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DAILY BENEFITS OF LEADER DOGS IN ADDITION TO MEDICAL TREATMENT FOR
INDIVIDUALS WITH USHER SYNDROME: A CASE STUDY

By

Samantha Zwolan

A capstone project submitted to the Graduate Faculty in Audiology in partial fulfillment of the
requirements of the Doctor of Audiology, The City University of New York

2021

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INDIVIDUALS WITH USHER SYNDROME: A CASE STUDY

By

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This manuscript has been approved by the Graduate Faculty in Audiology in satisfaction of the
capstone project requirements for the degree of Au.D.

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ABSTRACT**DAILY BENEFITS OF LEADER DOGS IN ADDITION TO MEDICAL TREATMENT FOR INDIVIDUALS WITH USHER SYNDROME: A CASE STUDY**

By

Samantha Zwolan

Adviser: Barbara Weinstein, PhD

Background

Adults with Usher syndrome seeking audiologic rehabilitation and treatment often experience everyday difficulties that are not fully resolved using typical medical treatments. This case study examines the difficulties faced by individuals diagnosed with Usher syndrome in their everyday life, including quality of life, safety, and social issues. Additionally, the non-medical benefits that leader dogs can provide such individuals is also presented.

Method

A thorough literature review was performed to provide background information regarding Usher syndrome and the impact it has on the hearing and vision of affected individuals. A related literature review was performed to examine the role that leader dogs for those with hearing and vision loss play in their rehabilitation. To highlight the connections, an in-depth phone interview was conducted with an individual who was diagnosed with Usher syndrome, who is also a long-time proponent and user of leader dogs. The goal of this case study is to further understand and report on the everyday difficulties faced by someone with vision and hearing loss and highlight the benefits that arise from having a leader dog.

Results

Usher syndrome occurs in approximately 4 to 17 people per 100,000 people. It is a highly impactful and devastating diagnosis since it typically results in loss of both hearing and vision—two senses that importantly contribute to safety and communication. There are various medical treatment options available for patients diagnosed with Usher syndrome to improve their hearing and communication challenges associated with this syndrome. One non-medical intervention option that can assist such patients with both safety and communication that is often overlooked is leader dogs. Leader dogs provide a wide variety of benefits to those with hearing and vision loss; benefits that aren't provided by typical medical treatments. These benefits include improvements in quality of life, safety, and psychosocial interactions.

Conclusions

Currently, there is limited data defining the benefits provided by hearing and vision leader dogs. Additional research on this topic is needed to better define the everyday benefits that those with hearing and vision loss can derive from use of a leader dog. Additional knowledge on this topic will enable clinicians to counsel patients regarding the benefits that a leader dog can provide when patients are dealing with everyday difficulties due to loss of vision and/or hearing.

Keywords

Usher Syndrome; leader dog; service dog; hearing dog; vision loss; quality of life; psychosocial; social isolation; therapy; aural rehabilitation.

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INTRODUCTION

Usher syndrome is a genetic syndrome that affects about 4 to 17 in 100,000 people (Kimberling, 2010). Usher syndrome consists of congenital sensorineural hearing loss and progressive vision loss. Usher syndrome is an autosomal recessive genetic disease, which includes symptoms of sensorineural hearing loss, progressive vision loss, and sometimes includes balance issues (Mathor, 2015). It is the most common cause for deaf-blindness, and accounts for 5% of all congenital deafness (Toms, 2020). Usher syndrome can be diagnosed as early as birth with genetic testing, although vision loss can start to deteriorate as late as 20 years of age and may continue to progressively worsen throughout age.

