

QUALITY OF LIFE OF SERVICE DOG PARTNERS

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Medical advances are constantly increasing survival rates of individuals experiencing traumatic accidents and infants born with disabilities. Medical advances have also significantly increased the life expectancy of individuals living with disabilities as well as the general population. Along with these factors, baby boomers are growing the elderly population. All of this will cause the number of individuals with disabilities to increase exponentially over the next several decades. Many of these individuals will need assistance to complete their daily activities. Research has shown that when applicable, assistive technology by itself is more beneficial than human assistance or a combination of both human assistance and assistive technology. Dogs are a form of technology humans have been developing for thousands of years. Also, they have lived so closely with humans for so long, they have evolved an ability to understand human cues, gestures, facial expressions, etc. Because of this, their immense loyalty, desire to please, and ability to overcome social barriers, dogs are an ideal assistive technology for some individuals with disabilities.

It was hypothesized that wheelchair users partnered with service dogs would score higher on quality of life indicators than wheelchair users not partnered with service dogs. Two hundred and fourteen individuals were included in a cross-sectional study. To be included in the study, subjects had to be 18 years of age or older and use a wheelchair for 75 percent of their mobility

needs. Ninety-nine subjects partnered with service dogs for at least 14 months but less than 8.5 years were compared to one hundred fifteen subjects not partnered with service dogs. Quality of life indicators were number of hours of paid and unpaid assistance, mobility, physical independence, social integration, occupation, economic self-sufficiency, self-esteem, depression, and loneliness.

The service dog group scored significantly higher on mobility although this group was comprised of significantly more individuals with severe disabilities and used almost significantly more hours of paid assistance. The service dog group outperformed the comparison group on nearly every other indicator although not to a significant degree. These results are similar to those in previous studies on the service dogs.

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1.0 INTRODUCTION

1.1 Wheelchair users in the United States

Historically, society has identified disability with mobility impairments. This dates back to medieval times, when it was commonplace to see the "lame" or "crippled" begging in the streets, and continues in modern times where the white stick figure in a wheelchair on a blue background often denotes any type of disability, not necessarily just mobility impairments (Iezzoni, McCarthy, Davis, & Siebens, 2000). There are 2.2 million wheelchair users that make up only about 4% of the 52.6 million people in the United States with disabilities (McNeil, 1997). Wheelchair users are often considered the most important segment of the disability community because mobility impairments are the most readily visible and architectural accommodations for wheelchairs are the most noticeable accommodations made for people with disabilities (Iezzoni et al., 2000; LaPlante, 2003; McNeil, 1997).

The use of wheeled mobility devices (WMD) is increasing faster than the prevalence of lower body mobility impairments because newer technologies are making the devices more intuitive and easier to use by larger populations; WMD are increasingly perceived with a positive image; and funding for them is more available (Barker, Reid, & Cott, 2004; Buning, Angelo, & Schmeler, 2001; LaPlante, 2003; McNeil, 1997). In 1969 there were 409,000 wheelchair users in the United States. By 1995 the number quadrupled to 1.7 million. This is based on the

National Health Information Survey (NHIS). Similarly, the Survey of Income and Program Participation (SIPP) reports that the use of WMD has sextupled over the last three decades (Kaye, Kang, & LaPlante, 2000; LaPlante, 2003).

Less than 20% of WMD users in the United States are employed. Eighty percent of WMD users report that their public transportation is difficult to get to or use. The use of mobility devices increases dramatically with age. Only two tenths of one percent of individuals under the age of 18 use some type of mobility device but there are seven times as many mobility device users among working age adults, and among the elderly, the percentage increases 10 times to 14%. The vast majority of WMD users (90%) use manual wheelchairs (Kaye et al., 2000). Mobility device users are six times more likely than non-users to have not completed high school, and among the elderly, non-high school graduates are twice as likely to use a mobility device as their peers with college educations (Kaye et al., 2000; LaPlante, 2003). Much has changed for people with disabilities during the past half century regarding civil rights, education, and employment, but public policy has fallen short in providing adequate supports that enable people with disabilities to live and work independently in the community (Hall & Fox, 2004; Novak, 2005).

1.2 The Growing Prevalence of Disability

There have been major changes in disease patterns and population structures over the last century in the more economically developed nations. Most notably, the population of developed countries is growing older due to the post-World War II baby boom (Feinberg & Newman, 2004). Other factors contributing to the growth of the elderly and disabled populations are

advances in medical procedures that extend life expectancy for the general population and increase survival rates of premature babies and individuals with traumatic injuries and chronic diseases (LaPlante & Kaye, 1998).

As the population ages, disability becomes increasingly probable. This growing population needs assistance to complete major life activities and is often dependent on other people, assistive technology, or both to complete these activities (Agree, 1999; Verbrugge & Sevak, 2002). Usually, much of this assistance is provided by family members receiving little or no compensation and sometimes losing personal income from other jobs to care for the disabled relative. Family members become caregivers because the quality or quantity of alternate sources of healthcare is inadequate (Abresch, Seyden, & Wineinger, 1998; Blood et al., 1994; Hooyman, Gonyea, & Montgomery, 1985; Karmilovich, 1994; Kent, Chandler, & Barnes, 2000; LaPlante, Kaye, Kang, & Harrington, 2004; Zarit, Todd, & Zarit, 1986). This can result in lower quality of life for the entire household, extended family members, and friends (Abresch et al., 1998; Feinberg & Newman, 2004; Gill, 1999).

Studies have been conducted to investigate the effects of using assistive technology (AT), human assistance, or a combination of both. Individuals maintain higher levels of self-sufficiency and self-esteem when AT is used instead of human help or a combination of both (Verbrugge, Rennert, & Madans, 1997). Other advantages to completing daily activities with AT are more freedom, and a sense of pride from task self-completion, and less confusion (about directing the care and deciding who does what); moreover, AT is more consistent (Verbrugge & Sevak, 2002). Once obtained, it is readily at hand, adaptable to changing needs, and remains the same from day to day. On the other hand, the availability, ability, and willingness of human assistants to do exactly what is needed can change from day to day and from assistant to assistant

(Agree, 1999; Verbrugge & Sevak, 2004). Also, the values of autonomy and privacy are important aspects to consider when determining the proper type of assistance (Agree & Freedman, 2003). To reduce symptoms of disability, use of AT in place of either human assistance or a combination of both has physiological and psychological benefits (Verbrugge & Sevak, 2004). Furthermore, the use of AT has been shown to increase quality of care and reduce the burden on informal caregivers, improving the quality of life of everyone involved (Agree, Freedman, Cornman, Wolf, & Marcotte, 2005).

1.3 Dogs: Ancient but Highly Developed Technology

1.3.1 Dogs and Humans Go Way Back Together

Dogs have had a positive effect on the quality of life of humans for thousands of years. The domestication of dogs, according to archaeologists using the latest DNA dating techniques, began much earlier than previously believed (15,000 years ago), possibly as early as 40,000 to 100,000 or more years ago (Mlot, 1997). Dogs were domesticated before any other animal or plant, even before goats, cows, or horses, and were the only domesticated animal present in both the new and the old world before trans-oceanic travel (Leonard et al., 2002; Pennisi, 2002). Dogs require food and care, and would be expensive traveling companions, so they must have served important functions for ancient hunter-gatherers to have migrated with them over the enormous distances that they did (Mlot, 1997; Weiss, 2002; Wolpert, 2002). It is believed that dogs were valued for their hunting skills, security, transport (pack animals), warmth, and as

goods for trade (Weiss, 2002). Also, they were probably well domesticated to have not run off into the wilderness during long migrations (Leonard et al., 2002).

Dogs learn from experience, but recently, scientists have discovered that, from living so closely with humans for so long, dogs have evolved a genetic predisposition to understanding human cues better than any other animal. Even puppies only a few weeks old, raised with minimal human intervention, can out-perform the smartest of primates in simple tests of understanding human gestures, pointing, glances, etc. (Hare, Brown, Williamson, & Tomasello, 2002). This, along with their “immense loyalty and a desire to please,” is one of the reasons that dogs surpass and may never be replaced by technology (Miles, 2004).

1.3.2 Working Dogs

Besides the more familiar jobs that dogs perform, like hunting, herding, and pulling (sleds), dogs have been used in warfare for ages and more recently have been found to be more effective than the latest technologies in several other civil applications. In 1942 the US military officially started using dogs as messengers, sentries, and scouts although they were used in World War I, in the revolutionary war, and by other militaries for at least 6000 years (Born, 2002; Dalton, 2002). Military working dogs continue to be used here and abroad for guarding and patrolling, search and rescue, apprehending, and explosives detection (Miles, 2004). Dogs are also widely used by law enforcement and other emergency response agencies for search and rescue, tracking, finding evidence or cadavers, detecting narcotics and explosives, arson investigation, and even picking suspects out of lineups (Hargreaves, 1996; Moore, 1995; Palman, 2006). It is also believed that dogs may be able to detect several types of cancer sooner than current technologies (McCulloch, 2006; Smith, 2006).

1.3.3 Assistance Dogs

Dogs have been assisting people with vision impairments for centuries, and although dogs have been trained to assist individuals with other disabilities for only a few decades, already there are over 75 agencies training such dogs in just the United States alone (Rintala, Sachs-Ericsson, & Hart, 2002). An umbrella category commonly referred to as assistance dogs (AD) includes but is not limited to: Guide dogs (to safely guide individuals who are blind or have vision impairments), hearing dogs (to alert individuals who are deaf or have hearing impairments to important sounds such as an alarm, a doorbell, their name, etc.), seizure response dogs (to alert and protect individuals with seizure disorders), and service dogs (SD) (to assist individuals with physical disabilities).

1.4 More about service dogs

Assistance Dogs International Inc. (ADI) is a coalition of nonprofit organizations that train and place ADs including SDs. There are nearly 75 organizations in the US that train SDs and belong to ADI. That's almost all of them. Among the many purposes of ADI are improving training and placement procedures, training staff and volunteers, sponsoring annual conferences for members to attend seminars and share ideas, and educating the public about assistance dogs and the rights of the individuals with disabilities that depend on them, but one of the most important services they provide is setting standards and ethics for the training and placement of these dogs ("Setting standards for the assistance dog industry since 1987," 2006).

1.4.1 Training

Although most service dogs are specifically bred Golden or Labrador retrievers or a cross-mix of the two, nearly all other breeds, including mixed breeds rescued from shelters can be trained as SDs. When dogs are bred to become SDs, the puppies are typically raised in foster homes by volunteers from about eight weeks of age until they are ready for more formal training. Most puppy raising programs require the volunteers to attend a minimal amount of obedience classes with the puppies as well as provide a minimal amount of socializing activities (Fitzgerald & Collins, 2005; Modlin, 2001).

