

Early to Bed/ Late to Rise

An Analysis of Community-Based Personal Assistance Services in Monroe County and New York State

A Publication of
The Center for Disability Rights, Inc.

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April 1993

**Published with the generous support of the
Ben and Jerry's Foundation.**

**The Center for Disability Rights, Inc.
280 Lakeshore Drive
Hilton, New York 14468**

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An Analysis of Community-Based Personal Assistance Services in Monroe County and New York State

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Early to Bed/Late to Rise is a publication of the Center for Disability Rights. The Center, a volunteer membership organization, was founded in December 1990. It promotes the full integration and civil rights of people with disabilities through systems advocacy and policy analysis.

This publication was produced with the generous support of the Ben and Jerry's Foundation, the CDR membership and Saint Mary's Church of Scottsville.

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Printed in the U.S.A.

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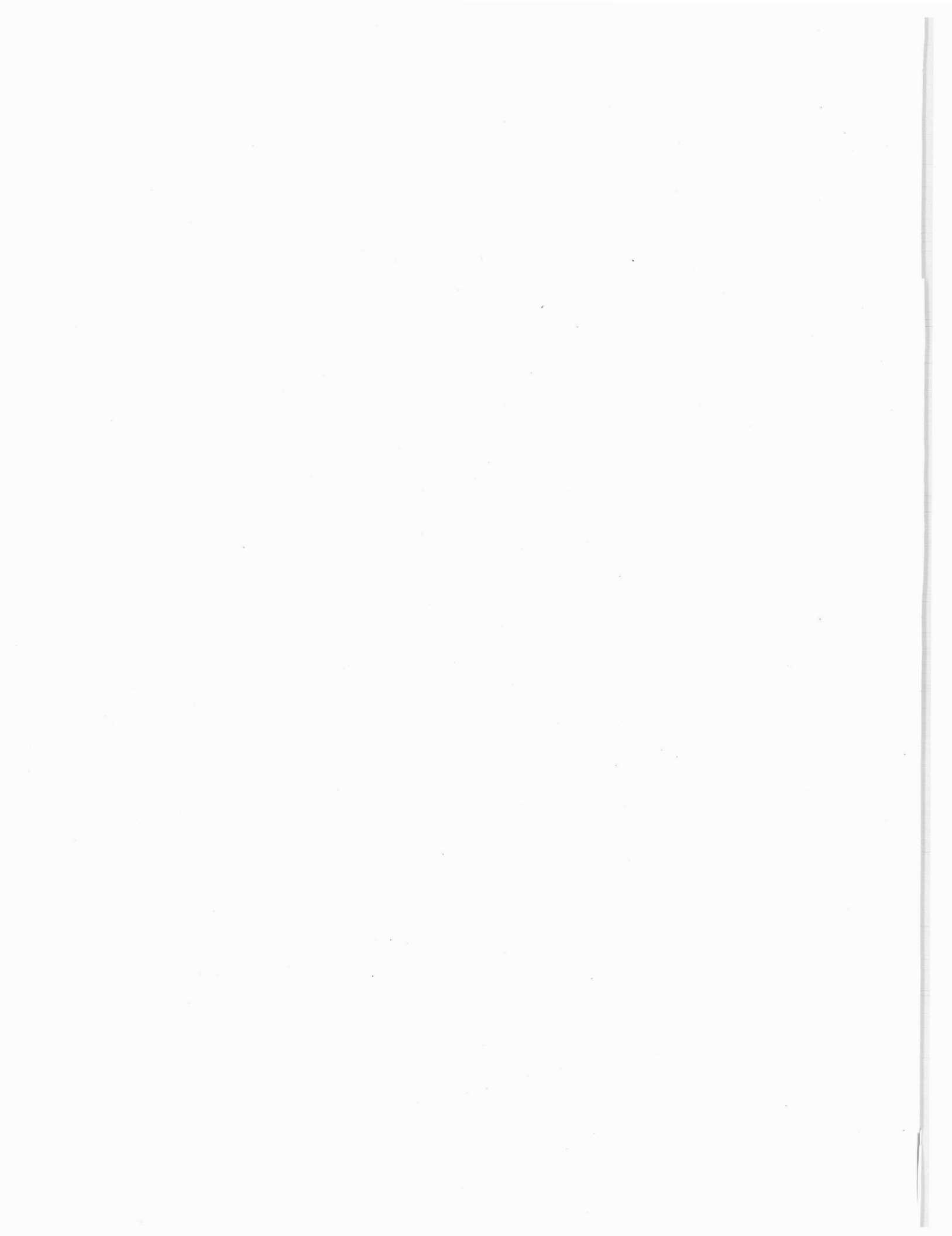
**Early to bed and early to rise,
Makes a man healthy, wealthy, and wise.***

Unlike the man in this proverb, attendant service users must plan their lives around the availability of services. They often have no other choice but to go to bed early and get up late. With these limited options, attendant service users may be denied the opportunity to improve their health, establish a career, and succeed in school.

Still, others remain in institutions because they are unable to get adequate support services in the community.

This paper is dedicated to people who are denied their fundamental rights in order to meet their basic physical needs.

***Benjamin Franklin, Poor Richard's Almanac**



Foreword

IN THE PAST, ADVOCACY TO ENSURE THE CIVIL RIGHTS OF PEOPLE with disabilities has relied on prima facie arguments appealing to our common humanity. Passage of the Americans with Disabilities Act has signalled not only a new era in the civil rights of people with disabilities, but a new era for advocates working on disability rights issues.

Policy makers do not make changes only because they are the right thing to do. More and more, policy makers require research, cost projections, and other analysis. Advocates fighting for the Americans with Disabilities Act often spoke about the importance of that civil rights legislation, but were prepared with cost implications, personal histories, anecdotal evidence, and other research.

The Americans with Disabilities Act assures equal access to employment, the services of State and Local Governments, Telecommunications, public transportation, and public accommodations. There still is no civil rights legislation, however, which protects the right of people with disabilities to live in the community, guaranteeing us the support services we need. Just as African Americans and women have been denied their basic civil rights, people with disabilities are now segregated and warehoused in nursing homes and other residential placements only because we need assistance with the activities of daily living. We believe that one day the concept of incarcerating people because of their need for physical assistance will be as appalling as slavery.

According to the World Institute on Disability 7.8 million people with disabilities in the United States require some kind of assistance to function independently. Those of us who require assistance with the activities of daily living are not only forced into institutions, but are forced into unsafe community living situations, poverty and a nearly inescapable cycle of dependence. We will remain unable to take advantage of many of our newly acquired civil rights unless there is significant change.

It may be simple to dismiss this issue as someone else's problem. But the fact of the matter is that many of us will -- at some point -- require assistance to live independently. Although some will be lucky to have family members to assist them, this is not always the case. Whether through injury or just the aging process, many of us will lose our jobs, homes and most of our civil rights simply because we need assistance.

This report is the culmination of over two years' intensive research and policy analysis by dedicated CDR volunteers. The report describes the

systems which provide community support services for people with disabilities and suggests ways these systems can be improved in Monroe County and New York State. It identifies key principles which must form the basis of any reform efforts and identifies other community groups who can help us make these changes.

On behalf of the CDR Board of Directors, we are proud to release this document. We hope it will generate discussion of these issues by policy makers and persons with disabilities. This report will also build the framework for a community-wide discussion of personal assistance issues.

With all of this said, the real work is yet to be done. This policy paper identifies problems and proposes possible solutions. We must begin our efforts by educating the disabled community about these issues and then strengthening our agenda by forming linkages with other affected communities.

The Center for Disability Rights, Inc. will continue its efforts to reform the systems which provide personal assistance services. We will also continue to provide our community with detailed research on this and other important disability rights issues. We ask that you join us in these efforts.

Thank you.

Susan E. Stahl
President

Sherry L. Shaw
President (1990-1992)

Acknowledgements

Many, many people made this report possible.
Without their efforts, our voice could not be heard.

The Center for Disability Rights, Inc. would like to acknowledge the many expert readers who provided their insights on this very complex issue. Altogether, they read untold pounds of text, and provided important ideas and fresh outlooks on this issue.

John Belanger	Carmen Hernandez
Debra Bonomo	Bryan Hetherington, Esq.
Joseph Bonomo	Julian Kaplow, M.A.
Alien Brown, Esq.	Robert Miller, M.D.
Adele Carlson	Amy Scaramuzzino
Patricia Carpenter	Loretta Scheg
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Burt Danovitz, Ph.D.	Robert Stoegbauer
Jessie Drew-Cates, R.N., Ph.D.	Melvyn R. Tanzman, M.S.W.
Simeon Goldman, Esq.	Sally Trafton, Esq.
James Haflett	David Veatch

Special thanks must be given to Simeon Goldman who completely changed the way we presented the work disincentive issue and Adele Carlson who read every published draft of this report.

We must thank those we profiled in this report. Their willingness to share the impact of these issues on their personal lives demonstrates a substantial commitment to the civil rights of people with disabilities. We are all in their debt.

Debbie Anderson	Patricia Carpenter
John Belanger	Teresa Carroll
Debra Bonomo	Carmen Hernandez
Joseph Bonomo	Craig Himes
Heather Booth	Janine Lawson
Shawneen Bowman	

We would like to express our appreciation for the technical support of Janine Lawson and Alice Carroll for their help in researching this document.

We would also like to express our appreciation to David Veatch. His personal and professional support kept us working on this tome during our most bleak hours. We are saddened that he will never see the final report.

Finally, we must thank our families, friends, and partners who support us in doing our work. Without their love and support, none of this would be possible.

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One:

Introduction

"It is so much easier to assume that we know it all. Or perhaps, having already reached conclusions in our own minds, we are loth to have them disturbed by facts. And yet how little we really know of these millions, -- of their daily lives and longings, of their homely joys and sorrows, or their shortcomings and the meaning of their crimes."

- W.E.B. DuBois
The Souls of Black Folk

ALTHOUGH THERE ARE VERY FEW PEOPLE WHO would openly advocate the institutionalization of people with disabilities, our society is unable to provide the support that allows these people to live independently¹ and safely in the community. People with disabilities who require assistance with activities of daily living inappropriately remain in hospitals, nursing homes, and group homes because of inadequate and at times non-existent services. Rather than being productive members of our community, they are locked away -- unseen and unheard.



¹ While we recognize that no person is completely independent, individuals with disabilities are striving for the same level of interdependence often taken for granted by the rest of society.

According to the World Institute on Disability (WID), personal assistance services can be broken down into six categories : Personal Services, Household Services, Cognitive Services, Communication Services, Security-Enhancing Services, and Mobility Services.

Personal assistance services allow individuals with disabilities to live independently and participate actively in the community by providing assistance with the activities of daily living. We deliberately avoid the use of the term "care" (for example attendant care and personal care) because it implies that the disabled person passively receives the assistance of the attendant.

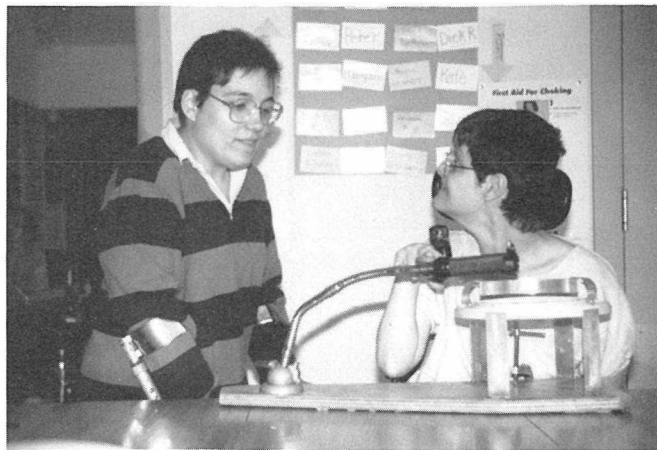
Potential users of personal assistance services are many and diverse. They include people of any age and with any disability - physical, sensory, intellectual or mental - which results in long-term functional limitations that impair their ability to maintain independence. It is generally accepted that people with physical disabilities often need assistance. More recently, people with mental or intellectual disabilities have also begun to use assistants to help them function effectively in the community. Such assistants may help people pay bills, keep financial records, make up shopping lists, communicate with landlords, etc.

According to the World Institute on Disability (WID), personal assistance services can be broken down into six categories : Personal Services, Household Services, Cognitive Services, Communication Services, Security-Enhancing Services, and Mobility Services.² For the purposes of this report, we will focus on personal and household services which are generally provided to people who have limited ability to perform these tasks because of physical disabilities. Consequently, these are the services we describe when we use the term "personal assistance services."

² Each of these services is defined in Appendix A.

The basic issues addressed in this report are:

1. The current model³ used for providing personal assistance services in New York State is based on outdated and inaccurate assumptions and is unable to meet the increasing needs of today's society.
2. Personal assistance services are currently provided through a patchwork system which is made up of many different programs -- each with a separate funding stream and different eligibility requirements. This system is full of holes which leave programs unable to meet quotas and people with disabilities unserved or underserved.
3. People with disabilities must have control over their lives, including a significant role in the redesign of the current personal assistance service system and the opportunity to manage their own services.



This report evaluates the personal assistance service system in Monroe County and, by

³ The most common model for providing attendant services is the Respite Model. It assumes that a person who needs attendant services has a primary caregiver who is responsible for that person's service. Respite services provide short term attendant services in order to relieve the family caregiver. The flaw of that model lies in the fact that not all people with disabilities live with their families; they require attendant services, not respite services.

Throughout this report seven principles are defined which should be used in the restructuring of our personal assistance service system.

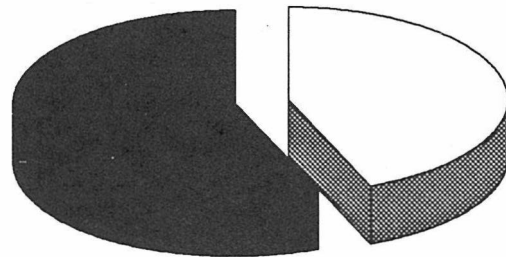
extension, New York State. It discusses the model which has been used as the basis for providing these services, the changes in society which impact on these services, and the resulting inadequacies of the system, including the shortage of qualified attendants. After detailing the patchwork of programs which comprises the current system, this report provides a framework for developing a coordinated and comprehensive personal assistance service system in Monroe County. Throughout this report seven principles are defined which should be used in the restructuring of our personal assistance service system. The restructured system we propose should serve as a model for personal assistance service programs throughout New York State. The final chapter of this report serves as a guide for disability rights advocates who are working on this complex issue.

Personal assistance service users must have the opportunity, if desired, to exercise control over the direction and provision of these services. The independence derived from this control empowers the person with a disability to make decisions about his⁴ own life. This does not mean that one must be able to perform all tasks alone without help from another human being. This distinction is critical for people with disabilities. Some individuals may be able to perform few, if any, daily living tasks without assistance. This has no bearing on their right to determine when, where and how these tasks are performed. Likewise people

⁴ For the sake of simplicity and clarity, in this report we use him/he to describe the person with a disability; Attendants are described as her/she. We respectfully acknowledge that many attendants are men and women have disabilities.

who are unable or unwilling to direct their own services require the option of receiving services from attendants who are trained and supervised by a public or private agency.

Demographic data on disability, which would help specify personal assistance service needs, are minimal at best. However, a look at national research provides some information. The World Institute on Disability estimates that 7.8 million people with disabilities in the United States require some kind of assistance to function independently.⁵ In 1986, Lou Harris surveyed people over 16 years old who have disabilities for the International Center for the Disabled (ICD) and the National Council on Disability (NCD). The ICD Survey of Disabled Americans found that 56% of those who said their disability limited their activity cited the cause of this limitation as their lack of needed assistance.⁶



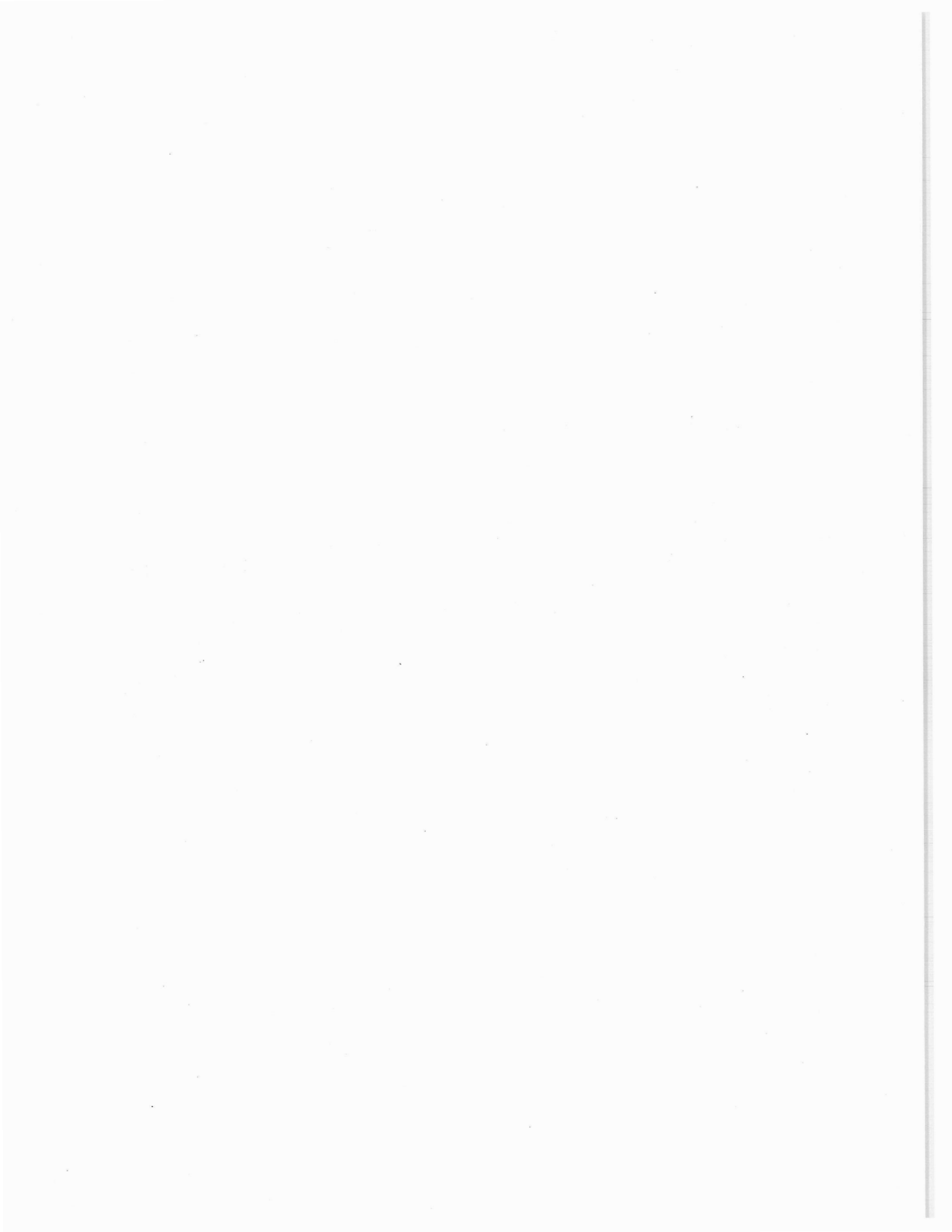
56 % of those who said their disability limited their activity cited the lack of assistance as the reason.