There are three classifications of Usher syndrome depending on the genetic mutation, resulting in different severities of hearing, vision and balance loss. Type 1 Usher syndrome is the most severe sub-type, as individuals with type 1 are born with congenital profound hearing loss, experience a decrease in vision by 10 years of age, and experience vestibular problems (Toms, 2020). Individuals with type 2 Usher are born with moderate to severe hearing loss at birth, have a decrease in vision in early adulthood, and typically have a normal balance system. Individuals with type 3 may show a progressive hearing loss during puberty at the same time of progressive vision loss, and have a normal vestibular system (National Institute on Deafness, and Other Communication Disorders, 2017). The first signs of Usher Syndrome following hearing loss may include night blindness, loss of peripheral vision, and loss of ventral vision, resulting in being considered legally blind.

Current Treatment Options

Clinical care for individuals diagnosed with Usher syndrome, which typically includes a combination of treatments, which, address both hearing and vision loss. A variety of options for correcting hearing ranging from use of hearing aids, cochlear implants, to use of assistive listening devices. The particular treatment recommended for an individual will vary depending on the severity of the hearing loss and the needs and preferences of the patient. Clinical care options for the visual loss associated with Usher syndrome may include mobility training, braille instruction, and low-vision services.

Hearing aids and cochlear implants can be a beneficial option for individuals diagnosed with Usher syndrome; however, the success of this intervention depends on multiple factors. The age at which an individual experiences a significant hearing loss often impact the type of success of the intervention selected for use with the individual. Historically, many individuals with Usher syndrome with significant hearing loss at birth have been taught to primarily communicate through ASL, particularly if the diagnosis of Usher syndrome was not known. Unfortunately for these individuals, as vision loss progresses, this mode of communication becomes increasingly difficult and less effective due to the reliance on the user's vision. This, early diagnosis of Usher Syndrome is important with early onset hearing loss so the optimal mode of communication can be determined early for the child. Currently, patients who receive an early diagnosis of Usher Syndrome are often encouraged to pursue an oral method of communication due to their anticipated loss of vision and the negative impact that such a loss of vision would have on their ability to communicate manually.

When an individual with Usher syndrome experiences a delayed onset of their hearing loss, they have likely already learned to communicate orally. Thus, the optimal intervention is likely to involve treatment that maximizes their oral communication skills. This typically includes use of hearing aids followed by use of cochlear implants once the hearing loss becomes significant.

Although the treatment options listed above are typically beneficial, there are still difficulties that patients with Usher syndrome will experience difficulties that cannot be resolved with these treatments, including safety issues, and impacts on their quality of life. One solution that has proven helpful for many individuals with Usher syndrome is use of a leader dog. Leader dogs are specifically trained to help individuals with hearing and vision loss perform daily activities that would otherwise be difficult or impossible to perform without assistance. There is currently limited information available regarding the benefits that leader dogs can provide to supplement the medical treatment available to patients with a severe dual-sensory disability, such as those with severe hearing and vision loss.

As there is currently no cure for Usher syndrome, the treatment options are focused on treating the symptoms of the syndrome and not the syndrome itself. Current medical treatment options include auditory rehabilitation with hearing aids, cochlear implants, assistive listening technology, visual communication such as American Sign Language (ASL), Braille instruction, and low-vision services. Those with type 1 Usher are likely to receive little to no benefit from hearing aids due to the severity of the hearing loss, and therefore are likely to benefit greater from cochlear implants. Those with type 2 or type 3 Usher syndrome have less severe hearing

loss and are more likely to benefit from traditional hearing aids. Other therapies for Usher syndrome include viral-based gene replacement therapy, genome editing-based therapy, drug therapy, and cell-based therapy (Whatley, 2020). Although these gene therapies attempt to treat the syndrome itself, they are not commonly used to treat Usher syndrome. Although auditory rehabilitation does help improve the hearing status of an individual, those with a dual-sensory loss still have difficulties in the day-to-day life.

Common Daily Life Difficulties

For patients with a progressive dual-sensory loss, daily activities can become increasingly difficult and often lead to long-term impacts on health and well-being. Hearing loss itself has shown to be a factor that may lead to social isolation. Social isolation occurs when an individual feels as though they do not have a sense of belonging socially, have difficulty engaging with others, and they lack quality relationships (Nicholson, 2009). Having a dual sensory impairment can lead to social isolation, depression, reduced independence, mortality, and cognitive impairment (Schneider, 2011). Self-esteem, self-confidence and well-being are all challenged when one experiences a dual-sensory impairment.