Some of the minimum standards to be followed by agencies wishing to be associated with ADI are:

- 1) a minimum of 120 hours of training over a period of no less than six months must take place under the supervision of a program's trainer; 2) during that time at least thirty hours of regularly scheduled training must be devoted to field trips and public exposure; 3) the dog must show social behavior skills of no aggression, no inappropriate barking, no biting, no snapping/growling, no inappropriate jumping on strangers, no begging and no sniffing of people; 4) the training time with the student prior to placement must be a minimum of no less than 60 hours, to take place in both public and private environments; and 5) the recipient must agree to abide by the Minimum Standards for Assistance Dog Partners

These are the minimum standards and agencies are encouraged to work at levels above the minimum

("Minimum standards for training service dogs," 2006).

Although most SDs are trained by professionals, more SD agencies are using prison inmates as trainers. The increased demand for working dogs has created a market where the available time that inmates have makes them ideal candidates to perform the time-consuming and intensive training required for dogs to be rehabilitated from rescue shelters or to go on to become SDs (Furst, 2006; Riedel, 2006). Further, with the intensity that prison training provides, it takes about half the time for a dog to be trained by a prisoner in these programs. These programs also provide other benefits: The prisoners get a chance to care for another living being and receive unconditional acceptance; the presence of the dogs bring about positive cultural changes within the entire prison; and the public at large benefits with lower repeat offender rates because the prison trainers have learned a marketable skill as well as better personal coping strategies (Strom, 2006).

1.4.2 Obtaining a service dog

Applying for a SD from many provider agencies can be done by filling out online forms, although some still require that applications be handwritten or typed, and submitted by standard mail. In many cases essays, site visits, and letters of recommendation from a physician or therapist are required (Sachs-Ericsson, Hansen, & Fitzgerald, 2002). Because service dogs are in such high demand and the cost of training and placing them is so high (\$8,500 to \$20,000), individuals must wait several months to years before being partnered with one (Duncan, 1998; Fitzgerald & Collins, 2005; Modlin, 2001). The cost to the recipient is usually minimal in comparison to the total cost, usually between no cost and \$500. When more than a minimal amount is required by the recipient, fundraising assistance is usually provided by the agency or

community organizations (Fitzgerald & Collins, 2005). As set forth in the minimum standards of ADI, recipients must be given a solid education in appropriate behavior of the team consisting of no less than 60 hours in both public and private settings. In most cases, this is accomplished by the recipients spending at least two weeks living near the provider agency and working closely with the professional trainers.

Another cost to SD partnership is the day to day care, veterinary bills, and food. In a study by Fairman and Heubner (2000), 75% of respondents reported spending a maximum of \$1000 per year on care and feeding, and 32% were receiving assistance for these costs from other sources including veterinary donations and state-government dog-allowance funds. The survey in the Fairman and Heubner (2000) study also contained questions regarding problem behaviors experienced with SDs. Only a minimum of respondents (less than 3%) reported always or frequently having a dog with a difficult temperament or having difficulty controlling their dog. Only 7.4 of respondents reported always or frequently having difficulty providing maintenance care for the dog, particularly bathing and trimming its nails. Other negative aspects of service dog partnership reported include having someone to walk the dog, especially during inclement weather; worsened relationships with family members; strangers petting their SD while it was working; and less access to transportation, housing, and public buildings despite federal laws. Still, the same respondents who reported these problems felt that the advantages far outweighed the disadvantages (Valentine, Kiddoo, & LaFleur, 1993).

1.4.3 Benefits

Animal assisted therapy, contact with animals, and pet-ownership is well documented to be associated with physiological and psychological well-being (Friedmann & Katcher, 1980;

Friedmann, Katcher, Thomas, Lynch, & Messent, 1983; Friedmann & Thomas, 1995; Raina, Waltner-Toews, Bonnett, Woodward, & Abernathy, 1999; Virues-Ortega & Buela-Casal, 2006). SDs have been trained to assist individuals with disabilities such as but not limited to spinal cord injury, multiple sclerosis, cerebral palsy, polio and post-polio syndrome, and muscular dystrophy. As a dog's mouth is able to perform many of the functions of the human hand, many individuals with physical disabilities rely on service dogs as a more loyal, convenient, portable, and reliable form of assistance over humans or other assistive technologies (Camp, 2001; Lane, McNicholas, & Collis, 1998; Rintala et al., 2002). In a descriptive study by Fairman and Huebner (2000), it was found that service dogs were assisting with 28 individual tasks that included activities of daily living (ADL) (e.g., bathing, dressing, eating, etc.); instrumental activities of daily living (IADL) (e.g. shopping, bills, cooking, cleaning, etc.); and work, school, and other activities. SDs increase functional mobility, occupational performance, and better overall independence.

Specifically, dogs can be taught to provide stability or support; assist with transfers; pull on or off clothing; pick up dropped objects; locate items (keys, cell phones, remote controls, people, locations, etc.); retrieve or carry items such as phones, bottles, books, papers; open and close doors; turn lights on and off; alert the owner to sounds or danger; and alert others when the owner needs help (Fairman & Heubner, 2000; Lane et al., 1998; Rintala et al., 2002). In addition to enhancing independence in self-care and work and leisure activities, SDs provide emotional and psychosocial benefits such as constant companionship, better feelings of safety and security, higher levels of confidence and self-esteem, less depression and feelings of loneliness, more social contact, and what everyone desires, unconditional love (Eddy, Hart, & Boltz, 1988;

Fairman & Heubner, 2000; Fitzgerald & Collins, 2005; Mader, Hart, & Bergin, 1989; Valentine et al., 1993).

1.5 The Key Importance of Quality-Of-Life

Because choosing to own a service dog is a lifestyle choice, one of the purposes of this thesis is to introduce quality-of-life (QOL) considerations into research on SDs. QOL will be defined as positive (optimistic) levels of the measures used in this study, which will be discussed in greater detail in section 2 (“Methods”). Also, because the Veterans Administration funded the studies that collected the data used for this thesis, two things should be mentioned. First, the studies were funded to provide information on the cost benefits of SDs, and it is unlikely that past or current studies will show a significant reduction in amounts of paid (formal) human assistance provided, because the longitudinal studies are 24 months or less in duration (not enough time for a service dog partnership to achieve synergy) (B. Canale, personal communication, December 8, 2006). Also, research has shown that individuals requiring assistance to complete daily activities rarely receive sufficient amounts of formal assistance to meet their needs and are quite often dependent on family and friends (informal) caregivers to make up the difference (Abresch et al., 1998; Blood et al., 1994; Hooyman et al., 1985; Kent et al., 2000; LaPlante et al., 2004; Zarit et al., 1986). Therefore, it is more likely that assistance provided by the SD would be used to relieve the burden on family and friends rather than reducing the amount of formal assistance.

Secondly, even though the Veterans Administration is still studying the cost benefits of providing service dogs, agencies are already working with Walter Reed Medical Hospital to

partner disabled vets (many using prosthetic legs *and* wheelchairs) with service-support dogs (Miles, 2006). These are dogs trained in the usual SD tasks but also trained to wear a metal bracket and act as a brace or crutch for support during transfers and ambulating with prosthesis. Of course, a pair of crutches is less expensive (approximately \$140) than a service dog (\$8,500 to \$20,000), but the crutches do not provide love and companionship, and the crutches don't promote public acceptance of the disability, quite the contrary. These are some of the quality-of-life enhancements that service dogs provide. Since they cannot be provided by any other means, they are invaluable, priceless.

The term "quality-of-life" was first used in the postwar period to describe the effect material affluence (ownership of expensive items such as cars, jewelry, etc.) had on people's lives, and was later broadened to include education, health and welfare, industrial and economic growth, etc. In social and medical literature, QOL has been equated with other terms such as but not limited to well-being, self-esteem, health, happiness, adjustment, functional status, and even the value or meaning of life (Carr, Thompson, & Kirwan, 1996). In 1948, The World Health Organization defined health in its Constitution as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (Grad, 2002). Since then, QOL and, more recently, health-related quality-of-life (HRQL) issues have become more prominent in research. During these past few decades this phenomenon has been growing exponentially. For instance, in 1973 there were only five articles listed with "quality-of-life" as a keyword in the MEDLINE database; but this number grew to 16,256 in 1998, and today the keyword phrase "quality-of-life" produces 85,186 results (Shuvayu S. SenGupchup, 1999).

The first published studies on QOL explored subjective personal well-being and objective, societal indicators (Brown, 1999). As more studies are published using the phrase

"quality-of-life," more controversy develops over what it means and how it should be defined (Abresch et al., 1998; DePalma, 2001; Felce, 1997; Lehman, 1995; Leplege & Hunt, 1997; Sen, Gupchup, & Thomas, 1999). Some researchers have even suggested that outcomes related to QOL could be more easily explored if it were referred to in different terms such as "subjective health status" or "quality of well-being" (Phillips, 2006). According to Leplege & Hunt (1997), the term "health-related quality-of-life" (HRQL) was coined in order to justify using current measures under a new name. The idea was that these *different* surveys would be able to indicate the impact of ill health or impairment on the QOL. The real problem not being addressed by this methodology is that QOL cannot be separated into health and non-health-related components. This view also fails to take into account the interconnectness with other aspects of life such as changes in income or job status, personal situations and relationships, self-image, responsibilities and the ability to manage them. These interconnected relationships between health and all the other aspects of life make it improbable that a means of specifically measuring HRQL can be developed. It is surprising that this difficulty has rarely been acknowledged by researchers in the health measurement field. There are also misconceptions that individuals living with disabilities, diseases, and possible comorbidities, naturally lead lives of lower quality than the rest of society, which is not necessarily true (Leplege & Hunt, 1997). Although the economics of policy making require that concepts such as "quality adjusted life years" and "disability adjusted life years" be developed, this can also be seen as the medicalization of everyday life, or in other words, forcing medical practitioners to act as social reformers, moral philosophers, etc. and make decisions beyond their field of expertise (Leplege & Hunt, 1997). HRQL as an outcome measure is also surrounded in controversy over how it should be defined and how to measure it, but there is a general consensus that it is typically used in reference to specific diseases or impairments

(Leplege & Hunt, 1997; Sen et al., 1999). Because this study sample contains individuals with a variety of disabilities, a more broadly defined term of QOL will be used.

A relatively new but flourishing field of psychology, *positive psychology*, focuses on the study of things such as positive emotions, strengths based character, and healthy institutions (Seligman, 2006). Positive psychology is based on the notion that happiness (one of the more common synonyms used to define QOL) is an unwieldy term, and that serious scientific study of it requires examination of its three major components: positive emotion, engagement, and meaning (Peterson, Park, & Seligman, 2005). Happiness is causal, and feeling good increases health, success, and social engagement; the causal direction runs both ways (Lyubomirsky, Sheldon, & Schkade, 2005). This is key to the working definition of QOL for this study in that the instruments and questionnaires used measure the same three concepts. As a matter of fact, two of the scientifically validated survey instruments used in this study are offered free to the public at the top of the front-page of AuthenticHappiness.com, a web site promoting the study of positive psychology sponsored by the University of Pennsylvania's Positive Psychology Center ("Authentic happiness," 2006). One of the purposes of this study is to explore the relationships between SD ownership and quality-of-life indicators.

