

## **The Need for a Personal Assistant: My Case of an Unmet "BENEFIT"**

*Rachel Ogami*

*Arizona State University*

The need of a personal assistant (PA), for certain kinds of medical conditions, is essential in achieving the most basic quality of life. There must be many thousands of disabled people who cannot participate in society because the severity of their conditions prohibits them from doing so without the services of a PA. However, the system of public assistance, which is the only way many low-income households can afford PAs, is ineffective in offering quality service that is safe and reliable. Through my experience of the system in Arizona, I will be discussing the problems the causes that make for difficult conditions for many of us.

First, a PA is not perceived as critical need for disabled persons. According to Deborah Johnston's book, *Managing Your Life with Personal Care Assistants*, "Just as other persons with less-extensive limitations compensate their disabilities with assistive devices like braces, crutches, or other prosthetics, personal assistance can enable more limited individuals to become fully-functioning members of the community." In my case, a PA helps me with everyday matters such as bathing, personal care, getting dressed, preparing food, and helping me eat. She is also be expected to do light household chores like making the bed, picking things up, vacuuming, doing the dishes, doing laundry, and cleaning the bathroom. She also helps me do maintenance exercises, such as working to increase my range of motion, which maintains my physical strength. It is important for me to maintain the strength that I have in order for me to bear weight on my legs when I am being transferred in and out of my wheelchair. Exercise also makes my whole body stronger so that I will be more resistant to illnesses.

I also depend on a PA to help me stay connected to society. She assists me in making phone calls because I have difficulty speaking and people do not easily understand me on the telephone. She also runs errands for me like going to the grocery store or the post office. Most importantly, a PA escorts me places to make sure the environment is safe and accessible. All of these activities are crucial to my personal health and independence which allows me to function as a social being with dignity and self-respect.

I have an inherited disease called Friedreich's Ataxia (FA) which is a rare disease that affects only "two out of every 100,000 people, or about 5,000 people in the United States" (Muscular Dystrophy Association). The condition does not affect my central nervous system or the brain, but does affect my peripheral nervous system including the spinal cord and other nerve fibers. This slows down the speed of instructions which my brain transfers to my muscles and sensory systems resulting in poor coordination, among many other things. Friedreich's Ataxia commonly has complications of heart disease, diabetes, spinal curvature, loss of peripheral vision, and problems with speech and swallowing. I sometimes choke even when I drink water. I am also severely restricted in my upper-body movements because of the three metal rods implanted in my back to prevent my spine from crushing into my lungs. Along with this, I have extensive loss of peripheral vision which makes it very difficult to maneuver a motorized wheelchair safely. It is essential for me to have someone assist me when I go anywhere, especially when it is a new environment that I am not familiar with.

As an example of the critical need for a PA to assist me in daily living, two years ago I took a terrible fall from the steps of a building on the campus of Arizona State University, where my husband and I were both enrolled as students. Here is the way he remembers that day:

It was the middle of an ordinary class discussion, held in the fine-arts building. Unexpectedly, an office person tapped me on the shoulder and told

me, "You have a phone call." I instinctively knew something was wrong with my wife. The medical staff was on the line then, asking me if I was the husband of the girl who just fell from the steps outside the Language and Literature building. I was told, "She is okay, but has to go to the emergency room." I said I would be there in a few minutes and I started to run even as I hung-up the phone. The Language and Lit building was not very far from where I was, but I ran as fast as I could. I was scared.

When I got to the building, I saw fire trucks and an ambulance with their red lights flashing. There were police officers, troops of medics, and a crowd of people in front of the building. Then I noticed Rachel, strapped on a stretcher, with her neck wrapped in a wide, white, plastic collar. I learned that she had driven her motorized wheelchair down four concrete steps thinking it was a sloped ramp because her eyes could not perceive the difference. She had landed on the concrete sidewalk, face down, still strapped in her wheelchair.

The medics feared that Rachel had a concussion, for when asked if she knew her name and address, she could not speak clearly. They did not know that she always has difficulty speaking; I was just glad she could speak at all, after what had happened.

