Personal Assistance Services for Workers with Disabilities: Case Studies

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Everyone has been made for some particular work,
and the desire for that work has been put in every heart.
Rumi

The following personal stories evolved from a study conducted by the USM Muskie School of Public Service. The purpose of the study was to obtain detailed information about the experiences, challenges, and needs of individuals with disabilities who are working or who want to work, and who require personal assistance services [PAS] and supports that are accessible, available, and affordable in order to maintain independence and succeed in their job.

In-depth interviews were conducted in 2002 and 2004, representing a variety of people with a range of disabilities. Five of these stories came from personal, one-on-one interviews. A sixth story was submitted in written form. People were recruited for interviews through the Home Based Care Consumer-Directed program. Elder Independence of Maine workers also were asked to identify potential participants. Those interviewed derived services from either MaineCare service options (Private Duty Nursing/Personal Care Services or Consumer-Directed Personal Care Attendant) or the Home Based Consumer-Directed option. Questions were asked concerning four main areas:

(1) the individual - identity, needs, supports;
(2) PAS services - access, navigating the system, met and unmet needs;
(3) employment or pre-employment - description, challenges, needs; and
(4) improvements - lessons learned.

Some recurring themes emerged from the interviews. People wanted to work. They wanted to feel independent and self-governing. They wanted the feeling of connection that comes from being an active participant in society. People did not want to be defined by their disability. Work provided for them that sense of relevance and identity.

There was an overall positive response to how services were provided, either consumer-directed or agency based. Most people interviewed received services through the Home Based Consumer-Directed option. People favored having control over how services were delivered. It was more labor, but worth it. Everyone praised the assessment processes by Alpha One. There were many comments about the process being very thorough and the people very available. While the emphasis is on hiring and managing one's own personal care workers, people mentioned all the support they received in making this option work. Meticulous instruction and support was provided on how to do things such as write job descriptions, conduct telephone and personal interviews, abide by state laws, manage payroll and records, and train the PCA once hired. For the one person who received assistance through agency based services, there was also a positive response to how those services were delivered. A good relationship with the Elder Independence of Maine worker, as well as little turnover in nursing or personal care staff, helped make this person's experience positive. While the agency provided the worker, this person felt they had control over how to train the worker to do the needed tasks.

All of the people interviewed agreed that PCAs made their lives more manageable. Most said their PCAs were wonderful. People usually had to hire several, however, to establish adequate coverage for their needs. Also mentioned as indispensable was the reliance on informal supports,

the unpaid aid and support of family, friends, and coworkers. People commented on large turnover rates of PCAs and attributed that to very low salaries, lack of benefits, and difficult, often part-time, hours. All were adamant that PCAs were not paid enough and that the quality of care would be improved if the profession were better compensated. “Everything revolves around money,” one person said. In order to keep their PCA with them, some admitted they paid extra money out of their own pocket, or provided some other indirect benefits.

People had overall appreciation for the options that provided their services, but needed improvements were identified. Some people worried that the incentive to work would be lost if, at a certain income level, all money goes to PCA care, a reality for those receiving MaineCare waiver services. A closely related topic involved raising income limits. Also stressed was the need to have options that are well funded to ensure that both essential services and sufficient hours are provided. Additionally, desire for changing regulations regarding who can be hired, such as a spouse, through the MaineCare Consumer-Directed option was also expressed. Finally, some people wanted more help with finding work, and more awareness and sensitivity among employers, and coworkers, concerning the need for alternate work arrangements and flexibility.

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These experiences provide a snapshot of how people use personal assistance services to support their ability to work. These stories also give examples of how people obtain personal care workers, the challenges they face, and successes they enjoy. It is our hope that the telling of these stories will help others with disabilities discover their dreams and fulfill their goals, better manage the support systems they use, and perhaps even become advocates for positive change. As was said during one interview, “I know that we ought not to let work be how we define ourselves, but I do.” It’s not surprising that work, and feeling productive, contributes greatly to self-esteem.