The personal assistance service issue is one of the deepest, most complex and profound problems currently facing the disabled community. Personal assistance services, by themselves, are not sufficient to empower people with disabilities to live to their

⁵ Presentation by Simi Litvak of the World Institute on Disability to the National Council on Independent Living, 1990.

⁶ Harris and Associates, "The International Center for the Disabled Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream," 1986.

maximum potential. However, these services are absolutely necessary for people with disabilities to achieve this goal. Consequently, the strides the disabled community has made during the past twenty years -- including passage of the Americans with Disabilities Act -- will be compromised unless people with disabilities have the assistance they need to live independently in the community.



Profile:

Craig Himes

Craig Himes always carried a fishing pole, bait and tackle, trap and a gun. He said, "If I couldn't catch it or trap it, I'd shoot it." An outdoorsman, in 1986, Craig was working as a General Contractor and owned a swimming pool business in Florida. While fixing his truck, he accidentally walked over an ant hill and was stung by a swarm of fire ants. The venom attacked his motor nerves and, within four hours, left him a quadriplegic with total sensation. He is a graduate of Data Processing for Disabled People and for three and a half years worked as a Computer Programmer for Monroe County. He was laid off by the County in 1992 during staff reductions.

The agency evaluation expected that my wife, Tammi, would assist me during the night, as well as raise our two young children. At that time, they were only one month and one-and-a-half years old. Within nine months, ...I moved to Monroe Community Hospital.

Craig Himes



I CAME TO ROCHESTER BY AIRAMBULANCE IN 1986. My wife, two young children and I lived at English Village and I began to use National Home Health Services. They allocated 12 hours of personal assistance services for me during the day. The agency evaluation expected that my wife, Tammi, would assist me during the night, as well as raise our two young children. At that time, they were only one month and one-and-half years old.

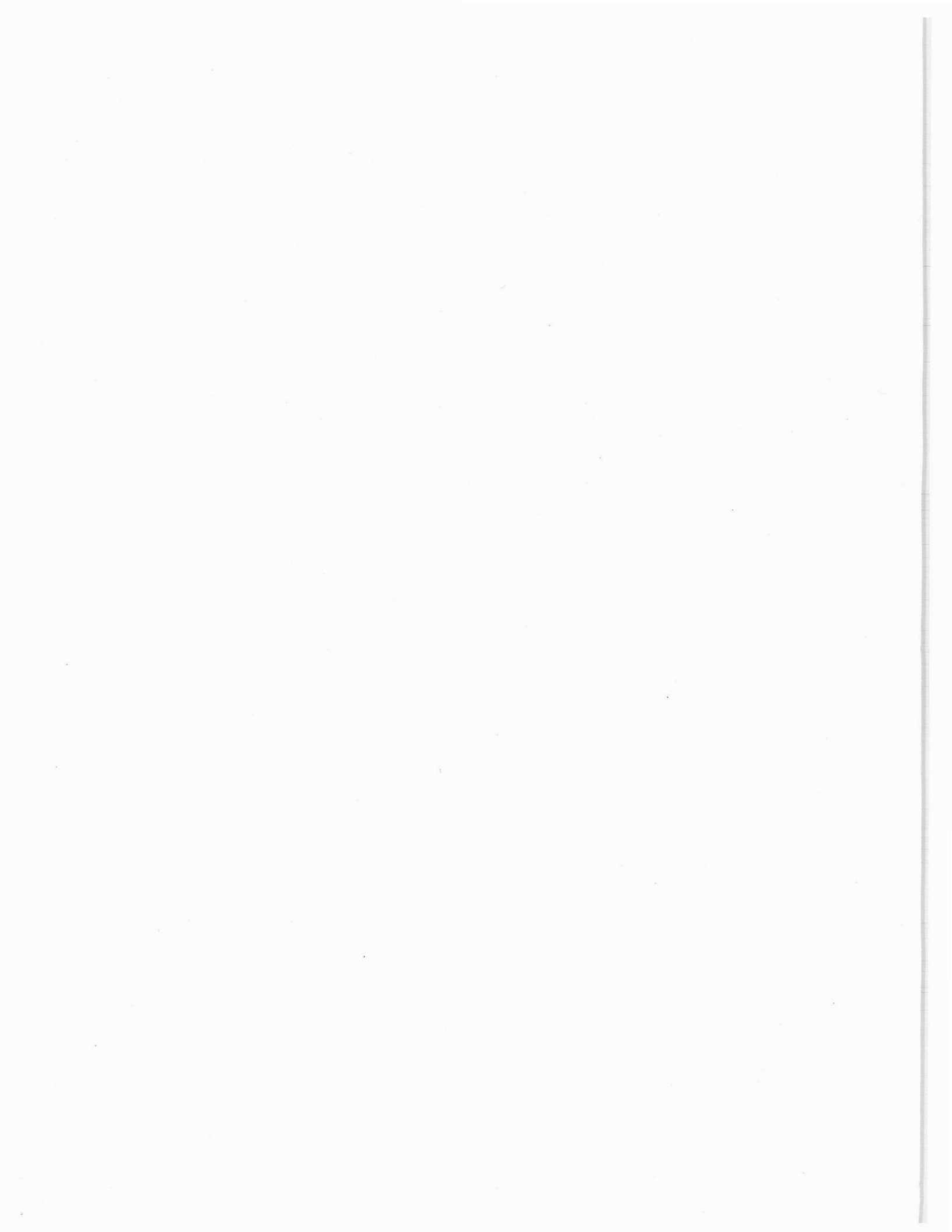
The services I received were inconsistent and unreliable. I was constantly retraining new aides. We had problems with aides being on time or showing up at all. Within nine months, my wife and I separated and I moved to Monroe Community Hospital.

When I moved into MCH I had a roommate, but I now have a private room with a telephone line, answering machine, and computer. I am able to use a mouth stick to operate these things. I also have a television but am not able to use the remote control.

With the sponsorship of the New York State Office of Vocational and Educational Services for Individuals with Disabilities, I started the Data Processing for Disabled Persons program. I graduated from this program in 1988. After an internship with Monroe County, I was hired full time as a COBOL computer programmer.

I worked for the County for three and a half years, but wasn't able to keep very much of what I earned. Most of my salary went to Tammi to offset welfare for her and the children. Much of the rest was returned to the County and Medicaid to cover the cost of living here at MCH. I did get satisfaction from working and I enjoyed having the job.

I love the outdoors. I spend most of my day on the outside of the hospital until I am put to bed at eight o'clock. I have pictures of my children and their drawings in my hospital room. I see my wife and children every two weeks. I also have two other sons and three grandchildren who come to visit when they can.



Two:

The Changing Role of Personal Assistance Services

"I simply could not find the right timing for offering him another puff or another sip. He could ask, of course, but obviously this was a bit of a drag. I knew he was aware of this. He may not have felt awkward, but I did. He was giving me a peek into the two-sided nature of social interaction with someone severely handicapped, and it was driving me up the wall."

- Irving Zola

Missing Pieces:
A Chronicle of Living with A Disability

PERSONAL ASSISTANCE SERVICE POLICY MAKERS have built the current system on the inaccurate assumption that all people with disabilities have a primary caregiver upon whom they rely for day-to-day assistance. Changes in society, demographics, medicine and technology have rendered the current system impotent in light of current and future needs. This chapter discusses the model used as the basis for the existing personal assistance service system, describes the societal changes to which that system must be able to respond, and recommends two principles for policy and service provision changes in the system.



The Original Role of Personal Assistance Services

Home Health Services in New York State were developed as respite services, or a supplement, to the assistance a sick or disabled individual received at home from family and other caregivers.

PERSONAL ASSISTANCE SERVICES, OFTEN referred to as Home Health Services in New York State, were developed as respite services, or a supplement, to the assistance a sick or disabled individual received at home from family and other caregivers. In the mid-1960's the employment of home health aides to assist patients with simple personal care became a burgeoning practice. In 1966, Ione Carey, Director of the Home Health Aide Program for Visiting Nurse Service of New York, described the role of home health aides (attendants) in her article "Training and Use of Home Health Aides." Carey said, "Substituting for the family's services is an important part of home health aide service." Nearly a decade later, Franz U. Steinberg, M.D., in "The Management of Patients with a Spinal Cord Injury by a Hospital-Based Home Care Programme", reinforced the role of home care as a supplement to family responsibility.

"Home care does not relieve patient or family of their primary responsibilities. It enables them to accept these responsibilities by providing support and security of knowing that help and advice are available at any time. Many of our quadriplegic patients would not have been accepted by their families had it not been for the back-up of home care."⁷

⁷ Steinberg, Franz U., M.D., "The Management of Patients with Spinal Cord Injury by a Hospital-Based Home Care Programme," Paraplegia, December 1975.

According to William G. Weissert, personal assistance services have functioned all but exclusively as a support system for family caretakers. They have not served as a substitute for nursing home care.⁸ Personal assistance services provided by Monroe County continue to be based on the outdated and inaccurate assumption that family members will be able to assist the personal assistance service user. Part of the initial assessment required by State regulations includes the "potential contribution of informal caregivers" which is used in the development of a home care plan.⁹

With growing numbers of people who have disabilities living independently in the community, the current model, in use since the 1960's, is outdated and must be revised. Some personal assistance service agencies in Monroe County do not guarantee service, insisting that every person has family members, friends, or others who can provide his care.

The Center for Disability Rights, Inc. (CDR) contacted several agencies which refused to accept people who did not have such back-up services. CDR has also interceded on behalf of personal assistance service users who were without assistance. Agency personnel insisted each time that it was the client's responsibility to solicit assistance from family, friends or even a minister.

Personal assistance services provided by Monroe County continue to be based on the outdated and inaccurate assumption that family members will be able to assist the personal assistance service user.

⁸ Weissert, William G., "Seven Reasons Why It Is So Difficult To Make Community-Based Long-Term Care Cost-Effective", Health Services Research, October 1985.

⁹ 18NYCCR 764.5(a)(4) and 505.14(b)(3)(ii)(b)

**Current
deinstitution-
alization and
mainstreaming
policies provide a
strong foundation
for redefining these
services.**

In a speakout hosted by the Action Center for the Disabled (ACD) in February 1990, John Belanger, a personal assistance service user said, "My understanding is that the agencies such as Visiting Nurse and the County will not take your case if you don't have backup service. This policy is unrealistic. Everyone doesn't have family or friends to assist them. Right now I know a woman who has been at a rehab unit over a month because she doesn't have backup care."¹⁰

Personal assistance services are essential support services which allow people with disabilities to live independently in the community. These services must be provided based on the understanding that people with disabilities should be integrated into the community and not separated from mainstream society simply because they need assistance with the activities of daily living. The importance of personal assistance services must be affirmed in our public policies, rather than allocated as supplemental services.

Current deinstitutionalization and mainstreaming policies provide a strong foundation for redefining these services. The Individuals with Disabilities Education Act (IDEA) affirms the right of children with disabilities to access a free and appropriate public education. Such an education must be provided, when appropriate, in an integrated setting. The Americans with Disabilities Act affirms the right of people with disabilities to access public

¹⁰ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

accommodations and governmental services in an integrated setting.

Just as our public policies acknowledge and affirm the rights of people with disabilities to access public education, governmental services, and public accommodations, they must also affirm the right of people with disabilities to have access to appropriate support services so that they may be able to take advantage of these other rights.

Personal assistance services must be available to every person with a disability to allow each person to participate in every aspect of community life. These services must be available 24 hours each day, seven days a week. Further, no individual should be denied personal assistance services, or forced into or kept in an institutional setting because of cost considerations.

Principle 1:

Personal assistance services must be redefined as a human and civil right. Such a policy is the logical extension of current deinstitutionalization and mainstreaming policies, and is consistent with the tenants of the Americans with Disabilities Act.

Personal assistance services must be available to every person with a disability to allow each person to participate in every aspect of community life... No individual should be denied personal assistance services, or forced into or kept in an institutional setting because of cost considerations.

Profile:

Janine Lawson

Janine Lawson is 28 years old. She graduated from Greece Olympia High School and has received an Associates Degree in Liberal Arts from Monroe Community College. In 1991 she got her driver's license, although there is no funding for the van modifications she needs to be able to drive. Janine, who has Spinal Muscular Atrophy, likes crafts, music and creative writing. She loves to shop.

It was very frustrating. Sometimes they would forget to schedule my services. Sometimes they would mistakenly schedule several aides to assist me on the same day. I had to keep calling them to make sure that someone would come.

Janine Lawson



I HAVE ALWAYS LIVED WITH MY MOTHER. SHE HELPS me get in and out of bed; She helps me get dressed; She assists me with bathing. I am 28 years old; my mother recently retired from her job as school bus driver.

I've had Home Health Aides assist me. When I was recovering from a bout of pneumonia, I was given those services. I only really needed a couple of hours each day, but the agency had four hours of service prescribed for me. They needed to make the trip out to my house worthwhile for the aide.

I live in North Greece, well outside the city. It was difficult to get aides who would come out to my house to assist me. The agency either sent no one or too many people. It was very frustrating. Sometimes they would forget to schedule my services. Sometimes they would mistakenly schedule several aides to assist me on the same day. I had to keep calling them to make sure that someone would come.

The aides they sent did not take direction very well. I needed to explain the simplest tasks. Some had little to no prior experience with this type of work. Most were even unable to pronounce my name. I felt like I had to watch them every minute so they wouldn't have a chance to steal anything from our house.

Some of my friends are encouraging me to move out on my own. I've honestly thought about it, but that isn't reasonable right now. It would be too hard on me -- physically and emotionally. I'd be nervous the aides wouldn't show up. I'd worry that the aides would steal from me. I'd worry that I wouldn't get the assistance I need. The reality of it is, my health could worsen if I didn't get that help.

I know I could be more independent and live on my own if I could get the assistance I need. At least, in my mother's home there is always help.

Demographic, Medical, Technological and Societal Changes

"...the Georgia Supreme Court ruled in 1989 that Larry McAfee, a 33-year-old quadriplegic who was injured in a motorcycle accident, could have his respirator turned off... Under pressure from disability-rights groups, the State of Georgia agreed to pay \$7,340.00 a month for attendants for Mr. McAfee and care in a private home. Mr. McAfee, a draftsman, was taught to operate a computer by sipping and puffing on a straw. He decided not to die."

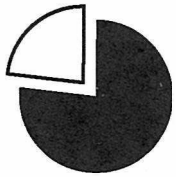
New York Times,
January 31, 1991

COMMUNITY SUPPORT SERVICES WHICH ONCE adequately served the elderly and people with disabilities, are no longer meeting the demands of our changing population. Advances in medicine and technology, as well as changes in society, have resulted in larger numbers of people with disabilities who are able to live independently in the community. Advances in medicine have increased the numbers of persons with disabilities. Technological advances have given people with disabilities the adaptive devices that allow more independence and self-reliance. But by far the most significant impacts on the personal assistance service system have been demographic.



An Aging Population

ACCORDING TO WORLD INSTITUTE ON DISABILITY research, 850,000 people in the United States are currently receiving community-based personal assistance services, but as many as three times that

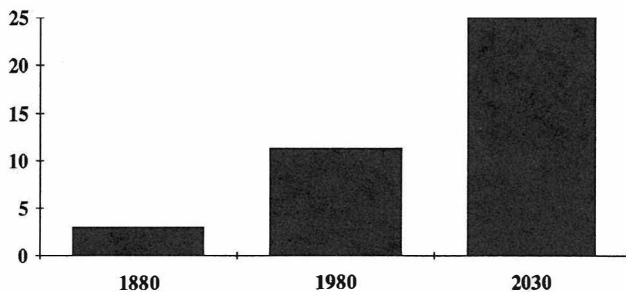


Of those receiving attendant services, 77% are more than 60 years old.

number could benefit from such services.¹¹ Of those being served by personal assistance service programs, 77% are more than 60 years old.¹² The elderly are, by far, the largest and fastest growing segment of personal assistance service users.