1.6 Previous Research on Service Dogs: A Brief Review

In 1988, Eddy, Hart, and Boltz studied the social acknowledgment of a person in a wheelchair by having an observer follow a subject in a wheelchair in public places, when accompanied with a service dog and without, and noting the reactions of passersby. When the

subject was not accompanied by a service dog, strangers exhibited behavior such as gaze avoidance, increased personal distance and briefer social interaction. When the subject was accompanied by a service dog, negative behaviors of passersby decreased while smiles, conversations, and other social interactions increased significantly (Eddy et al., 1988). A very similar experiment was conducted by Mader, Hart, and Bergin (1989) with children in wheelchairs. The results were identical.

Valentine, Kiddoo, and LaFleur (1993) interviewed 24 recipients of assistance dogs (14 hearing dog partners and 10 service dog partners) and seven trainers. The majority of assistance dog partners and trainers agreed that individuals partnered with service dogs were more content; experienced more friendliness from strangers; had an increased sense of belonging; were more active; were more relaxed; felt safer; were less lonely and depressed; and had more freedom to be capable.

A randomized clinical trial was conducted in which 48 individuals were followed for 12 months after receiving a SD (Allen & Blascovich, 1996). The results were phenomenal. After one year of SD partnership: paid and unpaid human assistance needs were reduced by 68% and 64% respectively suggesting a \$60,000 net cost benefit of SD partnership; the employment rate for the participants rose from 0% to 82%; and there were significant increases across all psychosocial measures (well-being, locus of control, community integration, and self-esteem). Due to the astounding results and other methodological inconsistencies, the validity of the study has been questioned and will not be considered further for purposes of this study (Beck & Fine, 2000; Eames & Eames, 1996a, 1996b; Rowan, 1996).

Lane, McNicholas, and Collis (1998) interviewed 57 recipients of service dogs. Subjects who had developed a relationship with their SDs that extended beyond a working relationship

were more likely to have self-perceived improvements in health. The researchers believed that these subjects, experiencing improved psychological well-being from the increased independence, social interaction, self-esteem, and close supporting relationship with their dog, had better coping strategies and more positive outlooks regarding their disabilities, and thus perceived improvements in their health.

Fairman and Heubner (2000), in another retrospective study, surveyed 202 SD partners on the functional, economic, and psychosocial benefits their SDs provided. The results were comparable to previous studies. Interestingly, subjects reported a decrease in paid and unpaid human assistance needs (two and six hours per week respectively), suggesting that SDs reduce the stress of caregivers (typically family members) in two significant ways. First, less assistance is needed, providing family members with more free time to pursue desired activities, and secondly, when family members are away, they can be more relaxed knowing that the SD is there to watch over their loved one.

In a qualitative study, Camp (2001) interviewed five SD partners. Recurring themes reported by subjects included increased community participation and social contact, personal skill development, responsibility, independence. Several respondents also reported that having a service dog made them feel "like an able-bodied person", and as if they had "someone to watch over me". Camp also notes that SDs are a type of assistive technology that promotes independence and social integration as opposed to other types that promote dependence and segregation. Further, "These quality of life issues of social interaction and autonomy may substantially influence satisfaction with assistive devices and must be accounted for in the assistive technology selection process" (Camp, 2001).

In a pre-post study by Rintala, Sachs-Ericsson, & Hart (2002), the findings reiterated, but with a slightly stronger study design beneficial effects of SDs such as social integration, independence, and safety. This study also found that self-esteem was enhanced significantly after partnership with a SD, and family members had more freedom and peace of mind. Collins (2004) in a longitudinal study examining economic self-sufficiency and hours of assistance, found no significant differences between groups (newly partnered SD recipients and individuals waiting to receive a SD). However, subjects were only followed for nine months, which is a critical adjustment period for new SD partnerships (Camp, 2001). During this time, depending on the functional level of the recipient, the individual newly partnered with a SD may require an increase of human assistance for the first few months of partnership to help teach the SD the specifics of a new environment and the particular routine of the individual. According to their National Client Services Coordinator at Paws with a Cause[®] (one of the largest SD provider agencies) SDs are not certified until after six to eight months of partnership, and complete synergy between SD and recipient may not transpire for up to a year or more (B. Canale, personal communication, December 8, 2006). For this reason, and because SDs only work for about six to eight years ("About circle tail assistance dogs," 2006), the purpose of this thesis was to analyze existing cross-sectional data excluding individuals who were partnered with a SD for less than 14 months or more than 8 1/2 years.

1.7 Specific Aims and Hypotheses

The purpose of this study was to examine relationships between long-term service dog partnership and quality of life indicators such as functional performance, independence,

assistance needs, social integration, occupation, and psychosocial well-being. At the same time, this study was conducted with the understanding that further studies need to gather more definitive information about whether or not service dog placements should be funded by the Veterans Administration and other federal agencies because they have a significant effect on quality of life.

1.7.1 Specific Aim 1:

To discover the long-term influence of service dog partnership on the functional performance of individuals partnered with service dogs for 14 months to 8.5 years.

Hypothesis 1a: People partnered with service dogs for 14 months to 8.5 years will score higher on the Mobility and Physical Independence portions of the Craig Handicap Assessment and Reporting Technique (CHART) compared to people with similar disabilities who are not partnered with service dogs.

Hypothesis 1b: People partnered with service dogs for 14 months to 8.5 years will use less paid and unpaid human assistance compared to people with similar disabilities who are not partnered with service dogs.

1.7.2 Specific Aim 2:

To discover the long-term influence of service dog partnership on the psychosocial well-being of individuals partnered with service dogs for one year or more.

Hypothesis 2a: People partnered with service dogs for 14 months to 8.5 years will score higher on the Social Integration, Occupation, and Economic Self-Sufficiency Portions of the CHART and the Rosenberg Self-Esteem scale compared to people with similar disabilities who are not partnered with service dogs.

Hypothesis 2b: People partnered with service dogs for 14 months to 8.5 years will score lower on the UCLA Loneliness Scale (Version 3) and the Center for Epidemiologic Studies Depression Scale (CES-D), compared to people with similar disabilities who are not partnered with service dogs.

2.0 METHODS

The data analyzed for this paper were collected during two studies investigating the functional, psychosocial, and socioeconomic benefits of service dog partnership. These studies used almost the same questionnaire and assessment tools and were funded by the U.S. Department of Veterans Affairs and the Veterans Administration Research and Development Center. One study was funded as a pre-doctoral grant (“Use of Dogs to Increase Function and Psychological Well-Being among Wheelchair Users”); the other was funded as a VISN 4 Competitive Pilot Project Fund (“Epidemiology of Service Dogs”). The studies were approved by the Rehabilitation and Development Board and subcommittee of the VA Institutional Review Board. Both protocols were questionnaire survey studies where the participants (wheelchair users) reported on their demographics (age, gender, race, marital status, education, income, etc.), length and type of disability, and how much and what type of assistance they required to complete basic and instrumental activities of daily living (ADLs) and (IADLs). Assessment instruments found to be valid and reliable (described in greater detail in Section 2.3) were used to measure mobility, physical independence, social integration, economic self-sufficiency, occupation, depression, self-esteem, and loneliness.

2.1 Study Design

This was a cross-sectional study designed to investigate the relationship between service dog partnership and quality of life indicators. Individuals completed questionnaires about disability, demographics, income, health insurance, human assistance used, depression, self-esteem, loneliness, and functional performance. The data collected allowed a comparison of mean scores between two groups: individuals using wheeled mobility devices and partnered with a service dog; and individuals using wheeled mobility devices but not partnered with a service dog. All subjects signed an informed consent document before the surveys were administered.

2.2 Subjects

After Internal Review Board (IRB) approval, recruitment of participants was conducted through Paws with a Cause® and Canine Companions for Independence (agencies that provide service dogs to people with disabilities). The agencies agreed to send IRB-approved letters to their clients describing the study. In addition, a website was posted on the University of Pittsburgh/VA Human Engineering Research Laboratory's homepage (<http://www.herlpitt.org/acs.htm>). The website and the letters contained details about the study, inclusion/exclusion criteria, and investigator contact information. To be eligible for inclusion, subjects had to be 18 years of age or older, and be using a wheelchair or scooter for 75% or more of their daily mobility needs. Individuals in the comparison group (not partnered with a service dog) were recruited through mailings, newsletter advertisements, and website announcements from various advocacy groups and disability-specific agencies such as the Muscular Dystrophy

and United Cerebral Palsy Associations, as well as the Human Engineering Research Laboratory's Wheelchair Users Registry, which is comprised of individuals who have previously participated in other lab-sponsored research studies and have given their signed consent to be contacted for future studies. To help recruit subjects for the comparison group, service dog agencies (Paws with a Cause® and Canine Companions for Independence) also notified individuals who had applied for service dogs but had not yet received them.

When interested individuals contacted study investigators, study packets which contained an unsigned consent form, blank study questionnaire, and a self-addressed, stamped envelope were sent. In addition, a letter from the investigators that described the informed consent process and the procedure for data collection was included. Once a signed consent form was received, an investigator would contact the participant to complete the informed consent process and schedule a phone interview to complete the data collection if the subjects preferred being interviewed by an investigator to filling out the questionnaire themselves. Subjects were assigned to either the service dog group or to the comparison group at the time of data collection. To compensate them for their time, a check for \$20.00 was sent to participants when they completed a questionnaire.

2.3 Study Protocol and Instrumentation

After a signed informed consent form was received from a subject, data were collected. Data collected included dog status; disability prognosis (progressive or non-progressive); demographics (e.g. age, gender, race, income, years living with a disability, years of education, etc.); self-esteem; depression; social integration; occupation; economic self-sufficiency; mobility; and paid and unpaid human assistance used. At the top of each survey was a

completion log form to keep track of when information was recorded, entered into the database, and verified. This information, along with all other information on each questionnaire, was entered into a secure database maintained by the network administrator at the Human Engineering Research Laboratory. Only investigators working on the study were granted access permissions to this database.

Dog Status:

This was based on whether or not the subject was partnered with a service dog or not. The date the subject received the service dog was also recorded to calculate how long the subject and the service dog have been working together (partnered). This information was recorded in the completion log. The completion log is located in the Appendix A

Disability Prognosis:

This was determined by how the subject answered the following question: What is your impairment/disability? Date of onset was also recorded to calculate how long the subject had been living with a disability. When this information was transferred to the database, it was coded into one of 50 categories of disabilities. Progressive and non-progressive status of the disability was also recorded at this time.

Question taken from the survey to determine disability prognosis:

What is your impairment/disability? _____

Date of onset of injury or diagnosis: ____/____/____

A table of the disability codes is in Appendix A.