We hope as well that the stories will assist educators, service providers, employers and others better understand the challenges faced by people who work and have a serious disability. Permission has been granted for these stories to be told. The interviews have been edited for length and ease of reading. The actual words spoken may appear in rearranged order or be slightly paraphrased, and identifiable information has been removed. However, the voices of the people remain true. The power of personal story telling is strong. There is frustration, anger, humor, pride, acceptance, desire, and sheer spunk in these voices, even contentment, and certainly remarkable resilience and spirit.

The greatest disability is the disability of heart and mind.
Story #5
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Story #1
[Home Based Care Physically Disabled, Consumer-Directed]

I am fifty-one years old, a writer, married, and the mother of a teenage daughter. I also have a chronic disability and I can't manage my life without care. I have multiple sclerosis. My central nervous system is over taxed and its way of revolting is to produce spasms of sudden involuntary muscle contractions. You only can do that so long before you become rigid. I have cramps in my legs twenty-four hours a day. They are ever present and they have damaged my legs. I can't put weight on them; sometimes the pain is unbelievable. Sometimes I hurt so much I can't do anything for weeks. If I can manage it with drugs, I pay the price both with the financial cost of the drugs themselves and with not being able to work because I feel too fuzzy.

My personal care assistant [PCA] helps me get ready for the day. She will stay with me while I go up the stair glide to my office, carrying whatever I need for the day. I can do that but… I tried to do it yesterday and I fell at the top of the stairs. One misstep and I was down, and once I am down I can't get back up. I always keep a phone in my pocket, so I called my husband at his office. I didn't want to spend the whole day on the floor. I have done that. That is why I keep all the magazines on the floor, so I have something to do.

Alpha One assessed my needs with a checklist. They even asked if I could put my socks on and if I could pull up my pants! They use all that information to determine the number of PCA hours they are able to give me. Three years ago I wasn't having as much trouble as I am now and they gave me fewer hours. As it became unsafe for me to do things alone in my house, they increased the hours. They are very available. There is a social worker who is my particular social worker and she is great. She stays on top of things and she always returns my phone calls.

Alpha One doesn't help you find a PCA and yet they feel that the heart of the whole program is to find the right person. The pay for a PCA through my program is $7.75 per hour. This is not a great deal of money, and it is without benefits. It is hard to find somebody to work for that. I am lucky. My friends have been wonderful and they have helped me find PCAs. I have never had to place an ad in the paper or interview a stranger. My present PCA came to me that way and she is wonderful. She is cheerful, physically strong, as well as really strong morally and mentally. She knows when to leave me alone, let me cry, and when to try to help.

I keep all of the necessary PCA financial records, and records of my primary PCA's hours, as well as those of the other two PCAs who help me. Typically I use three. When I pay them I withhold [Medicare] and Social Security. Some PCAs choose to have taxes withheld, but they make such a small amount of money that some like to waive that and pay the taxes at the end of the year. Whatever I pay I match in Social Security. I have a co-pay for that with Alpha One; they deduct that and send me a check. I opened a separate checking account just for PCAs. It is a little business.

[Clarification: A part of the Consumer-Directed Home Based Care Program involves an assessment of a person's financial assets and income. If someone's income and assets are over a certain amount, there is a co-payment required. That co-payment amount depends on a person's income and asset amount. Once a

person is eligible for the CD-HBC program, he/she hires his/her own workers for service. On a monthly basis, the consumer/employer submits the hours worked by their employees, completed in that past month. If they have a co-payment, this amount is deducted from the amount of hours for which they get reimbursed. For example: A person submitted the total hours worked for last month, which totals $1,000. Based on their income and assets, the person has a $100/month co-payment. Alpha One sends a check for $900 to the consumer/employer.]

I've been thinking a lot lately about what I would do if I didn't have PCA services. Before I had a PCA I would park in front of the post office and wait, sometimes for hours, until someone I knew came by who would walk in to buy stamps or mail something for me. I would park in front of CVS and wait for someone I knew to come along who would pick up my prescriptions. Now my PCA does all that, plus does my copying.