In 1880 fewer than 2 million people, or 3% of the total population, were over 65. By 1980 there were 25 million people over 65 in the United States, accounting for 11.3% of the total population. By 2030 an estimated one in four citizens (25%) is likely to be over 65.¹³

Percent of People Over Age 65



The most phenomenal growth is expected to be in the even-older age groups. People over age 85 constituted only one percent of the total population in 1980. By 2030 they may be three percent of the population and more than five percent in 2050. At that time, people over 85 could be nearly a quarter of all elderly people.¹⁴ The implications

¹¹ Litvak, S., Zukas, H., and Heumann, J. E., Attending to America: Personal Assistance for Independent Living, April 1987.

¹² Litvak, S., Zukas, H., and Heumann, J. E., Attending to America: Personal Assistance for Independent Living, April 1987.

¹³ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

¹⁴ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

for personal assistance services are important. While only three to five percent of people age 65 to 74 require assistance with basic activities of daily living, more than one-third do so by age 85.¹⁵

The numbers for Monroe County are equally significant. By the year 2000, the Center for Governmental Research (CGR) projects that there will be 13,500 persons 85 and older in Monroe County, a 42% increase over 1985.¹⁶ Health Futures for Rochester further estimates that the 75 and older age group could double between the years 2000 and 2035.¹⁷ The increase in the numbers of elderly persons will clearly impact on the demand for personal assistance services in Monroe County and across New York State.

Health Futures for Rochester further estimates that the 75 and older age group could double between the years 2000 and 2035.

Fewer Informal Caregivers

THE IMPACT OF PROJECTED INCREASES IN THE elderly is given greater importance by the decline in the number of "informal caregivers." In the past, many elderly persons were cared for at home by family members, often daughters. With increasing numbers of women in the labor force, many have difficulty balancing the demands of the workplace, their own families, and the needs of the older person. Those

¹⁵ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

¹⁶ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

¹⁷ Health Futures for Rochester, The Rochester Region at the Turn of the Century. Projected Population and Economic Capacity, 1988.

Health Futures for Rochester ... projects that, "The significant increase in labor force participation by females will remove non-paid caregivers from the home, thereby increasing demand for domestic help (including home health aides...)"

women who in the past were willing and able to provide support for elderly parents, are often less physically and mentally able to do so.

Over the next decade, the numbers of women in the workforce will significantly increase. Health Futures for Rochester estimates that the number of women in the labor force in the seven county Rochester region could increase by fourteen percent between 1985 and the year 2000 (with a continuation of 1980-85 migration patterns). By comparison the number of men in the labor force could only increase by two-tenths of a percent.¹⁸ The report also projects that, "The significant increase in labor force participation by females will remove non-paid caregivers from the home, thereby increasing demand for domestic help (including home health aides...)"

Additionally, with the post-World War II baby boom and the "echo boom" of the 70's and 80's over, the size of American families continues to shrink. Births are expected to drop through the year 2000.¹⁹ Our society's emphasis on geographic mobility results in families living further and further apart. There is pressure on women to contribute more to family income. Jobs with flexible hours and working conditions needed to accommodate caregivers are becoming less desirable. These jobs typically pay lower wages and

¹⁸ Health Futures for Rochester, The Rochester Region at the Turn of the Century, Projected Population and Economic Capacity, 1988.

¹⁹ Health Futures for Rochester, The Rochester Region at the Turn of the Century, Projected Population and Economic Capacity, 1988.

offer little chance of career advancement. Finally, the fact that one out of every two marriages ends in divorce will diminish the ties of women to their in-laws.²⁰ All of these factors contribute to the diminishing available supply of female caregivers who can provide informal and unpaid support to people who need personal assistance services.

Increased Numbers of Children with Disabilities

FOR YEARS INFANT MORTALITY HAS STEADILY decreased, in large part because of improvements in standards of living and prenatal care. These improvements have been especially supplemented by advances in neonatology. Though the numbers are still small, there are increasing numbers of low birth weight infants and infants with chronic impairments surviving into childhood and beyond.²¹ Due to advances in medicine, many children who would have died (from leukemia, spina bifida, and cystic fibrosis) now live well into adulthood. Other advances and life-extending technologies may help many young people with so-called "terminal" illnesses survive as well.²²

Though the numbers are still small, there are increasing numbers of low birth weight infants and infants with chronic impairments surviving into childhood and beyond.

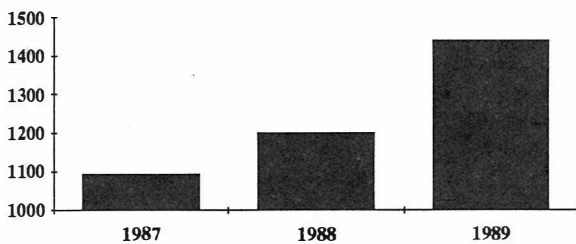
²⁰ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

²¹ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

²² Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

According to the Center for Governmental Research, there is strong evidence of a significant increase in the number of drug-addicted babies. Between 1987 and 1989, the numbers of referrals to Monroe County Certified Home Health Agency (M/CHHA) declined in virtually every age category except the "under one year old" category.²³ In that category, the projected number of referrals for 1989 (projected based on actual experience the first six months of the year) was 1,440 -- up 32% from the 1,094 in 1987 and an increase of 20% from the 1,199 in 1988.²⁴ M/CHHA officials attributed a significant portion of this increase to drug-addicted babies. Some of these children will require some level of personal assistance services as they grow older.

Number of Children under One Year of Age Referred to the Monroe County CHHA



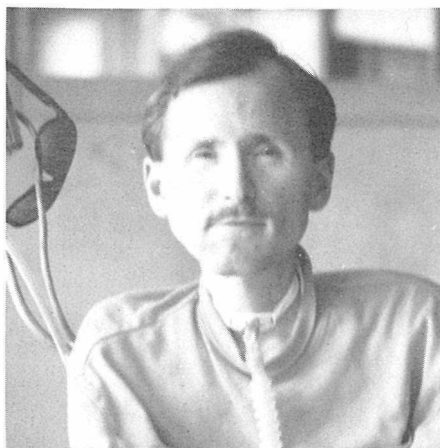
Increased Survival Rates From Advances in Medicine

THERE HAS BEEN A SIGNIFICANT IMPROVEMENT IN the survival rate of people with spinal-cord and other neurological injuries. As recently as the 1950s, death was likely in the very early stages or soon after a spinal cord injury because of respiratory or other

²³ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

²⁴ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

complications.²⁵ In World War I, only 400 men with wounds that paralyzed them from the waist down survived the initial trauma, and 90% of them died before they reached home. In World War II, 2,000 men with paraplegia lived and 1,700 (more than 85%) were still alive in the late 1960s. This improvement is due to the development of antibiotics, which help in the treatment of respiratory complications.²⁶ Each decade since WWII has seen a decline in the death rate and an increase in long-term survival of persons with spinal-cord injuries. These improvements in mortality continued in the 1980's with advances in treatment of head injuries.²⁷



Medical technology has also increased the ability of people with disabilities to live in the community. Improvements in motorized wheelchairs, portable respirators, and environmental controls offer individuals with disabilities the opportunity to live in the community when adequate supports are available. As more people survive with greater levels of disability and advancements are made in technology, more people will require personal assistance services.

²⁵ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

²⁶ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

²⁷ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

The Impact of Acquired Immune Deficiency Syndrome (AIDS)

Monroe County is expected to experience an influx of people from other counties seeking treatment.

PROBABLY NO OTHER DISEASE WILL HAVE A greater impact on our personal assistance service system in this decade than will AIDS. The increasing number of people with AIDS, coupled with improvements in the treatment of AIDS, is likely to increase the demand for personal assistance services in Monroe County.

According to the Monroe County Health Department Community Health Assessment prepared in 1989, Monroe County has the highest cumulative total of reported cases of AIDS in upstate New York.²⁸ The report also estimated that there are approximately 10,000 people infected with HIV in the Rochester/Monroe County area.²⁹

Additionally, the number of people needing service may have been underestimated by the report. Because Strong Memorial Hospital has been designated a regional treatment center for HIV disease, Monroe County is expected to experience an influx of people from other counties seeking treatment. Monroe County has also experienced an influx of

²⁸ Monroe County Health Department, Community Health Assessment, Monroe County, New York, 1989.

²⁹ Monroe County Health Department, Community Health Assessment, Monroe County, New York, 1989.

persons with AIDS who have returned to the area to be with family.³⁰

Increased Need

INCREASED DEMAND FOR COMMUNITY BASED personal assistance services is the trend for the next decade. Larger numbers of elderly persons, fewer informal caregivers, increasing numbers of children with disabilities, improved survival rates for disabled adults, technological advances which give people with disabilities the option of community living, and the rise of AIDS will all contribute to the increasing needs for personal assistance services in our community.

Principle 2:

Personal assistance services must deal with the growing needs of our community due to societal and demographic changes.

³⁰ Monroe County Health Department, Community Health Assessment, Monroe County, New York, 1989.

Profile:

Heather Booth

Heather is employed by the Psychiatry Department of the University of Rochester Medical Center. She has worked in the field of health care research and administration for over 10 years. She is currently working on a research project studying Psychopathology of the Elderly. She also has her own business, Mussel Sportswear, designing and selling activewear.

My mother will never be completely independent. If she and my father had some minor assistance, he would be able to care for her as long as he remains in good health. As he gets older, he will need more respite on a regular basis. Otherwise, he will burn out.

Heather Booth



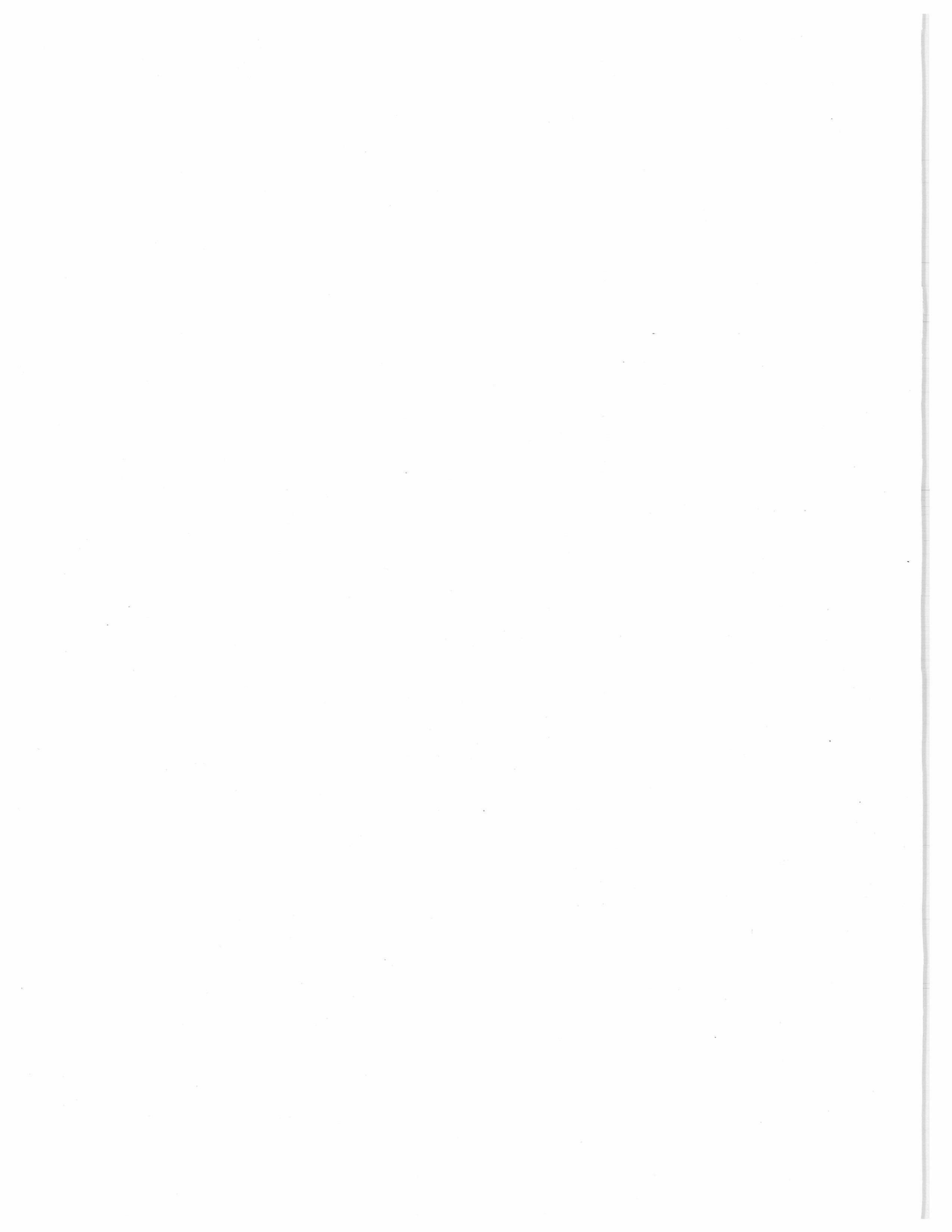
AT THE AGE OF 68, MY MOTHER HAD A MAJOR STROKE. She lost her ability to speak and was paralyzed on the right side. The doctors said that she would never come home. In fact, my mother's stroke was so severe that she barely met the criteria to be placed in the hospital's rehabilitation program.

One of the doctors grilled my father about his financial resources for long term care. My father was also advised by an HMO coordinator to consider nursing home placement and was asked if he knew what he was getting himself into by taking her home. After seven weeks she was discharged to her home with only my father to assist her.

My mother received speech, occupational, and physical therapy at home. She was also prescribed Home Health Services for three days a week, four hours a day for five weeks after her release from the hospital. Unfortunately, their HMO had only contracts with a few Home Health Agencies. None of these was able to provide services in the suburb where my parents live, 20 miles outside of Buffalo. My mother never received the prescribed level of service.

Both my sister and I live and work in Rochester. Every weekend, we would travel to my parents' home to help them and provide respite for my father. All of our time was spent assisting our mother with personal care and additional therapy, rather than providing her and my father with the emotional support they needed. I have also had to limit the time I spend at my business in order to help my parents.

My mother has learned to use her left hand for eating and writing. She is now able to walk and climb stairs with minor assistance and hardly ever uses the wheelchair. She still has a great deal of difficulty communicating. My sister and I still go to their home every weekend. My mother will never be completely independent. If she and my father had some minor assistance, he would be able to care for her as long as he remains in good health. As he gets older, he will need more respite on a regular basis. Otherwise, he will burn out.



Three:

Shortage of Qualified Attendants

"...The vast majority of these nurturers -- those totally necessary human beings who feed, bathe, dress, and comfort the members of the human family who can not do so unassisted -- are women. They are our mothers and sisters, daughters and daughters-in-law, neighbors and volunteers. They do so graciously, in comfortable surroundings or in bitter poverty."

- Karen DeCrow
"Care Tactics,"
Syracuse New Times,
February 21, 1991

ONE OF THE MOST PRESSING CONCERNS FOR THE users and providers of personal assistance services is the difficulty of finding and keeping qualified attendants. The shortage of qualified attendants is often attributed to the low wages they are paid. In fact, according to an article in *Hospitals*, "Low wages, few fringe benefits, and lack of identity are creating an environment that makes it more profitable for some home care aides to flip hamburgers than to deliver health care."³¹



Nola Aalberts, Director of the Homemaker/Home Health Aide Division at the National Association for

³¹ "Aide Shortage Limits Home Health Delivery," Hospitals, May 5, 1988.

Attendants may work in one or more of several different job titles: Home Health Aide, Personal Care Aide, or Homemaker. ...Generally, these workers do very similar jobs.

Home Care, was quoted in the above article. She said the average salary for home health aides is between \$4.50 and \$5.00 an hour.³² Erratic hours limit the earning potential of home health aides, and few or no fringe benefits also devalue their wage potential.

Job titles that vary from program to program do little to help establish a career identity. Attendants may work in one or more of several different job titles: Home Health Aide, Personal Care Aide, or Homemaker. The differences between these titles are minimal. Home Health Aides may perform a few "medically-related" tasks that Personal Care Aides can not perform. Generally, these workers do very similar jobs. There are no substantial differences in skills or experience for the job titles. The difference is based more on the funding stream than the job itself. Few people -- attendants and personal assistance service users alike -- understand the differences.³³ Even the New York State Regulations foster this confusion:

Personal care services shall mean some or total assistance with hygiene, dressing and feeding; nutritional and environmental support functions and health-related tasks...³⁴

Home health aide services means personal care and other related supportive services provided by a home health aide...The tasks a home health aide performs...include personal care services, health care services, and housekeeping services essential to the patient's health...³⁵

³² "Aide Shortage Limits Home Health Delivery," Hospitals, May 5, 1988.

³³ New York City Home Care Work Group, Building the Home Care Triangle, 1990.

