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Bridging Differences within the Disability
Community: The Assistance Dog Movement

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The underlying themes of sameness and difference, unity in diversity and subcultural variation have been central to the discipline of cultural anthropology from its inception. Recognizing that the acquisition of culture is the essential ingredient in being human, anthropologists have studied the various manifestations of cultural production. Thus, the authors believe the anthropological paradigm should be the core element in a holistic, historical and cross-cultural disability studies teaching and research program.

A universal theme permeating the anthropological view of human behavior is that all humans have culture, but the particular strands of intertwined norms, values and institutional structures are unique to a particular group of people. Thus, there is human culture as well as Samoan, Dobuan and Hopi culture. Even in these supposedly monolithic and homogeneous cultures, ethnographers recognized tremendous individual differences. Sometimes these are based on categorical membership, such as gender, age, rank, etc., but frequently they are based on other variables. From this recognition of difference the concept of subculture was derived. Rarely, however, were these categorically-based differences linked to disabling conditions. The major exception was the association of shaman or curing activities with physical and/or psychological disabilities. Nevertheless, the subculture concept has great value in the study of people with disabilities.

Disability Culture/Subculture

The controversy over the existence of a disability culture has been superbly summarized by Brannon (Brannon 1995). In many ways it parallels the heated discussion in anthropology and policy making circles about the culture of poverty concept generated by Oscar Lewis 30 years earlier (Eames and Goode 1973). Since the disabled community we are concerned with is part of a larger societal and cultural matrix, the concept of subculture

would appear to be more appropriate. As people with disabilities, we are developing our own art, literature, mythology, history and language, all of which are becoming elements of an emerging and unique tradition.

Within the disability community there has been a growing emphasis on equality of opportunity rather than sameness. An often heard statement incorporated into the Americans with Disabilities Act (ADA) is that with reasonable accommodation most disabled people are able to do what most nondisabled people can do. This credo applies to the areas of employment, education, travel and leisure time activities. Although many of us may strive toward the fictive goal of "normality," many others have come to terms with their disabilities and are striving toward the social goal of breaking down existing barriers rather than the more personal goal of passing.

Not only are the estimated 54 million Americans with disabilities part of but different from the larger society, they are different from one another. Obviously, every disabled person has a unique persona, but those sharing a particular disability have many common problems. Thus, members of the blind community share many more life experiences and coping mechanisms with other blind people than they do with those who are deaf or have disabilities other than blindness and deafness. One consequence of these differences within the disability community is the development of mutually exclusive consumer based groups such as the National Federation of the Blind (NFB), Self Help for the Hard of Hearing (SHHH), Paralyzed Veterans Association (PVA), etc. If we can view all disabled people as sharing a particular subculture, then blind, deaf and physically disabled people share more narrowly defined subcultures.

Those in the disability community, like members of other minority communities, are part of the larger cultural tradition. We share language, religion, art and other forms of symbolic representation with other Americans. However, we are beginning to develop some of our own unique forms of art, sports, mythology, history, language and other elements of an emerging subcultural tradition.

Within this broader context, a small segment of the three communities of sensory disabled Americans has chosen to accept partnership with canine assistants as a means of increasing their independence and enhancing their quality of life. Partnership with guide, hearing and service dogs has created an opportunity to breach the walls of difference that have traditionally kept these groups apart.

History of the Assistance Dog Movement

The pioneering guide dog school in the United States, The Seeing Eye, was established in 1929 (Putnam). It was inspired by earlier work with blinded veterans done in Germany during and after the First World War. Dorothy Harrison Eustis, a wealthy American living in Switzerland, had observed blind German veterans being guided by trained German Shepherd Dogs. She wrote

an article for the Saturday Evening Post describing what she had seen and offered to work with an interested blind American at her Fortunate Fields kennels in Switzerland. Of the hundreds of responses she received, Eustis chose the 19-year-old Morris Frank because he expressed an intense desire for independence and the drive to achieve their joint goal of establishing an American guide dog training program. Buddy, a German Shepherd Dog, and her blind partner, Morris Frank, a founder of The Seeing Eye, trained in Switzerland and came back to the United States where Frank publicized the advantages of working with a guide dog.

