further challenges between the DeafBlind individual and their spouses, friends, interpreters, and colleagues (Smith, 1993).

Access to authority while being DeafBlind is also a barrier. Although people with Usher Type II typically have English as a first language, they cannot simply look up the names of lawmakers and hop in a car to attend a meeting or read letters to other organizations that may be supportive of their cause (Smith, 1993). Before a DeafBlind individual can even begin, they must first obtain and learn how to use a Teletype Device for the Deaf, learn to read braille, and learn how to use interpreters (Smith, 1993). Even these assistive devices have limitations: “Conversations by TTY’s take much longer. Not much is available in braille. Who will pay for the interpreters? When information is finally gathered, agenda set, and the meetings are called, how will a person who is deaf-blind get transportation to attend?” (p.146). This is why allyship and SSPs are so very important. Not only could the SSP provide transportation, they could interpret phone calls and interpret information gathered on the Internet regarding the public forum.

Smith (1993) recognized that “Deaf-Blindness can be an incredibly isolating and dehumanizing experience. But it does not have to be” (p.141). Smith gave suggestions for the future for establishing ideal environments for DeafBlind individuals. First of all, there should be programs, agencies, and services established throughout the countries, starting in big cities first. There should be good public transportation systems and a pool of interpreters. Federal financial support should be given in the form of grants to institutions so they can serve people who are DeafBlind in their region. These “programs and services should address a wide range of issues beginning with the most fundamental: support service providers, interpreter training and referral, recreation programs, counseling, and advocacy” (Smith, 1993, p. 153).

Sauerburger (1993) gave amazing firsthand accounts of the difficulties DeafBlind adults experience made easier by appropriate services. The first issue Sauerburger outlined is the problem of isolation. For example, the author was giving a DeafBlind college student an orientation tour of Gallaudet University on a Wednesday evening. That night the author heard that Operation Desert Storm had begun and our country was at war. The following week when the author had met up with the DeafBlind student, she asked him if he was able to keep up with the news on the war. The DeafBlind student replied, “What war?” This story illustrates the isolation of information even for busy DeafBlind college students face is considerable.

Another reason for DeafBlind isolation is that tactile communication is time consuming, and for some reason, many families of even sighted Deaf individuals don’t sign, many family members are not willing to learn new methods of communication (Sauerburger, 1993). Many people have found that a remedy to this isolation is to move

to a metropolitan area with a DeafBlind community and public transportation system (Sauerburger, 1993). Seattle, Washington is a well-known haven for DeafBlind individuals:

When they previously lived in their hometowns with their families, they were unable to get anywhere without the assistance of others who could drive.

Interaction with friends, coworkers, and even family members was limited because of the communication barrier, and job opportunities were poor. After moving to Seattle, they were able to live independently and travel using public transportation, were accepted as part of the community and had extensive contact with people who share their language and culture. (p. 91)

An issue arises when an individual can't move. Are they just to be neglected?

Sauerburger (1993) suggested a way to help reduce isolation of a DeafBlind friend can be done by arranging volunteers to help with tasks such as reading mail, chatting, or shopping. Sauerburger suggested that some areas have organizations that recruit volunteers, or the DeafBlind person can advertise for assistance. I disagree with the author's recommendation about how to obtain assistance, as volunteers are sporadic. This is another example of the critical need for trained and safe SSPs.

Another lesser known symptom that isolation can cause is hallucinations. Over the years Sauerburger (1993) came to know many DeafBlind individuals, seven of which reported experiencing hallucinations. At first Sauerburger attributed this to being a psychiatric problem, but after further investigation found that only two had other symptoms of psychiatric problems that were probably causing the hallucinations and the third had Alzheimer's disease (Sauerburger, 1993). The remaining four had no other

psychiatric symptoms and were all lucid and showed no signs of dementia (Sauerburger 1993). These four individuals were profoundly Deaf and had limited vision, and two were limited to a wheelchair (Sauerburger, 1993). Their hallucinations were most likely caused by isolation and sensory deprivation. According to Slate and Bentall (1998, as cited in Sauerburger, 1993), hallucinations are common among people who are isolated for long periods of time, especially if they are under great stress. Therefore, hallucinations in DeafBlind individuals are not necessarily a sign of psychosis; they may be a symptom of isolation and sensory deprivation (Sauerburger, 1993). Sauerburger visited several DeafBlind individuals in nursing homes who spoke of imaginary situations. One man, in particular, who had frightening hallucinations, obtained a service provider who worked with him to avoid focusing on hallucinations and encouraged him to become more socially involved. This man later got a job and found friends with whom he could easily communicate. As a result, the author reported that the hallucinations diminished until they completely subsided. The author warns readers that some individuals may not want to give up the imaginary world without having a worthwhile alternative in the real world (Sauerburger, 1993). In the end, having hallucinations is one way of coping with isolation, and in some respects, it is a healthy alternative to suffering from the pains of isolation (Sauerburger, 1993). These stories illustrate how important it is for all people to have social opportunities and not be isolated.

Another way SSPs are trained to reduce DeafBlind isolation is to provide as much information as possible and let the DeafBlind person decide what is important.

Sauerburger (1993) wrote about a DeafBlind camper named Geraldine Lawhorn at a camp for the DeafBlind:

Some counselors gave me only important announcements, while those with more insight shared camp news and jokes. When the counselors realized I derived pleasure or benefit from their interpreting, they included me more. One question often asked is, “What can a deaf-blind person get out of it?” We must respond and show our friends that we get a great deal out of life with the right kind of assistance. (Lawhorn, 1991, p. 137 as cited in Sauerburger, 1993, p. 92)

Chou and Chi (2004) conducted a study from a sample of 2,003 elderly Chinese individuals aged 60 or above in order to study depression and its relationship to having a hearing loss, a vision impairment, or a dual sensory impairment. Chou and Chi recognized that the depressive impact that dual sensory loss causes, is understudied and has yet to receive much attention in the literature. Chou and Chi’s findings support the previously discussed research in stating that when analyzing visual impairment, hearing loss and the dual sensory loss, only visual impairment was still significantly related to depressive symptoms. Their findings also supported the statement that the association between visual impairment and depression remains significant and that a hearing loss alone was not. In addition, their key finding was that when comparing a hearing loss, vision loss is a stronger and more persistent risk factor for depression in elderly Chinese adults. It should also be noted that the presence of a hearing impairment does not add to the likelihood of depression when vision impairment is already present (Chou & Chi, 2004). Chou and Chi explained that this may be the case because from the outside, vision impairment is more obvious than a hearing loss. Other researchers (Wallhagen et al., 2001, as cited in Chou & Chi, 2004) have found that the general public views that possessing a hearing loss would not be as bad as having a vision impairment. It should

also be noted that a visual impairment can restrict physical activities to a greater degree than a hearing loss (Chou & Chi, 2004).

Chou and Chi (2004) remind readers of the importance of continued activity in later life in order to maintain positive physical health and social relationships. In accordance with previously stated data, Chou and Chi found that participants who received emotional support from loved ones were less likely to be depressed, concluding that “restrictions in daily activities may exert a detrimental effect on self-perceived health and social support” (p. 826). Chou and Chi’s (2004) research is consistent with the previously reviewed articles. This suggests that across different cultures and ethnicities, there is a connection between vision impairment and depression. It also suggests that a resource for depression prevention is to be involved socially and emotionally with others.

The issue of depression and social isolation relates to the second and third categories in Maslow’s Hierarchy of Needs of psychological security and social needs. Without appropriate supports, a DeafBlind individual may run the risk of suffering from depression as a result of social isolation. Without resolving issues of depression and social isolation, the movement up the hierarchy towards self-actualization is very difficult for any individual.

SSP duties

Theresa Smith (2002) is a versed interpreter in the Seattle community and an avid supporter of the DeafBlind community and service rights. Smith (2002) explained the basic duties of an SSP as well as the origin of the job. The president of the American Association of the Deaf-Blind (AADB), Roderick Macdonald, originally created the term “SSP.” According to Smith (2002), an SSP is a person who provides communication

support, environmental information, mobility support, and possesses at least some fluency in American Sign Language. It is also important to note that similar to sign language interpreters, SSPs do not teach or tutor the DeafBlind individuals (Smith, 2002). Most importantly, SSPs do not make decisions for the DeafBlind individuals (Smith, 2002). SSPs provide the needed information for the DeafBlind individuals so that they can make the decision on their own. People with disabilities frequently feel disempowered by paraprofessionals/caregivers making decisions for them. One of the most important elements in working as an SSP is to let the DeafBlind individual make decisions for themselves. By letting DeafBlind individuals make decisions for themselves results in the individual feeling further empowered.

Schneider et al. (2011) suggested that “services and supports required by people with dual sensory loss are simply a combination of those required by people with single vision and hearing loss, taking account of the unique communication difficulties posed by dual sensory loss” (p. 1). In reading these articles, it was interesting to see that authors did not mention the name Support Service Provider. The concept of Support Service Providing may still be in the developing stages and not be fully accepted as the norm yet.

Schneider et al. (2011) found that more than two-thirds of vision rehabilitation attendees reported communication difficulties when in groups with background noise; communication breakdowns are common among this group and often result in persons feeling offended or isolated. Schneider et al. (2011) also cited Henie and Browning (2004) in that “older people reported needing to exercise intense concentration, experiencing fatigue and anxiety, and disengaging from social contact” (as cited in Schneider et al., 2011, p. 6). “Approximately one in three persons with dual sensory

impairment desired more social activity, compared to one in five of their non-sensory impaired peers” (Schneider et al., 2011, p. 7). Social interaction difficulty and anxiety is something that SSPs can help alleviate by providing basic interpreting and communication services while in these kinds of social environments. Schneider et al. (2011) cited Henie and Browning (2002) in stating that it is evident that a reduction in hearing and sight ability compromises the capacity to gather information about environments and creates barriers to communication that can isolate people, as well as jeopardize independence and well-being (p. 10). In the National Health Interview Study, Schneider et al. (2011) cited that people with dual sensory loss had poorer self-rated health and were more likely to fall and break a hip when compared with individuals without sensory loss (p. 9). Perhaps if SSPs were available to guide these individuals in new locations, the number of falling accidents would decrease.

Danermark and Möller (2008) recognized that every DeafBlind individual is different and possesses varying amounts of residual hearing and/or sight that they depend on. Because of this, “each activity and participation in it needs to be assessed separately. That variation in functioning within each activity, and participation in it, may also be caused by environmental conditions” (p. S120). SSPs are trained to think outside of the box and work to find an accommodating option for the DeafBlind individual. Whether it is simply speaking louder in the individual’s “good ear,” or switching from visual ASL to tactile ASL, SSPs work out ways to find a better fit for the situation. Danermark and Möller also mentioned the importance of tackling barriers to obtaining meaningful and fulfilling social interaction: “Interaction, including communication is one of the most fundamental conditions for social well-being of the developing person” (p. S119). SSPs

can aid this by driving clients to social events and by doing light interpreting. SSPs are trained to be flexible, and as Danermark and Möller (2008) stated, it is important that one should share information with the DeafBlind person in the manner and at the pace they require (p. S121). In the absence of SSPs, the world is ever-changing and can be daunting. They cited Miner (1997), stating that “once a person with deafblindness has adapted to new conditions, almost immediately the conditions start to change again. The lack of predictability is also a constant: There are fears about making choices while facing an uncertain future” (as cited in Danermark & Möller, 2008, p. S121). A document called “Support Service Providers for People who are Deaf-Blind” by Bourquin et al., (2006) described the modern difficulties behind obtaining, recruiting, and paying for SSPs. DeafBlindness is first described by Bourquin et al. (2006) as a person with some amount of loss of sight and hearing that is severe enough to limit the individual’s functions of daily life. The individual may have some residual sight or hearing, but the effect of the combination of dual sensory loss creates a unique need for support to obtain independence (Bourquin et al., 2006). The current objective of an SSP is to strive to be helpful, supportive, empowering, while acting sparing in expressing their personal preferences while performing SSP duties (Bourquin et al., 2006).

A focus group of DeafBlind individuals at the 2006 AADB Conference outlined the most common tasks their SSPs do that assist them and empower them (Bourquin et al., 2006). A wide variety of responses were noted such as shopping, reading mail, attending social, family, sports, and theatrical events, camping, workshops, museum tours, etc. (Bourquin et al., 2006). Specifically, Bourquin et al. noted that SSPs can serve at the workplace by guiding a person to and from meetings, to a restroom, or through a

lunch line during a workshop. SSPs always provide visual and environmental information including, but not limited to, describing who is in a room, what the activity or mood is in the room, reading a menu or print if not legible to the client, providing communication support and minor interpreting, and helping locate items (Bourquin et al., 2006).

Ultimately, SSPs can be of aid to a DeafBlind person in any situation, from the home, to the workplace, the community, and elsewhere (Bourquin et al., 2006).

It is important to note that Bourquin et al. (2006) do mention a list of duties that SSPs should not do. This includes personal care, i.e. bathing and grooming. SSPs should not do errands alone for the DeafBlind person and should not make decisions for them (Bourquin et al., 2006). SSPs are not teachers and they should not interpret in medical, legal, business, or other settings (Bourquin et al., 2006). An SSP who also works as a professional interpreter should be careful to not mix the roles of an SSP and an interpreter (Bourquin et al., 2006). It should also be noted that SSPs do not replace the roles of other professionals such as personal care attendants, interpreters, orientation and mobility specialists, and teachers (Bourquin et al., 2006).

The duties of the modern SSP is described by Bourquin et al. in the following ways: To serve as the eyes and ears for the person who is DeafBlind, and, finally, to provide access to the community by assisting with transportation needs, to relay environmental information that cannot be seen or heard by the DeafBlind individual (Bourquin et al., 2006). One vital element in working as an SSP is to provide enough information for the DeafBlind individual to make an informed decision, but at no point should the SSP make the decision for them (Bourquin et al., 2006).