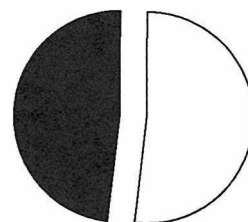
³⁴ 18NYCRR 505.23

³⁵ 18NYCRR 505.14

Rebecca Donovan, Assistant Professor at the Hunter College School of Social Work, New York City, conducted a joint study with Local 1199 of the Drug Hospitals and Health Care Employees Union to analyze the problems home health care workers are facing in that city. Donovan's study found a working force consisting almost entirely of minority women, the majority of whom were single mothers. Over 33 percent made less than \$5,000 per year.³⁶

A survey by the New York State Department of Health stated that 48 percent of all home care agencies reported severe recruitment problems for attendants. Thirty seven percent also reported severe retention problems.³⁷ This shortage was also noted locally by the Center for Governmental Research (CGR) in their 1989 report on the Monroe County Certified Home Health Agency.

Although the CGR report stated that there was no consensus on the extent of the shortage, it did acknowledge that the problem is widespread. CGR stated that interest in health care careers has been discouraged by low salaries, the perception of poor working conditions, and the lack of opportunity for



Forty-eight percent of Home Care Agencies reported severe recruitment problems.

³⁶ "Aide Shortage Limits Home Health Delivery," Hospitals, May 5, 1988.

³⁷ "Aide Shortage Limits Home Health Delivery," Hospitals, May 5, 1988.

Attendants continue to come and go, seeking out the employer who currently makes the most attractive financial offer.

advancement.³⁸ Today, sign-on bonuses and other perks are being offered to attract workers. While these inducements have had some degree of success attracting nurses back to work, less skilled and lower paid workers, particularly attendants, continue to come and go, seeking out the employer who currently makes the most attractive financial offer.³⁹

In order to provide incentives and address the realities of the situation, one local Certified Home Health Agency (CHHA) has attempted to provide innovative recruiting and training approaches, aimed primarily at low-income minority women who are looking for an opportunity to work. Training includes videotaping, simulated setting, and other hands-on types of learning. Job sharing and other flexible opportunities are offered as incentives. A plan has been developed for attendants to be trained and upgraded to LPN status as a means of providing career enhancement opportunities.⁴⁰ Despite efforts to recruit and keep qualified aides, the Monroe County CHHA was reported by the Center for Governmental Research to have a 30-40 percent combined no-fill and no-show rate.⁴¹

³⁸ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

³⁹ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

⁴⁰ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

⁴¹ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

The CHHA is responsible for ensuring that the service specified as part of a home health care plan is actually provided, even if the CHHA is not directly providing the service. Thus, for example, if personal assistance service is required as part of a plan being overseen by the CHHA and an aide from another agency does not show up as scheduled, the CHHA is responsible for providing backup services, even if it means sending one of its nurses to provide care in the interim.

Ensuring this service, however, is difficult, and the 30 to 40 percent no-fill, no-show rate cited by the Center for Governmental Research is also only part of the picture. According to Bryan Hetherington, of Monroe County Legal Assistance Corporation (MCLAC), "We found out that for one week in this county almost 100 people did not get the personal assistance service delivered to them that their doctor had ordered. That does not include the ones where the attendant didn't show up. Those are the ones where the agency could not provide what the doctor ordered and admits to not being able to provide what the doctor had ordered."⁴²

Personal assistance service agencies have also refused cases because of the location of the client's home. The Center for Governmental Research noted in its report that it is difficult to get attendants to go on jobs in rural areas because of transportation problems.

The provision of personal assistance services to persons living outside the City of Rochester will become a more pressing issue during this decade. The bulk of the

"We found out that for one week in this county almost 100 people did not get the personal assistance service delivered to them that their doctor had ordered. That does not include the ones where the attendant didn't show up. Those are the ones where the agency could not provide what the doctor ordered and admits to not being able to provide what the doctor had ordered."

**- Bryan
Hetherington,
MCLAC**

⁴² Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

Between 1985 and 2000, the 75 and older population within the suburbs is expected to *increase* by about 14,400, a 71% increase. Within the City during that period, the same population is projected to *decline* by 7%.

projected population increase in Monroe County between 1985 and 2000 is expected to be concentrated in the suburbs.⁴³ This is particularly true among the elderly population. Between 1985 and 2000, the 75 and older population within the suburbs is expected to increase by about 14,400, a 71% increase (to a total of almost 35,000 people). Within the City during that period, the same population is projected to decline by 7%. ⁴⁴

The low wages attendants earn impacts on their ability to reach these more distant cases. Attendants who must rely on public transportation are unable to service rural clients. Attendants are also not paid for travel time and therefore are reluctant to take cases further out of the city. Vincent Anderson, a social worker with Catholic Family Center, has relocated clients into the City and onto a bus route so that they could receive the personal assistance services they required. In a speakout hosted by the Action Center for the Disabled (ACD) in February 1990, he said, "I think that it is appalling that we have to move our clients from an environment which is conducive to them to one which is more conducive to the home health aides. I have done this in quite a few cases where the client had to be moved because the aide couldn't get there and

⁴³ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

⁴⁴ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

move them into the inner city where they are accessible to the bus line."⁴⁵

One person who was refused service because of the location of her home contacted Monroe County Legal Assistance Corporation (MCLAC) and sued to get the services prescribed by her doctor. Bryan Hetherington, one of the lawyers who took the case, described the situation at the ACD speakout. "We had a client who came to us and was not able to get personal assistance services because the client lived out in Hamlin. We brought a federal lawsuit on her behalf."⁴⁶

MCLAC asked that a class⁴⁷ be established of Monroe County residents who are on Medicaid and receive Home Health Services. MCLAC hoped to establish the principle that people must get the personal assistance services ordered by their physician. Judge David Larimer of Rochester agreed to the creation of the class. Judge Larimer has reviewed the case and agreed that people with disabilities must get the services ordered by their physicians. He issued a

"I think that it is appalling that we have to move our clients..."

**- Vincent Anderson,
Social Worker**

⁴⁵ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

⁴⁶ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

⁴⁷ A class is a group of persons who have the same qualities, characteristics, or attributes. A class or representative action provides a means by which, where a large group of persons are interested in a matter, one or more may sue as representatives of the class.

Judge David Larimer of Rochester has reviewed the case and agreed that people with disabilities must get the services ordered by their physicians. He issued a temporary restraining order and then a preliminary injunction requiring the County to provide these services.

temporary restraining order⁴⁸ and then a preliminary injunction⁴⁹ requiring the County to provide these services.

The preliminary injunction was appealed by the County. The Second Circuit Court in New York City upheld the injunction. According to Mr. Hetherington, at this time agencies no longer can deny people personal assistance services because of where they live, the amount of service needed, or the times that service is needed.⁵⁰

Although this injunction is in effect, Monroe County and MCLAC have not yet reached a settlement in this case. If a settlement can not be reached, MCLAC will request summary judgement⁵¹ and an order⁵²

⁴⁸ A temporary restraining order is an emergency action of a brief duration which may be issued in exceptional circumstances to prevent the violation of a person's rights. It only lasts until the trial court can hear arguments or evidence, as the circumstances require, on the subject matter of the controversy and otherwise determine what relief is appropriate.

⁴⁹ A legal remedy granted at the beginning of a suit, to forbid the defendant from doing some act which may be unjust or injurious to the plaintiff and which the defendant is threatening or attempting to commit.

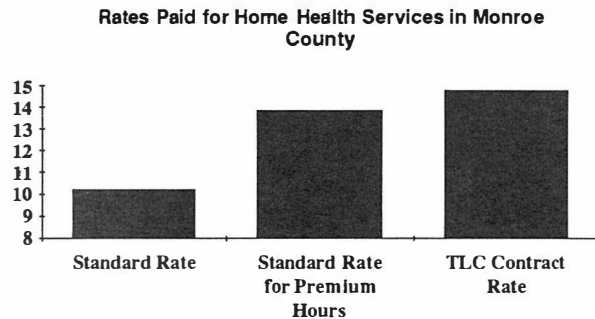
⁵⁰ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

⁵¹ A party may request summary judgement if he believes there are no facts which must be argued at a trial and that he is entitled to prevail as a matter of law.

⁵² A direction or command of a court or judge.

requiring the County to provide the services as prescribed by the physician.

To address the issue of ensuring that the prescribed services are provided, Monroe County has awarded to Tender Loving Care (TLC) a contract which pays the agency a higher reimbursement rate⁵³ in exchange for guaranteed service for County clients who choose TLC service. TLC, in turn, is able to hire on-call aides to cover its cases. Of the \$19.43 billed to Medicaid by the Monroe County CHHA and the higher reimbursement rate paid to TLC, regular aides still only start at \$5.50 per hour and get a dollar an hour bonus if they are on time for all of their cases, about what aides make at other agencies. TLC continues to recruit heavily. The agency has acknowledged that it is still difficult to keep staff.⁵⁴



Professionalizing the role of attendants is fundamental to reforming the system. Agency policies covering the employment of attendants impact not only on the lives of attendants, but on the lives of personal assistance service users. By providing attendants with recognition, advancement opportunities, appropriate wages and

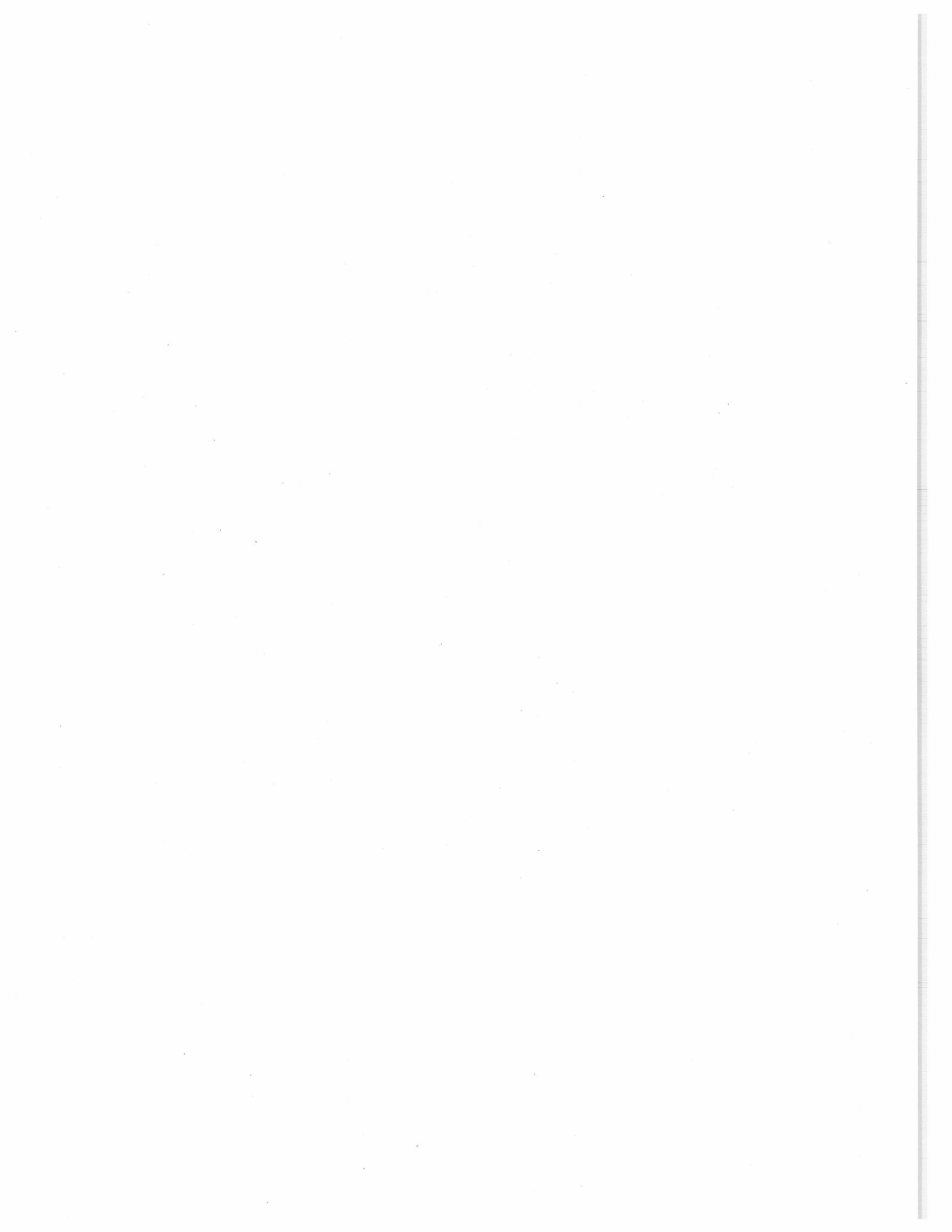
⁵³ Monroe County pays a standard rate of \$10.20 per hour for Home Health Services; the County pays \$13.81 for premium hours. TLC receives \$14.75 per hour for its services. The agency, however, has agreed to pay the County \$14.75 for hours it is unable to cover.

⁵⁴ Action Center for the Disabled Attendant Services Committee Meeting

benefits, the personal assistance service agencies will be better able to ensure that the required services are provided.

Principle 3:

The personal assistance service system must emphasize the professionalism of attendants and provide attendants with a reasonable wage, benefits and the opportunity for career advancement.



Profile:

Shawneen Bowman

Shawneen was a non-traditional Home Health Aide. She graduated from New York Institute of Technology with a Bachelor of Science in Architectural Technology, specializing in Historic Preservation and Restoration. Shawneen was not able to find work in her chosen field. In September 1991, she became a Home Health Aide. Shawneen moved to Alaska with her husband, Bruce during the summer of 1992.

When I began my Home Health Aide training, on that first day, I could see that many of the people in the class would not be very good at the job.

**Shawneen
Bowman**



IMAGINE NOT KNOWING WHO YOU WILL OPEN THE door to each day. Imagine not knowing who will bathe, dress, or help you out of bed. Imagine having to instruct someone you don't know -- step by step -- on how to do your daily activities and where to find what you need. Then imagine not knowing what time all of this would happen. I think of these things everyday, because I am the stranger who knocks on someone's door. I work as a Home Health Aide. This job isn't for everyone.

It takes a certain kind of person to be an attendant. When I began my Home Health Aide training, on that first day, I could see that many of the people in the class would not be very good at the job. Some people missed classes. Others didn't complete assignments. Some were chronically late or chronic complainers. Some even missed tests. Most of these people, however, completed the course. I believe that they are pushed through the training. Agencies seem desperate for aides, and the system is far too forgiving. Everyone seems eager to fill positions and not as careful about who fills them.

I am sure there is a tremendous need for attendants. It is very hard work. You must be prepared for many different situations and be ready to deal with all different kinds of people. You work long hours. We are not paid for travel time, and it could take me 12 hours to get in eight hours of paid work. We are also encouraged to be available for overtime. I, however, would not want to receive the last shift of an aide who has worked a sixty hour work week!

It is also difficult to gauge your work. For all the nursing supervision I've received, I've never had anyone give me a real evaluation. If I weren't doing at least an adequate job, I'd think I would hear about it. But, I don't know if my work is outstanding, good, or just adequate. I don't know what skills I should try to improve or where my strengths lie.

There are also too many people involved in providing these services. There is a terrible lack of communication and accountability, and a great deal of game-playing and manipulation. Everyone has someone else to pass the buck to: aides, the community health nurses, the aide coordinators, and the schedulers. Sometimes I think they wait for the second call before they do anything. That's how problems are dealt with and not necessarily solved.



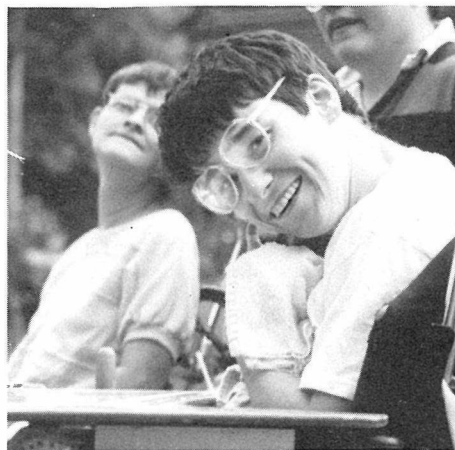
Four:

Varied Funding Streams and Regulatory Controls

"Taken as a whole, services exist as a formidable maze of fragmented public and private entities... There is no uniformity of services from locality to locality. Many programs serve only specific disabilities in specific communities."

- President's Committee on
Employment of People with Disabilities
From Paternalism to Productivity: Whatever It Takes

THERE ARE SEVERAL FEDERAL AND STATE programs that currently provide at least part of the many personal assistance services used by people with disabilities. The provision of personal assistance services cuts across at least three major sectors of the human service system -- health care, income assistance and social services. While the New York State Department of Health regulates all health care, other State agencies administer non-medical personal assistance services. This chapter will describe the current patchwork system of programs providing personal assistance services in Monroe County and describe how these programs should be coordinated.



The Patchwork System

As more services have been created by State agencies, but under different financial sponsors, different program criteria have been added. Each program has its own set of regulatory standards that are not consistent with the existing regulations and standards of other State agencies.

MEDICAID PAYS FOR HOME HEALTH SERVICES AND personal care. The Department of Social Services provides a personal care program under its Community Services Title XX Block Grant. The State Office for the Aging administers the Expanded In-Home Services for the Elderly Program (EISEP), as well as the Older Americans Act Funds and the New York State Community Services for the Elderly Program. Another State funding source for personal assistance services is the Home Health Care Grant Program. Established in 1979 to promote the establishment and expansion of Certified Home Health Agencies in rural areas, the program was expanded to include special populations such as the medically indigent, the geographically isolated and others requiring a more intense level of care.⁵⁵

The expansion of personal assistance services presents a unique set of problems. Most services have been funded by Medicaid. However, as more services have been created by State agencies with an interest in personal assistance services, but under different financial sponsors, different program criteria have been added. Each program has its own set of regulatory standards that are not consistent with the existing regulations and standards of other State agencies. The result is a patchwork of uncoordinated programs, with individuals still unserved. The broad variety of programs does not guarantee that everyone's needs are met.