My PCA first comes in around 8:00, when my daughter goes off to school and my husband leaves for work, and she stays until 10:30-11:00. One day is longer because she helps me prepare for the week, helps me organize my clothes, does laundry and vacuums. On a typical day, she helps me gather my clothes and get into the bathroom. Usually I need help getting from the wheelchair to the transfer tub stool. She puts everything within reach for me and then she goes down to the kitchen to make coffee and pick up a bit. When I am done bathing she helps me again. I have a hard time; I have no balance at all. It is very difficult to get dressed. The most important thing she does is to help me go up the stair glide into my office.

Years ago there were more young mothers at home. Now everyone has gone back to work. All of my wonderful neighbors are now at work during the day. My PCAs have been wonderful. While the emphasis is on personal care and helping me manage and be safe in my home, sometimes one will take me for a ride in the car to get a cup of coffee. That is such a big deal for me. There aren't many opportunities for that, and I have to use up my hours to do it. But when my PCA and I sat on a bench for half an hour I thought that it was the happiest day.

I am a freelance writer for a literary magazine. I have been doing this type of work since I was nineteen. I have an office upstairs. This is a small house and there was no room anywhere else. Everything I need is in my office within reach, but up the stairs. I had to pay out of my own pocket for a stair climb, $4,000. I also teach classes on essay writing, two or three workshops a year. For that I usually take a friend with me to help, not a PCA.

The quality of my life is questionable. I make it as good as I can. If I can get to my office and shut the door, I am okay. Then I feel like anyone else. Sitting at my computer, I feel normal. I know that we ought not to let work be how we define ourselves, but I do. It has kept me going. I never want people to define me as someone who has MS. I want them to define me as someone who is a good writer and teacher. Work keeps me connected with a professional group of women. It gives me a separate identity and makes me feel still part of adult life. I don't think I would have been interested in staying in this world this long without my work. I don't feel like I can work outside my house. I get tired real fast. Yesterday I worked for three hours and that was it. I would need to buy a vehicle with a wheelchair device … it feels absolutely undoable … absolutely undoable.

Story #2

[Home Based Care Physically Disabled, Consumer-Directed]

I am an adult female. I'm married and have three children, and I currently work as a property manager. I broke my neck in a car accident seventeen years ago. My husband and I and my two oldest kids were going out to dinner. I was pregnant at the time. We slid on a patch of ice and the car rolled over three times. Now I sit in a chair. I did have my baby, who is sixteen now. She is my miracle baby.

At the time of the accident I was a young mother used to doing things my way. I had to let someone into my life who could do the work for me, do it as well as I, someone who I could trust around my kids. I had to rely on a PCA for so many things, not just for me, but also for my whole house. Sharing responsibilities is not easy for a woman to do. It is not easy for people, but it is even harder for women. I would never recommend sharing my domain with another woman. My husband and my children would be at their disposal. I am like prey, an easy target, at risk of losing all to someone else. I am a very proud mother and wife and I always took pride in what I did. Having to let someone else help me just wasn't for me.

Life up to this point has not been all that great. It seems like every time I master something, something else happens, and I have to start all over again. I am all about making things work as best you can without external supports. This splint is the only device you will ever see me use; I don't have a grip without it. I don't believe in devices because if you rely on them and they break, then you are useless. My house is not accessible at all except for my ramp. Everything is in the cupboard where it belongs. I sit sideways and do the dishes. I sweep and mop my own floors. I clean the toilet with my own hands. I do have to rely on this wheelchair, which has never worked properly, and I have been stuck on the couch for days. I have been stuck in my van because the devices in my van have given out.

My husband wants to do things for me and my kids are the same way. But I ask them to just set me up and I will take care of the rest. I like to be left alone. I'm not all about having things done for me. Even though this irritates my family a lot, I choose to be this way. If I let them take care of me, what would I do when they are gone? Only one child is left at home now. She has been ill recently so I have been doing everything, and it is giving me a feel for what my life is going to be like when she is not here.