Importantly, the combination of hearing and vision loss leads to safety issues. Treatment options such as hearing aids and cochlear implants can help with localizing sounds, which is especially important when patients are unable to use their vision to help identify sound location thereby helping to optimize safety. However, some patients are unable to hear some sounds, even when amplified, due to the severity of their hearing loss. Additionally, patients with hearing in only one ear, such as those who use a unilateral hearing aid or cochlear implant,

demonstrate little or no ability to localize. When vision loss is added into this, the safety factors are then even more dependent on the hearing abilities of the individual. Those with hearing loss or vision loss have an increased risk of falls, and that risk is even greater when one experiences both hearing and vision loss. Older adults with vision loss have a higher risk of falling than their peers (Dhital, 2010), leading to a higher prevalence of injuries and fractures among those with vision loss. Although a white cane can provide help with guidance when vision loss is poor, it is still very limited with helping prevent falls.

Service Dogs as a Management Option

Assistance dogs are available to provide support to a human partner with various disabilities (Assistance Dogs International). These dogs come with a variety of titles and provide support for a variety of disabilities, including guide dogs, leader dogs, diabetic alert dogs, hearing dogs, autism support dogs, seizure alert dogs, seizure response dogs, psychiatric service dogs, emotional support dogs, and more (Martelluci, 2019). Leader dogs and other service dogs provide many benefits for those with various disabilities. Assistance dogs are considered service dogs which help persons with mobility issues (Rintala, 2008). They are trained to help individuals with mobility issues be more independent and assist by performing duties that the individual may not be able to perform themselves, such as pulling wheelchairs, opening doors, turning lights on or off, picking up objects, and more. Hearing dogs are trained to alert individuals with hearing impairments when environmental sounds occur, such as an alarm clock, doorbells, presence of other people, fire alarm, and oncoming vehicles. Depending on the type of service dog and the skill set needed, the type and length of training varies, but typically lasts an average of six to twelve months (Martelluci, 2019). Even through service dogs help those

with a large variety of disabilities, one of the main benefits gained from having a service dog is increased independence.

Benefits and Disadvantages of Utilizing a Service Dog

One of the main benefits provided by hearing assistance dogs is the improved ability to carry out daily tasks independently (Martelluci, 2019). For someone who was once able to complete daily tasks independently but is no longer able, being able to once again complete such tasks would be life changing. Service dogs not only benefit the individual with a disability, but, have also been found to benefit family members of the disabled individual due to the decrease in dependence on others (Yammamoto, 2019). In addition to gaining independence and relying less on family members, family member report having a greater sense of security knowing that if there was an emergency, the service dog would be able to help the individual when in need.

Owning a service dog has also been found to greatly improve the quality of life of hearing-impaired individuals. When owning a service dog, factors such as health, working status, learning, improved self-esteem, self-confidence, improved social networks, and independence have been found to greatly improve, thereby improving the individual's overall quality of life (Hall, 2017). In addition to psychosocial benefits, physical benefits such as improved health and wellbeing have also been reported and are likely related to the finding that individuals with service dogs are more likely to spend time outdoors and partake in outdoor recreational activities (Harting, 2011).

Although there are many benefits included with service dogs, there are also some drawbacks. First, owning a service is a large commitment and responsibility. The owner of the service dog must be willing to take care of the dog and follow all training rules in order to gain the most benefit.

Despite the benefits and the documented improvements in safety that a service dog can provide, the use of service dogs is not commonly recommended by physicians for their patients with hearing loss and safety concerns (Martelluci, 2019). Professionals need to be made aware of these benefits and should consider recommending a service dog as an additional aid for hearing-impaired individuals. Such dogs can supplement the common therapeutic strategies recommended for patients with hearing loss like amplification or cochlear implants.