⁵⁵ Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

The complex services and funding in New York State are a result of targeted lobbying for specific agency programs. Because the assistance provided by these different organizations and agencies has so many different names and is often combined with other types of support service, personal assistance services are difficult to use and nearly impossible to study.

There are eight major sources of funds for personal assistance services in Monroe County:

- 1) Medicaid
- 2) Social Services Block Grant
- 3) Older Americans Act Funds
- 4) Veteran's Aid and Attendance Allowance
- 5) Office of Mental Retardation and
Developmental Disabilities
- 6) Expanded In-Home Services for the Elderly Program
- 7) Other Local Human Service Funds
- 8) Insurance and Private Pay
- 9) Medicare

The following sections provide brief descriptions of each funding stream and its related programs.

Medicaid/Title XIX of the Social Security Act

MEDICAID WAS ESTABLISHED TO PROVIDE MEDICAL assistance to low-income people of all ages. There are no Federal funding limits. The program is financed jointly by Federal, State, and County funds. The bulk of Medicaid funds go toward hospital, nursing home and institutional services. States are required to deliver

The result is a patchwork of uncoordinated programs, with individuals still unserved. The broad variety of programs does not guarantee that everyone's needs are met.

A major difference between Medicaid Personal Care Services and Home Health Services is the amount of nursing supervision required. Personal Care cases only need to be supervised every six months. Home Health Cases, on the other hand, are required to be supervised every 60 days.

minimal health-related home services from a certified home health aide and/or nurse.⁵⁶

The Medicaid program allows a State to provide and be reimbursed for a wide range of home and community-based services. Non-medical services, such as case management, may also be covered by Medicaid. In New York State, the program covers home health care/personal assistance services as well as personal care, adult medical day care, homemaker services, respite care and other services.

Medicaid Home Health Services, which include nursing, home health aide and a variety of other support services, are typically provided through one of three basic programs: Certified Home Health Agencies, Licensed Home Care Services Agencies and Long Term Home Health Care Programs. The Home Health Services provided by these agencies -- either directly or through contract -- are administered by the New York State and Monroe County Departments of Health. Additionally, Certified Home Health Agencies monitor the Licensed Agencies with whom they have contracts.

Medicaid also funds **Personal Care Services**. The Department of Social Services can contract with licensed agencies to provide personal care services for

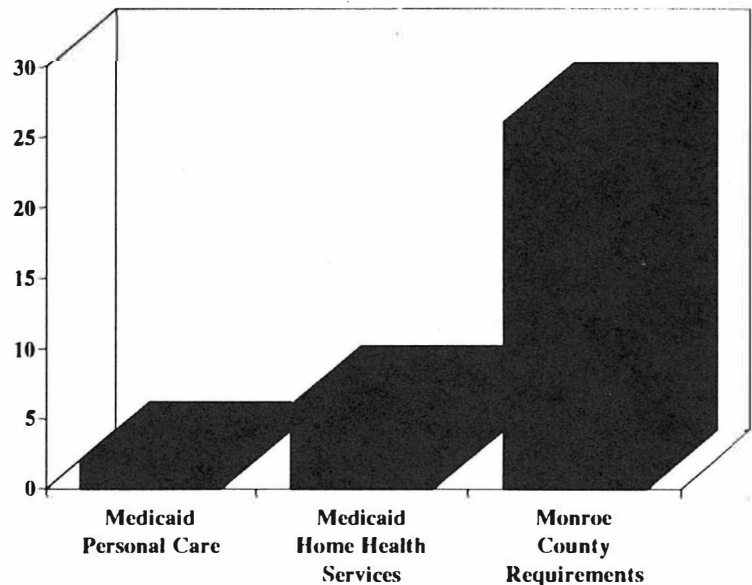
⁵⁶ Litvak, S., Zukas, H., and Heumann, J. E., Attending to America: Personal Assistance for Independent Living, April 1987.

people with disabilities who are self-directing.⁵⁷ The primary difference between PCA services and Home Health Services is the person receiving PCA services is able to self-direct or manage his or her services and has a stable disability or condition.

Another major difference between Medicaid Personal Care Services and Home Health Services is the amount of nursing supervision required. Personal Care cases only need to be supervised every 90 days or six months. Home Health cases, on the other hand, are required to be supervised every 60 days.⁵⁸

The difference in cost of these services is astounding. The Monroe County Certified Home Health Agency bills Medicaid \$19.43 for each **hour** of Home Health Service. DSS would bill Medicaid only \$9.93 per hour of PCA service.

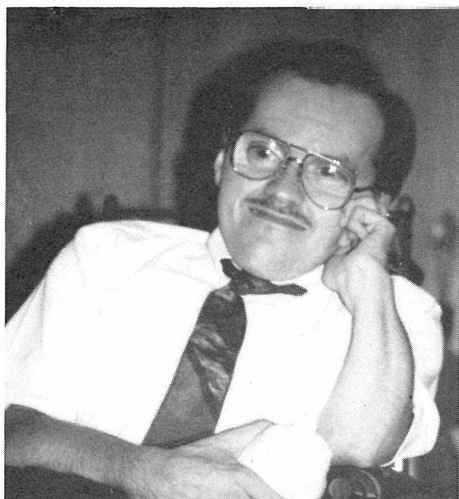
Number of Nursing Supervision Visits Required by Different Medicaid Programs Compared to Monroe County Requirements for Home Health Service Recipients



⁵⁷ Self-direction is defined as the ability to make choices about the activities of daily living, understand the impact of those choices and assume the responsibility for the results of those choices.

⁵⁸ In Monroe County, the Certified Home Health Agencies supervise every two weeks.

Finally, Medicaid funds pay for the **Long-Term Home Health Care Program**. This program, which is designed to keep people out of nursing homes, expands the scope of Medicaid-covered services. Under this program, Medicaid will pay for social day care and transportation, home modifications, case management and other supportive services up to 75



percent of the annual cost of a Skilled Nursing Facility or Health Related Facility level of care.

Although this program is primarily targeted for older persons, others may take advantage of these services, including people with HIV/AIDS or persons who have had strokes. One participant is a nine year old with spina bifida. The Monroe County

Long Term Home Health Care Program is one of five such programs locally. It serves about 300 people.

Social Services Block Grant/Title XX

MEDICAID FUNDING HAS OVERSHADOWED THE TITLE XX Program, created in 1975 as amendments to the Social Security Act. One intent of the program was to prevent institutionalization of people with disabilities by providing community-based services. In 1981 this program was restructured as a block grant program which gave the states options on the way funds were allocated. The funding at the Federal level for this program has, however, increased very little. In 1976,

\$2.57 billion was budgeted and by 1986 had only increased to \$2.7 billion.⁵⁹

In Monroe County, Social Services Block Grant monies are used to provide the Department of Social Services Personal Care Program which contracts with individual nurses or with licensed, certified or other home care agencies for personal care services to assist with personal hygiene, dressing, feeding, and household tasks (e.g., meal preparation, shopping) essential to the person's health. Generally, Social Services Block Grant monies pay for services which have no other reimbursement, including Meals-on-Wheels and homemaker services.

Title III was designed to either augment existing services or to develop new ones to meet the needs of people over 60 years old.

Older Americans Act/Title III

THE MOST RECENT SOCIAL WELFARE PROGRAM offering personal assistance services was established under Title III of the Older Americans Act. Title III was designed to either augment existing services or to develop new ones to meet the needs of people over 60 years old. Unlike Medicaid and Social Services Block Grant programs, there are no income eligibility rules for Title III, though Federal regulations encourage local area Agencies on Aging to target poorer people, because program funds are limited.

The program requires that states expend an "adequate proportion" of their allotted funds for a wide variety of services, including personal assistance services such as personal care, heavy chores, housekeeping, shopping,

⁵⁹ Litvak, S., Zukas, H., and Heumann, J. E., Attending to America: Personal Assistance for Independent Living, April 1987.

The Star Program offered by the Catholic Family Center offers assistance with non-medical home support services to "homebound elderly" individuals...

EISEP provides non-medical home support services for "frail older persons".

interpreting and translating, repairs, maintenance, renovations in the home, escort services and letter writing or reading unless the State agencies can demonstrate that such services are already adequately available through some other source.

In Monroe County, Title III funds support the Star Program offered by the Catholic Family Center. Star specifically offers assistance with non-medical home support services to "homebound elderly" individuals. These services include shopping, friendly visiting, transportation to medical appointments, and banking. These services are free, but donations are requested.

The Expanded In-Home Services for the Elderly Program (EISEP)

NEW YORK STATE MONIES FUND THE EXPANDED IN-Home Services for the Elderly Program (EISEP). EISEP began in early 1987 and is administered through the Office for the Aging. EISEP offers in-home, non-medical services for the elderly who are in need of long-term care but who are not eligible for medical assistance. EISEP services include case management, homemaker/personal care, and housekeeper services.

In Monroe County, EISEP is administered by the Catholic Family Center. EISEP provides non-medical home support services for "frail older persons". The EISEP services include housekeeping, chores, homemaking, and personal care services. Depending on an individual's income, services may be provided at no cost or on a cost-sharing basis.

The Office of Mental Retardation and Developmental Disabilities

THE OFFICE OF MENTAL RETARDATION AND Developmental Disabilities (OMRDD) currently provides ongoing personal assistance services through its Community Residences and Intermediate Care Facilities. Staff in these group-living facilities provide assistance and personal assistance services to their residents. OMRDD does not currently provide any ongoing assistance to people living independently in the community.

OMRDD has, however, developed short-term personal assistance services to meet the needs of some people with developmental disabilities who do not live in OMRDD facilities. These services, called Family Support Services, are primarily designed to support the families and caregivers of persons with developmental disabilities. Respite and Home Care are the two major programs available through the Monroe County Developmental Disability Service Office (DDSO).

Respite

According to the DDSO, respite services are out-of-home, overnight stays by the person with a developmental disability in a Community Residence or Intermediate Care Facility which give the family or primary caregiver a break or respite. These temporary visits may last from one to 29 nights.

Home Care

Assistance may be available within a person's home. The OMRDD Home Care Program provides home

The OMRDD Home Care Program provides home health aides for people with developmental disabilities living with their families. These services are only available in the case of family caregivers who want relief so that they may participate in social activities or go to doctor appointments. The services are not used to allow the caregiver to work.

Eligible veterans in need of regular aid and attendance receive either \$1,257.00 per month or \$1,872.00 per month to purchase the service of a personal assistant who is either a family member, hired through an agency or is an individual provider.

health aides for people with developmental disabilities living with their families. These services are only available in the case of family caregivers who want relief so that they may participate in social activities or go to doctor appointments. The services are not used to allow the caregiver to work.

Veterans' Aid and Attendance Allowance

IN ADDITION TO MEDICAID, SOCIAL SERVICE BLOCK Grant, Title III and State funded personal assistance programs, there is the "Aid and Attendance Allowance" furnished to veterans in addition to their monthly compensation for disability incurred during active service in the line of duty (Title 38, 1984). In 1992, eligible veterans in need of regular aid and attendance received either \$1,257.00 per month or \$1,872.00 per month to purchase the service of a personal assistant who is either a family member, hired through an agency or is an individual provider.⁶⁰ The individual receiving the higher rate of compensation requires daily assistance with nursing tasks. In 1992, pensions for retired veterans with non-service related disabilities could be increased by as much as \$1,644.00 or \$4,435.00 per month if the veteran is housebound or requires personal assistance services.⁶¹

Other Local Human Services Funds

IN MONROE COUNTY, A VARIETY OF PROGRAMS HAVE been created to supplement Federal and State

⁶⁰ According to Eastern Paralyzed Veterans Association, 1992.

⁶¹ According to Eastern Paralyzed Veterans Association, 1992.

programs, most notably, the development of respite care programs in recent years. Human service programs which provide some type of personal assistance service receive funding from a variety of sources, including Community Development Block Grant funds, and the United Way. Each of these programs is targeted to meet a specific perceived need in the community.

Several local agencies provide volunteer services which support people in the community. The criteria for these programs can be very specific. For example, Respite Cares serves only individuals with head injury, developmental disabilities, or Alzheimer's Disease.

Insurance and Private Pay

PEOPLE WHO NEED PERSONAL ASSISTANCE SERVICES may pay for those services with insurance coverage or out-of-pocket money, with insurance being the major source of payment. Blue Cross/Blue Shield owns Genesee Region Home Care, which specifically targets itself as a provider of private pay personal assistance services on a short-term, post-hospitalization basis.⁶²

Out-of-pocket personal assistance service users who are not relying on insurance coverage or Medicaid have greater flexibility, although they must bear the complete cost of their services. They may pay a home health care agency, hire a free-lance aide or hire an uncertified person to assist them. Generally, the cost of

Out-of-pocket personal assistance service users who are not relying on insurance coverage or Medicaid have greater flexibility although they must bear the complete cost of their services.

⁶² Center for Governmental Research, Toward an Improved CHHA in Monroe County, 1989.

agency services precludes their use by out-of-pocket payers. Most often, they rely on uncertified attendants.

Medicare

The 1988 Court decision in the case of Duggan v. Bowen resulted in expanded Medicare coverage for many elderly persons and people with disabilities.

MOST PEOPLE ARE AWARE THAT MEDICARE WILL cover the cost of short-term, post-hospitalization Home Health Services. Medicare coverage, however, has changed because of the 1988 District Court decision in Duggan v. Bowen. In this suit, Medicare recipients fought to standardize and clarify Medicare coverage of Home Health Services.

Katherine Duggan was diagnosed as having Alzheimer's Disease and needed skilled nursing care twice a month to service a Foley catheter and care for urinary tract infections. She needed the help of a Home Health Aide six days a week for an hour and a half each day. She received such services beginning in April 1981. The aide provided personal care, bathing, female hygiene, skin care, range of motion and assistance in getting going for the day after the care was completed.

Because Mr. Duggan had cardiac problems, the Home Health Aide was essential. Without it, Mrs. Duggan would have had no choice but to enter a nursing home. With it, she was able to remain at home.

Services were abruptly denied in July 1986 because the fiscal intermediary claimed they were not "part-time" or "intermittent" in nature -- even though the actual services received by the Duggans were similar to those previously provided.

The 1988 Court decision in the case of Duggan v. Bowen resulted in expanded Medicare coverage for

many elderly persons and people with disabilities. Although there has technically not been a change in Medicare policy, these policies were clarified in the April 1989 Transmittal Number 222 from the Health Care Financing Administration.

Medicare, according to the transmittal, may indefinitely pay for 30 or more hours of Home Health Care services if the recipient:

- 1) is homebound
- 2) is under the care of a physician
- 3) needs intermittent skilled nursing care or physical, occupational, or speech therapy.

A person is considered homebound if he or she is unable to leave his or her place of residence except with the aid of supportive devices such as crutches, canes, wheelchairs, and walkers, the use of special transportation, or the assistance of another person. A person who, due to a stroke, must use a wheelchair is considered to be homebound.

The home care services must be provided under a Plan of Care established and approved by a physician in order to be covered by Medicare. These orders must indicate the type of services to be provided and the frequency of these services.

The home care recipient must also need skilled nursing care on an intermittent basis or physical, speech, or occupational therapy. To meet the requirement for intermittent skilled nursing care, an individual must have a medically predictable recurring need for skilled nursing services. In most instances, this definition will be

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- 1) is homebound**
- 2) is under the care of a physician**
- 3) needs intermittent skilled nursing care or physical, occupational, or speech therapy.**

Home Health and/or Skilled Nursing Services in excess of the amounts of service which meets these definitions of part-time or intermittent may be provided to a home care beneficiary or purchased by other payers without bearing on whether the Home Health Aide and Skilled Nursing Care meets the Medicare definitions. Therefore, any services above the Medicare-allowable levels could be provided and billed directly to another payer without affecting a person's eligibility for Medicare coverage.

met if a person requires a skilled nursing visit at least once every 60 days.

In some instances, "intermittent" skilled nursing services may be provided less frequently than every 60 days. For example, a person with an in-dwelling silicone catheter change only at 90-day intervals would qualify according to the HCFA transmittal.

In order for Home Health services to be covered, the recipient must meet the above qualifications. Medicare will only pay for these services if they are part-time or intermittent. Part-time Home Health Services are those services provided any number of days per week up to and including 28 hours of skilled nursing and Home Health Services combined for less than eight hours per day or up to 35 hours per week subject to a review by fiscal intermediaries justifying the need for these services. Intermittent services are services which are not provided on a daily basis.

Home Health and/or Skilled Nursing Services in excess of the amounts of service which meets these definitions of part-time or intermittent may be provided to a home care beneficiary or purchased by other payers without bearing on whether the Home Health Aide and Skilled Nursing Care meets the Medicare definitions. Therefore, **any services above the Medicare-allowable levels could be provided and billed directly to another payer without affecting a person's eligibility for Medicare coverage.**

Monroe County could save large amounts of money by maximizing Medicare billing. Assuming that a personal assistance service user (with both Medicaid and Medicare coverage) receives 5 hours of home

health services each day from the Monroe County Certified Home Health Care Agency, the Monroe County CHHA bills Medicaid \$35,459.75 per year. (\$19.43 x 5 hours per day x 365 days per year) Monroe County pays 10 percent of that amount, \$3,545.98 per year.