I am on a program through Alpha One. It is based on income and need. There are different types of programs, but this [Home Based, Consumer-Directed] one allows you to hire a spouse. I receive a certain amount of money a month and I am responsible for paying my PCA. I take care of the taxes, the hiring, and all aspects of it. The other programs, through Medicaid, handle all those pieces, but they tell you who to hire. When I was first injured, I put an ad in the paper and went that route. But the turnover was very high because it is a very demanding job. People don't realize what they are getting into when they come into you home. They think they do this and that around the house and then a week later they just don't show up. This leaves anybody who lives alone very stranded. It is getting dangerous for some people, very frustrating. You have to be a very trusting person to allow PCAs into your house… that, I am not. I am very private, and specific, and particular. Maybe if I had been a kid, or someone who had dealt with their disability

their whole life, I would have been more trusting or more understanding. Perhaps I would have been a little more willing to give, to bend, but I am not.

For the first two years I had about six different PCAs. They burn out really fast. The pay for PCAs is horrible and the hours are very unusual. I need someone in the morning and then not again until ten o'clock in the evening. Most people end up with several different PCAs throughout the day. There are emergency PCAs who come in when nobody shows up. There are snow issues, car issues, and everyday issues.

I hired my husband as my PCA because he is always there. I don't have to worry about all of these issues. He knows me better than anybody. He knows how to take care of me without me having to say a word. It just became second nature for both of us. As my PCA, he sets me up with everything, but basically he sets me up to be independent.

My husband and I met at Culinary Arts School. I have always loved numbers, business, law, accounting, but that is not what I wanted to do. I wanted to own a restaurant and be the cook, because I had always worked in restaurants and bars. Obviously, after the accident I wasn't going to be a cook. I have to know where my boundaries are and it took me seventeen years to figure that out. When my kids were old enough to take care of themselves, I got my accounting and business degree and opened my own business. I owned my own business for the last seven or eight years. I closed it because I didn't want to be a boss anymore. Now I am a property manager for 44 units for those on low income or very low income: elderly, disabled. What is good about this position is that I have been on both sides. I have been very low income; I am disabled. I know when people actually have a need or if they are just 'using' the system. But, if I can help one person a day, no matter how little it seems, it gives me the courage to come back and do it again. Everyday is a new process, a new goal in this job. When I feel like I have reached my learning goals and I can't do it anymore, then I create new ones.

Seven dollars is a horrible wage for PCAs. What kind of care do we have in mind for that level of pay? I think that if they change the program a bit and offer more benefits, or more pay, it would allow people who are disabled to go out into the work community for a longer time. There is not enough hours, not enough financial support. People have to gear their lives toward what they can get for services, which slows their lives down dramatically. I firmly believe in the programs, but they are not organized or run by disabled people. The people who make the chairs don't have a clue what we are facing. They need input from the disabled. My chair is made for a person who does nothing. It is not made for a person who has three kids and goes all the time.

Every day is a new process. I let every day set my goals, because if I plan it, it doesn't happen that way. I am pretty much a believer in 'take one day at a time and make the best of it.' When you reach the best you can you start the next day with something different, because you don't know what life is going to throw you from one day to the next. If you plan it, you are either disappointed or you can't deal with what does happen.

Story #3

[Home Based Care Physically Disabled, Consumer-Directed]

I am an adult male computer programmer. I am married, and I am a quadriplegic. I got hurt just before my eighteenth birthday. I have been in a wheelchair for twenty-two years. My wife is disabled also, with MS.

For fifteen years I paid for personal care assistants out of my own pocket. I didn't explore other avenues. I thought I wouldn't qualify for assistance and that there was always a long waiting list. Finally, after a divorce and living on my own, I really needed help. I discovered that it was available and it has been great. It has allowed me a little freedom financially. But it is my independent side that struggles. At some level I feel I really do need the help. And I feel like I am getting out there and contributing back into the system, so why not use the services that are available? There comes a point when I wonder how much the struggling is worth it just to say that I did it myself.

When Alpha One did my assessment they were very open to what my needs are. They bent over backwards to make sure that I got the most benefit out of their program. There are things that I don't think about, that I take for granted. They made me realize that I could benefit from assistance. I thought they were really good.