Mobility:

The mobility subscale of the Craig Handicap Assessment and Reporting Technique (CHART) was used to determine individual mobility scores (Walker, Mellick, Brooks, & Whiteneck, 2003). Mobility is defined as "the individual's ability to move about effectively in his/her surroundings." A composite score is calculated for each subject using the number of hours per day out of bed, the number of days per week out of the house, and the number of nights per year spent away from home. Accessibility of the home and transportation is also factored into the scoring procedure. A weighted scoring method is used to determine a composite mobility score between 0 and 100 (Walker et al., 2003). The complete questionnaire and scoring procedure is in Appendix B.1.

The CHART is a highly reliable and well validated assessment tool developed to measure the level of restriction imposed by disability and environment that prevents an individual from participating in activities. The CHART uses a definition of "handicap" developed by the World Health Organization (WHO) based on a model of disablement that draws distinctions between impairment, disability, and handicap. Impairment occurs at the organ level and can be described as a loss or abnormality of physiological, psychological, or anatomical structure or function. Disability is a restriction or lack of ability (resulting from an impairment) to perform an activity considered normal for that individual (e.g., for individuals under 18, attending school is considered a normal activity; for individuals over 18, attending college or working would be considered normal activities).

According to the WHO model, "handicap" describes all effects and consequences of disability: cultural, social, economic, and environmental. The WHO identifies six dimensions

that describe the extent of an individual's handicap: 1) mobility, 2) physical, independence, 3) social integration, 4) occupation, 5) economic self-sufficiency, and 6) orientation or cognitive. The CHART was developed to assess these dimensions of handicap (Elliott, Uswatte, Lewis, & Palmatier, 2000; Nosek, Fuhrer, & Potter, 1995; Tate, 1994; Walker et al., 2003).

Paid and Unpaid Human Assistance:

Individuals with disabilities often require human assistance to complete basic and instrumental activities of daily living (ADL, IADL). To collect this data, subjects were asked: "During the PAST MONTH did you need someone to help you or provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?"; and "During the past month did you need someone to help you with things such as grocery shopping, housekeeping, or run errands because of your disability?" The questionnaire provided a form for reporting how many hours were used, who provided the assistance, whether or not they were paid, and whether or not the care was self-directed. The complete forms are in Appendix C.

Physical Independence:

Physical independence refers to the extent to which an individual is able to perform necessary life activities (ADL and IADL) independently without human assistance. The corresponding subscale of the CHART was used to compute the composite score for each subject. The individual scores used to complete this portion of the CHART were collected from the "Paid and Unpaid Human Assistance" section of the questionnaire. The actual subscale questions and scoring procedure are in Appendix B.2.

Self-Esteem:

Self-esteem was determined using the Rosenberg Self-Esteem Scale (RSE). It was originally developed in 1965 to measure self-esteem among adolescents (Rosenberg, 1965). The RSE has since been demonstrated to be reliable and valid across a number of different sample groups. It consists of 10 questions concerning overall feelings of self-acceptance and self-worth. The items are answered with a four-point scale ranging from “strongly disagree” (0) to “strongly agree” (3). Five items are worded positively and five negatively (e.g., “I take a positive attitude toward myself” or “I certainly feel useless at times”). The negatively worded items are scored inversely (0=3, 1=2, 2=1, 3=0) for a total score between 10 and 40 with higher scores indicating higher self-esteem. The Rosenberg Self-Esteem Scale is in Appendix D.

Social Integration:

Social integration was determined using the corresponding subscale of the CHART. Social integration is defined as "the ability to participate in and maintain customary social relationships" (Walker et al., 2003). Factors included in this subscale: household composition; romantic involvement; the number of friends, family, business associates with whom regular contact is maintained; and the frequency of conversations initiated with strangers. The complete questions and scoring procedure are in Appendix B.2.

Occupation:

Occupation was determined using the corresponding subscale of the CHART. Occupation is defined as "the individual's ability to occupy time in the manner customary to that person's sex, age, and culture." The amount of time spent on various activities is used to measure this dimension. The weighted scoring is based on the relative value society places on

each of the activities. Gainful employment, schooling, and active home making and maintenance are considered priorities. Recreational pursuits, volunteer work, and self-improvement activities are also given consideration (Walker et al., 2003). The occupation subscale questions and scoring procedure are in Appendix B.4.

Economic Self-Sufficiency:

Economic self-sufficiency was determined using the corresponding subscale of the CHART. It is "the individual's ability to sustain customary socio-economic activity and independence." The amount of disposable household income minus non-reimbursed medical expenses is calculated. Family size and poverty level are also factored in during the scoring procedure (Walker et al., 2003). The actual questions and scoring procedure are in Appendix B.5.

Depression:

Depression was determined using the Center for Epidemiologic Studies Depression Scale (CES-D). It was developed by The National Institute of Mental Health to measure frequency of depressive symptoms (Radloff, 1977). The CES-D is the most widely used and validated self-esteem measure in social science research (Mitra, Wilber, Walker, & Allen, 2005). It consists of 20 questions concerning how often depressed or negative affects, positive affects, somatic symptoms, and interpersonal problems have been experienced during the past week (Shafer, 2006). The respondents are asked to choose from four possible responses where "0" is "rarely or almost never (less than 1 day)" and "4" is "most or all of the time (5-7 days)". Sixteen of the items are negative (e.g., "I felt depressed" or "I felt fearful"), and four items are positive (e.g., "I

enjoyed life” or “I was happy”). The positive questions are scored inversely for a total score between 0 and 60, with higher scores indicating higher levels of depressive symptoms. The Center for Epidemiologic Studies Depression Scale is in Appendix E.

Loneliness:

Loneliness was determined using the UCLA Loneliness Scale (Version 3). It was developed to assess subjective feelings of loneliness and social isolation (D. Russell, Peplau, & Cutrona, 1980). The UCLA Loneliness Scale is the most commonly used measure of loneliness. In 1996, the response format and the wording of the items were changed to facilitate administering the measure to less educated populations (D. W. Russell, 1996). The 20-item scale consists of subjective statements that respondents answer using a four-point scale, from 1 (“not at all”) to 4 (“frequently”). Half of the items are worded to indicate loneliness, and the other half are worded oppositely, requiring these to be scored inversely. The scores are totaled and then averaged to produce a final score between 1 (low loneliness) and 4 (high loneliness). The UCLA Loneliness Scale is in Appendix F.

2.4 Data Management

Once phone interviews were conducted or completed packets were received, questionnaires were reviewed to ensure there was no missing information. The information was then transferred from the questionnaires to the secure database. In the best interest of the participants, if a depression (CES-D) score was calculated to be above 22, the subject was notified by phone. CES-D scores above 22 can be an indicator of clinical depression (Houston *et*

al., 2001). Each subject was given a unique identification number and the following data management processes were tracked through the completion log: date the data was collected, date the data was verified, and the date the data was entered into the database. The completion log is in Appendix A.

2.5 Methods for Statistical Analysis

The data were manually entered into Microsoft Access. Once data entry was complete, the database was exported as a Microsoft Excel file and then imported into SPSS for analysis. SPSS is designed to perform complex statistical analysis functions on large datasets (Famula, Oberbauer, & Williams, 2001). For all analyses, alpha was set a priori at 0.05.

There were 214 subjects in this study, 99 of whom had been partnered with a service dog for at least 14 months but not more than 8 1/2 years. There were 115 subjects in the comparison group. Every subject used a wheelchair for 75% of their mobility needs. Frequencies and distributions were calculated for all variables to check for missing data points, outliers, and skewness. Some erroneous dates were discovered in the date of survey and date of birth variables which caused outliers when the "years living with a disability" variable was calculated. Case records were examined, corrected dates reentered, and outliers were confirmed to fall within their perspective distributions. Outliers were found within the "paid assistance" variable. Three subjects reported greater than 24 hours per day of paid assistance. These values were truncated at the third standard deviation. Despite this, both paid and unpaid assistance hours had large ranges (336 ± 79.4 and 464 ± 97 , respectively). The mode for both variables was zero, primarily due to the fact that so many subjects reported no need for any human assistance.

Personal income was dichotomized above and below \$30,000. Number of household members was dichotomized into one-person household (yes or no). Race was dichotomized into Caucasian (yes or no). Disability status (50 categories) was reduced to four categories (tetraplegia, paraplegia, other non-progressive disabilities, and progressive disabilities).

To determine if the two groups differed, chi-square statistics were calculated for the categorical demographic variables (marital, employment and Caucasian status, gender, one-person household, personal income, and disability prognosis). Independent samples t-tests were used to determine if the groups differed by the continuous demographic variables (age, years living with a disability, and years of education) which were normally distributed. Groups were significantly different in gender, income, disability prognosis, Caucasian, years with disability and marital status. Analyses were then completed to determine inter-relationships between these variables. Disability prognosis was significantly correlated with gender and income. Income was also significantly correlated with marital status. Based on the findings from that analysis, four models were developed which would be used in the Analysis of Covariance (ANCOVAs). Therefore, four models consisting of four variables each were developed to be used in ANCOVAs to control for possible confounders when comparing groups on the dependent (continuous) variables. See Table 1. The best fit model was then chosen to report in the results.

Table 1. Models of Covariates

Model 1	Model 2	Model 3	Model 4
Years with a Disability Caucasian Gender Marital Status	Years with a Disability Caucasian Gender Income	Years with a Disability Caucasian Marital Status Disability Prognosis	Years with a Disability Caucasian Disability Prognosis Income

Hypothesis 1a:

People partnered with service dogs for 14 months to 8.5 years will score higher on the Mobility and Physical Independence portions of the Craig Handicap Assessment and Reporting Technique (CHART) compared to people with similar disabilities who are not partnered with service dogs.

The mobility scores were only slightly skewed (-1.3) so an independent samples t-test was calculated. The scores for the physical independence portions of the CHART were skewed (-2.6). Therefore, Mann Whitney U statistics were calculated to compare groups. However, because the subject groups significantly differed on six out of 10 demographic variables, chi-square statistics were used to determine significant relationships between those six variables. Modeling was completed to determine the best fit for the data, using variables that were not related as covariates within the ANCOVA.

Hypothesis 1b:

People partnered with service dogs for 14 months to 8.5 years will use less paid and unpaid human assistance compared to people with similar disabilities who are not partnered with service dogs.

Both paid and unpaid human assistance hours were skewed, (3.03, 1.7) respectively, therefore, Mann-Whitney statistics were used to compare groups. Modeling was completed to determine the best fit for the data, using variables that were not related as covariates within the ANCOVA.

Hypothesis 2a:

People partnered with service dogs for 14 months to 8.5 years will score higher on the Social Integration, Occupation, and Economic Self-Sufficiency Portions of the CHART and

the Rosenberg Self-Esteem scale compared to people with similar disabilities who are not partnered with service dogs.

The Social Integration, and Occupation scores were skewed, (-1.8, -2.2) respectively, therefore, Mann-Whitney statistics were used to compare groups. The economic self-sufficiency and Rosenberg Self-Esteem scores were not skewed, therefore an independent t-test was used to compare groups. Again, because the groups were different on six out of 10 variables, modeling was completed to determine the best fit for the data, using variables that were not related as covariates within the ANCOVA.