The Monroe County CHHA could bill Medicare for a portion of those services: 25 hours per week, Monday through Friday. During a year, Medicare would pay \$25,259.00 in total Medicare eligible billing. Deducting the \$25,259.00 from the overall billing leaves \$10,200.75 which is billed to Medicaid. Monroe County only pays \$1,020.08 of that, **reducing the County's costs by \$2,525.90 per year.** (\$3,545.98 - \$1,020.08)

The savings to Monroe County could be substantial. If only 50 such personal assistance service users were billing this level of their services to Medicare, the County would save \$126,295.00 each year.⁶³

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⁶³ $\$2525.90 \times 50 = \$126,295.00$

Profile:

Debra and Joseph Bonomo

Debra and Joseph Bonomo were married in August 1984. Joseph, who has Osteogenesis Imperfecta (Brittle Bone Disease), has worked for the Eastman Kodak Company for 11 years. Debbie, who has Cerebral Palsy, is a Community Outreach Services Specialist for the Rochester Center for Independent Living. They live in Henrietta and are very active in the community. Both are strong advocates for people with disabilities. Debbie was instrumental in the fight for accessible buses in Rochester, New York. Joe has served on the CDR Board of Directors. They are most noted for their presentations on sexuality and disability. They have two cats.

If someone isn't responsible to me, I won't pay them. I have withheld pay and fired people who didn't do the job. People on Medicaid should have the same option of managing their own services.

**Debbie
Bonomo**



WE NEED HELP WITH LAUNDRY AND BASIC household cleaning. We pay to have someone come to our home and do the vacuuming, mop the floors, change the bed linens, and clean the bathroom. They come once a week for two and-a-half or three hours. We pay them about \$45.00 each week.

I find my help through word of mouth, the local Pennysaver, and the newspaper. I have never needed to actually run a newspaper ad to find someone, but have written them when recruitment was bleak.

When I am looking for someone to help me around the house, I look for someone who is very reliable. They should not consider this job their primary income. It should only be extra money. It works out better for me that way.

I prefer to pay flat rate, rather than hourly because I found that some people dragged out the work when they were paid hourly. It is also easier to budget a flat rate. We have enough unexpected emergencies -- we really don't need another.

They often clean during the day while we are at work. That is why references are very important. I need to be able to trust these people in my home. I ask references how candidates do the job, how thorough they are, whether they are open to direction.

I've never had Medicaid aide service. I lived with mother before marrying Joe. I have friends who rely on Medicaid aides and express frustration with them. They tell me they wish they had the say that I have over the people who assist me. If someone isn't responsible to me, I won't pay them. I have withheld pay and fired people who didn't do the job. People on Medicaid should have the same option of managing their own services. I rely on Joe to get my shoes and socks on. If Joe were injured, I wouldn't be able to get them on. That has not happened yet. We have always been able to work something out. Thank God. It is a real fear of mine. Especially, when he broke his arm recently. I don't know what I'd do.

Coordinating the System

A functional need is the basic level of assistance that a person requires to perform the activities of daily living. A diagnosis is an analysis of a person's needs based on medically defined symptoms.

"The multiplicity of nutrition programs that can provide a hot meal to an elderly home bound person illustrates the array of choices, as well as the confusion and potentially wasteful and inefficient duplication of services. Depending on who cooks the meal and/or how the meal is delivered to the person, the cost of the meal can range from \$2.50 to \$25.00."

- Susan Stetson

"Affordability v. Quality Care:
Can the Long Term Home Care System Meet Both Goals?,"
Empire State Report, December 1990

AS DEFINED BY THIS REPORT, COMMUNITY BASED personal assistance services include home health care services, personal care services, respite care services, homemaker services and a wide range of other supportive services. These services are provided by a large array of agencies and organizations. Each personal assistance service program, with its own funding stream, eligibility criteria and regulations, provides part of the patchwork of community based support services in New York State.

Functional Need, Not Diagnosis

HISTORICALLY, PROGRAMS SERVING PEOPLE WITH disabilities have been diagnosis-specific, rather than based on functional needs. A functional need is the basic level of assistance that a person requires to perform the activities of daily living or participate in the activities of their choosing. On the other hand, a diagnosis is an analysis of a person's needs based on medically defined symptoms. A diagnosis could be cerebral palsy, spinal cord injury, multiple sclerosis, post-polio syndrome, or arthritis. Individuals with any of

these diagnoses have a range of differing abilities. Conversely, people with different diagnoses may have very similar functional needs. They might be able to walk without assistance, require an assistive device to walk, or be unable to bear any weight on their lower extremities.

Many of the personal assistance service programs for people with disabilities are provided by diagnosis rather than functional need. For example, Respite Cares! provides volunteer assistance for family caregivers who are caring for someone with Alzheimer's Disease, a developmental disability or a brain injury. Their services are not available to caregivers of Persons with AIDS.

When community needs are identified, new diagnosis-specific programs are created to meet those people's needs. If society continues to compartmentalize individuals with disabilities by their diagnosis, there will always be fragmented personal assistance service programs. All funding sources and services should identify people's needs based on their functional abilities and not their medical diagnosis.

It is important that the evaluation of a person's functional need be holistic. Community-based personal assistance services must support an individual's independence at home and in the community. Such an evaluation must take into consideration a person's living situation and lifestyle. A functional need approach supports the individual rather than limiting that person to a medical model rehabilitation evaluation.

If society continues to compartmentalize individuals with disabilities by their diagnosis, there will always be fragmented personal assistance service programs. All funding sources and services should identify people's needs based on their functional abilities and not their medical diagnosis.

The ACCESS demonstration project, however, was designed to meet the needs of the least independent people receiving personal assistance services. Self-directed people with disabilities had a difficult time working within a system which did not allow them the flexibility they needed.

Local Coordination

IN THE 1980'S THE STATE ENCOURAGED THE creation of a few Comprehensive Alternatives Systems Agencies or CASAs. CASAs were created to implement a case management approach that coordinated the patchwork of programs in a county. The goal of this case management was cost-containment and a better use of resources to meet people's needs.

Monroe County had already implemented a CASA-like program under a Federal grant. ACCESS (Assessment of Community Care Services), the Monroe County Long Term Care Program, Inc., which was established in 1975, provided case management services to both DSS and the Monroe County Health Department, created a single point of entry into the complicated system of personal assistance services, and evaluated people's personal assistance service needs under a Medicaid 1115 waiver. The Medicaid waiver demonstration program ended in 1988 in an effort to save some of the \$700,000 in ACCESS administrative costs⁶⁴. The Monroe County Long Term Care Program, however, has secured funds to develop other programs.

The ACCESS demonstration project, however, was designed to meet the needs of the least independent people receiving personal assistance services. Self-directed people with disabilities had a difficult time

⁶⁴ Rochester Business Journal, August 1-7, 1989; and Letter from W. Burton Richardson to Gerald M. Eggert, dated May 12, 1988.

working within a system which did not allow them the flexibility they needed. People with disabilities who were receiving services from ACCESS to this day continue to voice complaints about the ACCESS program. One personal assistance service user had her "case closed" by ACCESS. Without appropriate community-based services, she was forced to go to Monroe Community Hospital. She recently said that "If they put it (ACCESS) back, I'll leave Rochester." Any coordination effort must include safeguards to ensure that people do not have their services cut off. It must also include efforts to foster the independence of self-directed personal assistance service users.

Coordinating State Regulations

ACCORDING TO MONROE COUNTY, PERSONAL assistance service regulations conflict with each other. The Monroe County Departments of Health and Social Services explored these inconsistencies in their joint 1988 report, "Regulatory Conflict in Home Care".

In this report, the Monroe County Department of Social Services and the Monroe County Certified Home Health Agency noted they have been experiencing problems in complying with their respective regulations for the delivery of personal assistance services to Medicaid patients. Issues have been brought to the attention of County officials as a result of strict enforcement of State Health Regulations and the identification of incompatibilities between State Health and State Social Services Regulations.

The primary area of incompatibility lies in the DSS Personal Care Program. Locally, DSS contracts with CHHAs to provide personal care services. The CHHAs

The primary area of incompatibility lies in the DSS Personal Care Program. Locally, DSS contracts with CHHAs to provide personal care services. The CHHAs are subject not only to the DSS regulations by that contract, but also to Department of Health regulations for CHHAs.

Some of these difficulties could be resolved locally. Monroe County DSS could avoid the conflict in the state regulations by hiring its own nurses to supervise the Personal Care Program, or by contracting directly with licensed agencies rather than Certified Home Health Agencies.

are subject not only to the DSS regulations by that contract, but also to Department of Health regulations for CHHAs. By contracting directly with CHHAs, Monroe County DSS allows a person to continue working with the same agency if that person's PCA services must be upgraded to the Home Health Aide level.

The conflict within the regulations is that both DSS and the Department of Health are ultimately responsible for the service delivery plan. This is further complicated by specific prohibitions against delegating responsibility to each other or a third party.⁶⁵

Some of these difficulties could be resolved locally. Monroe County DSS could avoid the conflict in the state regulations by hiring its own nurses to supervise the Personal Care Program, or by contracting directly with licensed agencies rather than Certified Home Health Agencies.

On the State level, it would be in the best interest of both personal assistance service recipients and taxpayers, if both the State Health Department and the State Social Services Department adopted uniform regulations with respect to the delivery of personal assistance services. A serious effort must be undertaken to rectify the differences between the two regulatory bodies at the State level. This would be a significant undertaking and compromise would be necessary on the part of both agencies. This exercise, however, must be taken to clarify the responsibilities of

⁶⁵ Monroe County, Regulatory Conflict in Home Care, April, 1988.

all parties subject to multiple sets of regulations and to ensure service for New York State's residents.

The State should also make a commitment to review other State agencies and initiatives in terms of potential conflict with home care regulations. The State Office for Aging's initiative has also created conflict between two sets of regulations, those of State Office for the Aging and those of the State Health Department for CHHA services, particularly with respect to the provision and supervision of personal assistance services.

In the 1991 State of the State address, Governor Cuomo began to address this issue with the Managed Access to Aging Services Program (MAAS). The MAAS Program would centralize responsibility for assessing the needs for long term care services, determine an individual's needs, coordinate a package of services and authorize payments.

The MAAS Program would provide overall coordination for skilled nursing, home health care/personal assistance services, EISEP, enriched housing, personal care, and long term care services. This program, administered through the State Office for the Aging, would meet the needs of most people who require assistance.

The Governor's initiative, however, did not meet the needs of younger people with disabilities or other chronic health needs who require assistance in order to live independently in the community. The Office for the Aging serves the elderly -- not young people with disabilities. Advocates question whether the State Office for the Aging's advocacy role would be

Rather than developing mechanisms to coordinate the many different regulations and bureaucracies, the State might consider consolidating these agencies under a single department of health and human services.

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compromised by providing these services and whether the relatively small office could adequately coordinate the vast amount of services. The MAAS Proposal also did not address the many conflicting regulations which have been enacted by the State.

In October 1991, Alice P. Lin prepared a public policy paper on long-term care for the elderly and persons with disabilities. The paper, titled Long-Term Care for the Aged and Disabled Persons in New York State -- a Public Policy Framework, detailed a series of principles for the reform of these services.

To maintain individual dignity and autonomy; promote independence of individuals and family;

To develop a community-based system of care, beginning with the least intensive level of care necessary;

To ensure the availability of appropriate needs-driven services, not prescribed program models;

To foster an environment in which the quality and quantity of long-term care can be developed with joint partnership between the public and private sectors;

To protect the vulnerable population, and assure equitable distribution of resources;

To recognize that while the long-term care population shares core services and needs, intervention strategies may differ.⁶⁶

⁶⁶ Lin, Alice, Long-Term Care for the Aged and Disabled Persons in New York State -- A Public Policy Framework, October 1991.

Based in part on these principles, the Lin paper addresses key issues and makes some recommendations for the reform of these services in New York State.

1) Reform financing of long-term care/personal assistance services

The Lin paper correctly points out that Medicaid is the principle payer of these services and the current system is driven by Medicaid. The Medicaid bias promotes over-medicalization, institutionalization, and dependency. The Lin paper also emphasizes that such a program erodes consumer control of these services.

The Lin paper raises a significant policy issue which must be dealt with. The State has tried to maximize the use of Medicaid dollars by covering a variety of supplemental services (i.e. case management). The State is also simultaneously trying to contain the costs of the Medicaid program. This dichotomy must be resolved in order to effectively reform the personal assistance service system.

Lin proposes that the State could apply for a federal Medicaid waiver or utilize some private sector models, including long term care insurance.

2) Close major service gaps

The Lin paper identifies several gaps in the current service system which would need to be addressed in any reform efforts. These gaps include appropriate day services, respite services, and congregate/supportive housing options.

The Lin paper raises a significant policy issue which must be dealt with. The State has tried to maximize the use of Medicaid dollars by covering a variety of supplemental services (i.e. case management). The State is also simultaneously trying to contain the costs of the Medicaid program. This dichotomy must be resolved in order to effectively reform the personal assistance service system.

Any reform of personal assistance services must recognize that Medicaid recipients do not have the income to afford co-payments. Even "minimal" copayments (\$3.00/per day for example) would have catastrophic impacts on the lives of Medicaid recipients.

3) Return control to the consumers and local communities while improving accountability

The paper supports service coordination/integration at the local level, as proposed in the MAAS program, although the Lin paper agrees that the MAAS proposal fails to include younger people with disabilities.

4) Redesign the Infrastructure for long-term care/personal assistance services

The Lin paper highlights the need for an overall mission statement and the consolidation of services within a single state agency with a regional structure and local service delivery systems.

The Lin paper also highlights co-payments as a means to "share the burden of cost", but also to "enhance consumer control." Any reform of personal assistance services must recognize that Medicaid recipients do not have the income to afford co-payments. Even "minimal" copayments (\$3.00/per day for example) would have catastrophic impacts on the lives of Medicaid recipients.⁶⁷ Reform efforts can not be developed at the expense of very low income persons.

Finally, a task force chaired by Dr. Lin has been appointed by the Director of Health, Education, and Human Services to develop future policy options for the State. Advocates have written to Mr. Michael Dowling to express concern that people with disabilities and

⁶⁷ Even \$90.00 per month constitutes over 17 percent of the total monthly income of a person on SSI. With \$90.00 in co-payments each month, an SSI recipient would only have \$430.00 to cover the cost of rent, food, transportation, and other Medicaid co-payments.

personal assistance advocates have been excluded from this process. They have argued that people with disabilities require some of the most intensive services over the longest period of time. Without input from this segment of our population such policy work will at best be inadequate.

In reviewing the complexity of existing personal assistance service systems, it becomes imperative that a consolidated system be developed. The State must consider consolidating current personal assistance agencies under a single state agency, possibly a Department of Health and Human Services, in order to maximize these services and minimize the duplication of services and the cost of their administration.

Principle 4:

The personal assistance service system must coordinate the patchwork of funding streams and programs which allow people to "fall through the cracks". These services must be provided based on a person's functional need rather than diagnosis.

The State must consider consolidating current personal assistance agencies under a single state agency, possibly a Department of Health and Human Services in order to maximize these services and minimize the duplication of services and the cost of their administration.

Profile:

Debbie Anderson

Debbie Anderson was born in 1949. She has cerebral palsy as a result of breathing difficulties at birth. Debbie's mother fought to keep her in public schools. She attended City School #5 and Jefferson High School. She graduated in 1971 and married in January of 1972. Her marriage didn't work out, however, and she lived on her own until 1985. Because there were no emergency services available to her, she moved into Hill Haven Nursing Home for six months. Then she moved to a United Cerebral Palsy Association group home and then to an Intermediate Care Facility. She is a graduate of Empire State College.

In order to get the emergency support I needed, I moved into a nursing home and then into two different UCPA facilities.

**Debbie
Anderson**



WHEN YOU NEED ASSISTANCE, IT SEEMS THAT everything is a struggle. When I applied to go to High School, I was told that if I couldn't feed myself, I couldn't go. Another student's mother came in to feed the two of us, but I still had no way to use the bathroom while I was at school. When I attended college, my mother assisted me there. She took me to school and wrote my notes from class. My mother also helped me with the housework.

In 1985, I was living independently in my own apartment. I had about two hours of aide services each day. I began to get sick. I wasn't able to transfer myself and I needed more assistance than the two hours a day provided by my aides. In order to get the emergency support I needed, I moved into a nursing home and then into two different UCPA facilities.