In the United States, despite positive media coverage, when Frank approached several well-known organizations working with blind people for support, his dream of developing a guide dog training program in the United States was summarily dismissed. Fulfilling Eustis' faith in him, Frank persevered and attracted the needed public support to convert their dream into reality. The Seeing Eye was born and within ten years a second school was established. As a result of the Second World War, several new programs were created to serve blinded veterans. The majority of the 15 guide dog schools operating in the United States at the present time were founded after World War II.

Each year approximately 1500 blind person/guide dog teams graduate from the 15 United States schools (Diamond, Eames and Eames, in press). Approximately half are seeking partnership with dogs for the first time, and the remainder are training with successor dogs. It is estimated that 9,000 teams are currently working in this country (ibid.). With an estimated population of 1,100,000 legally blind Americans, this constitutes a very small portion of those who could benefit from such partnerships.

In contrast to the more than 70 years of blind Americans being partnered with guide dogs, deaf and hard of hearing and physically disabled Americans have had only 25 years of working with hearing and service dogs. Interestingly, these two innovative approaches to the training and use of dogs do not seem to have influenced each other and developed along separate, but parallel lines.

Bonita Bergin is the pioneer in the service dog movement. Having observed donkeys and other animals, in several underdeveloped areas assisting people with physical disabilities, she conceived the idea of harnessing the energy and intelligence of dogs to work with mobility impaired individuals. When she sought advice from guide dog training programs, they were not responsive and offered little help in transforming her idea into reality. Paralleling the determination and single-mindedness of Morris Frank, Bergin persevered and developed the first service dog training program in the country, Canine Companions for Independence. As public awareness of the value of dogs serving people with disabilities was sparked by extensive media coverage, the demand for trained service dogs exploded and many new training programs were established to meet the need.

With waiting lists ranging from one to three years to be matched with a trained dog, many disabled people have chosen to

train their own dogs or hire private trainers to prepare their pet dogs for service work. As a result, a large number of breeds can be seen assisting people with physical disabilities.

While Bergin was initiating the service dog movement in the mid-seventies, Agnes McGrath was independently establishing a program to train dogs to assist people who were deaf or hard of hearing. The first training school began operation at the Minnesota Society for the Prevention of Cruelty to Animals and within a year was taken over by the American Humane Association in Colorado. Unlike The Seeing Eye and Canine Companions for Independence, the AHA hearing dog program did not survive. However, it spawned a number of hearing dog training centers that can be seen as direct descendants of McGrath's original efforts.

More than 60 organizations prepare dogs for working with people with disabilities other than blindness. Two major factors make it impossible to obtain accurate statistics for the number of teams trained each year and the number of working teams. First, many training programs do not belong to Assistance Dogs International (ADI), a coalition of more than 30 guide, hearing and service dog organizations. Second, many dogs are privately trained, making an accurate census impossible. Our best estimate is that 4,000 hearing dog and 4,000 service dog teams are currently working. Combining the figures for guide, hearing and service dogs, a total of 17,000 assistance dogs are currently working in the United States (Eames and Eames 1997).

Language

Words can empower, encourage, confuse, denigrate, delight or depress. George Orwell, in his book 1984 illustrated the political power of words. Some Orwellian disciples continue to track the way words are used to modify the impact of reality. Following the lead of feminists and African-Americans, disabled people have recognized the power of language in reshaping societal attitudes and images. Terms such as cripple, invalid, wheelchair-bound and deaf and dumb are no longer acceptable. With the signing of the ADA, the politically correct term for those of us with impairments categorized as sensory, mobility, psychiatric or hidden is disabled. Handicaps are defined as the barriers placed in the path of disabled people preventing them from full participation in society. Thus, blindness is our disability. One of our handicaps is not being able to read a print newspaper.