This paper reminds readers that the phenomenon of an SSP is still not widely known and utilized. At the time of their writing, Bourquin et al. (2006) mentioned that there were only five statewide SSP programs, 14 states with partial SSP programming, which leaves the remaining 31 states with no SSP services for DeafBlind individuals.

Bourquin et al. (2006) emphasized that part of the issue in lack of national SSP services is due to the general unawareness between the roles of an SSP compared with the roles of an interpreter. Interpreters work with people who are hard of hearing, hearing, Deaf, and DeafBlind. SSPs work strictly with individuals who have a combination of hearing and vision loss. Interpreter education has slowly grown to colleges and can culminate in obtaining state and national certification (Bourquin et al., 2006). SSP education is currently much less formal and often taught in workshops or with hand-on experiences within the DeafBlind community (Bourquin et al., 2006). At the time Bourquin's et al., (2006) writing and still today, there is no state certification, national certification, or licensure for SSPs. Interpreters on the other hand are paid based upon their certification and experience level, while SSPs in areas without established programs often volunteer or even barter their services (Bourquin et al., 2006). Both duties share the importance of maintaining confidentiality and remaining impartial (Bourquin et al., 2006). Both the field of interpreting and working as an SSP require the professional to analyze the language of the client and to match their production to better suit the language most readily understood by the client. Language modalities in the DeafBlind community are exceptionally diverse. The most popular modalities include tactile sign language, assistive listening devices, text reading on computer screens, braille communication, as well as a variety of visual signing methods (Bourquin et al., 2006).

Unlike the field of interpreting, SSP also have the responsibility to safely and effectively guide the DeafBlind client through a variety of environments. SSPs work to assist with independence by assisting the DeafBlind individual with shopping, reading mail, etc. (Bourquin et al., 2006)

In many ways, the role and professionalization of SSPs are facing the same challenges that interpreters faced 30 some years ago (Bourquin et al., 2006). Bourquin et al. noted that it is going to require additional time and effort for society to recognize the SSP as a notable and vital profession. Bourquin et al. (2006) reminds the readers to the negative aspects of not having a professionalized and nationally recognized SSP program. In areas that SSP funding is not available, DeafBlind individuals rely on family members and friends to provide SSP support (Bourquin et al., 2006). It is rare that the family and friends providing support have any formal training or is reliable (Bourquin et al., 2006). Many times the DeafBlind individual find themselves feeling that they are a burden or are infringing on others' time (Bourquin et al., 2006). This fear oftentimes results in the DeafBlind individual canceling their plans and not going out, for fear that they are bothering a friend for a ride or assistance. Bourquin et al. (2006) and other authors in this review have noted that such feelings lead to isolation, depression, lower self-worth and frustration for the DeafBlind individual (Bourquin et al., 2006).

Catto (2008) wrote an article in the Western Oregon University Magazine stating that there are currently more than 10,000 children who are DeafBlind across the country, and that fewer than six percent of the DeafBlind children are served by a teacher with the appropriate specialty training. It could be suggested that if SSPs were a mandatory service, similar to how interpreters are required as a result of national legislation, there

would be much more training opportunities available for people who want to work in this field.

The American Association of the Deaf-Blind (AADB) is a non-profit organization whose mission is to aid DeafBlind individuals in achieving their maximum potential through increased independence, productivity, and involvement in their community (AADB, 2010a). In 2005, the AADB conducted two focus groups with DeafBlind individuals; one meeting took place in Virginia and the other in Maryland. The purpose of the focus groups was to hear first-hand from the consumers what issues remained regarding DeafBlind support services. The main issues that were uncovered from these events were the issues of family support, mobility, and social/recreational needs (AADB, 2010c). The brainstorming of these issues was immediately followed with the statement that all of these issues of can be alleviated with the assistance of an SSP (AADB, 2010c). The group agreed that most rely on family or friends to volunteer to assist them with basic needs. The result of this is that the task at hand gets completed, but leaves the DeafBlind individual feeling shame that they had to yet again ask their overburdened family and friends for assistance (AADB, 2010c). One participant from the Virginia focus group stated that she does not like to go shopping with her family, and to avoid problems she will go by herself. With only a few items to purchase it should be a quick trip, but this participant confessed that such a trip typically takes her four to six hours to look and locate the few items (AADB, 2010c). The participant also mentioned that when she cannot find a specific item, she tries to seek aid from an employee. Unfortunately, she and the employee typically struggle to understand each other, which leaves both individuals confused and frustrated (AADB, 2010c). A completely DeafBlind participant

from the Maryland focus group commented that she can take on motherhood without a problem. She confessed that it would be nice to have someone available to communicate visual information about her small child's facial expressions, specifically whether or not they are happy or crying (AADB, 2010c). She commented that other mothers may think seeing these expressions can be annoying, but she would give anything to have that visual information (AADB, 2010c).

The AADB website also provided information from a later Maryland conference in June 2006 that was organized in order to obtain information regarding SSP services. Participants there defined an SSP as a person who provides visual and auditory information about a new environment (AADB 2010b). SSPs can accompany a DeafBlind individual in order to provide communication support and to ultimately provide information to allow the DeafBlind individual to feel aware and empowered (AADB 2010b). SSPs aid in this empowerment by allowing the DeafBlind individual to think for themselves and make their own decisions (AADB, 2010b). The focus group noted that some geographical areas have successfully implemented SSP services and programs such as in Minnesota, Utah, and New York, with other areas such as South Carolina and Florida with no services at all (AADB, 2010b). Across the board it was noted that DeafBlind people expressed the need to have more SSP hours per month and an easier way to access such services. In the end, many participants agreed on a few elements: (1) that at the moment, there are not enough funded SSP entities, and (2) in general there are not enough trained SSPs or a good way to access them. Ultimately, it was agreed that the federal government should allocate funds for SSP services and support SSP training (AADB, 2010b). It was also noted that in order to achieve national funding and service

implementation working as an SSP needs to be recognized as a paid profession, not a volunteer job or a luxury service (AADB, 2010b). Several personal accounts from DeafBlind individuals are posted on the AADB website showing consumer's pleas for further SSP services.

One DeafBlind consumer named Toni Fraser (2010) stated that as her degenerative disease progresses, she still wants to maintain independence as much as possible for as long as possible. Fraser (2010) uses SSP services for reading mail, going out for errands, shopping, recreational activities, even to help dye her hair! Fraiser (2010) feels lucky to have these services, and wishes more states had them as well.

Donald Allis's (2010) personal account is also featured on AADB's website. Allis (2010) was born with Usher syndrome type one and is the founder and president of the Indiana Deaf-Blind Association. Allis (2010) has witnessed many DeafBlind members miss meetings because they cannot afford to hire drivers or SSPs to transport them to these meetings. Allis (2010) recognizes how vital it is to get out and to be a part of the community, and in order for a DeafBlind individual to do that they need better access to interpreters and SSPs.

Stender (2010) gave the following heartfelt statement regarding the impact of SSPs on the AADB website:

I am deaf-blind. I can only see dim and blurry light from the sun. The world is nearly black to me... Some deaf-blind people are very lonely. They sit at home alone all the time. They are very bored. SSPs can help take them to socials, events and deaf-blind camp. Deaf-blind people should be allowed to have fun and meet other people. It is sad when deaf-blind people are left at home with nothing to do.

But SSP's can help so much. With SSPs, deaf-blind people can do many things.
Then we will all be happy.

In consideration of the literature review thus far, there appears to be a clear and consistent pattern between the lack of support services and the deepening social isolation and depression for DeafBlind individuals. It is assumed that increasing available services can positively influence DeafBlind quality of life by providing simple assistance in the areas of social support, social interaction, and transportation. By providing assistance in these areas, it is expected that DeafBlind individuals will move up to higher categories on Maslow's Hierarchy of Needs and ultimately achieve self-actualization. In the coming pages, the methodology, results, and discussion of the research conducted will be discussed.

CHAPTER 3: METHODOLOGY

In this section, the design, population, sample, and data analysis procedures will be discussed

Design of the Investigation

This research was conducted with two online surveys utilizing SurveyMonkey. One survey was designed for DeafBlind individuals with SSPs, and the other survey was for DeafBlind individuals without SSPs. The two surveys asked similar questions in order to compare the results and identify which group has a larger number of positive responses, thus identifying which group has 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 national 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 majority of the questions asked the respondents to respond "Never," "Seldom," "Quite often," "Very often," or "Always" according to the frequency with which they experience the situation described by the prompt. The last two questions on both surveys were "Yes" or "No" response with the option to select "Other" and to type in the box below to specify.

The DeafBlind individuals surveyed in this study were adults over the age of 18. The reason for using a survey designed for children was based upon patterns of language usage in the target population. Some Deaf adults possess reading and writing skills that do not match their age and grade level of their hearing peers (Dyer, MacSweeney, Szczerbinski, Green, & Campbell, 2003). Seaborn, Andrews, and Martin (2010) wrote that for this reason, police departments have copies of the Miranda Rights Warning written at fourth to ninth grade reading levels to provide flexibility and accessibility in the written version for as many Deaf community members as possible. Though little, if any, research is available specific to the reading level of DeafBlind individuals, as members of the larger Deaf community, I decided to use an instrument that had a more universally accessible reading level. As there are very few quality of life surveys available for adults that are written at a third-grade reading level, KIDSCREEN's (2004) youth survey was used. This study is not concerned with the educational history of its respondents or their second language comprehension. With that in mind, one of the overall goals in this research was to gather the quality of life data while doing everything possible to ensure that the survey was as accessible as possible to as many DeafBlind respondents as possible.

Population

The target population for this research is DeafBlind individuals who culturally identify themselves as being "DeafBlind." The term "DeafBlind" is an encompassing identifier that indicates at least some combination of a hearing loss and vision loss. This combination of vision and hearing loss is caused by a variety of diseases and affects each DeafBlind person differently. This study targeted DeafBlind individuals regardless of

their level of residual hearing and vision ability and aimed to survey the needs of the DeafBlind population as a general group.

The principal researcher contacted a variety of agencies serving DeafBlind individuals and requested that they send the survey links to their rosters of the DeafBlind individuals they serve. Organizations that were contacted during the outreach process of spreading the survey included: American Association of the DeafBlind, DeafBlind Services Minnesota, South Carolina Commission for the Blind, State of New Jersey Department of Human Services Commission for the Blind and Visually Impaired, Health and Human Services - The Massachusetts, DeafBlind Autonomy Facebook Page, Seabeck DeafBlind Camp Facebook Page. All of the Helen Keller National Centers (HKNC), including, HKNC Region 1: New England, HKNC Region 2: Mid-Atlantic, HKNC Region 3: East Central, HKNC Region 4: Southwest, HKNC Region 5: North Central, HKNC Region 6: South Central, HKNC Region 7: Great Plains, HKNC Region 8: Rocky Mountain, HKNC Region 9: Southwest, and HKNC Region 10: Northwest. Many of the contacted representatives replied and offered to share the survey with other related organizations.

The largest service agency contacted in the distribution of this survey was the HKNC regional centers. HKNC serves DeafBlind individuals who have an array of hearing and vision abilities caused by a variety of diseases. Since this survey reached a variety of individuals in the DeafBlind community, it is safe to assume that this survey represents the general DeafBlind community, not one specific niche of the DeafBlind population. This study possesses high external validity because of the variety of DeafBlind individuals it reached.

This study possesses sound internal validity. Studies run into issues with internal validity because of history, mortality, and instrumentation. History issues occur when one group responds at a much earlier time than another group. This poses a problem if something tragic happens before one group responds but not the other. This research avoided issues with history by opening both surveys at the same time for the same duration. Mortality issues occur in research when a large number of participants from one group drop out of a study, therefore skewing the results by having one group overrepresented and another group underrepresented. This study avoided mortality issues by having equal number of respondents in both surveys. Instrumentation issues occur in research when the measurement or survey tools are not similar. This study addressed this issue by using the same instrument tool, same consent, same directions, and the same survey questions with the exception of the last two questions (see Appendix A for survey consent form). The last two questions are specific to each group regarding their services or their lack of services.

Sample

Individuals were invited to participate through various DeafBlind service agencies. I, the principal investigator, contacted these agencies and asked them to distribute the links to the surveys to their rosters of DeafBlind individuals. The survey links were also shared on a variety of Facebook pages. It was posted on “DeafBlind Autonomy’s” page and the “DeafBlind Member Section (DBMS) of Registry of Interpreters for the Deaf” page. After the initial posting, the links spread wider as individuals shared the link on their own personal pages. The DeafBlind individuals who

actually participated in the survey self-identified the survey group they qualified for and therefore which version of the survey they should complete.

Data Analysis Procedures

The data were studied using SurveyMonkey's analytics feature. In this feature, each question is broken down showing what percentage of the population marked which option. On the analysis feature, there is a bar graph showing the results of each answer. The type of data that was collected in this research was quantitative. The individuals would read each question and choose 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."

CHAPTER 4: RESULTS AND DISCUSSION

The following section shows the results from the two surveyed groups while comparing and contrasting the rate of their positive and negative responses.

Results

A total of 55 DeafBlind individuals participated in this online study. 27 filled out the survey for DeafBlind individuals with SSPs, and the other 28 filled out the other survey for DeafBlind individuals without SSPs. The two surveys were identical with the exception of numbers 26 and 27. These questions asked the participants specific questions about their situation in living with or without SSPs.

The following results have been organized in terms of topic, not by the question number in which they appeared in the survey. The goal in doing this was to identify possible trends in similar categories regarding the quality of life for both groups. Responses are categorized as positive or negative as they relate to quality of life and are explained in more detail in each section. With the exception of questions 26 and 27, all responses are categorized on three different 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. Therefore, the overall positive results of “Always,” “Very often” and “Quite often” were added to calculate the total positive percentage for the question. In the same manner, the overall negative responses were calculated by adding up the totals in the “Seldom” and “Never” categories. 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.”