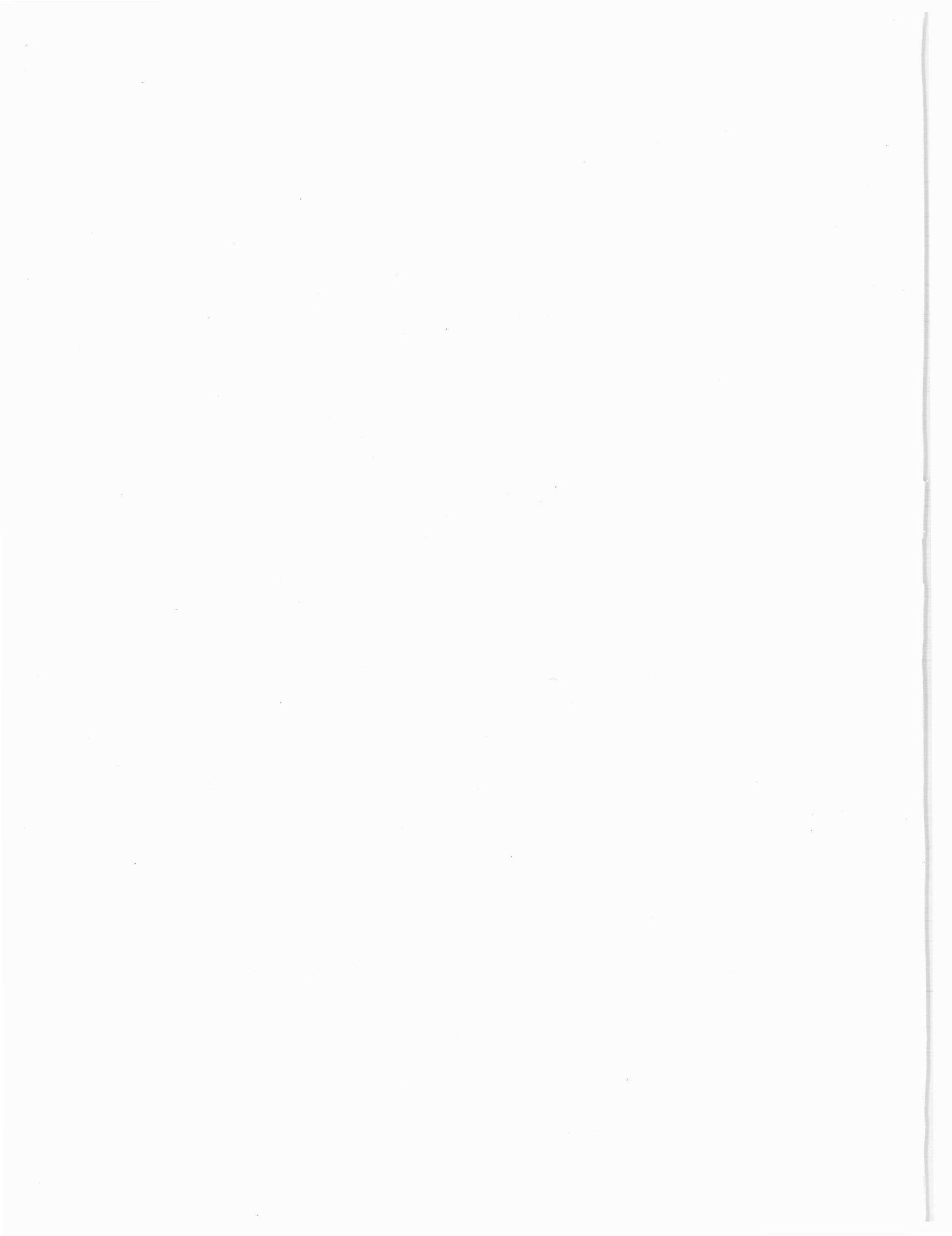
Nursing homes were not designed for young people with disabilities. I didn't belong in a nursing home. UCPA residences have all the regulations associated with serving people with mental retardation. I don't belong in that kind of place.



In the UCPA Intermediate Care Facility, life is very regimented. I must be out of the house 6 hours a day. I like being involved in the community, but I'd also like the option of staying home on occasion. Right now, my life is charted to meet some inane regulations. I have goals and objectives to meet. Goals and objectives are for school and work. I thought home was where you relaxed.

I know what home should be like. I used to live in my own home in Sodus. My husband and I had ducks, geese, goats, pigs, chickens and a dog. Now, I only have a little room which I can call my own. I really don't belong here.

I would like to move into the community, but right now, there just isn't the right kind of support. There isn't enough flexibility in the service system. I have friends who are forced to wait a dozen hours to go to the bathroom. I couldn't do that. Because I need assistance I have been forced to accommodate the system. It is time the system learned to meet my needs.



Five:

Personal Assistance Services as a Disincentive to Employment

"Government must act decisively to eliminate the bureaucratic and regulatory disincentives to employment which now exist at every level of government and service provision...We must rethink and modify Federal, State and local programs to ensure that the system as a whole creates incentives to productivity rather than dependency."

- President's Committee on Employment of
People with Disabilities

From Paternalism to Productivity: Whatever It Takes

THE MAJORITY OF PERSONS WHO USE LONG-TERM personal assistance services in New York State are recipients of Medicaid, which covers the cost of these services. Medicaid eligibility requirements pose a tremendous disincentive to many recipients who rely upon personal assistance services, and who would like to be gainfully employed.



Persons who use personal assistance services and receive Medicaid will fall into one of two categories: 1) those who receive, or have received, Supplemental Security Income (SSI) -- known as SSI related, and 2) those who although medically eligible can not receive SSI due to excess income and/or resources. Individuals in the first category are able to earn income through

There are two sections of the Social Security law that allow people who receive benefits and are working, to keep either some cash benefits and their Medicaid, or just their Medicaid, depending on how much they earn.

employment without jeopardizing their Medicaid eligibility, and by extension, their funding source for personal assistance services, under what are known as the SSI Work Incentives (1619 a and b)⁶⁸. Individuals in the second category cannot take full advantage of these SSI work incentives. These are individuals whose unearned income through Social Security Disability Insurance (SSDI), Workers Compensation, or other governmental or private benefits exceeds the maximum income or resources allowable for SSI eligibility. (In 1992 the amount was \$508 for an individual living alone, less if he lives with others.)

There are two sections of the Social Security law that allow people who receive benefits and are working, to keep either some cash benefits and their Medicaid, or just their Medicaid, depending on how much they earn. These two sections are known as 1619 (a) and (b).

Section 1619 (a) allows SSI beneficiaries to receive SSI cash benefits even when their earned income exceeds the level at which, in the past, they would have lost their benefits. This level is known as "Substantial Gainful Activity Level" (SGA) and still applies in the Social Security Disability Program. However, in the SSI program it is only used as a guideline.

⁶⁸ Department of Health and Human Services Social Security Administration Office of Programs, Office of Disability, Red Book on Work Incentives -- A Summary Guide to Social Security and Supplemental Security Income Work Incentives for People with Disabilities, SSA Publication Number 64-030, June 1991.

To qualify for this incentive:

- 1) the person must be eligible for an SSI payment for at least one month before he or she begins working at the SGA level;
- 2) the person must continue to be disabled;
- 3) the person must meet all other eligibility rules, including the income and resource test.

The person's SSI payment amount will be calculated in the same way as for a person who is not working at the SGA level. This means that a person on SSI can earn more than \$500 per month and still retain some cash benefits. More importantly, the person remains eligible for Medicaid.

An example:

Robert is an SSI recipient who lives alone and receives \$520 per month in SSI benefits. Robert has just gotten a part-time job where he earns \$600 per month. To figure out how much Robert will still get from SSI,

Start with earned income	\$600.00
Subtract \$20 (general exclusion) which leaves	- <u>20.00</u> \$580.00
Subtract \$65 (earned income exclusion) which leaves	- <u>65.00</u> \$515.00

Divide \$515 by 2 which results in \$257.50

The \$257.50 is called countable income.

Subtract \$257.50 from \$520.00, which leaves \$262.50. This means that Robert will have \$262.50 in earned

This means that a person on SSI can earn more than \$500 per month and still retain some cash benefits. More importantly the person remains eligible for Medicaid.

income every month. In addition, he will receive \$262.50 in SSI every month and keep his Medicaid.

Section 1619 (b), on the other hand, continues Medicaid coverage for most SSI beneficiaries when their earnings become too high to allow any SSI cash payment.

Section 1619 (b), on the other hand, continues Medicaid coverage for most SSI beneficiaries when their earnings become too high to allow any SSI cash payment. To qualify for this incentive, a person must,

- 1) have been eligible for an SSI cash payment for at least one month;
- 2) still meet the disability requirement;
- 3) still meet all non-disability requirements;
- 4) need Medicaid in order to work;
- 5) have gross earned income which is insufficient to replace SSI, Medicaid, and any publicly funded personal assistance services.

Social Security uses a threshold to measure whether a person's earnings are high enough to replace his SSI and Medicaid benefits. The threshold amount is based on the amount of earnings from a job which would cause SSI cash payments to stop in the person's state, plus the annual per capita (per person) Medicaid expenditure for the State.

However, if the person's gross earnings are higher than the threshold amount for his state, Social Security can figure an individual threshold if the person has:

- 1) impairment related work expenses (IRWE)
- 2) blind work expenses
- 3) a plan to achieve self support (PASS)

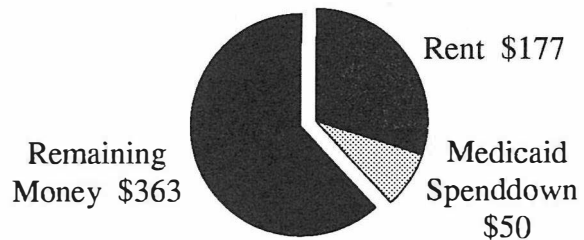
- 4) publicly funded personal assistance services
- 5) medical expenses above the state per capita amount.

The situation is different under Social Security Disability Insurance (SSDI). The incentives built into the SSI program do not apply. Let us use the following example.

The situation is different under Social Security Disability Insurance (SSDI). The incentives built into the SSI program do not apply.

Larry, who has severe Multiple Sclerosis, has been receiving \$590.00 per month in SSDI. Larry requires and usually receives five hours of personal assistance services each day, seven days a week (a total of 35 hours each week). Because Larry's SSDI income exceeds that required for receiving SSI and automatic Medicaid eligibility, he must spend down his income to that required for Medicaid eligibility, \$520.00 per month. Because \$20 of unearned income is disregarded, Larry must spend \$50.00 per month on medical expenses before Medicaid will pay his expenses for personal assistance services. Larry receives Section 8 Housing Assistance and pays rent of \$177.00 per month on a \$600.00⁶⁹ per month apartment.

**Larry's Total SSDI Income : \$590
(Remaining Money \$363)**



Larry is considering a job with an annual salary of \$18,000.00. His gross earned income would be \$1,500.00 per month. We will assume Larry has

⁶⁹ Based on the market-value for a one-bedroom apartment on Lake Avenue (\$601.00).

previously used his trial work period, and will not continue to receive his SSDI benefits.

For Medicaid purposes \$85.00 is excluded.

Larry must spend \$187.50 for his personal assistance services, or other previously covered medical expenses to maintain his Medicaid coverage.

Monthly income	\$1,500.00
Subtract \$85 (earned & unearned income exclusion)	- <u>85.00</u>
which leaves	\$1,415.00

Larry is entitled to exclude one-half of his remaining income, leaving him with \$707.50 for Medicaid purposes. The \$707.50 is called countable income.

Larry would be required to reduce his income through payment for medical expenses to the Medicaid threshold for a single person (\$520.00 per month).

Countable income	\$707.50
Subtract \$520.00 (Medicaid eligibility standard)	- <u>520.00</u>
which leaves	\$187.50

Larry must spend \$187.50 for his personal assistance services, or other previously covered medical expenses to maintain his Medicaid coverage. Larry's income is also subject to payroll deductions for New York State taxes, Federal taxes, and FICA. These are approximately \$330.00 per month.

Gross Monthly income	\$1,500.00
Subtract \$330.00 (mandatory payroll deductions)	- <u>330.00</u>
which leaves	\$1,170.00
Subtract \$187.50 (Spendedown for personal assistance services)	- <u>187.50</u>
which leaves	\$982.50

Larry is left with \$970.50; He will, however, have more living expenses. His gross income disqualifies him from participation in the HUD Section 8 Housing Voucher Program. His rent was based upon 30% of his \$570.00 per month SSDI income or \$170.00 per month. Larry must now pay the full \$600.00 monthly rent which is \$430.00 more each month.

His gross income disqualifies him from participation in the HUD Section 8 Housing Voucher Program.

Monthly income	
after payroll and deductions	\$982.50
Subtract \$600.00	- <u>600.00</u>
(total rent)	
which leaves	\$382.50

Larry must also pay for transportation to and from work by bus (He lives in a city with an accessible mass transit system.), which costs \$2.00 per day or \$45.00 per month for a bus pass.

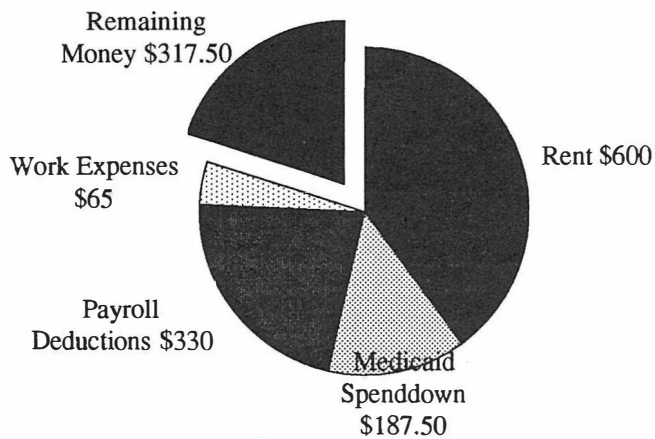
Remaining money	\$382.50
Subtract \$45	- <u>45.00</u>
(transportation costs)	
which leaves	\$337.50

Because of the dress code at work, Larry will need to purchase new shoes, shirts, ties, slacks, and jackets at a cost of \$240.00 or \$20.00 each month.

Remaining money	\$337.50
Subtract \$20 (clothes)	- <u>20.00</u>
which leaves	\$317.50

Larry has \$317.50 left. While receiving benefits, Larry had \$363.00 per month after his rent and spend-down. Thus Larry is left with \$45.50 less to live on each month

**Larry's Total Work Income \$1500
(Remaining Money \$317.50)**



than he would have had if he had not secured gainful employment. His dealings with the local Department of Social Services Medicaid Unit will be significantly more complicated. He faces the possibility that his disability may prevent him from continuing his employment at some future date, which could imperil his hard-to-find accessible housing. It will likely take Larry a few months to begin receiving SSDI again and well over a year to receive his Section 8 Voucher. Larry could conceivably end up homeless

or institutionalized. He risks all of this and he loses \$45.50 each month.

Due to the high cost of personal assistance services, a person who is working and not earning a high income may still not be able to afford to pay for his personal assistance services. For this reason many people who wish to work are forced to remain on benefits. Personal assistance service users will need these services whether or not they are working. If people who need personal assistance services are allowed to work, they will pay taxes, thereby decreasing the net cost to the social service system.

Similarly, people with disabilities who rely on personal assistance services may be prevented from marrying

because the spouse's income would need to be spent down to Medicaid levels.

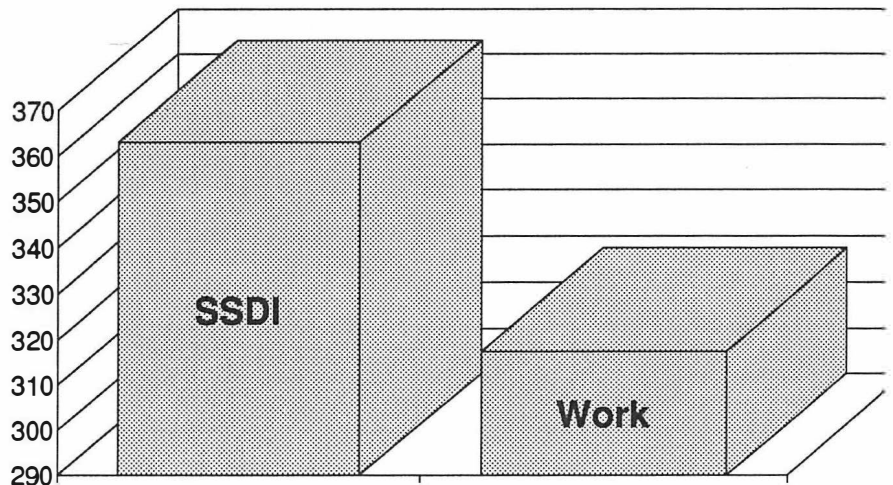
Although the NYS Spousal Impoverishment Act allows spouses to shelter some of the couple's resources when the other spouse is institutionalized, there are currently no real protections for the recipients of community-based services in New York State.

In researching this report, we discussed several strategies for removing the work disincentive. Nationally, there is growing support for developing a separate funding stream for personal assistance services. While we support such efforts, we can not deny that the principal source for funding these services has traditionally been Medicaid. Thus the reform of the personal assistance service issue is closely tied to the reform of our health care system.

One solution to the work disincentive issue is to include personal assistance services as part of a universal health coverage plan. If personal assistance services were covered in a universal health plan for the State, they would no longer be a disincentive to employment.

To date, no plan considered by the State of New York includes personal assistance services as a covered

Comparison of Larry's Remaining Monthly Income from SSDI and Work



At the Federal level, advocates from the Consortium for Citizens with Disabilities argue that any child or adult whose income falls below 300% of poverty should receive such services at no cost. Those with incomes over 300% of poverty might pay for a portion of the cost of their services, but should pay no more than 2% of their net income, after disability related expenses are deducted.

expense. If any of these plans were implemented, people who need personal assistance services would be forced to spend down to Medicaid levels. No other group of people would be forced to remain at the current Medicaid levels.

At the Federal level, advocates from the Consortium for Citizens with Disabilities argue that any child or adult whose income falls below 300% of poverty should receive such services at no cost. Those with incomes over 300% of poverty might pay for a portion of the cost of their services, but should pay no more than 2% of their net income, after disability related expenses are deducted.

Principle 5:

Personal assistance services must be available to people of all income levels. Personal assistance services must not be a disincentive to employment or marriage.



Profile:

John Belanger

John Belanger was born in Wayland, New York in 1954. He graduated from Wayland High School in 1973 with a Regents Diploma. He began to work for 3M in Honeoye that July. While deer hunting on November 20, 1973 John fell 15 feet into a ravine and became a C6-C7 quadriplegic. John owns and drives his own modified van. He is a graduate of Monroe Community College and Nazareth College, where he got a Bachelor of Science in Social Work with a 3.63 average. He is currently a Master Degree candidate at the University of Buffalo and lives independently in his own apartment.