This accident would never have happened at all if a personal assistant had been there with her. (Ogami)

The irony is that my personal attendant had just quit a few days before without even giving notice. Back then I could control my electric wheelchair by myself with more confidence than I have now and I thought I could manage getting to class on my own. However, the fact that I mistook those steps for a ramp demonstrated how my eyesight has deteriorated because of the Friedrich's Ataxia. The accident was enough to convince me and my husband that I needed a full-time PA. Convincing those who control the funding for PA services, though, is another matter. To date it has been 18 months that I have been without the services of a PA although I am entitled to receive attendant care for 45 hours per week.

The State of Arizona has a health-care system that helps disabled persons in financial need (and, as college students, my husband and I are clearly in need of financial assistance). It is the Arizona Health Care Cost Containment System (AHCCCS, sometimes ironically called "Access"). This system was created as a result of legislation in 1981 and was intended as a state-funded resource alternative to the federal welfare service known as Medicaid. However, as the very title of the project suggests, Arizona Health Care *Cost Containment* System's main objective is to control the rising medical costs that had created a financial crisis for the historical predecessor of this system, Indigent Health Care, which had been a service in Arizona since 1864 (State of Arizona IV). By the end of the 1970s, health care was costing Arizona more than \$100 million a year with a projected rise to \$250 million by the mid-Eighties (State of Arizona IV). AHCCCS was created to control those costs and utilized a network of primary-care physicians in the role of gatekeepers to do so.

Even with AHCCCS, Medicaid, and Medicare, however, disabled people who required home health-care services had nowhere to turn until very recently. A subdivision of AHCCCS was created within the past few years whose function is to provide state-funded home-health services. This subsystem is called the Arizona Long-Term Care System (ALTCS), and one of its functions is to coordinate PA services through agencies who bid for contractual privileges to serve ALTCS clients. However, because the lowest bidders receive those contracts and because the low-bidding agencies have to control their own costs, the wages that ALTCS PAs earn must be lower than average. In short, ALTCS and its parent system, AHCCCS, are indeed delivering home-health to disabled Arizonans, but are also putting them at risk by offering only \$6.70 per hour wages to PAs

whose job responsibilities are sometimes on a par with those of private nurses.

Arizona is not alone in its low-scale wages for (what should be) highly trained PAs. In my own family, who live in another state, my two sisters have died from complications of Friedreich's Ataxia: my younger sister, Gretchen, died at 17; and my older sister, Stacey, died at 29. For most of their lives neither of my sisters enjoyed the services of personal attendants. In my opinion, my older sister's self-abuse was clearly caused by her depression over having to struggle to participate in society on her own without crucial assistance that a PA might have offered.

During my most recent visit to AHCCCS, when I complained that the PAs sent to me by the agency were both unqualified and irresponsible, my case-manager chastised me. ALTCS is a welfare "privilege," she said: "It is a free service provided for you; thus, we are not obligated to provide an attendant for you." To my way of thinking, AHCCCS benefits are not free, for they are paid for by taxpayers. I am entitled to receive this service because my basic life qualities depend on such assistance. If ALTCS fails to provide the service, then taxpayers are being cheated. Even when attendants are available from the experiences I have had it is clear that taxpayers are not getting value for money.

First, the employees willing to work for minimum wages are undependable. When I had attendants over a year ago some were consistently late every day by as much as twenty minutes. Each of them abruptly quit, without any prior notice, when they found a better-paying job. Secondly, many of the PAs were dishonest - some of my possessions were stolen by these in-home employees. This is quite common apparently. A study by the University of Kansas, in which "91 consumers with disabilities who employed personal attendants" were interviewed, found that forty percent reported "exploitation" by attendants including theft of money, checks, clothes, medication, and other personal and household equipment" (Malone 45). But more importantly, none of the PAs that ALTCS referred to me were provided with any training beyond the basic level. It is crucial that a personal assistant be trained to meet the individual needs of each client as each disabled person requires different types of assistance.