Transportation

One of the most important services SSPs offer is transportation. The impact of this element is made clear by question 22, which asked, “Have you been able to go places when you want?” By adding up the positive responses “Always,” “Very often,” and “Quite often,” 60% of individuals with SSPs can often go where they want (see Figure 1). Conversely, only about 39% of individuals without SSPs are often able to get where they want to go (see Figure 1).

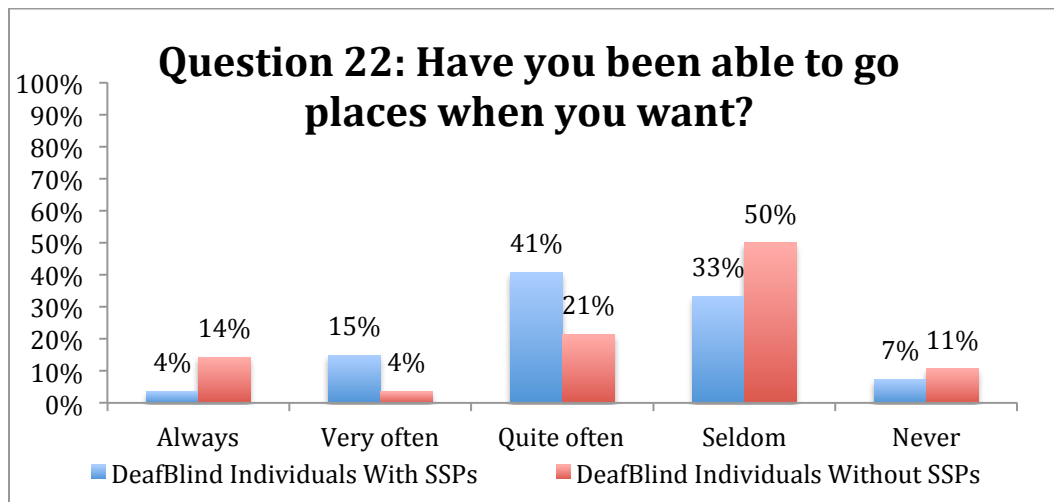


Figure 1. Have you been able to go places when you want?

Questions 23 and 24 have very similar response rates for both groups. Question 23 asked, “Are you able to go to the store when you want?” Of the DeafBlind Individuals with SSPs, 67% responded at a positive rate (Always, Very often, Quite often) indicating that they are able to go to the store when they want. Similarly, 64% of DeafBlind individuals without SSPs also responded positively to this question. The negative response rates (Never, Seldom) to this question were again similar between the two groups. The negative response rate for DeafBlind individuals with SSPs was at 34%, and DeafBlind individuals without SSPs at 35%. So it would seem that regardless of working with an SSP, around 35% of DeafBlind individuals from both groups are still unable to go to the store when they please.

Similarly, question 24 asked, “Does your transportation options help you feel independent?” With SSPs positive response rate was at 63% and individuals without SSPs positive response rate was at 49%. This indicates that individuals with SSPs are more likely to say that their transportation options help them feel more independent. The negative response rate for individuals with SSPs was at 37%, and the without SSPs’ negative response rate was at 52%. This negative response rate again shows the individuals with SSPs having an upper hand in that they are less likely to indicate that their transportation options do not help them feel independent.

Question 25 asked “Do you feel safe walking to your destinations?” This evoked a variety of responses without showing a particular trend. DeafBlind individuals with SSPs responded at a positive rate (Always, Very often, Quite often) at 52%, and DeafBlind individuals without SSPs positive response rate at 59% (see Figure 2). The negative response rate for DeafBlind individuals with SSPs was at 48% and DeafBlind

individuals without SSPs at 46% (see Figure 2). The positive and negative responses for both groups are pretty evenly divided between the two groups. The vital statistic in this situation that may need attention is that nearly half the DeafBlind individuals from both groups indicated that they feel unsafe walking to their destinations.

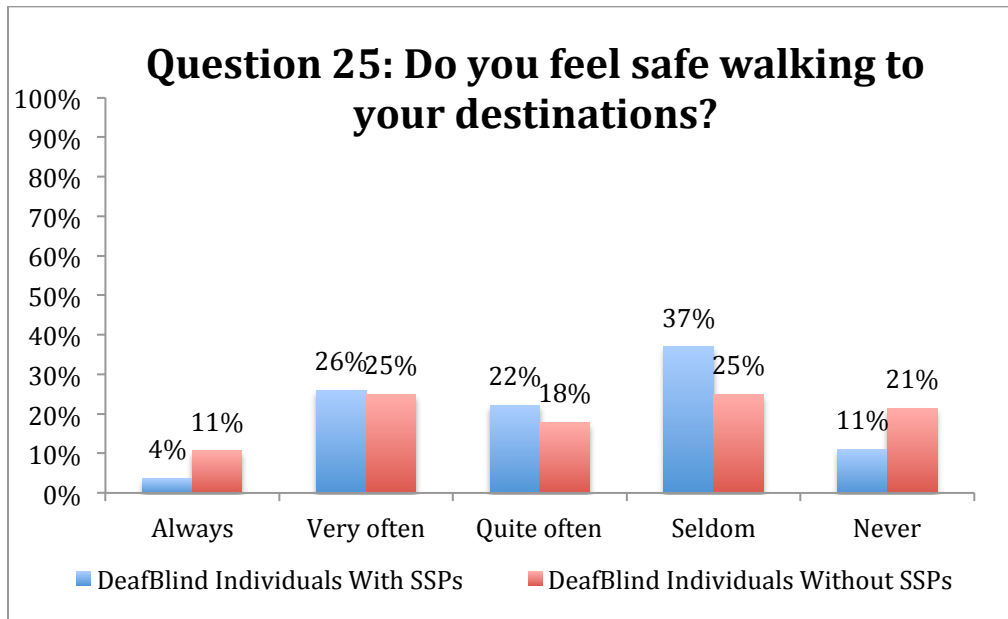


Figure 2. Do you feel safe walking to your destinations?

Specifically for individuals without SSPs, question 26 asked, “Do you feel you have enough access to transportation?” Responses to this question in each category varied minimally, which might be due to the inconsistency of availability of public transportation (see Figure 3).

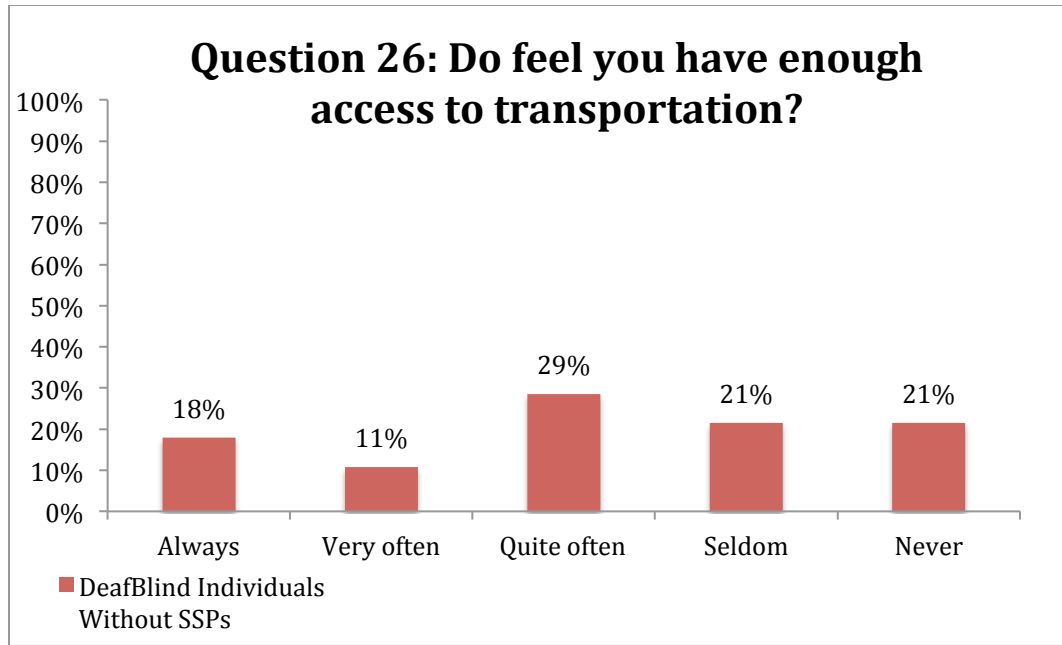


Figure 3. Do you feel you have enough access to transportation?

Time

The response to question 11, “Have you had enough time for yourself” had individuals with SSPs responding “Seldom” at 7%, and “Quite often” at 29%. The individuals without SSPs responded “Seldom” at 0%, and “Quite often” at 54%.

Individuals without SSPs only get to travel when public transportation is available or when a volunteer steps forward. This is drastically different than DeafBlind individuals who have an allotted amount of time with an SSP each month to travel and complete errands. A follow up question to this response could be “Have you had enough time to do errands?” “Have you had too much time to yourself?” or even “Have you had so much time to yourself that you feel isolated?”

Question 12 asked “Have you been able to do all the things that you want in your free time?” Adding up the positive responses (Always, Very often, Quite often), 71% of the individuals with SSPs have been able to do the things that they want in their free time

as compared to 47% of the DeafBlind individuals without SSPs (see Figure 4). The *negative response rate (Seldom and Never)* to this question had individuals with SSPs responding at 29% and DeafBlind individuals with SSPs responding at 53%.

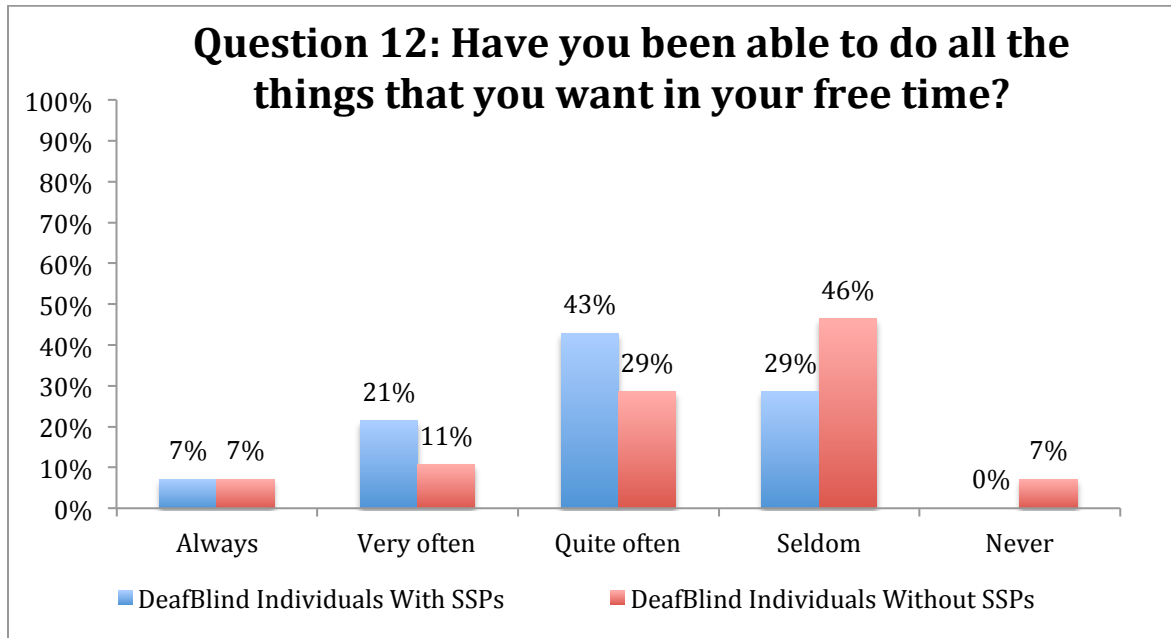


Figure 4. Have you been able to do all the things that you want in your free time?

Family and Friends

Question 13 asked “Has your family had enough time for you?” To this question, 53% of DeafBlind individuals with SSPs responded at a positive response rate (Always, Very often, Quite often). DeafBlind individuals without SSPs’ positive response rate was at 64%. DeafBlind individuals with SSPs negative response rate (Never, Seldom) was at 64%. DeafBlind individuals without SSPs negative response rate was slightly less severe at 36%.

Question 14 elicited a similar rate of positive responses for both groups in asking, “Has your family treated you fairly?” Respondents with SSPs answered at a 73% positive rate to this question; similarly, DeafBlind individuals without SSPs responded positively

at 76% (see Figure 5). DeafBlind individuals with SSPs responded negatively at 27%.

DeafBlind individuals without SSPs had a negative response rate at 25% (see Figure 5).