The degree of benefit that is likely obtained from a service dog also depends on the individual. In a study done by Gravrok and colleagues (2019) found that the challenges that are experienced by first-time handlers were numerous. Factors such as the handler's medical condition, cognitive ability, and social environment all impacted the benefits and challenges that arose from obtaining a service dog. Those with disabilities that changed or were more intermittent than a steady disability experienced more difficulties with the leader dog (Gravrok, 2019). More difficulties arose when the environment of the handler was constantly changing when compared to leader dogs who were placed in more predictable environments. Thus, such factors should be taken into account when an individual is considering including a leader or service dog into their treatment plan. Even though leader dogs are able to help those with dual-sensory loss and Usher syndrome, additional comorbidities decrease the benefits gained from a

service dog. This study reports on the findings of one adult before and after receiving a leader dog, in addition to pursuing cochlear implantation and proper medical treatment. No IRB was required as this is a single case study on one individual with Usher syndrome.

Case Study

Ms. J., is a 62-year-old woman, diagnosed with Usher Syndrome at age 24. She was diagnosed with congenital hearing loss at age four and was fit with bilateral hearing aids shortly thereafter. She was enrolled into a School for the Deaf where she learned to communicate via both American Sign Language and spoken language. Her parents and teachers noticed she was failing to communicate with others at school and decided to enroll her in a mainstream school setting. While in the mainstream, she attended regular speech therapy that focused on oral language and lip-reading.

A progressive vision loss, previously considered to be night-blindness, was diagnosed when she was 11 years of age. Following this, her vision progressively worsened throughout time. At the age of 24, her vision severely digressed, and then diagnosed with Usher syndrome. A walking cane was recommended as an option to help with her lack of vision for safety reasons. Before her vision loss became too severe, she was employed full-time as a registered nurse and worked in a hospital. Even though she also had a severe hearing loss, work accommodations such as enlarged print for reading and use of a stethoscope connected to her hearing aids helped her adapt. Following the progression of her vision loss, in addition to her longstanding hearing loss, she was told by hospital personnel that she was no longer able to work as a nurse due to the severity of her disabilities.

Combined with receiving minimal benefit from amplification, her vision loss became progressively worse, causing great difficulty with lip-reading. This, coupled with no longer being able to participate in work, resulted in a lack of self-confidence, reduced self-esteem, and decreased socialization. Daily tasks, especially those performed outside of the home, became increasingly difficult, and using a cane in public at such a young age brought about embarrassment and resulted in an even lower self-esteem. Although she was used to having a hearing loss, she learned to compensate for the hearing loss with amplification and visual cues. Losing the ability to rely on her vision loss amplified how much the hearing loss impacted her daily life and made evident how much she was missing. She reports that this shined light on the fact that the hearing loss greatly increased the difficulties she was experiencing in her everyday life.

Personal Experience with Leader Dogs

In 2000, she was first accepted into the Leader Dogs for Deaf-Blind Individuals Program, where she obtained her first leader dog. She noticed immediate benefit, particularly when she was with the leader dog. She reports her self-confidence and self-esteem improved quickly with the addition of having a leader dog with her at all times outside of the home. Safety issues improved greatly; she reports feeling safer at home and gained a feeling of independence since she was able to go outside or out in public without needing assistance from another individual. She reported a greater sense of security when falling asleep as there was the comfort knowing that the leader dog was present and would alert her in case of a fire or any emergency. She indicated that the ability to go on walks by herself, free from worry about being disoriented or

lost, knowing that she would be able to return home safely because of her leader dog, gave her great comfort. What once was impossible because of her disabilities then became possible. Not by treating the cause, but by providing an option to better help deal with her disabilities.