Hypothesis 2b:

People partnered with service dogs for 14 months to 8.5 years will score lower on the UCLA Loneliness Scale (Version 3) and the Center for Epidemiologic Studies Depression Scale (CES-D), compared to people with similar disabilities who are not partnered with service dogs.

The scores for the UCLA Loneliness Scale were not skewed, therefore a t-test was used to compare groups. The CES-D scores were skewed, therefore Mann-Whitney statistics were used to compare groups. Once again, because the groups were different on six out of 10 variables, modeling was completed to determine the best fit for the data, using variables that were not related as covariates within the ANCOVA.

3.0 RESULTS

3.1 Demographics

There were 214 subjects in the study. All study participants were 18 years of age or older and used a wheelchair or scooter for 75% of their mobility needs. Ninety-nine individuals had been partnered with a service dog for at least 14 months but less than 8.5 years, with an average of 3.40 (+/- 2.06) years of partnership. One-hundred-fifteen individuals were in the comparison group. Both groups were predominately comprised of individuals who were Caucasian, with the SD group having a significantly higher percentage (97.0%/88.7%). There were also significantly fewer males in the SD group (29.3%/42.6%).

There were no significant differences between groups based on age, years of education, and employment. Subjects in both groups were approximately 44 years of age (+/-13), with an average of 15 (+/-2) years of education. Only about 35% of the subjects in either group were employed, although SD partners were significantly more likely to have an income below \$30,000. The difference was not significant, but more SD partners lived alone (37.4%), compared to the comparison group (29.6%) and the SD group had a significantly lower percentage of individuals who were married (43.2%), compared to the comparison group (62.3%).

Disability prognosis, categorized into 50 codes (see Table 4), was further sub-categorized into these four groups: tetraplegia, paraplegia, other progressive disabilities, and other non-progressive disabilities. The groups were significantly different by disability prognosis. The service dog group had a higher ratio of individuals with tetraplegia to individuals with paraplegia (13.8%/11.7%). The comparison group had an inverse ratio (21.4%/27.7%). The service dog group also had a higher percentage of individuals with progressive disabilities (47.9%), compared to the comparison group (33.9%). Further, the individuals in the service dog group were significantly more likely to have more years living with a disability (24.1 +/-14.3) than individuals in the comparison group (20.1 +/-14.5).

Forty-three (43%) subjects in the SD group reported using manual wheelchairs versus 62 (53%) in the comparison group. Sixty (61%) subjects in the SD group reported using power wheelchairs versus 55 (48%) in the comparison group, and 12(12%) subjects in the SD group reported using a scooter versus 15 (13%) in the comparison group. Eighteen subjects reported using more than one mobility device.

Table 2. Demographic Variables by Dog Ownership

	<i>Comparison Group</i>	<i>Service Dog Group</i>	<i>Sig.</i>
	n=115 (St.Dev/%)	n=99 (St.Dev/%)	
Male	49(42.6)*	29(29.3)*	.044
Caucasian	102 (88.7)*	96 (97)*	.034
Age	43.7(+/-13.3)	44.4(+/-12.5)	.695
Years with Disability	20.1(+/-14.5)*	24.1(+/-14.3)*	.041
Years of Education	14.8 (\pm 1.9)	14.6 (\pm 2.1)	.566
Working	39 (34.2)	36 (36.4)	.743
Personal Income >\$30K	30 (35.7)*	17 (20.2)*	.025
One Person Household	34 (29.6)	37 (37.4)	.226
Married	71 (62.3)*	43 (43.2)*	.006
Disability Prognosis			.005
Tetraplegia	24 (21.4%)	13 (13.8%)	
Paraplegia	31 (27.7%)	11 (11.7%)	

Other Disabilities (Progressive)	38 (33.9%)	45 (47.9%)	
Other Disabilities (Non-progressive)	19 (17.0%)	25 (26.6%)	
*p<0.05			

3.2 Specific Aim 1

To discover the long-term influence of service dog partnership on the functional performance of individuals partnered with service dogs for 14 months to 8.5 years.

Hypothesis 1a: People partnered with service dogs for 14 months to 8.5 years will score higher on the Mobility and Physical Independence portions of the Craig Handicap Assessment and Reporting Technique (CHART) compared to people with similar disabilities who are not partnered with service dogs.

Results of the t-test, showed a trend to significance ($p=0.07$) that mobility scores for the service dog group were higher 88.3 (+/-15.6) than those of the comparison group 83.9 (+/-19.6). When controlling for the following factors -- years with a disability, Caucasian/non-Caucasian status, marital status, and disability prognosis -- results showed that the difference in scores was significant (0.038), as can be seen in Figure 1.

The mean Physical Independence score for the SD group was 87.0 (+/-19.1). The mean score for the comparison group was 83.9 (+/-25.3). The Mann-Whitney U did not show a significant difference between groups. When using ANCOVAs to control for confounders, no significant differences were found. When looking at the mean scores of the two groups for the mobility and physical independence subscales of the CHART displayed in Figure 1, the SD

group scored slightly higher than the comparison group on both subscales, although the difference in physical Independence scores was not significant.

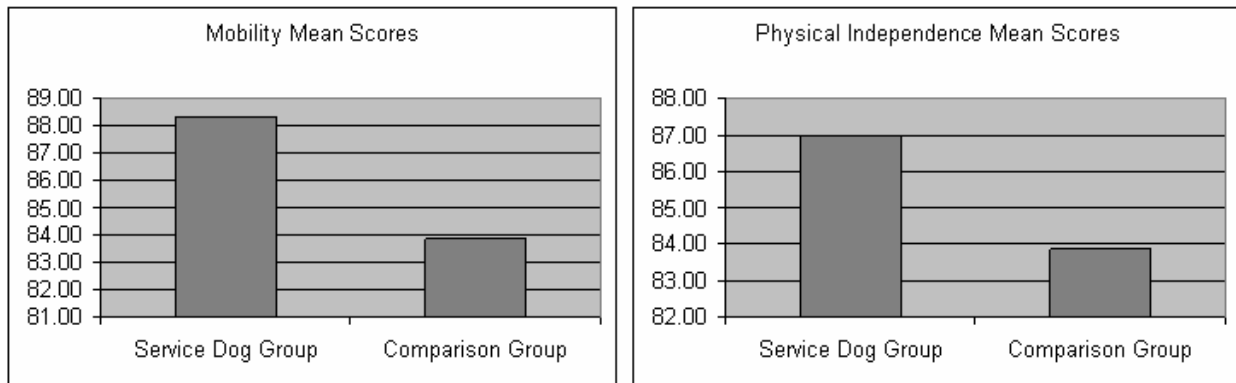


Figure 1. Mobility and Physical Independence (CHART) Scores

Hypothesis 1b: People partnered with service dogs for 14 months to 8.5 years will use less paid and unpaid human assistance compared to people with similar disabilities who are not partnered with service dogs.

The SD group used an average of 56.4 (+/-82.5) hours per week of paid assistance, while the comparison group used an average of 39.7 (+/-76.1) hours per week. The SD group used an average of 61.0 (+/-86.0) hours per week of unpaid assistance, and the comparison group used an average of 81.4 (+/-105.3) hours per week. The Mann-Whitney U approached significance for paid hours (.058), whereas the difference in unpaid hours was not significant (.273). When using an ANCOVA to control for confounders, there was no significant difference between groups for paid or unpaid hours. When looking at the number of paid and unpaid assistance hours in Figure 2, the SD group used slightly more paid assistance but slightly less unpaid assistance.

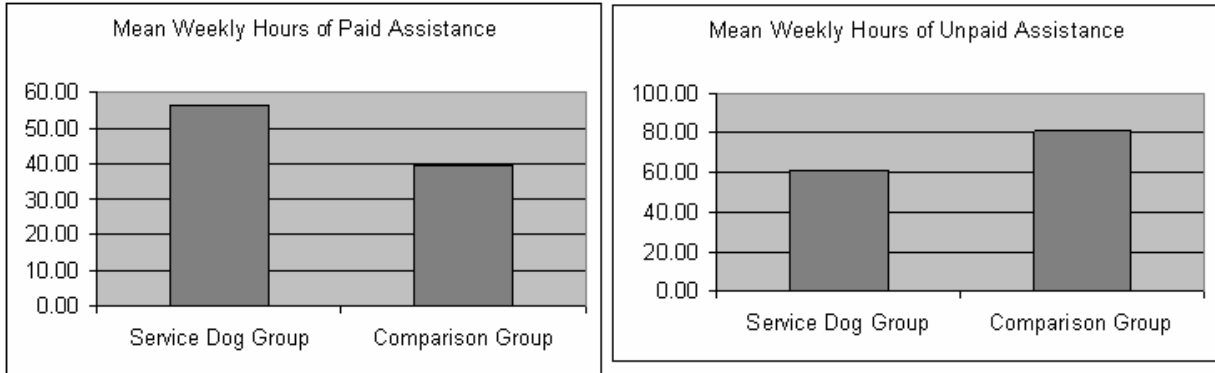


Figure 2. Weekly Hours of Paid and Unpaid Assistance

3.3 Specific Aim 2:

To discover the long-term influence of service dog partnership on the psychosocial well-being of individuals partnered with service dogs for one year or more.

Hypothesis 2a: People partnered with service dogs for 14 months to 8.5 years will score higher on the Social Integration, Occupation, and Economic Self-Sufficiency Portions of the CHART and the Rosenberg Self-Esteem scale compared to people with similar disabilities who are not partnered with service dogs.

The mean social integration score for the SD group was 89.6 (+/-17.9). The mean score for the comparison group was 85.0 (+/-21.9). The Mann-Whitney U did not produce significant results. When controlling for confounders using ANCOVAs, the difference was not significant. The mean occupational score for the SD group was 65.4 (+/-29.0), and the mean score for the comparison group was 63.8 (+/-32.7). The t-test did not produce significant results, and when controlling for confounders using ANCOVAs, the difference was not significant. The mean

scores for the social integration and occupational subscales of the CHART for both groups are displayed in Figure 3. The SD group scores tend to be slightly higher for both subscales.

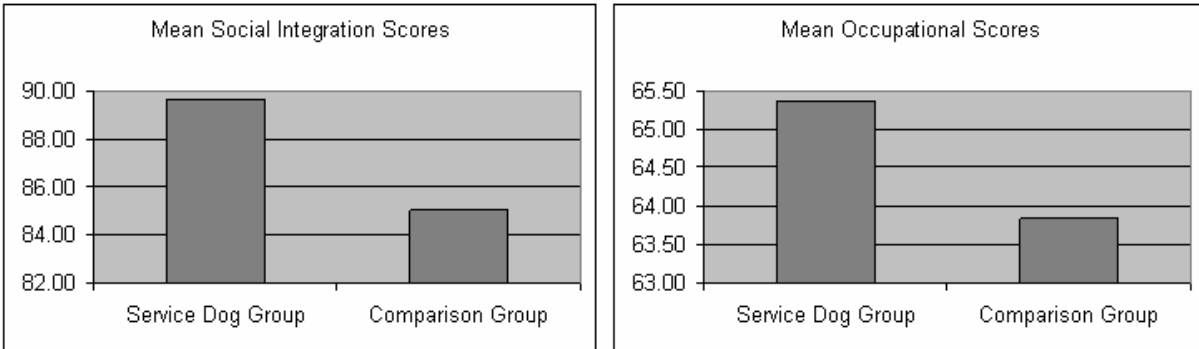


Figure 3. Social Integration and Occupational (CHART) Scores

The mean economic self-sufficiency score for the SD group was 74.0 (+/- 34.8). The mean score for the comparison group was 74.8 (+/- 32.0). The t-test did not produce significant results. When controlling for confounders using ANCOVAs, the difference was not significant.