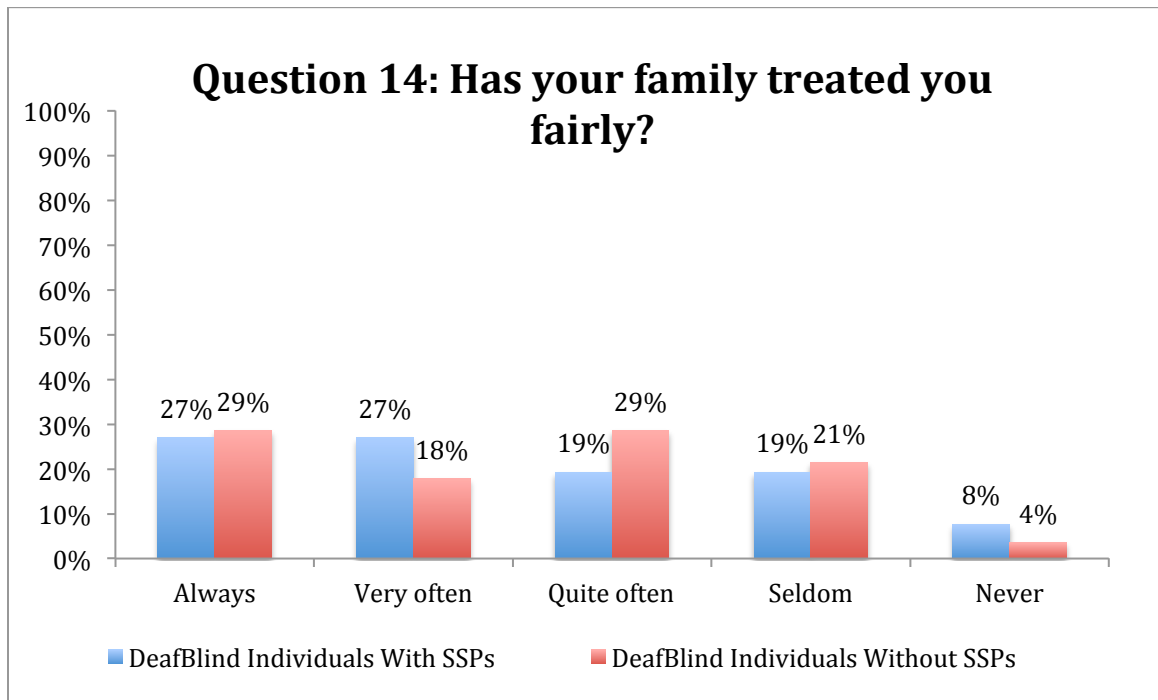


Figure 5. Has your family treated you fairly?

Question 15 asked, “Have you been able to talk to your parents when you wanted?” Individuals with SSPs responded at only a slightly higher positive rate compared to the group without SSPs. The individuals without SSPs responded “Never” similarly to the other group at a rate of 8% (see Figure 6). DeafBlind individuals with SSPs had a higher positive rate (Always, Very often, Quite often) of response totaling 82%, as compared to the DeafBlind individuals without SSPs totaling at 69% (see Figure 6).

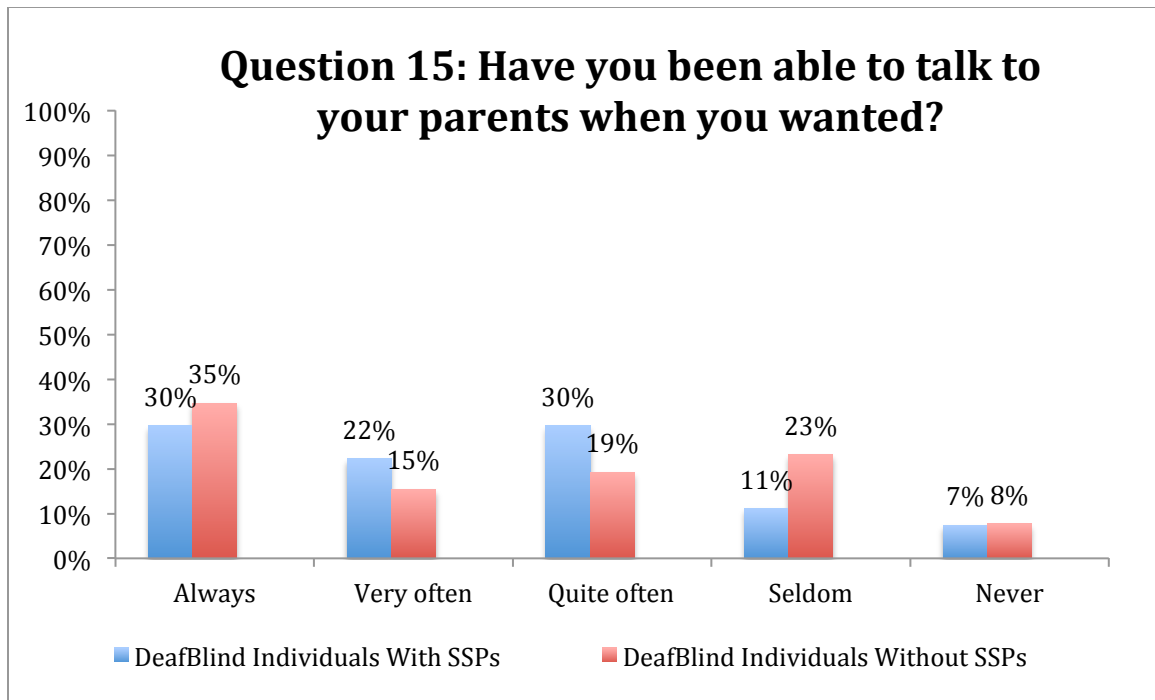


Figure 6. “Have you been able to talk to your parents when you wanted?”

The responses to question 18, which asked “Have you spent enough time with your friends?,” evoked drastically different responses between the two groups. DeafBlind individuals with SSPs positive rate is significantly larger than the DeafBlind individuals without SSPs. Individuals with SSPs totaled a positive response rate at 52% (“Always,” “Very often,” “Quite often”), as compared to DeafBlind individuals without SSPs at 15% (see Figure 7). The negative responses (“Seldom,” “Never”) are equally significant, showing DeafBlind individuals with SSPs responding at a rate of 48% compared to DeafBlind individuals without SSPs at 86% (see Figure 7).

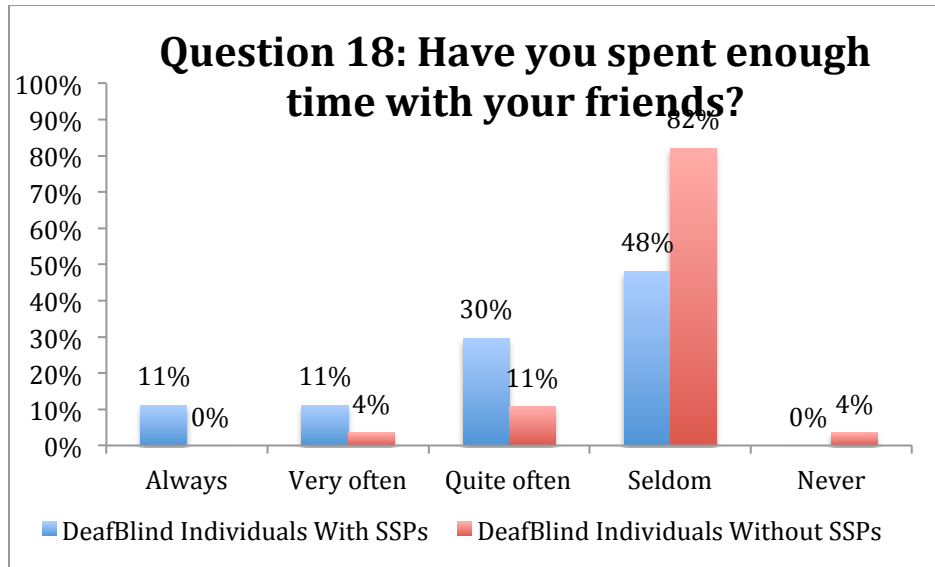


Figure 7. Have you spent enough time with your friends?

Question 19 asked, “Have you had fun with your friends?” Individuals with SSPs responded “Never” at 0% (see Figure 8), compared to individuals without SSPs stating “Never” at 7% (see Figure 7). This question had individuals with SSPs responding at a more positive rate of 81% as compared to the individuals without SSPs responding at 61% (see Figure 8).

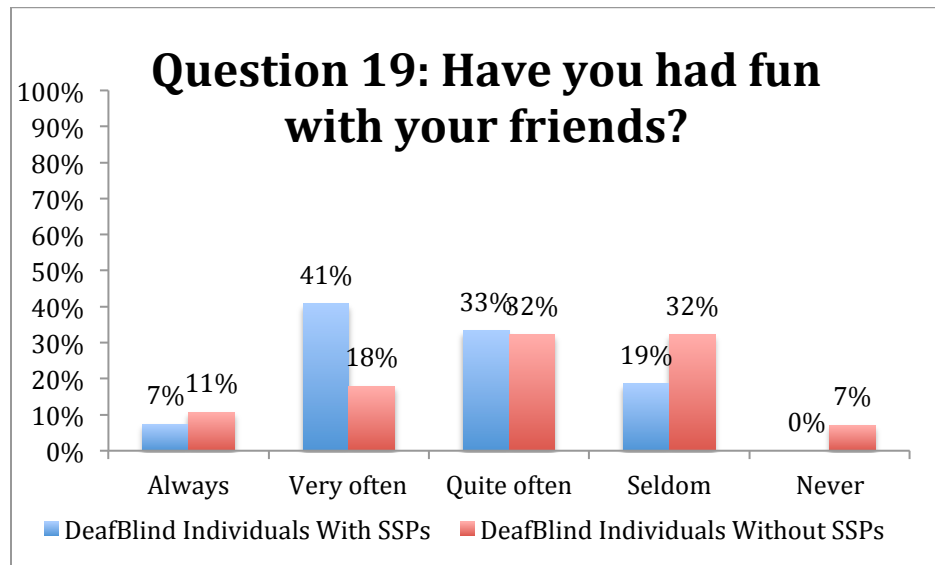


Figure 8. Have you had fun with your friends?

Questions 20 and 21 asked similar questions. Question 20 asked, “Have you and your friends helped each other?” and question 21 asked, “Have you been able to rely on your friends?” These questions again evoked a higher rate of positive responses for the group with SSPs than for the group without SSPs. In question 20, individuals with SSPs had a positive response rate (Always, Very often, Quite often) of 77%, and Individuals without SSPs’ positive response rate was 54% (see Figure 9). The negative response rate is just as stark. The negative response rate (Seldom, Never) for DeafBlind individuals with SSPs total at 23%, and DeafBlind individuals without SSPs double that rate at 46% (see Figure 9). Question 21, “Have you been able to rely on your friends,” had individuals with SSPs exhibiting a positive response rate (Always, Very often, Quite often) at 59%. Conversely, DeafBlind individuals without SSPs positive response rate only totaled to 32% (see Figure 10). The negative response rate (Seldom, Never) is just as telling with DeafBlind individuals with SSPs at 41%, and DeafBlind individuals without SSPs at 68% (see Figure 10).

Overall these questions illustrates overall trend of low positivity related to social and fun time spent with friends, and again, a higher percentage of negative responses for the group of DeafBlind individuals without SSPs.

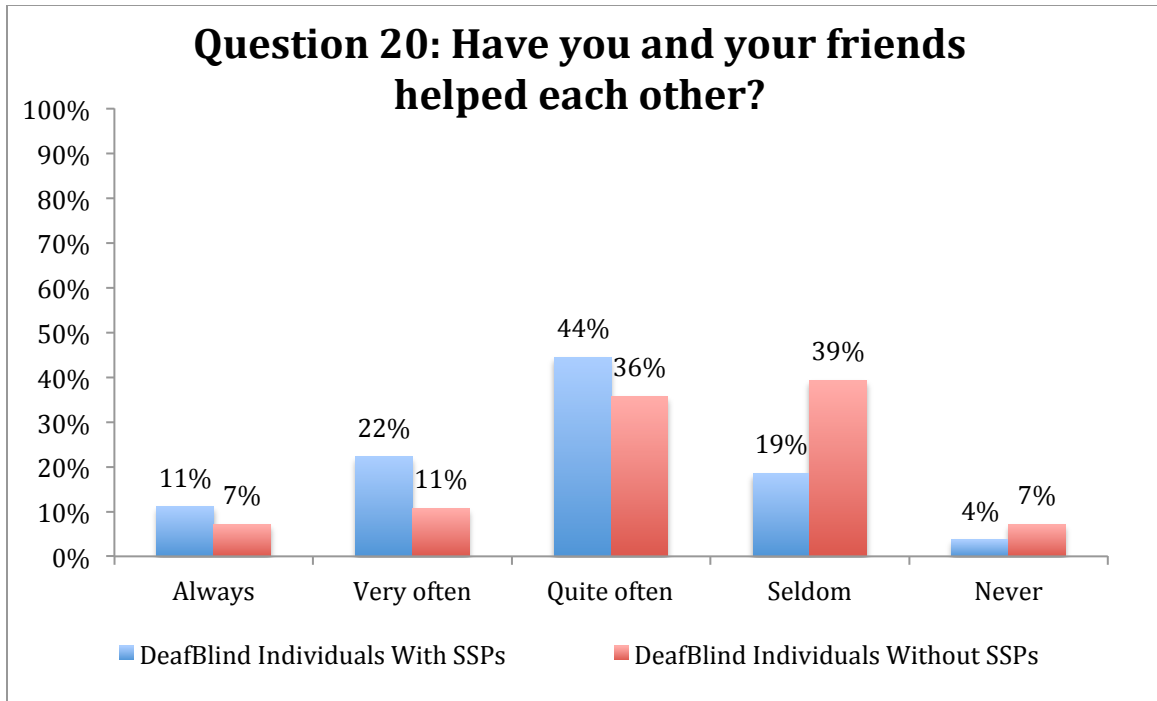


Figure 9. Have you and your friends helped each other?