This newfound ability to be independent led to an increase in her willingness and desire to participate in social activities. This increased socialization, however, shed light on how much she was missing during conversation because of the severe nature of her hearing loss and the poor benefit she received from hearing aids. With the vision loss progressively worsening over time, her ability to communicate using lip reading and sign language became increasingly difficult. This then led her to explore the option of a cochlear implant. Audiometric testing performed at the time of her evaluation for a cochlear implant is provided in Figure 1, and indicates a bilateral severe to profound sensorineural hearing loss.

CI Pre-Operative Test Results

Pre-operative candidacy testing for cochlear implants revealed poor speech perception with the use of power amplification, bilaterally. Criteria were met for cochlear implant candidacy in either ear. A decision was made to implant the left ear as this was the poorer ear.

Figure 2 presents the functional gain audiogram obtained with clinic stock hearing (comparatively to Figure 3 of the unaided hearing thresholds). Thresholds obtained with the use of power amplification were obtained in the normal hearing sensitivity range at 250 Hz, sloping to severe hearing loss in the right ear through 8000Hz, and profound in the left ear through 8000Hz.

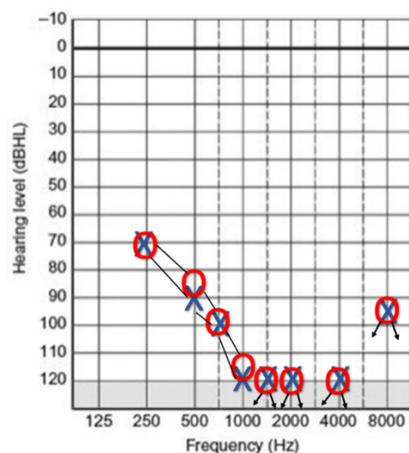


Figure 1. Audiologic Test Results

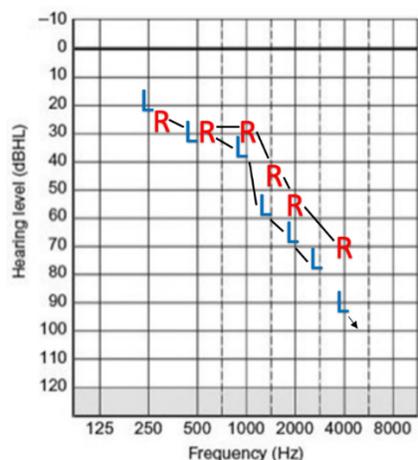


Figure 2. Functional gain obtained as part of the evaluation to determine candidacy for a cochlear implant

Table 1 presents the scores measured on tasks of auditory speech perception. With the use of a right behind the ear hearing aid, she was able to demonstrate a score of 24% correct on the CNC Monosyllabic Words Test. With a left hearing aid, she obtained the same score of 24% correct on another CNC word list. For the AzBio sentences list, a score of 51% was obtained with a right hearing aid, and a score of 39% was obtained with the left hearing aid. When using both the right and left hearing aid, the score on the AzBio sentence test was less than the score

obtained for the right hearing aid alone, at 49%. All scores fell within the FDA criteria for a cochlear implant, which indicate an individual should score less than 60% in the best aided condition, and less than 50% in the ear to be implanted, in order to be considered a candidate. In addition to audiological results, the fact that she was a full-time user of hearing aids improved the likelihood that she would receive benefit from cochlear implants.

Table 1. Speech Perception Scores Obtained During the Appointment to Evaluate Candidacy for a Cochlear Implant

	CNC	AzBio, Quiet
Right HA	24%	51%
Left HA	24%	39%
Bilateral HA	DNT	49%

CI Post-Operative Test Results

This patient elected to move forward with a cochlear implant in her right ear; she was implanted with a Nucleus CI24RE (CA). At one year post-implantation, she obtained the following scores with the right cochlear implant (Table 2), and demonstrated improvement in detection as well as significant improvement in word and sentence recognition.

Table 2. Sound field Detection Thresholds obtained with right cochlear implant

	250 Hz	500 Hz	1000 Hz	2000 Hz	4000 Hz	SDT
Right CI	15	20	15	15	20	15

Table 3. Speech perception scores obtained one-year post-activation with a cochlear implant.