The mean Rosenberg self-esteem scores for the SD and comparison groups were 32.3 (+/- 5.2) and 31.4 (+/-5.6) respectively. The t-test did not produce significant results, and when controlling for confounders using ANCOVAs, the difference was not significant. These results are displayed in Figure 4.

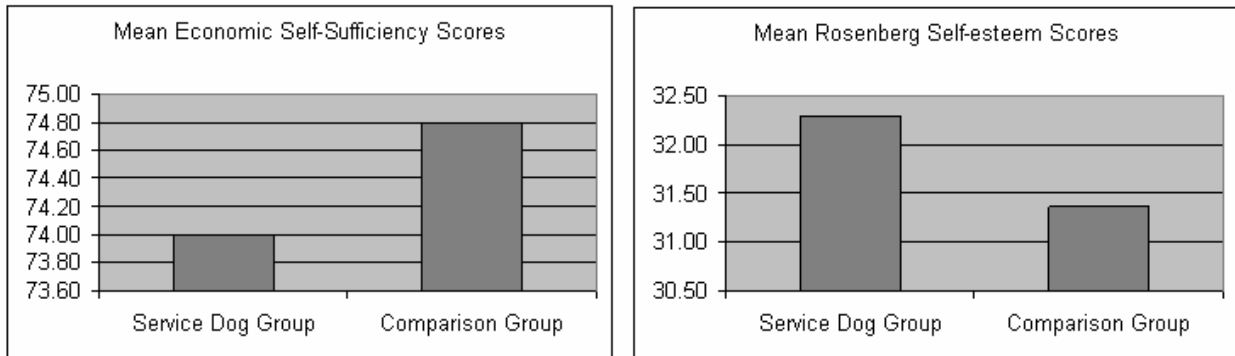


Figure 4. Economic Self-Sufficiency (CHART) and Rosenberg Self-Esteem Scores

Hypothesis 2b: People partnered with service dogs for 14 months to 8.5 years will score lower on the UCLA Loneliness Scale (Version 3) and the Center for Epidemiologic Studies Depression Scale (CES-D), compared to people with similar disabilities who are not partnered with service dogs.

The UCLA loneliness scores for the SD and comparison groups were 38.4 (+/-5.1) and 40.0 (+/-12.3) respectively. The t-test did not produce significant results, and when controlling for confounders using ANCOVAs, the difference was not significant.

The mean CES-D scores for the SD and comparison groups were 11.6 (+/-9.1) and 14.2 (+/-11.7) respectively. The Mann-Whitney U did not produce significant results, and once again, when controlling for confounders using ANCOVAs, the difference was not significant. It should be noted that 10 of the subjects in the SD group (10.1%) scored above 22 (a possible indicator of clinical depression), whereas 18 (15.6%) of the subjects in the comparison group scored above 22. The loneliness and depression scores depicted in Figure 5 show that the SD group scored lower on both scales.

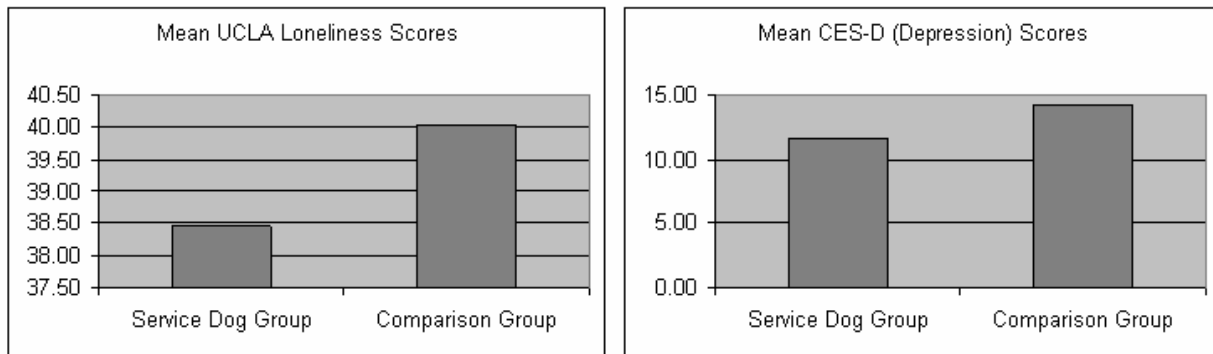


Figure 5. UCLA Loneliness and CES-D (Depression) Scores

3.4 Results Summary

Table 3. Outcomes

Variable	SD Group	Comparison Group	Significance
Mobility	88.3 (+/-15.6)	83.9 (+/-19.6)	Yes (p=0.038)
Physical Independence	87.0 (+/-19.1)	83.9 (+/-25.3)	No
Paid Assistance	56.4 (+/-82.5)	39.7 (+/-76.1)	No
Unpaid Assistance	61.0 (+/-86.0)	81.4 (+/-105.3)	No
Social Integration	89.6 (+/-17.9)	85.0 (+/-21.9)	No
Occupation	65.4 (+/-29.0)	63.8 (+/-32.7)	No
Economic Self-sufficiency	74.0 (+/- 34.8)	74.8 (+/- 32.0)	No
Self-esteem	32.3 (+/-5.2)	31.4 (+/-5.6)	No
Loneliness	38.4 (+/-5.1)	40.0 (+/-12.3)	No
Depression	11.6 (+/-9.1)	14.2 (+/-11.7)	No

4.0 DISCUSSION

The results of this study show that service dog (SD) partners are significantly more "mobile" than individuals without service dogs. Also, even though the individuals partnered with service dogs in this study had more severe disabilities and required almost significantly more formal assistance, they tended to slightly outperform the comparison group (although not to a significant degree) on all but two of the other hypothesized quality of life indicators (hours of paid assistance and economic self-sufficiency); individuals in the SD group reported including less unpaid (informal) assistance, higher levels of physical independence, and self-esteem, and lower levels of depression and loneliness. These results could confirm those of previous studies. According to the Craig Handicap and Assessment Reporting Technique (CHART), higher mobility means that individuals are more able to move about effectively in their communities, including being able to go where and when they wish (Dijkers, Yavuzer, Ergin, Weitzenkamp, & Whiteneck, 2002; Walker et al., 2003). Given the cross-sectional design of the study, causality cannot be determined, but the data indicates a relationship between SD partnership and mobility as measured by the CHART.

Mobility is possibly the most important activity of daily living for individuals with severe mobility impairments. For example, Dijkers et al. (2002) cite the claim by the The World Health Organization and the National Institute on Disability and Rehabilitation Research that "impairment, ADLs (activities of daily living), and mobility interact with the cultural, social and

physical environment to impact social participation." Social participation refers to "the satisfaction of needs and the accomplishment of personal, professional and public goals in direct and indirect contact with others, in one's immediate family and neighborhood, and in society at large."

According to the analysis, the 4.4 point difference in mobility scores between groups was statistically significant, but from a clinical standpoint, this small of a difference in mobility scores may seem insignificant in a "real-world" setting. However, examination of the scoring procedure for the mobility subscale of the CHART may put things in perspective. Such a decrease equates to an additional two hours spent in bed every day. Spending one day a week indoors without exiting the home, or not being able to exit the home or access transportation without human assistance are all scored as five points each. Having independent access to the sleeping area, bathroom, kitchen, and TV or radio is also scored as five points. For individuals whose mobility has already been reduced by 12 to 16 points according to the previous criteria, an additional reduction or increase of even a few points could have a major impact on quality of life.

Lane, McNicholas & Collis (1998) found that when SD partners were asked "What are the most important tasks your dog performs for you?", the second most popular response after "retrieving and carrying" (84%) was "opening doors" (40%). In Fairman and Heubner's (2000) study, the next most popular tasks reported after "retrieving" (99.9%) were "getting around the community" (84.2%), "getting around the house" (82.2%), and "shopping" (75.7%). The next two most popular responses were that SDs allowed their partners to participate in more play and leisure activities (66.8%) and assisted them by actually participating in play and leisure activities (63.4%).

As mentioned previously, the SD group scored better the comparison group (although not to a significant degree) on all but two of the hypothesized measures. One measure that produced contrary results (paid assistance), might be explained by the significant differences of disability prognosis between groups. The SD group had a higher ratio of individuals with tetraplegia to individuals with paraplegia. The comparison group had an inverse ratio. Also, the SD group had a higher percentage of individuals with progressive disabilities than the comparison group. Individuals with more severe disabilities are typically prescribed more hours of paid (formal) assistance. This would account for individuals in the SD group using almost significantly (.058) more paid assistance, but does not explain why they used a lower number of unpaid assistance hours. This might be explained by the fact that SD partners have a personal assistant (their SD) with them 24 hours a day, seven days a week, relieving the unpaid assistants to pursue other activities. It is also interesting to note that the SD group had significantly lower incomes thereby causing them to be even more reliant on the unpaid (informal) assistance.

In a retrospective study by Fairman and Heubner (2000), respondents reported a decline of six hours per week of unpaid assistance. It was also noted that family caregivers were able to relax more when away knowing that the SD was there to assist and "watch over" their loved one. In a study by Rintala, Sachs-Ericsson & Hart (2002), 63% of participants reported burdening their caregivers less after receiving their SDs.

The SD group had higher physical independence scores (although not to a significant degree), in spite of the fact that this group was more severely disabled. It should be noted that the primary factors used to calculate the physical independence subscale of the CHART are the number of hours assistance is provided for such things as bathing, toileting, dressing, eating, grocery shopping, laundry, housekeeping, cooking, cleaning, household maintenance, or for

infrequent medical needs because of the disability. Fairman and Heubner (2000) found that SDs were assisting their partners with health maintenance (59.4%), dressing (48%), personal grooming (44.1%), emergency response (42.6%), bathing (19.8%), feeding and eating (18.3%), toileting (17.8%), oral hygiene (17.8%), cleaning (54.5%), clothing care (40.1%), meal preparation (39.1%), and household maintenance (33.2%). SDs assisting their partners with these various activities may explain why the SD group scored slightly higher than the comparison group on physical independence. However, the results were insignificant. The SD group had higher physical independence scores (although not to a significant degree), again, in spite of the fact that this group was more severely disabled. When scoring the occupational subscale of the CHART, hours per week spent on pursuing education, volunteering, homemaking, sports, and recreational and leisure activities including going to movies are all added together with hours spent working for pay. Fairman and Heubner (2000) found that SDs were assisting their partners with work-related activities (45.5%), school related activities (22.3%), cleaning (54.5%), play or leisure activities (66.8%). Service dogs assisting their partners may be the reason for the difference in scores.