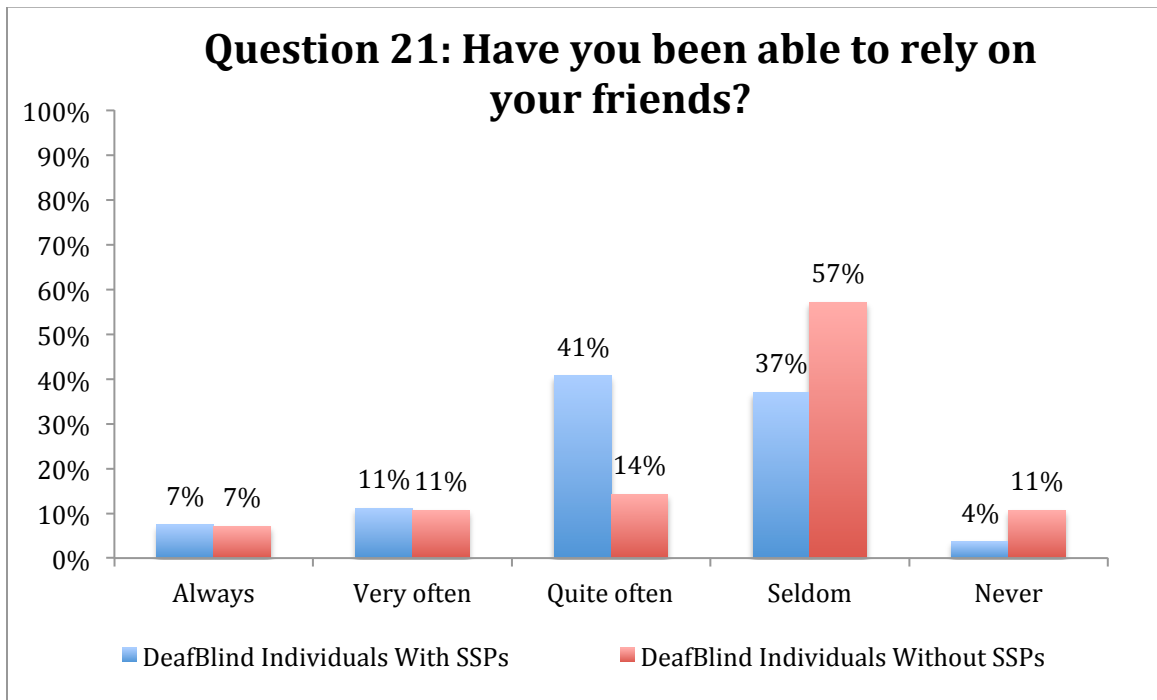


Figure 10. Have you been able to rely on your friends?

Emotional Health

Question 4 asked “Has your life been enjoyable?” Of the respondents with SSPs 43% said “Very” (see Figure 11). In comparison, only 18% of individuals without SSPs responded that their life has been “Very” enjoyable (see Figure 11). The selections of “Very” and “Extremely” have been combined to represent the overall positive rate of response to this question. Individuals with SSPs responded at a positive rate of 57% as compared to individuals without SSPs responding at less than half the rate at 25%. It also must be noted that 4% of DeafBlind individuals without SSPs noted that their life has “Not at all” been enjoyable. No one from the group of DeafBlind individuals with SSPs marked this most negative option as a response at all.

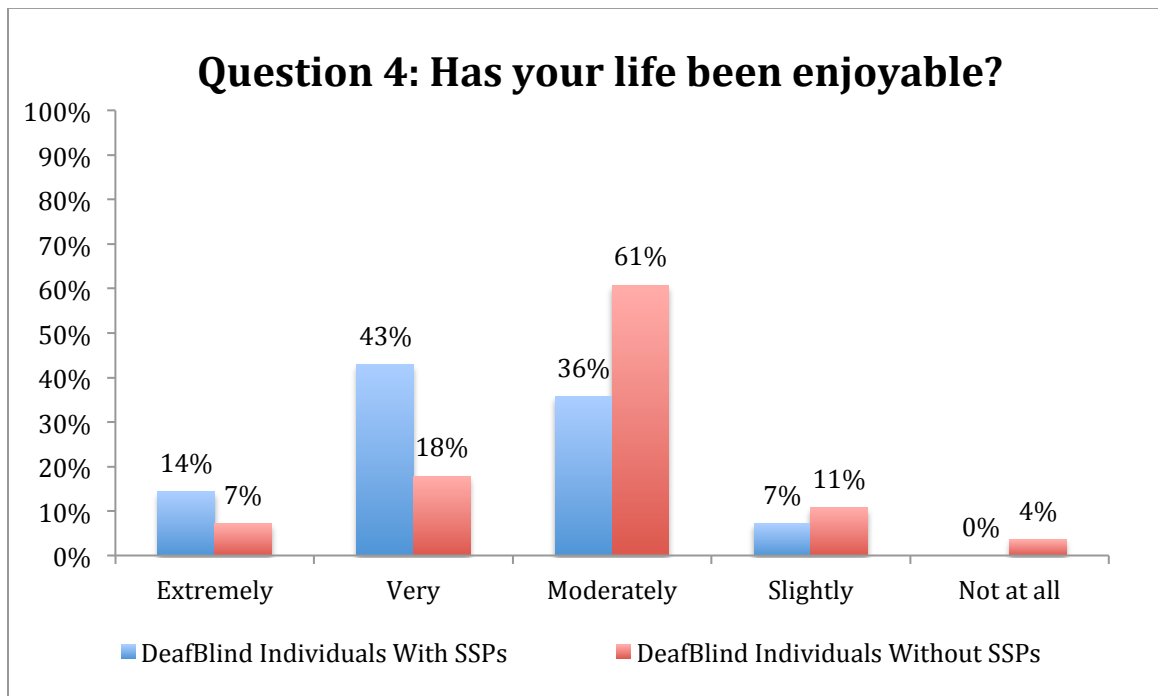


Figure 11. Has your life been enjoyable?

Questions 5 and 6 asked, “Have you been in a good mood,” and “Have you had fun?” Results were similar for both groups.

Question 7 simply asked, “Have you felt sad?” Individuals with SSPs responded at a more positive rate by selecting “Seldom” and “Never” at 64%, as compared to the individuals without SSPs responding at a lower rate of 43% (see Figure 12). Even more telling is the negative response rate calculated by adding the responses in the “Always,” “Very often,” and “Quite often” categories. Individuals with SSPs totaled a negative response rate of 36%, as compared to DeafBlind individuals without SSPs at 58% (see Figure 12).

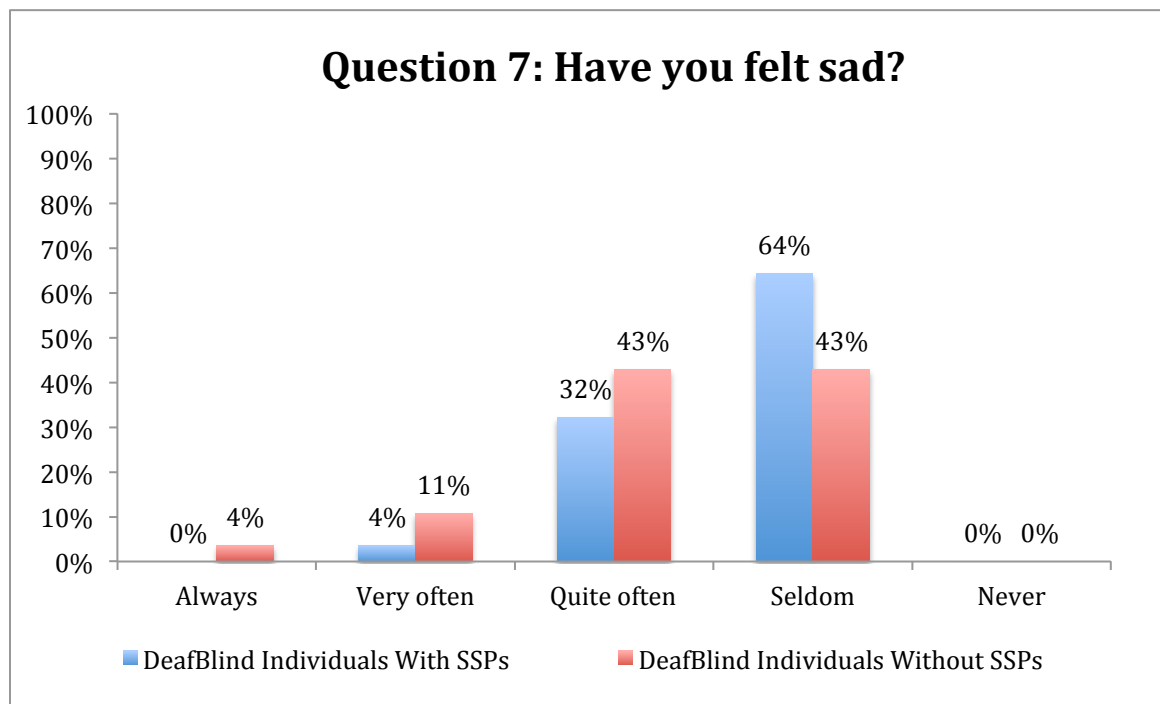


Figure 12. Have you felt sad?

Question 8 asked “Have you felt so bad that you didn’t want to do anything?” Negative responses were calculated in this question by adding the scores from “Always,” “Very often,” and “Quite often.” Individuals with SSPs had a negative rate of 21%, as compared to DeafBlind individuals without SSPs at 47% (see Figure 13). Four percent of DeafBlind individuals without SSPs marked the most negative response that they have

“Always” felt so bad that they didn’t want to do anything. This most negative response was not selected at all for the DeafBlind individuals with SSPs.

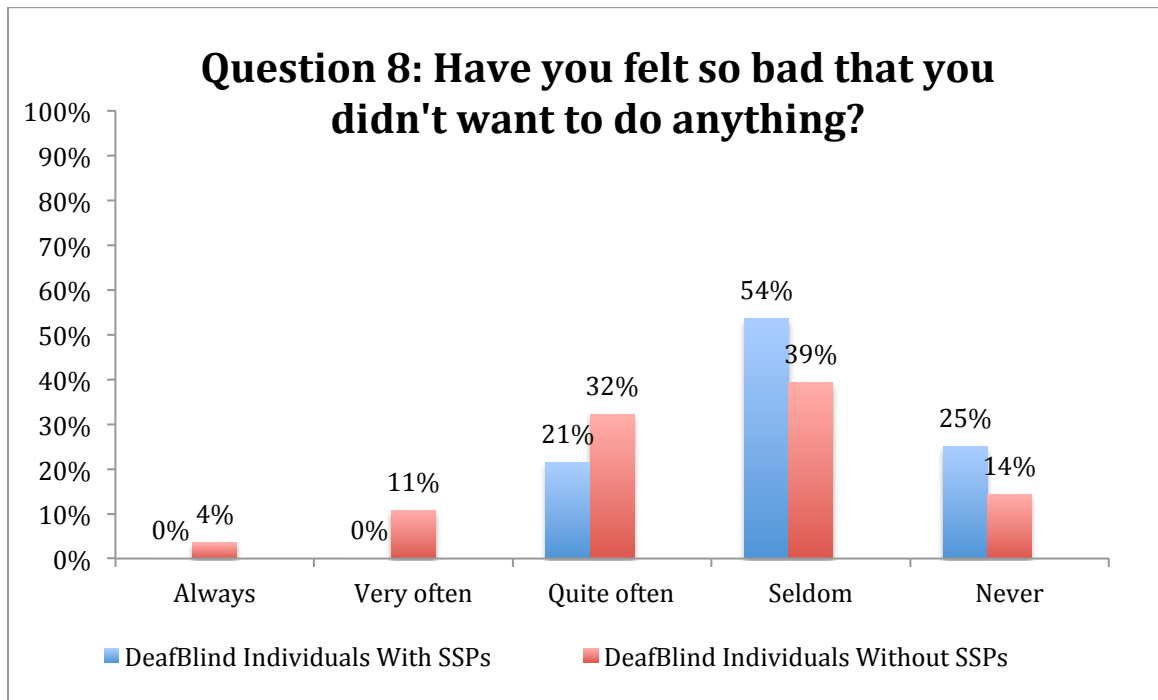


Figure 13. Have you felt so bad that you didn't want to do anything?

Question 9 asked “Have you felt lonely?” The results for both groups were similar. This suggests that that the phenomenon of living as a DeafBlind individual can be a lonely experience, whether or not they have an SSP. Although there are many factors involved in the isolation of DeafBlind individuals, this research suggests that it can be improved by increasing services.

Responses for question 10, “Have you been happy with the way you are?,” differ drastically between the two groups. The most staggering difference in this category is the response of “Seldom” (see Figure 14). Nearly one-third (32%) of individuals without SSPs indicated this answered this, as compared to 7% of individuals with SSPs (see Figure 14). The positive responses (Always, Very often, Quite often) to this question had

DeafBlind individuals responding at 92% as compared to DeafBlind individuals without SSPs at 61% (see Figure 14). The negative responses (Seldom, Never) to this question are drastic as well. The negative responses for the DeafBlind individuals with SSPs total a mere 7%, as compared to the DeafBlind individuals without SSPs at 39% (see Figure 14).

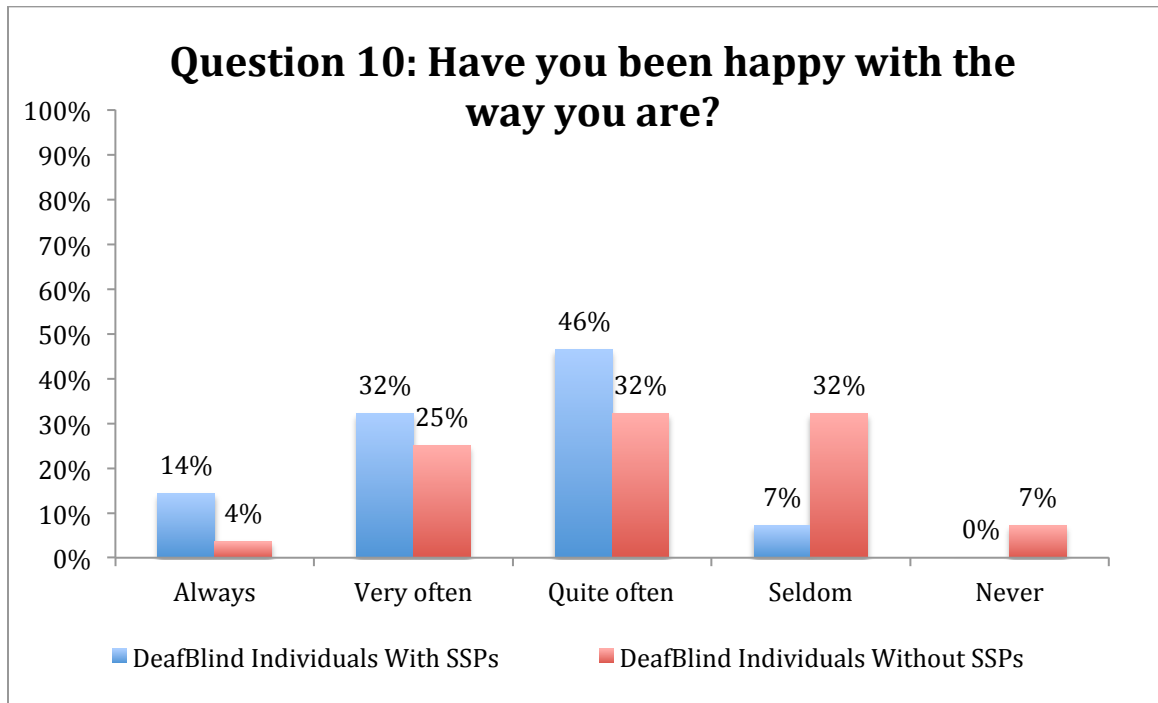


Figure 14. Have you been happy with the way you are?