	AzBio, Quiet	CNC
Right CI	77%	64%

After much success after receiving a cochlear implant in her right ear, a decision to proceed with a cochlear implant for the left ear was then agreed upon. Following two cochlear implants, the detection to sound measured in an annual evaluation was in the normal hearing to mild hearing loss range, using the individual processors shown in Table 3. Overall, a significant improvement in speech perception was observed in all conditions as seen in Figure 3. This not only evident in the sound booth with speech perception testing, but also in the real world as she reported much benefit from both cochlear implants, and it has provided much better access to sound and ease of communication.

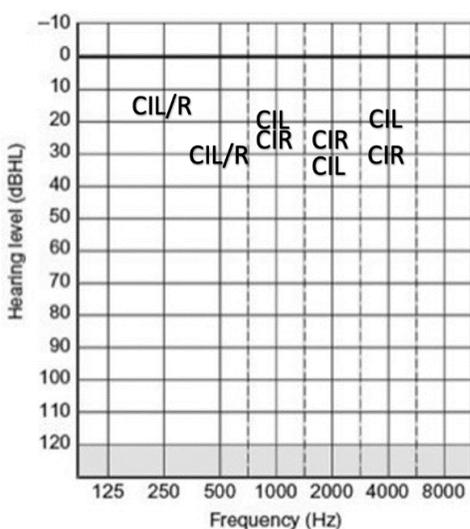


Figure 3. Aided Detection Thresholds Obtained with Cochlear Implant in Each Ear

Table 4. Audiologic Test Results Post bilateral sequential implant

	CNC	AzBio, Quiet
Right CI	88%	85%
Left CI	84%	88%
Bilateral CI	DNT	94%

Ms. J. was able to demonstrate significant improvements in her speech perception scores when compared to the scores obtained pre-operatively with hearing aids. She reported that she participated in aural rehabilitation by listening to books on tape and that doing so greatly improved her ability to recognize words. Ms. J took several positive steps to improve her hearing, her independence, and her quality of life. She received proper medical treatment in the form of bilateral cochlear implants for her bilateral severe to profound hearing loss. The addition of a leader dog provided additional benefits to her life in the form of renewed independence, increased confidence, and a renewed interest in socializing with others. By using both a leader dog and cochlear implants, she was able to reduce many of the difficulties she faced because of her dual-sensory loss to Usher syndrome. She reports that she remains active in Leader Dogs for the Blind, with a special emphasis on patients with dual sensory losses. She importantly shares that these two factors greatly improved the quality of her life.

DISCUSSION

As Usher syndrome consists of various severities of hearing loss and digressive vision loss, individuals face great difficulty in their everyday life settings; difficulties that may be unexpected and that they may not have faced before. Although current medical treatments are available to improve hearing for such individuals, they continue to face difficulties in their everyday lives. Unfortunately, these difficulties can have severe long-term impacts for many patients with Usher syndrome. For the individual highlighted in this case study, a leader dog was able to provide her with a sense of independence that mimicked the life she had before she experienced a devastating loss of both vision and hearing. She reports that the improved hearing

she received from the cochlear implants combined with the benefits of the leader dog increased her sense of independence, provided her with a sense of safety in the home and in public, increased her socialization, and improved the overall quality of her life.

Although there is currently limited research on this topic, previous research has shown the benefits provided by including leader dogs in the rehabilitation process. Lundqvist and colleagues (2018) found that service dogs or hearing dogs may have a positive impact on health-related quality of life, well-being, and activity level. Hall et al., 2017 found similar positive results with hearing dogs and reported that they help alleviate strain, foster increased independence, and decrease the risk of social isolation for the affected individual. They additionally report that such dogs foster learning and independence, and lead to improvements in health and work life (Hall, 2017).