I am fortunate in the fact that my husband, who has now graduated from college, is able to assist me with all the needs I discussed above - dressing, bathing, feeding, running errands, escorting me to campus, taking notes for me in class, and so forth. But Mitsuru's role as my PA is not beneficial to our marriage nor does it leave him time or energy for an outside job where his salary could support us. Undoubtedly, the services of a PA would relieve some of the stress in my marriage caused by my husband having to be my carer. It would mean more time for Mitsuru and I to enjoy life and we would appreciate each other more. If I had a PA, Mitsuru would be free to pursue his career while I completed my college degree and prepared to enter the career world myself. For now, though, we have no other choice than for my husband to be my carer. As my case-manager at ALTCS keeps reminding me, there is a shortage of qualified PAs willing to work for the \$6.70-per-hour wage that the health-care system offers.

There is a further glitch in the Pandora's box of PA provision: even if Mitsuru must continue in his role of my personal attendant, because he is my husband he is prohibited from collecting even the menial wages that ALTCS gives its PAs. Federal law is firmly against any scheme that involves spouses from working for each other. The intention of the law is to prevent couples from making a profit from a relationship where both parties are reliant on one another. Parents, children, and siblings are permitted to earn salaries for work they perform for family members - but spouses are not. Randy R. Werner, a disability consultant, personally has some ten clients who became divorced, against their will, in order to get around this bureaucratic problem (Werner, personal interview). Rather than choosing this extreme action, divorcing Mitsuru so that he might be paid for all his work as my PA, it seems far simpler and wiser to offer higher salaries to personal attendants reflecting the responsibility and training that they must have.

Teddie Scharf, who is the director of Disability Resource for Students at Arizona State University and a wheelchair-user herself, pays her own privately-hired attendant \$10.00 an hour.

Scharf's job responsibilities are such that she cannot afford to miss work because of an irresponsible attendant, She pays (from her personal finances) more for a good attendant rather than suffer the ineptness of a PA willing to work for \$6.70 an hour - only until a more attractive job comes their way (Scharf, personal interview).

Scharf is an example of disabled persons' ability to contribute to society which the Americans with Disabilities Act (ADA) has encouraged. But while disabled people's rights of employment and access to buildings and transportation may be dramatically improved by the ADA (Department of Justice, ADA home page), this legislation has failed as far as ensuring that basic human rights for disabled people are properly observed. Disabled people are no different from other citizens in their desire to participate in the social and business domains of society, but this entails an endless variety of difficulties caused by equal numbers of disabling conditions and different levels of ability. For disabilities like mine, having a PA is an essential requirement for my independence rather than the luxury that AHCCCS seems to perceive it to be. For some of us, it matters little that the ADA requires access to public buildings because we cannot get there in the first place. And without legal provisions for well-paid services of PAs, there is small chance that many of us will participate in and contribute to society.

As the First Lady, Hillary Rodham Clinton, has written:

[M]illions of Americans live with disabilities and can bring enormous energy and creativity to our workforce. Studies show that the vast majority wants to work, yet 75 percent of them are unemployed. . . .

Nine years ago. . .the Americans with Disabilities Act became law, opening doors in the same way that the Civil Rights Act did three decades ago. Whereas, at one time, we presumed that a disability meant a lifetime of dependence, now, we know that those with disabilities want to - and can - lead independent lives and contribute to our nation's prosperity. . . .

In many ways, work helps build our self-respect as well as our nation's economy. But although our nation is enjoying its lowest unemployment in a generation, too many Americans with disabilities cannot participate because of the barriers that still stand. (Clinton)

One barrier that concerns me is the misconception, or ignorance, on the part off the Government regarding the necessity, for some of us, of personal assistants. If the problem were understood, it would be clear that a larger salary for PAs is the necessary solution so as to make these jobs competitive in the market. To work as a PA should not be seen as finding an emergency or temporary income source, as a job at McDonald's might be; yet the salary ranges are comparable. Minimum wage attracts the unreliable, short-term, irresponsible teen - not the sort of employee I want tending to my personal needs and assisting me in my desire for a quality life. A personal attendant's responsibility is for a human life, not a hamburger. And her salary should reflect that difference.

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