Health

Question 1, “In general, how would you say your health is?,” featured DeafBlind individuals with SSPs possessing a greater response of “Excellent” at 36% (see Figure 15). Individuals without SSPs responded with “Excellent” at a rate of 14% (see Figure 15). No respondents with SSPs said their overall health was “Poor,” but 7% of the respondents without SSPs responded that their health is poor (see Figure 15). The overall negative response rate (Fair, Poor) for DeafBlind individuals with SSPs totaled 4%, while the negative response rate for DeafBlind individuals without SSPs totaled 28%.

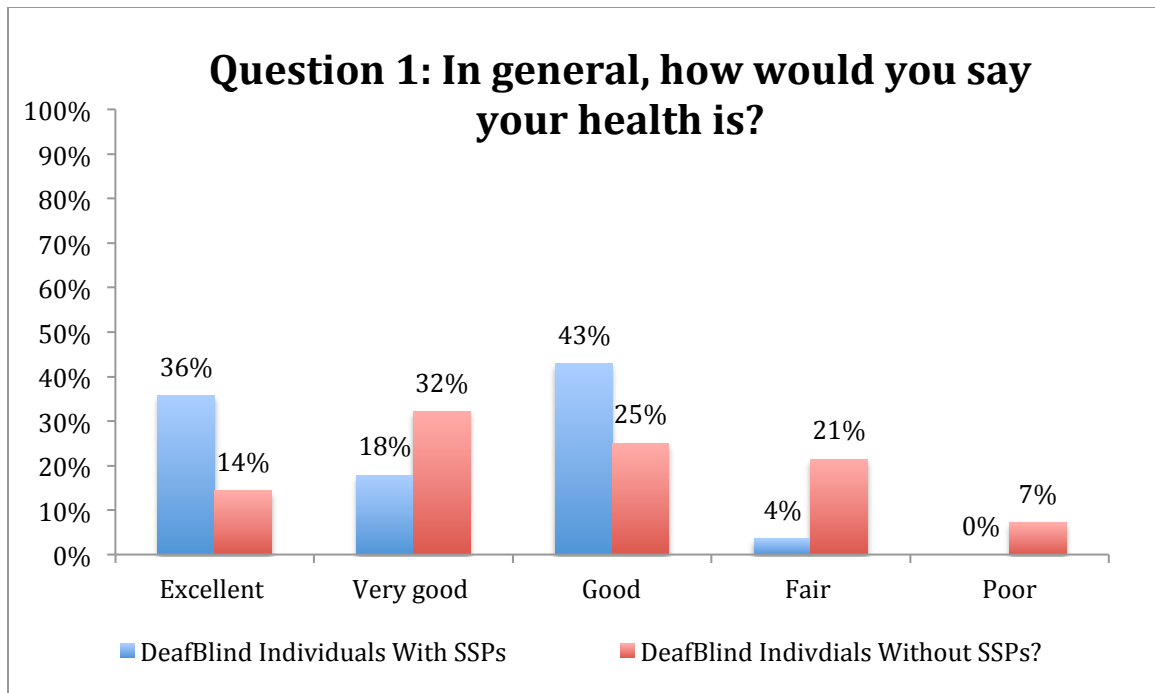


Figure 15. In general, how would you say your health is?

Responses were similar for question 2, which asked “Have you felt fit and well?” with the exception of the response of “Extremely.” Individuals with SSPs responded that they felt “Extremely” fit and well at a rate of 15% (see Figure 16). Zero individuals without SSPs gave the rate of feeling “Extremely” fit and well. The overall positive (“Extremely,” “Very,” “Moderately”) and negative (“Slightly,” “Not at all”) responses were similar for both groups.

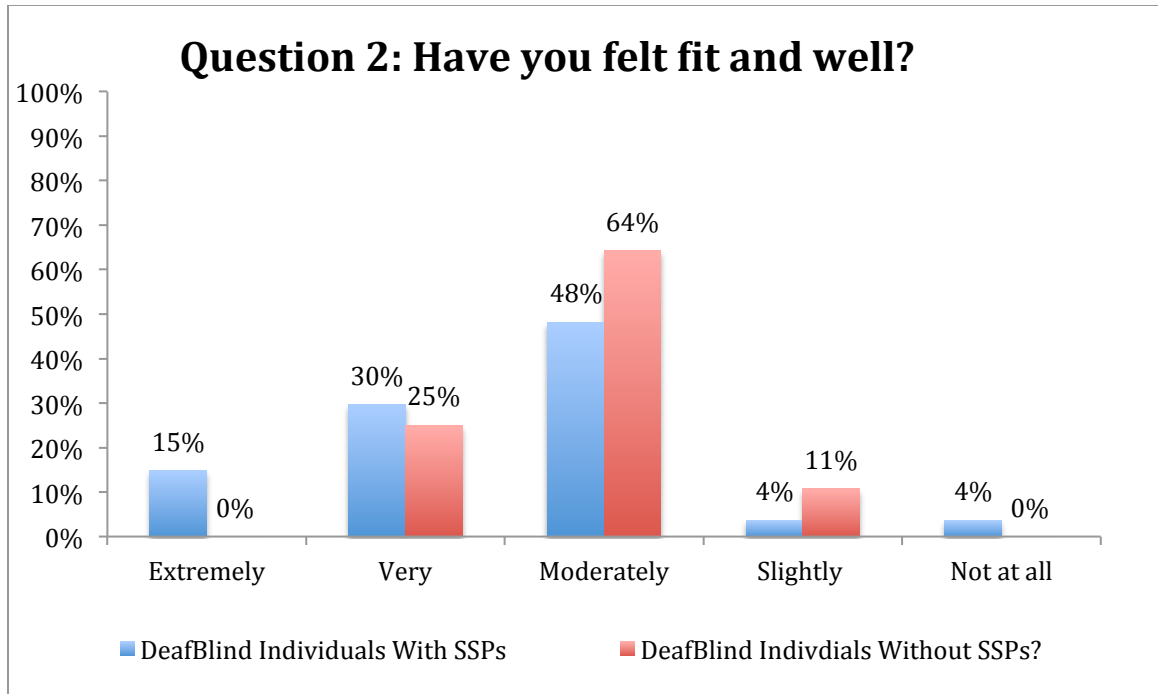


Figure 16. Have you felt fit and well?

Individuals with SSPs responded to question 3, which asked “Have you felt full of energy?,” with “Seldom” at 11% (see Figure 17), while the individuals without SSPs responded “Seldom” at 50% (see Figure 17). Respondents with SSPs responded “Very often” to feeling full of energy at 39%, while only 14% respondents without SSPs felt this way. Adding up the “Always,” “Very often,” and “Quite often,” responses calculated the positive responses for this question. The positive rate for individuals with SSPs came to 89%, while individuals without SSPs came to 50%.

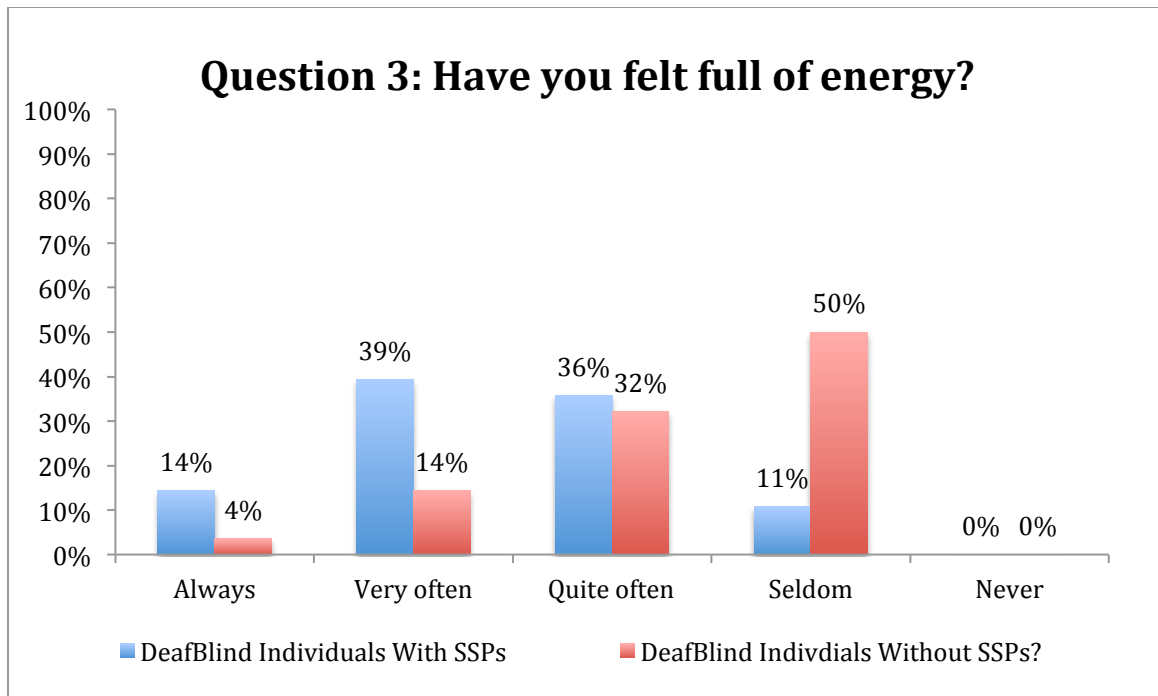


Figure 17. Have you felt full of energy?

Money

The responses for question number 16, “Have you had enough money to do the same things as your friends?,” are thought provoking. The positive response rate (“Always,” “Very often” “Quite often”) for DeafBlind individuals with SSPs totaled at 60% while DeafBlind individuals without SSPs totaled 33% (see Figure 18). Conversely, the negative response rate (“Seldom,” “Never”) elicited interesting statistics (see Figure 18). Of DeafBlind individuals with SSPs, 41% felt they typically didn’t have enough money to do the same things as their friends, as compared to 68% of DeafBlind individuals without SSPs.

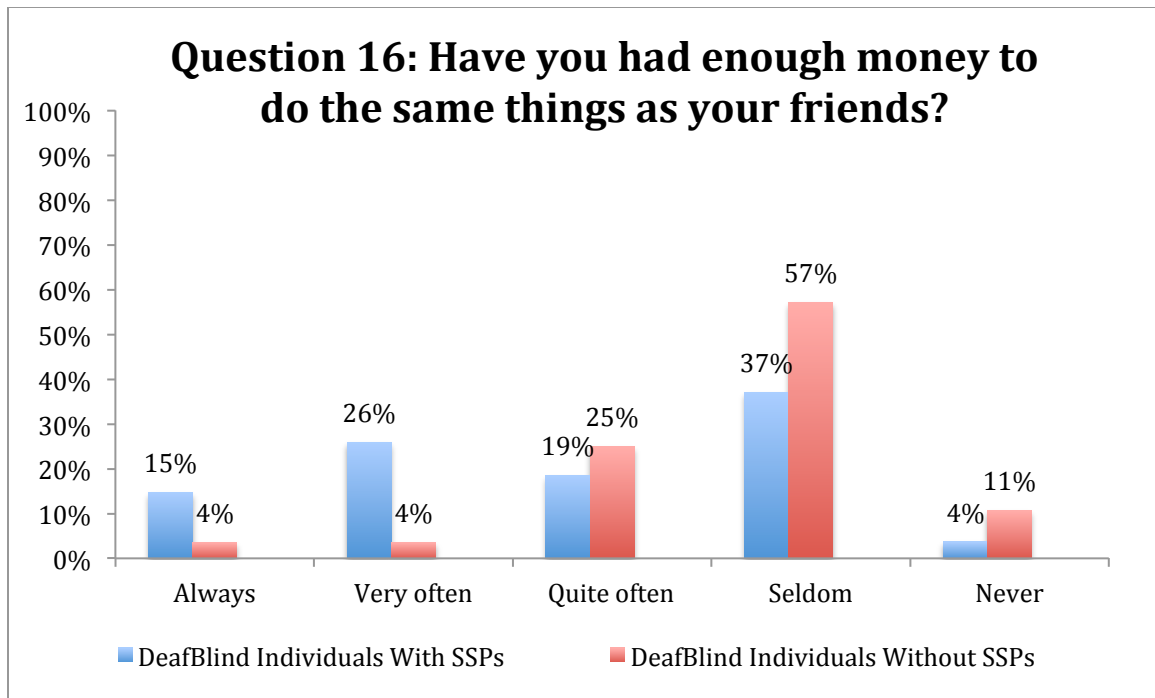


Figure 18. Have you had enough money to do the same things as your friends?