Leader dogs are able to provide much benefit to those with various disabilities. However, it is important to take into account that the conditions, cognitive ability, and social environments that the individual is involved with on a daily basis can impact the benefit that can be gained from a leader dog (Gravrok, 2019). When deciding if a leader dog is appropriate for an individual or one's self, it is important to remember that although leader dogs are capable of providing many benefits, they do require much work and attention. As seen by the case study presented here, when managed appropriately alongside adequate medical treatment, leader dogs can provide significant benefits to an individual with hearing loss, vision loss, and balance loss.

In our case study, this patient demonstrated an improved quality of life, and an improved sense of self-confidence and self-esteem. She reported that she was once shy and embarrassed of her disability and that having improved hearing and access to her leader dog has helped transform her into someone who is now confident enough to serve as a public speaker. She travels across the country, spreading awareness of the various benefits that leader dogs and improved hearing provide for those with disabilities that impact their everyday life.

An informational guide may be helpful for clinicians and/or patients who are seeking information regarding various service dogs. For clinicians who are not aware of the benefits of service dogs in addition to not sure about where to find this information, different links providing information are included. This information guide may also be helpful for providing information to patients who want to learn more about service dogs, and help determine together with their clinician if this is something they want to pursue in addition to the current medical treatments.

CONCLUSIONS

Those with hearing and vision loss tend to have lower quality of life, even when being treated appropriately with medical treatment and auditory rehabilitation. By including leader dogs or service dogs into the overall treatment plan, daily activities become less difficult. This results in improvements in quality of life, enhanced safety at home and outside, increased social interaction, and numerous positive long-term impacts on life. Current research has shown that for individuals with such disabilities, significant improvements in the day-to-day life have been found from inclusion of leader dogs with appropriate medical intervention, especially for those

with dual-sensory loss, such as those diagnosed with Usher syndrome. Further research on the topic should be conducted in order to spread awareness to leader dogs will likely result in a reduction in the daily difficulties faced by patients who have hearing and vision loss, such as those with Usher syndrome.

Informational Guide for Service Dogs

Service Dogs

A dog specifically trained to perform work or tasks for a person with a disability or multiple disabilities.



<https://www.leaderdog.org/blog/when-you-meet-a-leader-dog/>

What is a Leader Dog?

Leader dog is a type of service dog that specifically trained to help individuals with hearing and vision loss perform daily activities that would otherwise be difficult or impossible to perform without assistance

Additional Types of Service Dogs:

<https://www.akc.org/expert-advice/training/service-dog-training-101/>

- ❖ Guide Dogs: assist humans who are blind or visually impaired.
 - Leading their handlers around obstacles, helping navigate in public, assist with going up/down stairs.
- ❖ Hearing Dogs: Act as ears for those who are deaf or hearing impaired.
 - Alert to important sounds such as fire alarms, doorbells, alarm clocks, etc.
- ❖ Seizure Alert Dogs: Trained to recognize signs that the owner is about to have a seizure.
- ❖ Mobility Assistance Dogs: For those with impaired mobility functions
- ❖ Autism Support Dogs: Trained to assist individuals with challenges of autism

How can they be helpful?

Found to improve independence of the owner, improve the safety, increase socialization, improve self-esteem, and ultimately increase the quality of life of the owner.

Some of the daily tasks that they train for include (but are not limited to):

- ❖ Alert the owner if the phone is ringing
- ❖ Alert the owner if someone is at the door
- ❖ Alert the owner if there is a fire or a fire alarm going off
- ❖ Help them cross the street at a cross walk or through a parking lot
- ❖ Able to open doors
- ❖ Turn lights on or off

Online Sources for Service Dogs:

Leader Dogs for the Blind

<https://www.leaderdog.org/>

Paws with a Cause

<https://www.pawswithacause.org/>

US Service Animals, Service Dog for the Deaf

<https://usserviceanimals.org/blog/service-dog-for-the-deaf/>

Service Dogs 101-Everything You Need to Know

<https://www.akc.org/expert-advice/training/service-dog-training-101>

Autism Service Dogs of America

<https://www.autismservicedogsofamerica.org/>

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