The SD group had better scores than the comparison group (although not to a significant degree) on the social and psychological quality of life indicators. If SD partnership is responsible for these differences, it would be consistent with the findings of several previous studies that have shown that SDs increase both social interactions and self-esteem, as well as reducing symptoms of depression and loneliness (Camp, 2001; Fairman & Heubner, 2000; Fitzgerald & Collins, 2005; Lane et al., 1998; Mader et al., 1989; Rintala et al., 2002).

It was hypothesized that significant findings would result from limiting the SD group to only individuals who had been partnered for at least 14 months and no more than 8.5 years.

However, results did not differ from previous cross-sectional studies on service dogs, where the SD group included all individuals with SDs regardless of how long they had been partnered with their dog (Collins, 2004).

4.1 Limitations

Limitations of this study included reliance on self-reported data which can result in data inconsistencies. Many of the questions in the survey instrument used for this study required subjects to recall and quantify the number of hours or the number of times certain activities took place over the past day, week, or month. Subjects may not have remembered events accurately. Questionnaires produce subjective data making it difficult to compare subjects. Using a cross-sectional design, causality cannot be established to explain the difference in mobility scores or determine if the results extend over time. Also, it cannot be determined to what extent the sample can be generalized to larger populations.

Some of the questionnaires were completed by the subjects without assistance at their homes, while others were completed over the phone with the assistance of researchers. Not having a researcher available to answer questions could have resulted in inconsistencies, wrongful answers and missing data points that might otherwise have been avoided. Questionnaires completed via telephone interviews could have resulted in wrongful answers and inconsistencies for other reasons. For instance, misunderstandings could have resulted from the use of speaker phones. Many individuals with severe disabilities are dependent on them or could have been using them to avoid holding the handset during long phone conversations (questionnaires could take up to an hour or more to complete). Also, researchers could have had

trouble interpreting accents or dialects. Further, subjects may have grown weary or impatient during long phone conversations resulted in loss of interest or concentration. Further, some individuals completing questionnaires at home may have desired or needed assistance but did not seek it to avoid the expense of a long-distance phone call.

Pets may have been a factor in this study. Data regarding how many subjects in the comparison group had pets, dogs in particular, was not available. Therefore, it is not possible to determine if psychosocial outcomes were a result of having a dog as a pet or as a type of assistive technology.

Differences in the findings may have been the result of basic underlying differences between individuals that choose to be partnered with a service dog and those who do not. Also, data was available on comorbid conditions, but were not factored into the analysis which could have contributed to a better examination of the assistance hours used.

4.2 Future Studies

More rigorously designed pre-post and longitudinal studies with large samples and comparison groups following subjects for more than two years should be conducted to further examine the benefits of service dog partnership. Preliminary qualitative studies should be conducted to determine possible variables to be measured.

If questionnaires and survey instruments are to be used, they should be kept as short as possible so participants don't grow weary or lose interest completing them. For instance, rather than inquiring as to the specific relationship that exist between the subject and the caregiver, it may suffice to simply find out if the caregiver was a significant other, family member, friend, or

other paid helper. Also, instead of expecting participants to recall weeks or months after the fact how many minutes were spent during travel time, wait time, visit, and total time for each individual medical appointment, it may be less confusing to simply ask “how many medical appointments have you had, and including travel time, how much time did you spend for each appointment?” Further, perhaps the five currently used psychosocial assessment tools consisting of a total of 94 questions could be replaced with a quality of life assessment tool such as the Quality of Life Inventory (32 questions), Meaning in Life Questionnaire (10 questions), or the Satisfaction with Life Scale (five questions).

The administration of survey instruments should be done in a more uniform manner to prevent inconsistencies and missing data points. Journals, activity diaries, or logs that could be filled out on a daily basis as events take place would be preferable to expecting participants to recall events weeks or months after the fact. This would eliminate some of the recall problems with questionnaire surveys.

The cost benefit of using a service dog instead of a reacher or a pair of crutches should be quantified. A method of measuring the value of working, recreating, shopping, and performing other daily living activities independently compared to being dependent on human assistance should be devised. The ever-increasing demand for service dogs is evidence that they provide benefits to their partners and translating these benefits into quantifiable data however difficult merits further investigation.

5.0 CONCLUSION

There is a relationship between service dog partnership and mobility as measured by the Craig Handicap and Assessment Reporting Technique. The groups differed significantly on six out of ten demographic variables. The groups did not differ significantly on any of the dependent variables except mobility. The service dog group did however tend to outperform the comparison group on all but two quality-of-life indicators, even though this group had significantly more individuals with severe and progressive disabilities and had significantly lower incomes. Future studies should be devised that can quantify the quality of life benefits of service dog partnership.

Appendix A. Completion Log and Disability Codes

COMPLETION LOG:	DATE:	INITIALS:	TIME:
Subject ID# _____			
Data Collection	/ /		
Data Entry	/ /		
Verification	/ /		
Date of Receipt of Dog	/ /		
Dog's Name			
Dog's Breed/Type			
Agency: (1) Paws (2) CCI (3) other			
Successor Dog?			

Figure 6. Completion Log

Table 4. Disability Codes

Disability Codes		
Progressive	Code	Description:
0	1	SCI, combination (spinal cord injury, combination of levels)
0	2	SCI, C-1/2 (spinal cord injury, cervical level)
0	3	SCI, C3 (spinal cord injury, cervical level)
0	4	SCI C4 (spinal cord injury, cervical level)
0	5	SCI C5 (spinal cord injury, cervical level)
0	6	SCI C6 (spinal cord injury, cervical level)
0	7	SCI C7 (spinal cord injury, cervical level)
0	8	SCI C8 (spinal cord injury, cervical level)
0	9	SCI T1 (spinal cord injury, thoracic level)
0	10	SCI T2 (spinal cord injury, thoracic level)
0	11	SCI T3 (spinal cord injury, thoracic level)
0	12	SCI T4 (spinal cord injury, thoracic level)
0	13	SCI T5 (spinal cord injury, thoracic level)
0	14	SCI T6 (spinal cord injury, thoracic level)
0	15	SCI T7 (spinal cord injury, thoracic level)
0	16	SCI T8 (spinal cord injury, thoracic level)
0	17	SCI T9 (spinal cord injury, thoracic level)
0	18	SCI T10 (spinal cord injury, thoracic level)
0	19	SCI T11 (spinal cord injury, thoracic level)
0	20	SCI T12 (spinal cord injury, thoracic level)
0	21	SCI L1 (spinal cord injury, lumbar level)
0	22	SCI L2 (spinal cord injury, lumbar level)
0	23	SCI L3 (spinal cord injury, lumbar level)
0	24	SCI L4 (spinal cord injury, lumbar level)
0	25	SCI L5 (spinal cord injury, lumbar level)
0	26	SCI S1 thru S5 (spinal cord injury, sacral level)
0	27	CP (cerebral palsy)
1	28	MD (muscular dystrophy)
0	29	SB (spina bifida)
1	30	MS (muscular dystrophy)
0	31	Other
1	32	RA (rheumatoid osteoarthritis)/Degenerative Joint Disease
1	33	Spinal Muscular Atrophy
1	34	Post Polio Syndrome
0	35	TBI (traumatic brain injury)/head injury
0	36	CVA (cerebrovascular accident)
0	37	CVD (cardiovascular disease)
0	38	Amputee
0	39	Osteogenesis Imperfecta
1	40	RSD (reflex sympathetic dystrophy)
1	41	Arthrogryposis
0	42	SLE or Lupus
1	43	ALS
1	44	Spinal Astrocytoma
0	50	Hearing impairment

Appendix B. Craig Handicap and Assessment Reporting Technique

<p>9. On a <u>typical day</u>, how many hours are you out of bed? _____ hours</p>	<p>A. Multiply the number of hours out of bed by 2.</p>	<p>MOBILITY</p> <hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">+</p>
<p>10. In a <u>typical week</u>, how many days do you get out of your house and go somewhere? _____ days</p>	<p>B. Multiply the number of days per week out of the house by 5.</p>	<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">+</p>
<p>11. In the <u>last year</u>, how many nights have you spent away from your home (excluding hospitalizations?) _____ none _____ 1-2 _____ 3-4 _____ 5 or more</p>	<p>C. Assign points as follows: no nights out = 0; 1-2 nights out = 10; 3-4 nights out = 15; 5 or more nights = 20.</p>	<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">+</p>
<p>12. Can you enter and exit your home without any assistance from someone? yes ___ no ___</p>	<p>D. For questions #12-#17, assign 5 points for each "yes" response and 0 points for each "no" response.</p>	<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#12)</p> <p style="text-align: center;">+</p>
<p>13. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)? ___ yes ___ no</p>		<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#13)</p> <p style="text-align: center;">+</p>
<p>14. Can you use your transportation independently? ___ yes ___ no</p>		<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#14)</p> <p style="text-align: center;">+</p>
<p>15. Does your transportation allow you to get to all the places you would like to go? ___ yes ___ no</p>		<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#15)</p> <p style="text-align: center;">+</p>
<p>16. Does your transportation let you get out whenever you want? ___ yes ___ no</p>		<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#16)</p> <p style="text-align: center;">+</p>
<p>17. Can you use your transportation with little or no advance notice? ___ yes ___ no</p>	<p>E. Add the sums from "A", "B", "C", and "D". If the total sum is greater than 100, enter 100.</p>	<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(#17)</p> <p style="text-align: center;">=</p> <div style="border: 1px solid black; width: 100%; height: 20px; margin-top: 5px;"></div>

Figure 7. Mobility Subscale of the CHART

<p>1. How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility? _____ hours paid assistance _____ hours unpaid (family, others)</p>	<p>A. Total the hours of paid and unpaid care.</p>	<p>PHYSICAL INDEPENDENCE</p> <hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">+</p>
<p>2. Not including any regular care as reported above, how many hours in a <u>typical month</u> do you occasionally have assistance with such things as grocery shopping, laundry, housekeeping, or infrequent medical needs because of the disability? _____ hours per month</p>	<p>B. Divide the hours of occasional care by 30.</p>	<hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">(_____ / 30)</p> <p style="text-align: center;">=</p>
<p>3. Who takes responsibility for instructing and directing your attendants and/or caregivers? _____ Self _____ Someone Else _____ Not applicable, does not use attendant care</p>	<p>C. Add the sums of "A" and "B".</p>	<hr style="width: 80%; margin: 0 auto;"/>
	<p>D. If the respondent instructs and directs his/her own attendants or caregivers, multiply the answer of "C" by 3. If someone other than the respondent instructs and directs the attendants or caregivers, multiply the answer of "C" by 4.</p>	<p style="text-align: center;">X 3 or 4</p> <p style="text-align: center;">=</p> <hr style="width: 80%; margin: 0 auto;"/>
	<p>E. Subtract the total in "D" from 100.</p>	<p style="text-align: center;">100</p> <p style="text-align: center;">minus</p> <hr style="width: 80%; margin: 0 auto;"/> <p style="text-align: center;">sum from "D" above</p> <p style="text-align: center;">=</p> <div style="border: 1px solid black; width: 100%; height: 20px; margin-top: 5px;"></div>