“Have you had enough money for your expenses?” was asked in question number 17. Again, the DeafBlind individuals with SSPs possessed a higher positive rate (“Always,” “Very often,” “Often) of response in regard to finances (see Figure 19). More than two-thirds (70%) of DeafBlind individuals with SSPs totaled a positive response of having enough money for their expenses, as compared to 54% of DeafBlind individuals without SSPs (see Figure 19).

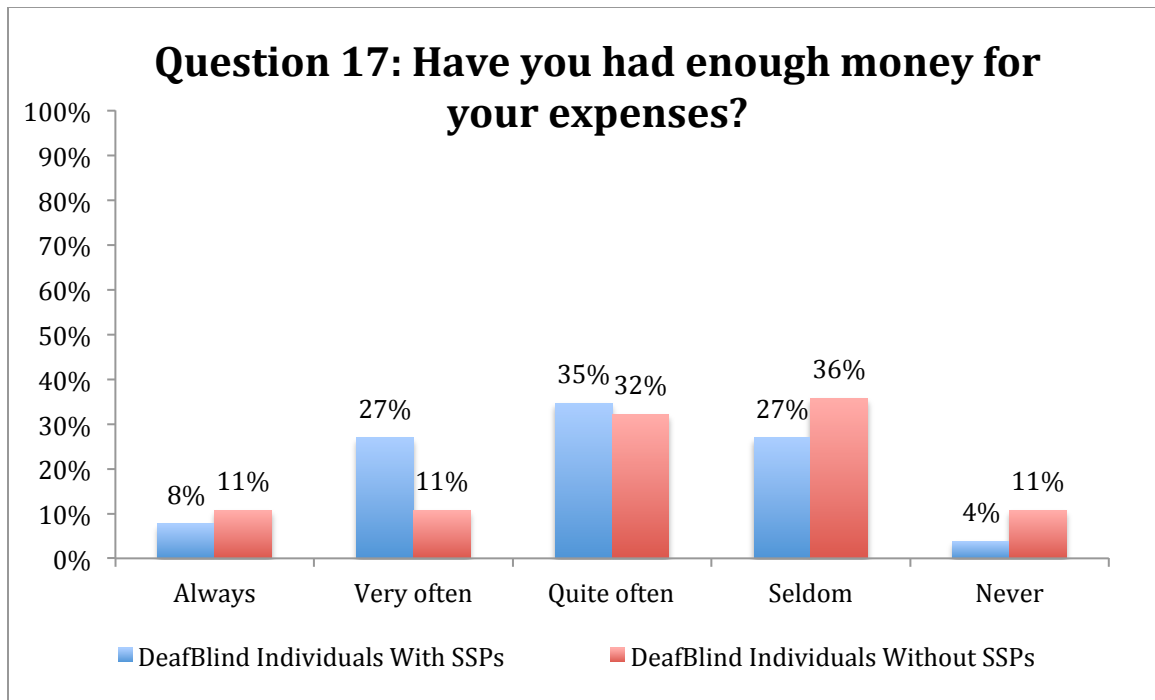


Figure 19. Have you had enough money for your expenses?

SSP Services

At questions 26 and 27, the groups were asked different questions. Both questions 26 and 27 for DeafBlind individuals with SSPs' questions were regarding SSP services that they were currently receiving. Question 27 for DeafBlind individuals without SSPs was related to the topic of SSP services as well.

Question 26 for the individuals with SSPs asked, "Do you want more Support Service Provider hours?" To this question, 52% responded "Yes," 15% responded "No," and 33% responded "Other" (see Figure 20). In a comment box one respondent typed this 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 response 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 by the fact that they may not have to choose a home based on the availability of the public transportation system or by an area that has pre-existing services available. The frustration with bus services suddenly becoming unavailable is a fear expressed by the individual's response above. This respondent's comment suggests that their "caregiver" provides similar services that SSPs do. It is not mentioned if this caregiver is someone who is fluent in the DeafBlind person's language preferences or if they have training in DeafBlind culture, guiding, visual description, and communication support.

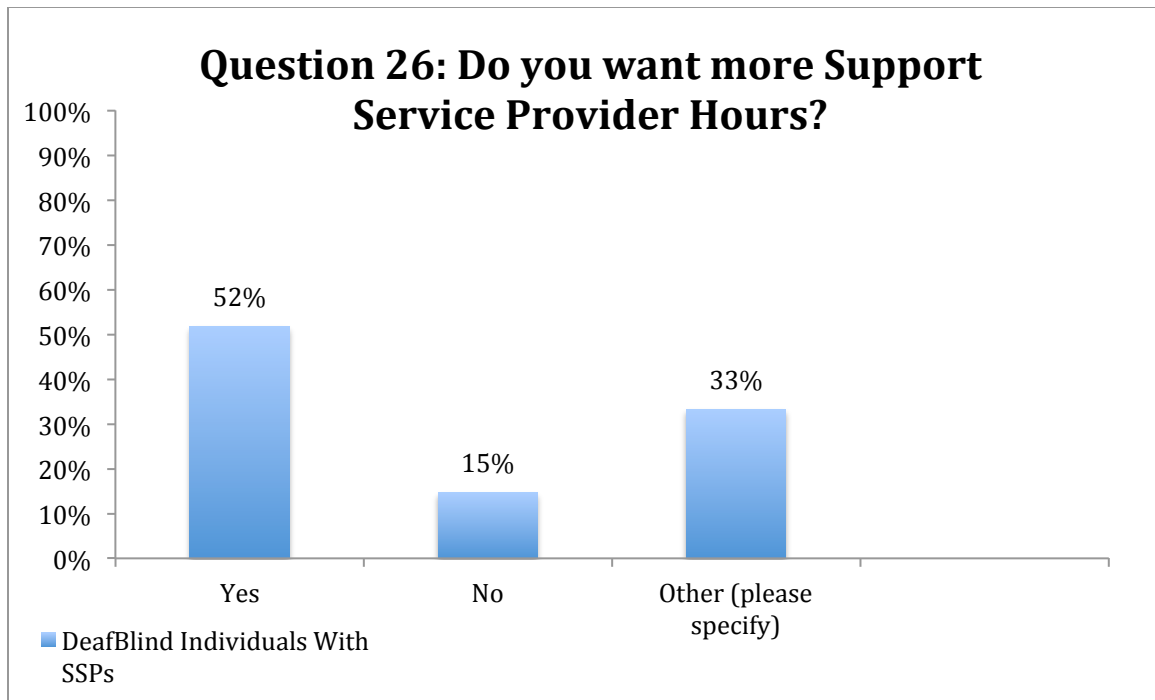


Figure 20. Do you want more SSP hours?

Question 27 for DeafBlind individuals with SSPs

The responses for question 27 for individuals with SSPs demonstrated why specifically trained SSPs have a positive impact in providing assistance. The question asked, “Does having a Support Service Provider increase your feelings of independence and freedom?” To this question, 70% of individuals responded “yes,” with 11% responding “No,” and 19% responding “Other, please specify” (see Figure 21). Five respondents typed into the comment box, with one respondent saying,

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! :)

Another respondent commented, “As [I] deteriorate, [I] need SSPs more and more. They [help me] maintain my independence.”

Question 27 evoked another individual’s response, “[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 in obtaining SSP services.

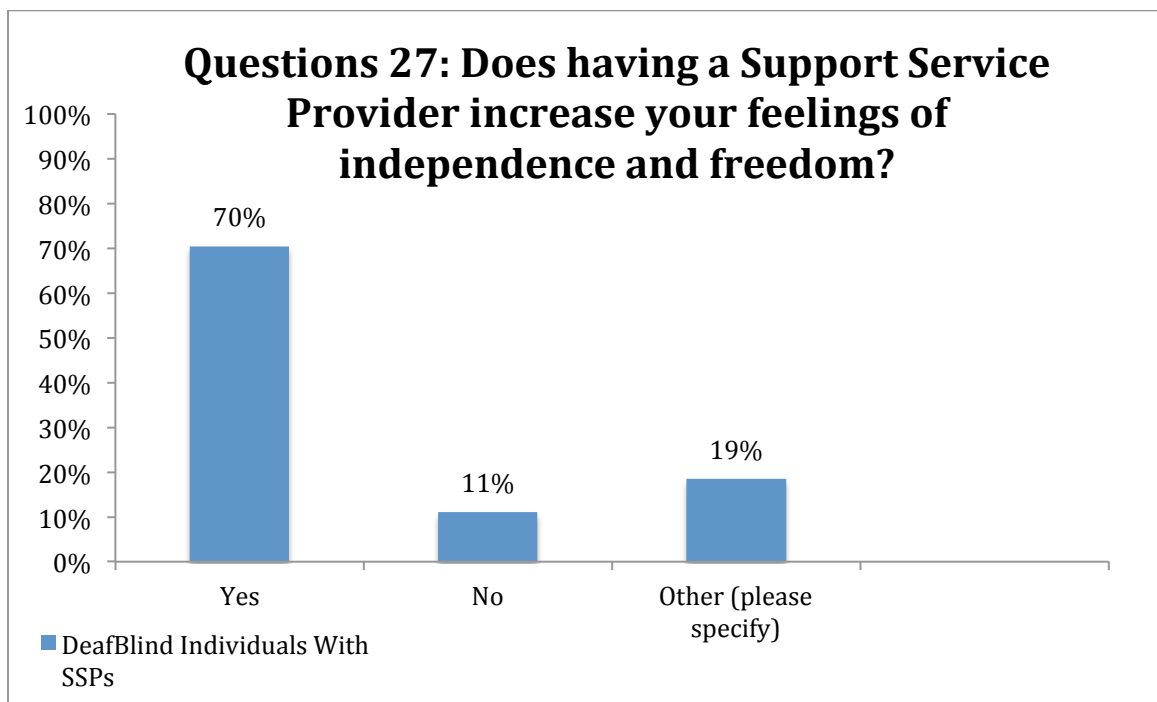


Figure 21. Does having an SSP increase your feelings of independence and freedom?

Question 27 for individuals without SSPs asks, “Do you know what a Support Service Provider is?” About two-thirds (68%) of respondents said “Yes,” 14% said, “No,” and 18% marked “Other” (see Figure 22). 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.”

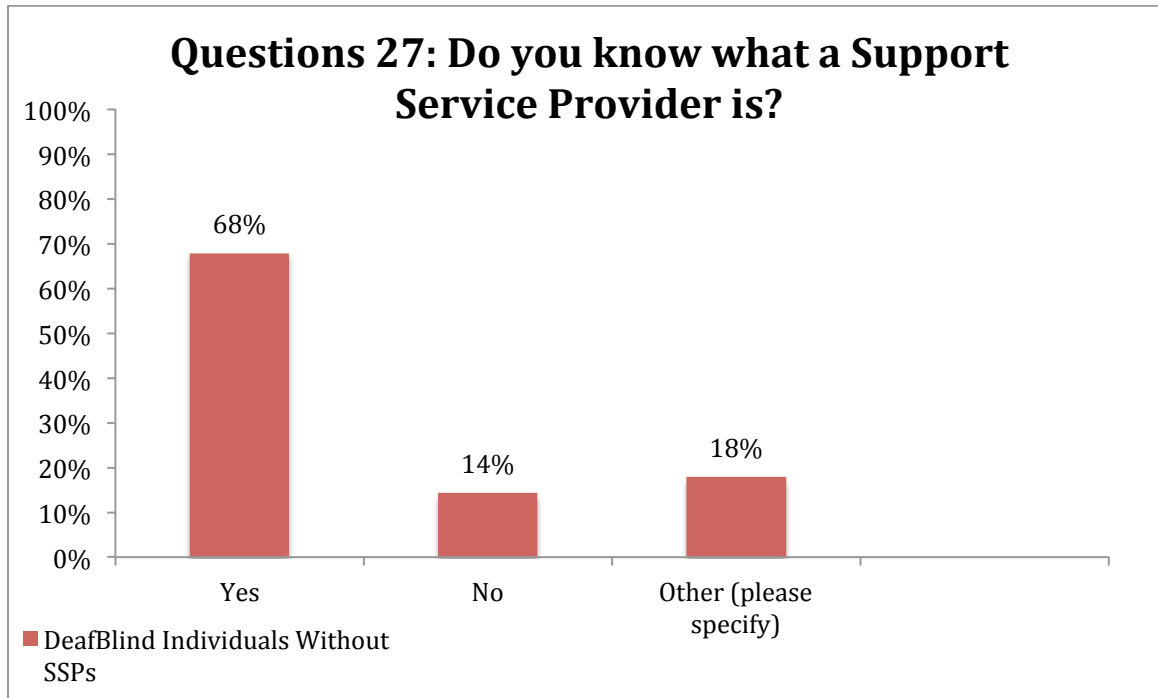


Figure 22. Do you know what a Support Service Provider is?

Discussion

The following discussion presents the results in the order of categorical likeness. The results will be discussed in these categories with the intent of clarity and with the intent of identifying trends.

Questions regarding transportation were asked of both groups in questions 22, 23, 24, and 25. Part of the challenge in living in today’s American society is transportation. If one is blind, there is no way to obtain a driver’s license. Public transportation in many areas in the United States is generally underdeveloped, which leaves individuals who are blind and DeafBlind walking to destinations. There are only a few other transportation options for these individuals to run errands. They could use their limited or non-existent

SSP hours, hitch a ride with a friend or family member, or operate at the mercy of the public transportation system that may or may not be available in their specific area. The question, “Do you feel safe walking to your destinations?” evoked a variety of responses without showing a particular trend. One conclusion that can be drawn from these answers is that both groups reported that they seldom felt safe walking to destinations. For a DeafBlind individual, getting to a bus stop requires extensive planning, execution, and trust in the general public—trust that one will not take advantage of the DeafBlind individual’s sensory deficits. This finding parallels Smith’s (2002) comment about how challenging it is to live as a DeafBlind individual in today’s society: “Clearly the world is not designed for Deaf-Blind people. The streets are dangerous. Deaf-Blind people have very few defense mechanisms. To continue to participate in the world takes real courage” (p. 21). Question 25 inquired if the respondents felt safe walking to their destinations. The responses in this question were pretty evenly divided, but the vital statistic in this question is that nearly half the DeafBlind individuals from both groups indicated that they feel unsafe walking to their destinations. Without the ability to drive, walking to destinations is a real part to a DeafBlind individual’s life. In the literature review, the importance of socialization to combat isolation and depression has already been stated. With half of these individuals feeling unsafe to get out and walk to a destination, one might wonder what social repercussions will result.