However, with use of modern-day technology, even this handicap can be minimized. Restaurants that do not provide Braille menus and hotels that do not provide tactile or Braille numbers on rooms impose barriers to our being independent. These are socially generated handicaps. A goal of the disability rights movement is to eliminate these handicaps and change societal attitudes. In all these efforts, clear, consistent, concise and consumer generated language is essential.

Within the assistance dog movement a number of terms and concepts have emerged needing clarification. Assistance Dogs International has adopted the following language for dogs working

with disabled people.

1. Guide dog is the generic term for a dog who guides a blind or visually impaired person. Dog guide is used by some programs and consumers, but the authors believe this usage is incorrect and confusing. Another source of confusion is the widespread use of the phrase seeing eye for all guide dogs. The title The Seeing Eye belongs to the first guide dog school in this country and is a registered trademark. Most Americans use the term seeing eye interchangeably with the generic term guide dog. However, it should only be used for dogs graduated from the school in Morristown, New Jersey. The public's confusion and incorrect usage is reinforced by journalists, television reporters and writers who continue to use seeing eye as an equivalent term for guide dog.

2. The preferred term for dogs assisting deaf or hard-of-hearing people is hearing dog.

3. The generic term for dogs assisting people with disabilities other than blindness and deafness is service dog. Although service dog is the term preferred by ADI, a variety of other terms are used for these working canines. Occasionally, they are referred to by their functions, such as support, wheelchair pulling or seizure alert dogs. Some service dogs are being trained to assist those with psychiatric disabilities, autism, Parkinsons, etc.

In its attempt to guarantee access for disabled people partnered with dogs who assist them, the writers of the guidelines for the ADA confused the language issue by using the term "service rather than assistance animals." The broader term "animals" was chosen to protect the rights of disabled people partnered with Capuchin monkeys. However, the use of the word "service" was not well thought out. One wonders why writers of regulations feel they must invent new terms rather than maintain already established and clear language.

In April 2001 representatives of two consumer organizations, the International Association of Assistance Dog Partners and Guide Dog Users Inc., joined with the two assistance dog provider organizations, Assistance Dogs International and the US Council of Dog Guide Schools to create a coalition of assistance dog organizations. CADO's main goal was to work with the US Department of Justice to clarify and correct some of the language and definitions used in the regulations drafted by the US Department of Justice in 1992.

Building a Sub-Culture

Accepting partnership with an assistance dog becomes the building block for a unique sub-culture within the larger disability subcultural movement. Thus, of the 17,000 people partnered with assistance dogs, most have been trained at residential programs away from their home settings. All have to deal with the daily tasks of feeding, grooming, and providing relief time for their canine assistants. Graduation from a training program or the completion of training with a dog trainer

does not mean the end of the training process. Problems continue for those working with assistance dogs as they confront real life situations without the instructor's presence as mediator or advocate. Traditionally, those partnered with assistance dogs turned to the professionals (program or private trainers) for help when confronting access and behavioral problems, but that emphasis has been shifting as national and regional consumer groups have emerged.

Access problems are not the only feature which unifies the community of assistance dog partners. One consequence of the shorter life span of canine assistants is that human partners have been forced to break the bond through retirement, euthanasia or natural death. Not only is the grief a shared element in the community, but the need to train with a successor dog becomes another aspect of the building of the sub-culture based on shared experience.