When I need to hire a PCA I run an ad in the paper that asks specifically for a PCA to work with a quadriplegic. This person must be dependable, reliable, and able to work mornings, part-time. No experience is necessary because I train whoever comes to work for me. If you put "experienced required" in your ad you are going to get PCAs and CNAs that require $20 per hour, and there is nothing medical about what a person has to do with me. It is just bathing, dressing; it is all very simple. I just need to have someone with a little patience.

I think my biggest barrier in finding help is that I typically only require a couple of hours of morning assistance and a couple more at night. It is not a full-time job. The person has to be part-time and if they take on another job, then scheduling gets difficult. I like to get up and get to work. I try to get up; I start getting up around six. I like to get to work early so I can be out of work early in the afternoon, say three or four o'clock. The quality of my PCAs has varied from year to year. I once had one last for three or four years but I moved too far away from her. She was part-time for a while and I hired and fired a couple of others in between. Just recently I had to let someone go; actually they just quit and disappeared.

Right now my PCA is my mom, and my wife. My mom is retired and she kind of likes to come down and help out. It gives her an opportunity to make a little money and to stay in touch with me. As far as actual services, I mean bathing, dressing. I wear an external catheter, so that needs changing daily, occasionally in the middle of the day. I do a bowel program every other day or so, and I need assistance with that. And our PCA is expected to help with some general housekeeping types of stuff.

Right now the financial assistance I get takes into account my wife's income when figuring out the co-pay. She has MS and is battling her own problems, but they don't take that into

consideration. They just combine our incomes and tell us what we are entitled to. Everything revolves around money. I make a decent wage. I can't imagine making minimum wage and being disabled. I know they have come a long way and have increased the amount you can earn and still receive benefits. But still… For people that are disabled and don't have an education, or who can only find very low paying jobs, what incentive is there to get off Medicaid or Social Security and go to work if you are going to spend all your money on a PCA or lose other benefits?

When I first got hurt, voc rehab tried to get me to do the most that I could. I didn't like my counselor at the time and fought with him. I was a teenager and it was a whole lot of stuff at once to cope with. For the first year I ignored him and hoped that he would go away, but he didn't. During the second year he encouraged me to take the test to see if I could become a computer programmer. I had worked outdoors as a construction worker and could not imagine being inside. I ended up scoring really high on the test and entered a training program that went through one year of college and an internship.

Voc rehab paid for all my schooling, housing, and aid. I even think I got money from them to live on. I was only 19 or 20 then; my mom was handling all my finances. Voc rehab got me moving. They never gave up on me. I finished high school while I was in the hospital. I only needed one class, so I was lucky there. But then I just hung out and partied with my friends for a couple of years. That got old fast. I got back into the job stream after a lull of two years. Alpha One helped me to get my license; they got me back driving. That was a huge thing, and voc rehab was right there.

As a computer programmer, I design and develop computer software for the insurance business. I really enjoy the technical aspect of my job. I'm not striving to be something else. To advance much further I would either be in the project leader role or management role, which I don't want.

I am independent, easygoing, competent, and probably a model employee. I don't have a lot of demands. I get along well with all my team workers. I am considered a mentor or leader among the team as far as sharing knowledge. I work on the computer all day. The only adaptation I have is a handcuff with a pencil and an eraser on it. Other than a bunch of friendly people, I don't need a whole lot more to do my job.

It is the morning that is most difficult. Getting up and getting off to work, that is important. I could probably struggle with it for a couple of hours, but then I would be exhausted and wouldn't even feel like going to work. Instead, I can hire someone to come in and help. It makes my day much more pleasant.

At work, everybody helps out. It's a case of coworkers being nice coworkers. Sometimes I can't reach a piece of paper on a shelf or I might drop something. People are always doing little things that they know I have difficulty with. Maybe it just takes me longer; people pick up on that. Our photocopy machine is upstairs, so I have our administrative assistant copy the materials I need. I haven't raised the issue because if I did they would change it instantly. I am the type that finds my way around things rather than make a big issue out of them, trying to make them perfect. Things are never going to be perfect. My situation is just my situation.