Questions 13, 14, 15, 18, 19, 20 and 21 ask questions regarding family and friends. Question 15 asked “Have you been able to talk to your parents when you wanted?” Individuals with SSPs responded at a more positive rate compared to the group without SSPs. As stated previously in the review of the literature, isolation and lack of

personal relationships is a key factor in causing depression. Unfortunately, lack of meaningful communication and issues forming meaningful relationships sometimes start at an early age. Vaccari and Marschark (1997) elaborated further on this isolation, stating that 90% of Deaf children are born to hearing parents, and the majority frequently do not learn sign language and cannot effectively communicate with their Deaf child. This lack of sound interaction can have detrimental effects on the child as they progress into adulthood (Vaccari & Marschark, 1997). At a young age, children learn facts, interactional norms, cognitive strategies, and behavioral strategies (Vaccari & Marschark, 1997). When parents and children do not have such meaningful interactions it can jeopardize the Deaf child's potential to reach their full cognitive potential (Vaccari & Marschark, 1997). Vaccari and Marschark referenced other researchers in stating that Deaf children who have ease in communication with their loved ones display a more positive amount of self-confidence. They soberly stated that many hearing parents who do try to sign with their children do not continue to do so or are not able to develop any fluency of skill. These findings might explain why involvement in the DeafBlind community is precious for DeafBlind members. The ease of communication and the feeling of belonging are vital in living a positive and productive life. Although Support Service Providers cannot get involved in a minor's language development, providing DeafBlind individuals with SSPs is important: SSPs understand the language needs of the DeafBlind individual and can communicate with them on a deeper level. Questions 20 and 21 asked similar questions: "Have you and your friends helped each other?" and "Have you been able to rely on your friends?" These questions again evoked a higher rate of positive responses for the group with SSPs than for the group without SSPs. These

statistics can relate back to the idea that individuals without SSPs have a greater dependency on family and friends. Without an allotted amount of time provided each month/week for the DeafBlind person to run errands with an SSP, the DeafBlind individual must ask for favors from friends and family members in order to travel to the grocery store, doctor appointments, and much more. DeafBlind individuals without SSP services might feel that they are overwhelming and exhausting their friends and families in asking for favors. They may try to limit the amount of times they request assistance as to not burn out their support. Further research in acquiring family and friends' feelings in aiding a DeafBlind friend is recommended.

Questions 4, 5, 6, 7, 8, 9, and 10 all inquire about emotional aspects of the DeafBlind individual's life. Specifically, question number seven asked "Have you felt sad?," which elicited a consistent response of individuals without SSPs responding at a higher negative rate. Smith (2002) described how engrained society is in disregarding the needs of DeafBlind individuals that could contribute 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)

To further drive this point home, Smith (2002) continued by stating that to consider accessibility to be 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 can be linked to feelings of inadequacy, being disregarded, and not feeling like one’s basic needs are met. In a perfect world the government would look at these results and see that funding for Support Service Providers is essential to improving DeafBlind individual’s quality of life, and therefore establish programs and provide money across America for such services.

Questions 16 and 17 ask “Have you had enough money to do the same things as your friends?” and “Have you had enough money for your expenses?” Responses suggested that individuals with SSPs report having 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 don’t 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 could be faced with needing to pay out-of-pocket for the services that are provided for free to others in a different geographical area.

Upon reading Vaccari and Marschark (1997), I began to wonder if the lack of national SSP services is somehow linked to the overall lack of support of the usage of ASL versus spoken English. Vaccari and Marshark stated that even in the United States there is a long-running debate of whether to introduce young deaf children to sign

language, in fear that it could impair their ability or motivation to acquire spoken language. Vaccari and Marshark (1997) completed an extensive review of the research regarding this fear and concluded that there is no evidence to support that claim; the idea is mainly based on personal beliefs that favor spoken language over introducing a signed language (Vaccari & Marshark, 1997). Could it be that this apprehension in teaching young Deaf children ASL is carried through into adult services? Does this general lack of support of sign language usage make ASL-fluent providers seem an accessory rather than a necessity?

Question 27 asked individuals with SSPs “Does having a Support Service Provider increase your feelings of independence and freedom?” This question evoked the largest majority response in one answer, with 70% of individuals responding “yes.” One respondent typed into the comment box, stating that as his/her vision and hearing abilities deteriorate, they depend on SSPs more in order to maintain independence. Independence is a cornerstone value to the duties of an SSP. The Washington state Deaf-Blind Service Center Support Service Provider (SSP) Policy handbook written by the Deaf-Blind Community of Seattle (2012) gives excellent definitions of the role of an SSP, which could help explain the overwhelming positive response given to question 27. It states:

The DeafBlind Service Center (DBSC) Support Service Provider (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. (Deaf-Blind Community of Seattle, 2012, p. 1)

The handbook further describes the SSP role by describing in-depth the importance of visual information and the specifics in communication support. During training, an SSP is taught that every decision they make needs to empower the DeafBlind individual. It also describes that contracting SSPs provide visual information for the purpose of orienting the DeafBlind individual to the environment. This orienting helps the DeafBlind individual to accomplish the task at hand (Deaf-Blind Community of Seattle, 2012). Communication facilitation is described as an SSP relaying questions, comments, and brief pleasantries into the language understood by the DeafBlind client (Deaf-Blind Community of Seattle, 2012). Underlined in the handbook is a part that states “The deaf-blind person decides 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 do it FOR them. When an SSP supports a DeafBlind person properly it empowers the DeafBlind person to make their own independent decisions. After revisiting the specifics of the Deaf-Blind Service Center’s policy book, it clearly explains why 70% of DeafBlind individuals responded “Yes” to the question, “Does having an SSP increase your feelings of independence and freedom?”

Many individuals who have residual sight may still culturally identify themselves as “DeafBlind.” Smith (2002) shed light on this by describing, “The label, ‘Deaf-Blind’ is a cover term like the term ‘Deaf.’ It does not always mean totally deaf and totally blind any more than the use of the label deaf means that the person cannot hear at all” (p. 10). Smith (2002) continued to clarify that typically when culturally identified DeafBlind individuals have residual sight, it often is the case that they have tunnel vision or that they may or may not be able to see from a distance. Smith (2002) concluded that at best,

“DeafBlind” is a general term, and one will need to get to know the DeafBlind individual in order to know what vision or hearing the person has and how it is useful to them in communication and daily living.

The Deaf-Blind Service Center handbook for Washington State states that each DeafBlind individual’s SSP hours are decided on a case-by-case basis. The intake process is as follows:

Deaf-blind people wishing [for] SSP service will meet with DBSC Case Manager to discuss how DBSC can best meet their needs. The Case Manager (CM) 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. (Deaf-Blind Community of Seattle, 2012, p. 4)

This research has revealed that the difference in need between fully blind DeafBlind individuals and DeafBlind individuals with residual vision varies.

CHAPTER 5: CONCLUSION, RECCOMENDATIONS, AND LIMITATIONS

In the process of this research, it has become apparent that the term Support Service Provider is a newer phenomenon that is slowly expanding throughout the United States. The fact of the matter is that many accommodations are unavailable, underutilized, and/or not well known. Signed language interpreters today are still asked if they are a family member or volunteer for the Deaf. The spike in availability of interpreting services for Deaf and hard of hearing individuals came about as a result of the Americans With Disabilities Act (ADA) that was signed into law 1990. Title I of the ADA states that it is illegal to discriminate or exclude against individuals with disability in the workplace (Wylonis, Wylonis, & Sadoff, 2017). Since the law restricted employers from discriminating against Deaf and DeafBlind individuals based on disability, the need for interpreters started to grow. Since then, more disability rights, issues, and concerns have slowly made their way into legislation. Services and equality issues for the Deaf are slowly becoming mainstream, but unfortunately DeafBlind needs and services have lagged. This research aims to be a starting point for further research as the rallying for improved and broadened services continues.

The literature review has revealed that lack of consistent support services impacts life for DeafBlind individuals in numerous ways including family dynamics, satisfying social interacting, and overall quality of life. Scholars have repeatedly stressed the importance of mobility in order to live happy and productive lives. Without consistent support services, DeafBlind individuals continue to solicit aid through available public transportation, family friends, and often strangers.

The second major element unveiled in both the literature review and in the study was the negative effects of isolation and lack of social interaction. The difficulties in communication, often associated with losing a primary mode of 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). It is estimated that the reasoning behind this is the cultural bond that forms among individuals who speak the same language. This is why providing DeafBlind individuals with SSPs who are fluent in ASL and the community's unique communication is vital.

The repeated disparity in quality of life measures between DeafBlind Individuals with SSPs and those without SSPs indicates that DeafBlind individuals with SSPs have a higher quality of life than individuals without SSPs. Some may look at this research and wonder why such SSP funding and services are not widespread and consistently implemented across the country. I believe the simple answer is there is a lack of knowledge regarding the duties, definition, role, and impact a Support Service Provider has on the quality of life for a DeafBlind individual. The bottom line is that, in America, DeafBlind individuals' needs are not being met on a larger scale. The research has demonstrated that the general quality of life is higher for individuals with SSPs as represented by the higher rate of positive answers.

One interesting element uncovered in this research is the suggestion that DeafBlind individuals without SSPs are further economically disadvantaged as compared to DeafBlind individuals with SSPs. Through questions 16 and 17, individuals with SSPs consistently reported a higher positive response to these monetary questions than

individuals without SSPs. Further research is needed to confirm the relationship of location, services, and economic disadvantage DeafBlind individuals without SSPs face. Further research is also needed to identify exactly where services exist, and to what extent funding is available. Further research is needed to establish a knowledge base of the kinds of funding that are available and applicable.

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. I, the principal investigator in this case, decided not to use the coding system in an effort to prevent a skewed frame of reference. As previously noted, this survey is intended for children. It was feared that further coding could override this important feature of this population, that they are adult individuals struggling and working towards a higher quality of life. This study is meant to be a starting place for future research in examining quality of life for DeafBlind individuals, as there is no previous research available on this topic. If a peer reviewer would like to review the available coding in comparison to this study, The KIDSCREEN Questionnaires Handbook by Ravens-Sieberer et al. (2006) is included in the references section for this purpose.

This research has revealed that there is a difference in the type and amount of services needed between fully blind DeafBlind individuals and DeafBlind individuals with residual vision. If and when services become widespread, it should be noted that they should be established on a case-by case basis. Further research in examining the difference in amount of service depending on residual sight and hearing abilities is recommended.

Previous research has unveiled a general lack of support and knowledge of the benefits in using signed language-fluent providers with Deaf children. Further research is recommended to explore whether this lack of support for signed language providers translates from youth care into adult care. Specifically, future research is recommended to uncover if there is a connection to the lack of support in ASL usage is connected to the lack of SSP services for DeafBlind individuals.

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, they don't depend on an SSP all the time because they are still using their residual vision. Residual vision could be a vital factor in pinpointing the needs of DeafBlind individuals depending on their severity of sensory loss. Further research is needed in order to denote which types of DeafBlindness sensory loss requires more services.

Another limitation of the study is that the results are 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." It is recommended that for future research an algorithm is developed for coding these responses so that the writer's personal opinions are further disassociated with the results.

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APPENDIX A: Consent Form For Both Surveys

Purpose: The purpose of this study is to examine the quality of life for DeafBlind individuals who have Support Service Providers services to those who do not have Support Service Providers.

This research is a part of Sheridan Lachney's Graduate Thesis Research. Participation in this survey is completely voluntary, and responses will be remain anonymous.

Procedure: The procedure of this survey will consist of two groups of DeafBlind individuals filling out similar surveys. One group will be DeafBlind individuals without SSP services and a second group will be DeafBlind individuals with SSP services. Once all the responses are collected, the research team will examine the results to see which if there are differences in quality of life between the two groups. This survey is expected to take approximately 15 minutes.

If this survey is not accessible to you, contact the principle investigator, Sheridan Lachney. Ms. Lachney will do her best to best to explore options for accommodations to provide alternative formats.

Benefits: The benefits of participating in this survey can consist of a sense of pride in being involved in a never before studied phenomenon. There will be no compensation for participating in this survey.

Risks: The risks for participating in this survey are minimal. Some discomfort may occur while filling out the survey in thinking about unpleasant past events in one's past regarding family life, friends, and accessibility.

There will be no compensation for participating in this survey.

The Institutional Review Board at Western Oregon University has approved this interview and research project. If you have any questions or concerns regarding the review process, please contact the IRB at (503) 838-9200 or irb@wou.edu. This survey is being conducted under the guidance of Dr. Elisa Maroney maronee@wou.edu.

This survey is based on "The Kidscreen Group" survey.

The KIDSCREEN Group Europe. (2006). The KIDSCREEN Questionnaires - Quality of life questionnaires for children and adolescents. Handbook. Lengerich: Pabst Science Publishers.

If you have any questions regarding this interview or the research in general, please feel free to contact the investigator.

Sheridan Lachney
Cell (text or voice) 253-548-7250
Email: slachney12@mail.wou.edu

This survey consists of 27 multiple-choice questions. Please choose the answer that most accurately describes how you felt in the past week. There are no wrong answers in this survey, it is purely informational.

You can stop participating in this survey at any time without penalty. Simply click the “X” button if you would like to quit.

If you would like to participate in this study, click “Next.” Please understand that by clicking “Next” you are giving your consent to participate in this survey.