For those partnered with assistance dogs a common experience is the need to advocate for the presence of the canine assistant in situations where access is denied or attempted to be denied. This most frequently happens with taxi drivers, restaurant managers and hotel clerks. Almost every person partnered with an assistance dog has his/her favorite airline or taxi story. Although many access denial confrontations assume the discourse of advocating for the rights of the canine assistant, the human partner is obliquely advocating for his or her own rights. Placing the emphasis on the dog makes the initial advocacy efforts easier for many disabled people who have been infantilized and paternalized and accepted societal views of themselves as passive and helpless. Thus partnership with the dog becomes a transformational experience in which the individual's self concept is enhanced and feelings of empowerment gained. This initial advocacy then often expands into a willingness to combine with other assistance dog partners in furthering the rights of their community. A further element in constructing this new subculture is the ability to use modern modes of communication. An Internet group has been developed devoted to issues of assistance dogs and their partners.

A Minority Within a Minority

Despite the more than 70 year history of guide dog use in the United States, many blind people remain opposed to their use as mobility aids. In a special issue of the Braille Monitor, the official publication of the National Federation of the Blind, the largest and oldest blind consumer organization in the United States, 21 articles were published focusing on the controversy about guide dog partnership. Those most critical of the guide dog included Kenneth Jernigan, NFB's President Emeritus and editor of the October 1995 issue. He took the position that the decision to work with a guide dog engendered an image of dependence and pity, creating a barrier against full citizenship and equal participation in society (Jernigan 1995).

Within the deaf community, a similar antipathy toward

hearing dogs is discernable. The presence of a hearing dog, clearly identified by leash, collar and cape, proclaims to the world, the human partner is deaf or hard-of-hearing. Such identification runs counter to the deep-seated value in the community of being inconspicuous. Deafness is a hidden disability and staunch proponents of deaf culture claim they are a linguistic minority rather than a segment of the disability community.

Those who are blind or physically disabled do not have this option. Thus, partnership with a guide or service dog does not set them any further apart than the white cane, wheelchair or crutches. For many in the deaf community, partnership with a hearing dog symbolizes helplessness and dependence rather than independence and self-sufficiency (Eames 1995).

Coalition Building: The Political and Social Process

In 1993 a number of disabled people, partnered with guide, hearing and service dogs met in St. Louis to create the first consumer-driven organization whose focal point was partnership with assistance dogs. A governing board was elected consisting of individuals drawn from the blind, deaf and physically disabled communities. The goals established at this inaugural meeting were education, legislation, advocacy and mutual support. These goals were articulated in a mission statement developed by the organization which became the International Association of Assistance Dog Partners (IAADP).

With an estimated 17,000 assistance dog partners dispersed throughout the United States, IAADP felt it necessary to reach as many constituents as possible. Notices were placed in the mainstream and specialized disability-related publications. Through a grant from Paws With a Cause, membership in IAADP was offered without charge for two years.

Currently, more than 1,000 individuals subscribe to Partners' Forum, the quarterly newsletter published by IAADP. From the beginning, this newsletter was viewed as the core element in the organization's drive to provide a voice for disabled people partnered with canine assistants. For many novice writers Partners' Forum became the vehicle to have their work published. Regular features include columns devoted to access denial cases, quality of training, canine behavioral problems, etc. IAADP's first national conference was held in conjunction with the annual conference of ADI. The initial goals developed a year earlier were reaffirmed and a number of committees were established to pursue these efforts. At the second annual conference in Las Vegas in September 1995, the group met in the evening after the conclusion of the day-long ADI meetings.

Continuing to focus on access issues, a number of skits were performed by Board members to illustrate common problems and suggested solutions. The response from assistance dog partners in the audience reinforced our notion that there was an emerging collective consciousness based on common experience. An up-date was provided about a number of denial of access cases being

pursued by IAADP.

Each year since then IAADP has held a one-day conference in conjunction with ADI. Common features have been the demonstration of new equipment and new training techniques and tasks. More than 150 registered at the 2001 conference and it is anticipated more than 200 will register for the 2002 conference in San Antonio.

Problems of Coalition Building

Building a coalition in which different disabilities are given equal weight and power is difficult. The original Board consisting of two individuals partnered with guide dogs, two with hearing dogs and two with service dogs, has undergone transition. The current Board consists of two guide, two hearing and five service dog partners.