There have been times when I've needed to ask my coworkers for help, like to empty my leg bag. I've got guy friends that have no problem with that. They have been out socializing with me so they know the little odds and ends of stuff. The cafeteria staff here goes out of their way to help, almost to a fault. They just want to help. I have never had someone assigned to me for help. It is just friends being friends, coworkers being friends. Part of that is my having worked here for eighteen years, being here a long time. Part of it is just attitude.

Story #4

[MaineCare Private Duty Nursing/Personal Care Services]

I am a 50-year-old female. I have three sons and am divorced. I completed four years of college with courses taken towards a nursing degree and am a registered nurse, although my RN status is inactive. I also have an Associates degree in mortuary services. I have a head injury and have spasms. Additionally, I have paralyzed vocal cords and have had a tracheotomy.

I have a Goold assessment every year, at which time they determine how many hours of service I can get. In the beginning I had four hours a week, and now I have fourteen. I have had help for the last six years. Goold looked at what I needed for personal care and nursing services, but they did not address employment or work issues.

I am impressed with Elder Independence of Maine [EIM]. I have a very good relationship with my EIM worker. The nurse and nurse's assistants come in from a Home Care agency and MaineCare pays for these services. I don't know the name of the program I'm on to get these services but I know MaineCare pays for it. I think it is on Level III with EIM [Level III Private Duty Nursing/Personal Care Services].

I started with Visiting Nurses. They didn't have nursing assistants but I was grandfathered in for a while. Then it was switched to a Home Care agency. I guess EIM got it started. I haven't had problems with getting services. My services are excellent, especially my nurse who really knows her business. I don't need any more services than what I am currently getting.

I have a certified nursing assistant that comes in for fourteen hours a week and a nurse that comes for one hour per month. My nurse breaks up her time so that she sees me three times a month. The nurse's assistant helps me with my bath. I can't do that myself. I can do some exercises but she helps with the passive ones. Sometimes she also helps with housecleaning and laundry. I can do the laundry myself but I need someone to help get it down. Sometimes a friend or one of my sons helps do this. I can get ready in the morning by myself or with the help of my sons.

Sometimes I have to break in a new person to help me in the bathroom. I have to train them, tell them what to do - how to wash my hair, for example, while being careful of water and the trachea. I have been lucky that I haven't had too many changes of helpers and different people to train. I don't know how people without a nursing background do it. I would be overwhelmed and scared if I hadn't had nursing training.

I am happy and independent, for the most part, but I don't know how to get connected to work. I am currently unemployed. Not working and not feeling connected is very frustrating. I need to be needed. I would like to help people, like being an inspirational speaker for other people with head injuries. But you don't get paid for that, and I really need paid work.

No one has ever helped me find work. Everyone thinks I am too damaged. I'm not. I've got things I can do. Everyone I talk to says it would be good for me to work, but that it's not their job to get me a job. It's very frustrating. I could do it; I just need a little more time to do things.

If I had a job, getting ready would take me a while, but I can do it myself. I cannot lift my arms over my head but I do not need help getting ready in the morning. I would not need any help at the workplace. The barrier for me would concern speech. I am very self-conscious about my tracheotomy. They are working on a speaking valve, but there are still some issues with medications to be worked out.

Story #5

[MaineCare Consumer-Directed Personal Assistant Services]

I am an adult female. I was born with Spastic Paraplegia. In the past I relied on canes and walkers, but I currently use a wheelchair for mobility. Also, I have a specially equipped car that I can drive independently.

My disability affects my balance. I need a personal care assistant to help me with activities of daily living, such as personal hygiene, dressing, hanging clothes, preparing meals, and doing housekeeping tasks such as laundry, washing floors, changing the bed, cleaning the bathroom, and vacuuming.

Out in the community my personal assistant helps me shop for groceries, get in and out of the pool at the YWCA, and with showering and dressing after my swim. As an American citizen with a disability I have worked hard all my life to have the freedom and independence most non-disabled Americans take for granted. I got an education and married; I own a home, drive a car, and have a steady job. For many years I served my community as a voting warden during elections. I am physically limited but not emotionally or mentally limited.