Figure 8. Physical Independence Subscale of the CHART

		SOCIAL INTEGRATION
25.	Do you live alone? ___Yes ___No	
25a.	(If you don't live alone) do you live with a spouse or significant other? ___Yes ___No	
25b.	How many children do you live with? _____	
25c.	How many other relatives do you live with? _____	
25d.	How many roommates do you live with? _____	
25e.	How many attendants do you live with? _____	
26.	(If you don't live with a spouse or significant other) are you involved in a romantic relationship? ___Yes ___No ___N/A	
27.	How many relatives (not in your household) do you visit, phone, or write to at least once a month? _____Relatives	
28.	How many business or organizational associates do you visit, phone, or write to at least once a month? _____Associates	
29.	How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month? _____Friends	
30.	With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)? ___none ___ 1-2 ___ 3-5 ___ 6 or more	
	A. Assign 30 points if living with spouse/partner <u>OR</u> assign 20 points if living with unrelated roommate and/or an attendant.	_____
		+
	B. Assign 20 points if in a romantic relationship, unless points are assigned in "A". If in a romantic relationship and points are assigned in "A", then "B" equals 30 minus "A".	_____
		+
	C. Add the number of children in household and number of other relatives in household to number of relatives contacted monthly. Multiply by 5. A maximum score for this component is 25 points.	_____
		+
	D. If living with more than one attendant, add <u>extra</u> attendants to number of business or organizational associates contacted monthly. Multiply by 2. A maximum score for this component is 20 points.	_____
		+
	E. If living with more than one roommate, add <u>extra</u> roommate to number of friends contacted monthly. Multiply by 10. A Maximum score for this component is 50 points.	_____
		+
	F. Assign points as follows: none = 0 points; 1-2 = 10 points; 3-5 = 15 points; 6 or more = 20 points.	_____
	G. Add the sums from "A", "B", "C", "D", "E", and "F". If the total sum is greater than 100, enter 100.	_____
		=
		[]

Figure 9. Social Integration Subscale of the CHART

<p>18. How many hours per week do you spend working in a job for which you get paid? hours _____</p> <p>19. How many hours per week do you spend in school working toward a degree or in an accredited technical training program (including hours in class and studying)? _____ hours</p> <p>20. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation? _____ hours</p> <p>21. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? _____ hours</p> <p>22. How many hours per week do you spend in ongoing volunteer work for an organization? _____ hours</p> <p>23. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio. _____ hours</p> <p>24. How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? Please do not include time spent watching TV or listening to the radio. _____ hours</p>	<p>A. Multiply the number of hours working by 2.</p> <p>B. Multiply the number of hours in school by 2.</p> <p>C. Multiply the number of hours in active homemaking by 2.</p> <p>D. Multiply the number of hours in home maintenance by 2.</p> <p>E. Add the number of hours in volunteer work to the number of hours in recreational activities and the number of hours in other self-improvement activities.</p> <p>F. Add the sums of "A", "B", "C", "D", and "E". If the total sum is greater than 100, enter 100.</p>	<p>OCCUPATION</p> <p>_____</p> <p>+</p> <p>_____</p> <p>+</p> <p>_____</p> <p>+</p> <p>_____</p> <p>+</p> <p>_____</p> <p>(#22)</p> <p>+</p> <p>_____</p> <p>(#23)</p> <p>+</p> <p>_____</p> <p>(#24)</p> <p>=</p> <div style="border: 1px solid black; width: 100px; height: 20px; margin: 0 auto;"></div>
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Figure 10. Occupation Subscale of the CHART

<p>31. Approximately what was the combined annual income, in the last year, of all family members in your household? (consider all sources including wages and earnings, disability benefits, pensions and retirement income, income from court settlements, investments and trust funds, child support and alimony, contributions from relatives, and any other source.)</p> <p>\$ _____</p> <p>32. Approximately how much did you pay last year for medical care expenses? (Consider any amounts paid by yourself or the family members in your household and not reimbursed by insurance or benefits.)</p> <p>\$ _____</p>	<p>A. Calculate family size by adding respondent, plus partner (if living with respondent), plus number of children in household, plus other relatives in household.</p> <p>B. Subtract the unreimbursed medical expenses from the annual income (amount in question #31 minus amount in question #32).</p> <p>C. Determine poverty level from family size calculated in "A".</p> <p>D. Divide the value from "B" by the poverty level from "C".</p> <p>E. Determine points as follows: If the sum from "D" is:</p> <p>0.0 to <0.5 = 0 points 0.5 to <1.0 =25 points 1.0 to <1.5 =50 points 1.5 to <2.0 =75 points 2.0 or greater =100 points</p>	<p>ECONOMIC SELF SUFFICIENCY</p> <p>_____</p> <p>Family size</p> <p>_____</p> <p>(#31)</p> <p>minus</p> <p>_____</p> <p>(#32)</p> <p>=</p> <p>_____</p> <p>divided by</p> <p>_____</p> <p>Poverty level</p> <p>=</p> <p>_____</p> <p>Convert to points as indicated</p> <p>=</p> <div style="border: 1px solid black; width: 100px; height: 20px; margin: 0 auto;"></div>
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Figure 11. Economic Self-Sufficiency Subscale of the CHART

Appendix C. Hours of Human Assistance Used

During the PAST MONTH did you need someone to help you or provide **PHYSICAL ASSISTANCE FOR PERSONAL CARE ACTIVITIES** such as eating, bathing, dressing, toileting and mobility?

	(0)	No →	PLEASE GO TO QUESTION #13
	(1)	Yes →	Please complete the table below:

Please answer the following information based on help you receive on a weekly basis:				
Who helps you?	How many hours per week do they help you? **	Do you pay them? (Circle YES/NO)	Do they take time off from work to help you? (Circle YES/NO)	What is the occupation of the person(s) helping you?
Spouse/Partner	____ hrs/ ____ code	YES NO	YES NO	
Parent	____ hrs/ ____ code	YES NO	YES NO	
Daughter/Son	____ hrs/ ____ code	YES NO	YES NO	
Other Relative	____ hrs/ ____ code	YES NO	YES NO	
Friend:	____ hrs/ ____ code	YES NO	YES NO	
Friend:	____ hrs/ ____ code	YES NO	YES NO	
Paid Helper (\$ ____ /hr)	____ hrs/ (n/a code)	Not Applicable	Not Applicable	Not Applicable

Figure 12. Human Assistance ADL

During the PAST MONTH did you need someone to help you with things such as **GROCERY SHOPPING, HOUSEKEEPING, OR RUN ERRANDS** because of your disability? (Do not include any help or time related to seeing physicians or any health professional – this will be addressed separately in another question)

	(0)	No →	PLEASE GO TO QUESTION #14
	(1)	Yes →	Please complete the table below:

Please answer the following information based on help you receive on a weekly basis:				
Who helps you?	How many hours per WEEK do they help you? **	Do you pay them? (Circle YES/NO)	Do they take time off from work to help you? (Circle YES/NO)	What is the occupation of the person(s) helping you?
Spouse/Partner	____ hrs/ ____ code	YES NO	YES NO	
Parent	____ hrs/ ____ code	YES NO	YES NO	
Daughter/Son	____ hrs/ ____ code	YES NO	YES NO	
Other Relative	____ hrs/ ____ code	YES NO	YES NO	
Friend:	____ hrs/ ____ code	YES NO	YES NO	
Friend:	____ hrs/ ____ code	YES NO	YES NO	
Paid Helper (\$ ____ /hr)	____ hrs/ (n/a code)	Not Applicable	Not Applicable	Not Applicable

Figure 13. Human Assistance IADL

Appendix D. Rosenberg Self-Esteem Scale

Please read each of the following statements and indicate the extent to which you agree or disagree with each statement

1	2	3	4
strongly disagree	disagree	agree	strongly agree

1. _____ I feel that I'm a person of worth, at least on an equal plane with others.
2. _____ I feel that I have a number of good qualities.
3. _____ All in all, I am inclined to feel that I am a failure.
4. _____ I am able to do things as well as most other people.
5. _____ I feel I do not have much to be proud of.
6. _____ I take a positive attitude toward myself.
7. _____ On the whole, I am satisfied with myself.
8. _____ I wish I could have more respect for myself.
9. _____ I certainly feel useless at times.
10. _____ At times I think I am no good at all.

Figure 14. Rosenberg Self-Esteem Scale

Appendix E. Center for Epidemiologic Studies Depression Scale

Circle the number next to each item that best reflects how frequently you have experienced that event in the past seven days .	Rarely or None of the time (less than 1 day)	Some or a little of the time (1- 2 days)	Occasion- ally or moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I did not feel like eating; my appetite was poor.	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
*4. I felt that I was just as good as other people.	0	1	2	3
5. I had trouble keeping my mind on what I was doing.	0	1	2	3
6. I felt depressed.	0	1	2	3
7. I felt that everything I did was an effort.	0	1	2	3
*8. I felt hopeful about the future.	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11. My sleep was restless.	0	1	2	3
*12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
*16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get going.	0	1	2	3

Figure 15. Center for Epidemiologic Studies Depression Scale

Appendix F. UCLA Loneliness Scale (Version 3)

Instructions: The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by writing a number in the space provided. Here is an example:

How often do you feel happy?

If you never felt happy, you would respond "never"; if you always feel happy, you would respond "always".

	<u>NEVER</u>	<u>RARELY</u>	<u>SOMETIMES</u>	<u>ALWAYS</u>	
	1	2	3	4	
*1.	How often do you feel that you are "in tune" with the people around you?				_____
2.	How often do you feel that you lack companionship?				_____
3.	How often do you feel that there is no one you can turn to?				_____
4.	How often do you feel alone?				_____
*5.	How often do you feel part of a group of friends?				_____
*6.	How often do you feel that you have a lot in common with the people around you?				_____
7.	How often do you feel that you are no longer close to anyone?				_____
8.	How often do you feel that your interests and ideas are not shared by those around you?				_____
*9.	How often do you feel outgoing and friendly?				_____
*10.	How often do you feel close to people?				_____
11.	How often do you feel left out?				_____
12.	How often do you feel that your relationships with others are not meaningful?				_____
13.	How often do you feel that no one really knows you well?				_____
14.	How often do you feel isolated from others?				_____
*15.	How often do you feel you can find companionship when you want it?				_____
*16.	How often do you feel that there are people who really understand you?				_____
17.	How often do you feel shy?				_____
18.	How often do you feel that people are around you but not with you?				_____
*19.	How often do you feel that there are people you can talk to?				_____
*20.	How often do you feel that there are people you can turn to?				_____

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