More than half of the 17,000 assistance dog teams in the United States are represented by guide dog partners who already have two consumer driven groups, one affiliated with the American Council of the Blind and the other with the National Federation of the Blind. Therefore, their interest in the coalition has been limited.

Like many other special interest groups, the most pervasive problem is informing those partnered with assistance dogs about IAADP's existence and mission. Another issue is the emergence of service dogs partnered with individuals with psychiatric disabilities. Many of these partners believe IAADP does not represent their interests and some splinter groups are being developed.

Results of Coalition Building

Despite the limitations noted above, IAADP's accomplishments have been noteworthy. It has assumed an active voice in the assistance dog movement representing all disabilities. As anticipated, communication across disability boundaries has been beneficial for all involved. As one of IAADP co-founders, Ilene Caroom, notes when working with blind friends: "We constitute an audio-visual team. My blind friends provide me with the audio cues and I provide them with visual information."

Partners' Forum under the editorship of Joan Froling, has fulfilled its mission as the voice of people partnered with assistance dogs. In 1995, 1996, 1998 and 2000 Partners' Forum received recognition through an award from the Dog Writers Association of America. An agreement has been negotiated with the American Kennel Club providing free membership to all assistance dog partners in a lost dog retrieval program developed by the AKC. In addition, a relationship has been established with AVID, a manufacturer of microchips for pets, to provide free microchips and registration in AVID's lost dog recovery system.

On behalf of its membership, IAADP has worked with a number of veterinary teaching hospitals to provide a reduced fee structure for all assistance dogs being diagnosed or treated by these referral institutions. Currently 18 of the small animal veterinary teaching hospitals connected with veterinary schools

are offering discounts ranging from 20% to 50%. IAADP has also established a program to provide financial relief for assistance dog partners unable to meet the high cost of veterinary care for diagnostics, emergency care or treatment for their canine assistants. This effort, the IAADP Veterinary Care Partnership, is supported by several corporations belonging to the animal health care community. The goal is to ensure that no IAADP member will have to break the partnership with a canine assistant because of the inability to pay for animal health care. Information about this and other issues can be found on IAADP'S web site <www.iaadp.org>.

Through IAADP's Information and Advocacy Center, members of the Board have participated as advisers in numerous cases of access denial. A well known situation involved a member of the President's Committee on Employment of People with Disabilities (Froling 1995). This case pitted two individuals with disabilities against each other. For three months Wilson Hulley and his service dog were barred from entering the workplace because of a complaint filed by a mentally disabled colleague who had a documented dog phobia. Hulley's case which was eventually resolved by accommodating both employees became a rallying point for IAADP board members and many others partnered with assistance dogs. More recently, an in-patient at Johns Hopkins Medical Center, Nikki Deptula was denied the right to have her service dog with her in the hospital. IAADP worked with her to change the Hopkins policy. Unfortunately, the final policy negotiated between the hospital and the Department of Justice undermined the right of disabled people to be accompanied by their assistance dogs in medical facilities. IAADP initiated a national campaign to prevent this policy from being adopted by DOJ as a model for other hospitals. The campaign was successful and DOJ withdrew its endorsement.

Throughout the development of the disability rights movement, the consistent theme of empowerment has permeated the discussion. The same theme informs the assistance dog movement. Until recently, people with disabilities have been "recipients" of assistance dogs with minimal input into the organizational decision-making process. Therefore, consumer organizations like IAADP have been developed to provide a voice for disabled people.

Most media portrayals of people with disabilities depict us as powerless and dependent. Recognizing this negative image, which many of us incorporate into our views of ourselves, leaders of the disability rights movement provide us with the emotional ammunition to strengthen and empower our lives. One of the founding goals of IAADP was to provide a vehicle through Partners' Forum where disabled people partnered with assistance dogs could find a voice and openly express their views.