I have achieved and continue to maintain my independence with the help of MaineCare's Consumer-Directed Personal Assistant Services, which are administered by Alpha One. This program enables me to receive the assistance I need at home so that I can remain active in the community and not have to live in a nursing home. With Maine's patient care costs in a nursing home being the ninth highest in the nation, at about $77,000 a year, and in-home patient care costs at about $15,000, it saves taxpayers money to support in-home care. I believe that I am happier, and have a better quality of life, with in-home care services.

Until recently things had been going well for me. Then I received a letter from the Department of Human Services telling me that because my monthly Social Security check increased, my MaineCare services would be terminated. I was devastated. My Social Security was increased because the recent year's earnings replaced lower earnings from previous years. Social Security calls this "automatic re-computation of benefits." For three years, I have been working part-time as a customer service representative. My hourly wage is $8.50 and I work approximately eighteen hours a week, resulting in a gross monthly income of $626.94. With my SSD check of $935, my total monthly income is about $1,561.94. My total monthly expenses are $1,323.77. Obviously, my finances do not make it possible for me to pay for my PCA, medications, and other health care costs.

MaineCare has another category of coverage called the Waiver which could allow me to keep my services as long as my monthly income (earned and unearned) doesn't exceed $1,656. Additional rules of this program are that I am allowed a monthly income 'disregard' of $935. Any income above the disregard must be paid to the state as a co-pay or cost share. This means that I will have to live on $935 per month, minus a couple of small deductions for taxes taken out of my pay, and minus out of pocket medical costs. Most of my pay from my job will go toward the co-pay! Why then should I work?! If I receive raises or increased hours at work, I will go over the income limit and lose my coverage! I will no longer be able to afford food!! I have been

told I would be eligible for $90-95 worth of food stamps. Instead of being rewarded for a lifetime of working and paying taxes, I feel I am being forced into additional public benefits.

When MaineCare developed the programs which provide services that make it possible for people with disabilities to live independently at home, not much thought was given to the idea that we would work and earn money. Times have changed and more people with disabilities are out in the work force. MaineCare regulations need to be revised so that I, and others who receive personal assistant services, can work, pay taxes, and contribute to our communities! Although Alpha One benefits specialist, DHS, Social Security reps and others are helping me to understand the present rules and my limited options, the unearned income limit for community MaineCare must be raised, along with the MaineCare Waiver disregard and combined income limits!

My strong faith in God, my confidence in the honorable Governor Baldacci's commitment to health care for all Maine citizens, and my belief that Maine lawmakers will implement changes gives me strength to continue to advocate for myself and others.

I don't see myself as disabled. We are all individuals, different and yet equal to one another. I feel the greatest disability is the disability of heart and mind.

Sources for Additional Information

Access Maine
http://www.accessmaine.org

Alpha One
http://www.alphaonenow.com

CHOICES Project
http://choices.muskie.usm.maine.edu

Department of Health and Human Services (DHHS):
Department of Behavioral and Developmental Services (BDS)
http://www.state.me.us/bds

Elder Independence of Maine (EIM)
http://www.elderindependence.org

Maine Bureau of Elder and Adult Services (BEAS)
http://www.state.me.us/dhs/beas/

Maine Bureau of Rehabilitation Services (BRS)
http://www.state.me.us/rehab

MaineCare
http://www.maine.gov/dhhs/bfi/MaineCare.htm

MaineCare Option for Workers with Disabilities
http://state.me.us/dhs/beas/work

Maine PASA (Personal Assistance Services Association)
http://www.mainepasa.org/

Maine Real Choices, Person-Centered Services
http://www.mainerealchoices.org/pcs.htm

This document is also available on the Internet, at
http://choices.muskie.usm.maine.edu/PAScasestudies.htm

Available in alternative formats upon request.

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Research and Public Service Programs
Institute for Child & Family Policy
Institute for Health Policy
Institute for Public Sector Innovation

National Centers:
- Community Partnerships for Older Adults
- New England Environmental Finance Center
- National Child Welfare Resource Center for Organizational Improvement

University of Southern Maine

Muskie School of Public Service

MaineCare Workers with Disabilities

Case Studies