Focusing on the empowerment theme as a central issue in the disability rights movement, the authors found it disturbing that a number of letters to the editor began appearing with the writer's name being withheld. This quest of anonymity seemed antithetical to the entire thrust of IAADP orientation toward

giving voice to assistance dog partners through collective organization.

The authors wrote the following:

In our view, an opinion column in which contributors remain anonymous loses validity and authenticity. Since Partners' Forum is a publication by and for all assistance dog partners, we should be willing to stand up for our opinions. Just as a signed column gives us the opportunity to get to know the people behind the words, a signed letter or opinion piece provides the same opportunity. In our role as advocates for the rights of people with disabilities, we see far too many people who are fearful of the nondisabled world, the rehabilitation system and the programs providing their canine assistance. When we see ourselves as helpless victims, we victimize ourselves. As advocates, we want to foster, promote and nurture disability pride. If you believe your view is important, stand behind that view. Be proud to sign your names to the opinions you express in our newsletter. (Eames and Eames 1995)

In a subsequent issue of Partners Forum, Lori Powers rejoined with an alternative point of view. Her position is that an anonymous voice is better than no voice at all. Powers writes:

Opinions are neither right nor wrong, yet many people have been told differently. How many times have any of us expressed an opinion just to be laughed at, scoffed, or otherwise degraded? Stating an opinion is a risky adventure at best. Adding one's name or face to it is even riskier. Anonymity is a safe way to voice an opinion that may go against the grain of the majority. Anonymity may also bring out a voice waiting to be heard and may be a springboard for that voice to continue speaking, gaining confidence every time. (Powers 1996)

The authors feel this is such a central issue in the disability rights movement and disability culture that it requires additional discourse.

IAADP's Future

In addition to the challenge of expanding its membership and developing a core of committed volunteers, the organization's major challenge will be establishing a solid financial base. Another perennial problem is the expansion of IAADP's constituency. Despite all attempts to increase membership, the number of individuals partnered with assistance dogs who have never heard of the organization is disturbing. An approach to membership recruitment being actively pursued is providing a package of benefits to induce more individuals to join. In a way, IAADP is following the model pursued by AARP which developed so many benefits for those joining and paying minimal annual dues

that the vast majority of seniors in this country are members of the organization.

Is an Assistance Dog Subculture Emerging?

The authors believe the answer to this question is yes. Members of this community are developing a language of their own. The experience of working with canine assistants creates a common core of mutual understanding. Grief at the loss of a working partner is something that can be more readily shared within the community. Recognition of the bond between human and canine partner as multiplex and intertwined is gaining greater recognition. Many canine assistants are seen as extensions of the human partner and perceived as members of a family of affiliation. Asymmetrical power relations with training programs also fosters a sense of community within the consumer movement. Perhaps the greatest potential source of subcultural development is the sense of identification and pride as an assistance dog partner and the conviction and willingness to advocate on behalf of one's canine assistant. In story after story, we hear the common refrain: "I wasn't much of a fighter for my own rights, but after getting my dog I became an advocate for our rights as a working team."

Carol Gill has been one of the most articulate proponents of a disability culture. She has articulated 10 core values to describe this emerging phenomenon (Gill, 1995). Members of the assistance dog movement not only share many of these 10 core values, they also share the major differentiating value that focuses on assistance dog partnership. For them the benefits far outweigh the costs. For many, the canine assistant is seen as the linkage with the larger society. In autobiographical account after autobiographical account, a constant theme is the recognition of the assistance dog as icebreaker. Hard-of-hearing partners write about the wall of silence breached by a hearing dog. Youngsters with service dogs report their peers no longer refer to them as the kid in the chair, but rather the kid with the dog.

Many proclaim the transformational nature of the relationship and the changes in world view resulting from the partnership. Surely these are the building blocks of a subculture in its initial phase. If IAADP can continue to expand and meet the needs of its constituents, it will become the organizational structure within which the subculture can become articulated.

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