I was offered a regular full-time position, but had to refuse it because if I had accepted it I would have lost my Medicaid benefit which pays for my personal assistance services.

John Belanger



IN 1973, I WAS WORKING FOR 3M AND LOOKING forward to a long and successful career. In November of that year, I became a quadriplegic. Because I need assistance with the basic activities of daily living, I find it nearly impossible to accept a job. Not because I lack ability or education. Not even because employers are unwilling to hire a quadriplegic, but because I can not accept most jobs and keep my personal assistance services.

In May 1974 -- six month after my injury -- I moved back to my parents' home. Six years later I moved to a rehab nursing home in Massachusetts and attempted to attend Salem State College. I lived there for one-and-a-half years, but the hospital did not maintain my health, and I was unable to work on my college degree. I moved to Monroe Community Hospital in 1981.

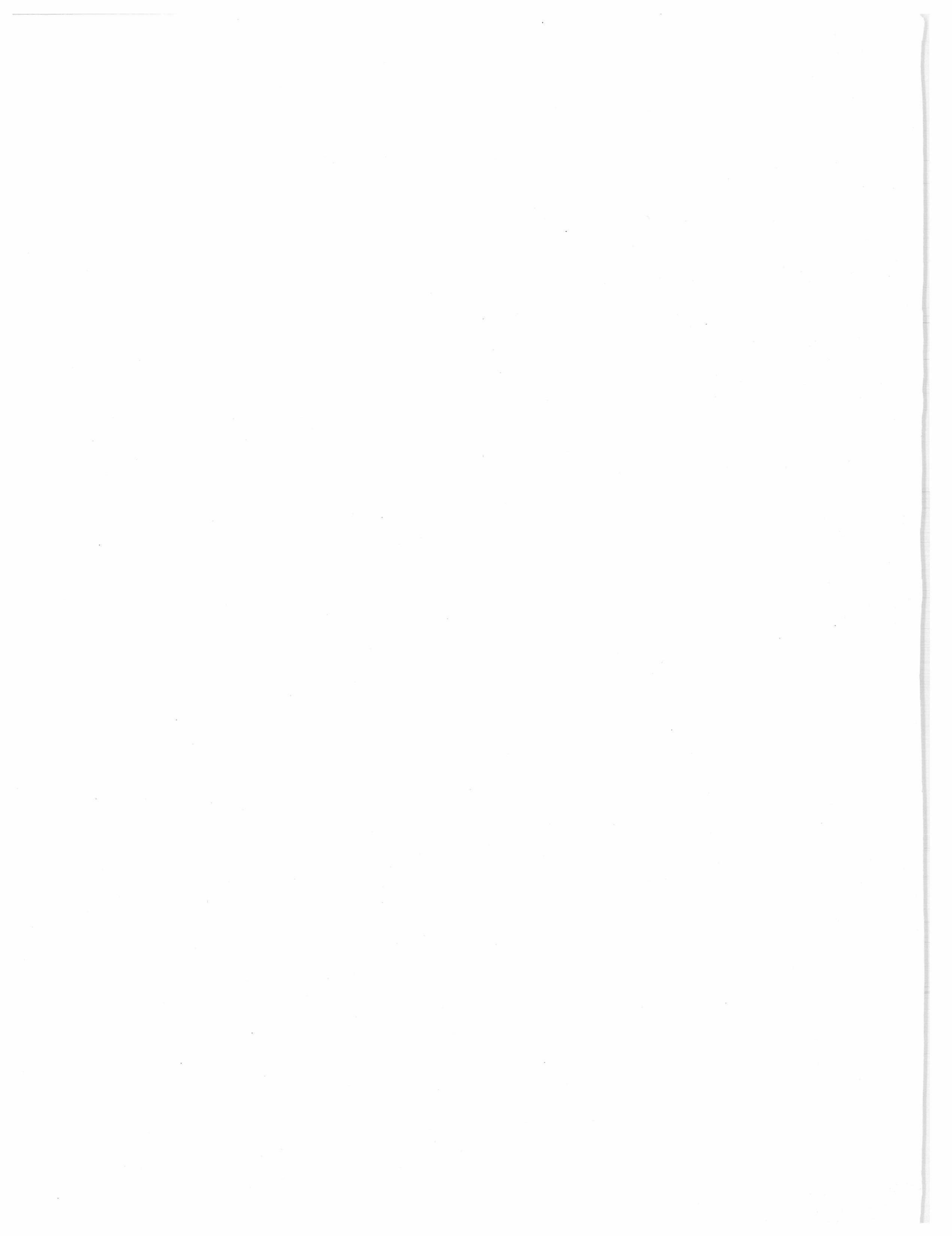
While at Monroe Community Hospital, I began to attend Monroe Community College, where I had a 3.94 grade point average and received the Bronze Medallion. While in school, I moved into an apartment with a roommate and began to receive Home Health Services.



I have successfully completed my B.S. in Social Work at Nazareth College. At the Rochester Center for Independent Living, I have worked as a part-time Group Specialist and worked six months as a Counseling Coordinator. I used a Plan to Achieve Self-Support, in order to keep my benefits for a limited period of time. When the PASS Plan expired, I could not continue to have a job and keep my benefits.

I was offered a regular full-time position, but had to refuse it because if I had accepted it I would have lost my Medicaid benefit which pays for my personal assistance services.

I wish I could get rid of my SSDI. People on SSI are able to keep funding for their personal assistance services, even if they no longer have SSI. Like me, many people who have had spinal cord injuries receive SSDI and are unable to benefit from those incentive programs. I hope to get a job when I complete my Master degree. By that time, I might even be allowed to work.



Six:

Medical Model or Consumer-Directed Services

"If you personally owned a fancy restaurant which had a very posh reputation...You -- as the owner -- would want direct control over hiring your waiters...You would not tolerate being told that someone else would hire all your waiters for you, that you would be forced to use whatever waiters were referred to you by an employment service, that you would have to open and close your restaurant each day merely according to whenever waiters from the service happened to show up for work, or that you would have to share the same waiters with three other restaurants."

- Alfred DeGraff

Home Health Aides:

How to Manage the People Who Help You

THERE ARE CURRENTLY TWO MAJOR MODELS FOR the provision of personal assistance services. This chapter describes the two models, discusses the limitations of the Medical Model, and describes Consumer-Directed programs currently operating in the State of Massachusetts and New York City. Finally, the empowerment of personal assistance service users is discussed at a systemic level.



The differences between the Medical Model and the Consumer-Directed Model are striking, and the implications for service delivery are significant. Generally, the more prevalent Medical Model sees the person with a disability as a patient, with money for care funnelled through an

"Most home care is an institution without walls," says Edward Lichter, Director of Concepts of Independence, Inc.

agency that provides attendants, doctors, nurses, et cetera. The agencies involved in this model control the services. In the less prevalent Consumer-Directed Model, the person with a disability may be given the money directly, along with the ability to hire and fire attendants and decide how his services should be delivered.⁷⁰

The Medical Model

"What is unique to the medical world is that here, where one's very life and destiny are at stake, one has less recourse to social justice than in any other sphere."

- E. Pieper

Sticks and Stones:
The Story of a Loving Child

AGENCY-DIRECTED HOME HEALTH SERVICES ARE intended to meet a person's episodic acute-care needs during post-hospital convalescence.⁷¹ These Medical Model services, however, have been extended to the elderly and people with disabilities who require ongoing assistance with the activities of daily living.

While these services have promoted the concept of people with disabilities living at home, a medical

⁷⁰ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

⁷¹ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

attitude often pervades the homes in which these services are delivered. "Most home care is an institution without walls," says Edward Lichter, Director of Concepts of Independence, Inc. -- New York City's only consumer-directed personal assistance service program.⁷²

In the home health system, a person with a disability does not direct his own service. Instead, care is provided by an agency-supervised home health aide. The home health agency functions as manager in the provision of personal assistance services and carefully specifies the duties to be performed by the home health aide. Furthermore, the aide's duties are supervised by an agency-employed registered nurse, in accordance with a Physician's Treatment Plan. The person with a disability is a passive recipient of services.

The underlying paradox of the current home health system is that although these services must be prescribed by a doctor and supervised by a registered nurse, the user is ultimately responsible for ensuring service through backup and support by family and friends. Most personal assistance service agencies in Monroe County do not guarantee service. The user must have a list of volunteer backups who will provide the necessary services if the agency is unable.⁷³

In the home health system, a person with a disability does not direct his own service. ...The person with a disability is a passive recipient of services.

⁷² "Personal Care," Disability Rag, January/February 1989.

⁷³ According to the Monroe County Department of Health Home Health Agency and Community Nursing Service Patient Bill of Rights and Responsibilities, a patient of the Home Health Agency is responsible to provide a caregiving person who will assume responsibility for the person's care in an emergency, and who will understand and learn the care given at home.

**In Monroe County,
Registered Nurses
must assist with
bowel programs
which could be done
by Personal Care
Aides in the
Medicaid Personal
Care Program
according to New
York State
regulations.**

Professional intervention and supervision, however, are at the core of the Medical Model. Ongoing supervision by health care professionals, however, tends to undermine an individual's confidence and independence.

Limitations of the Medical Model

THE MEDICAL MODEL IMPOSES EXCESSIVE regulations and costs on our personal assistance service system, inadequately prepares attendants and provides service based as much on the needs of an agency -- sometimes more -- as on the needs of the consumer.

Excessive Regulations

THE MEDICAL MODEL IMPOSES EXCESSIVE regulations on the tasks normally performed by able-bodied people every day, dividing the responsibilities among the various levels of health care providers. For example, a person who requires assistance to clip his toenails must have at least an LPN do this. In some agencies, attendants also may not use eye drops, apply prescription ointment, or change dressings on even minor cuts.

In Monroe County, nurses assist with bowel programs which could be done by Personal Care Aides in the Medicaid Personal Care Program, according to New York State. A person with a disability, who has fine motor control, is able to manage a bowel program independently without nursing supervision.

The requirement that nurses provide such assistance seems excessive and is costly. While the cost of a Personal Care Aide doing such a program is relatively

small⁷⁴, in Monroe County these programs are done by nurses and may cost between \$5,815.68 and \$11,539.32 per year.⁷⁵

High Costs

THERE ARE OTHER EXCESSIVE COSTS ASSOCIATED with Medical Model programs. Monroe County routinely assigns Home Health Aides to cases which could be assigned to a PCA program. One Home Health recipient we are aware of costs Medicaid almost \$50.00 each day (\$19.43 per hour/2.5 hours per day) simply to assist her with putting on her shoes and laundering her clothes.

The decision to place the majority of cases in the Home Health category is a costly one. PCA services are less than half as expensive as Home Health services, nearly ten dollars cheaper per hour. Assuming that a self-

The decision to place the majority of cases in the Home Health category is a costly one. PCA services are less than half as expensive as Home Health services, nearly ten dollars cheaper per hour.

⁷⁴ Bowel programs are generally done three time a week (156 time a year) and they last about two hours. The cost of a PCA doing this program is \$2,964.00 per year (\$9.50 per hour x 2 hours x 156 programs per year).

NOTE: All cost projections in this report are based on the most recently available figures from the local Medicaid office. Although there may be incremental changes in these numbers, the overall impact on County and State budgets will be about the same. In fact, the costs of these services (and the related savings) will increase.

⁷⁵ An LPN would cost \$18.64 per hour and an RN costs \$22.52 per hour. Multiplied by 2 (hours per program) and 156 (programs per year) the billable hourly charges are \$5,815.68 and \$7,026.24 respectively. If the nursing visit is billed as a nursing visit, there is a flat rate of \$73.97 per Monroe County CHHA nursing visit. Multiply that rate by 156 visits and the bowel program costs \$11,539.32 per year.

directing client with a spinal cord injury (or other stable condition) receives 6 hours of service each day, the Medicaid billing for that client would be decreased by \$21,746.70 per year if that client were transitioned to a PCA program. Monroe County would save \$2,174.67⁷⁶ per year. If 50 clients were transitioned, the County would save over \$100,000.00 per year!⁷⁷

There could be additional savings by reducing nursing supervision for Home Health cases. Home health aides must be supervised by a nurse at the initial visit and then every two weeks thereafter.⁷⁸ This level of supervision, while intended to ensure a high quality of service, undermines the control of the consumer and

⁷⁶ Home Health Services : \$42,551.70
(\$19.43 per hour x 6 hours per day x 365 days per year)

Personal Care Aide Services: \$20,805.00
(\$9.50 per hour x 6 hours per day x 365 days per year)

$\$42,551.70 - \$20,805.00 = \$21,746.70$ Total Medicaid Savings

$\$21,746.70 \times .1 = \$2,174.67$ Monroe County Savings.

NOTE: Monroe County pays 25% for Medicaid expenses; In an agreement with New York State, the counties are now only paying 10% of the cost for long term care services.

⁷⁷ $\$2,174.67 \times 50 = \$108,733.50$ Potential savings by transitioning 50 HHA clients to a PCA program

⁷⁸ In Monroe County, we exceed the minimum required supervision. Regulations only require that Home Health Aides be supervised every 60 days unless a skilled nursing service or therapy is provided in the home. This level of supervision is a common practice in other counties. If skilled services are provided, supervision is required every two weeks. In Monroe County Home Health Aides are supervised every two weeks whether or not therapy or skilled nursing services are provided in the home.

adds cost. The aides consider the nurse their supervisor and are reluctant to allow personal assistance service users to direct their own assistance.

At times this supervision is truly counterproductive. Several personal assistance recipients have been made to get back in bed so the nurse (who was late to the case) could supervise their transferring out of bed. They complained that their lives were only complicated by such requirements. "If we were unable to do the transfer without the nurse, she would have found me on the floor," said one personal assistance service recipient. Many PAS recipients agreed that the best way to assure their safety was to maximize their ability to self-direct, because they best understand their own needs.

The cost of these supervisory visits may be very high. The cost of a Registered Nurse can be nearly four times that of a home health aide.⁷⁹ Visits by a nurse from the Monroe County CHHA are billed at \$73.97 per visit. Home Health cases are only required to be supervised every 60 days at a total Medicaid cost of \$443.82 per year. Bi-weekly visits cost \$1,923.22 per year, \$1,479.40 more per year. If those same cases were transferred to the PCA program, nursing supervision could be reduced even further to twice a year, which would only cost \$147.94 per year.

The cost of nursing supervision would decrease by \$1,775.28 per year for each client who receives twice yearly supervision. As a result of this reduction in cost

There could be additional savings by reducing nursing supervision for Home Health cases... At times this supervision is counterproductive. Several personal assistance recipients have been made to get back in bed so the nurse (who was late to the case) could supervise their transferring out of bed.

⁷⁹ The Monroe County CHHA bills Medicaid \$73.97 for a nursing visit; Home Health Aides cost \$19.43 per hour.

the total Medicaid billing for 50 clients would be reduced by an additional \$88,764.00 annually. ($\$1,775.20 \times 50 = \$88,764.00$) Of that, the County would save an additional \$8,876.40 each year.

An attendant may have assisted over 50 people with the same needs as a new client, but will continue to be supervised at every additional visit whether such supervision is needed or not.

Nurses also supervise at an attendant's first visit with **each specific** client. An attendant may have assisted over 50 people with the same needs as a new client, but will continue to be supervised at every additional new client whether such supervision is needed or not. Such supervision only undermines the confidence of attendants, without improving quality, and adds cost. It is difficult to project the cost of these additional visits. However, only two additional visits per month increase the total Medicaid bill by \$1,775.28 per year.⁸⁰

By changing this policy for only 400 clients, the County's Medicaid billing could be decreased by \$710,112.00 each year. Monroe County could save \$71,011.20 annually.⁸¹

Limited Attendant Training

MANY PERSONAL ASSISTANCE SERVICE USERS complain that attendants are inadequately trained. Paul Longmore, a historian, former administrator at the University of Southern California, and personal

⁸⁰ $\$73.97 \times 2 \text{ visits per month} \times 12 \text{ months} = \$1,775.28$

NOTE: The figure of two visits per month was based on the personal experiences of those who attended the focus groups.

⁸¹ $\$1,775.28 \times 400 = \$710,112.00$ Total Medicaid Savings

$\$710,112.00 \times .1 = \$71,011.20$ Monroe County Savings

assistance service user described agency training of attendants as "detrimental" in an article published in the *Disability Rag*.⁸² It leads, he said, to the attendants thinking they're helping, rather than working for, the person with a disability. His views were echoed by personal assistance service user Patricia Carpenter, "We need the attendants to be educated by personal assistance service users instead of supervisors."⁸³

Inappropriate Levels of Service

EVEN THE LEVEL OF SERVICE PROVIDED BY personal assistance service agencies is not controlled by the user under the Medical Model. During the evaluation and prescription for services, a consumer may be interacting with discharge planners, medical sub-specialists, home care agencies, and a variety of therapists. This is often confusing with either everybody or nobody being in charge.⁸⁴

Physicians' unfamiliarity and their inaccessibility also tend to complicate the referral process. More often than not, a referral is initiated by the hospital's discharge planners (either social workers or public health nurses). The doctor becomes another passive participant in a process perceived as only filling out

"We need the attendants to be educated by personal assistance service users instead of supervisors."

Patricia Carpenter

⁸² "Personal Care," *Disability Rag*, January/February 1989

⁸³ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

⁸⁴ Koren, Mary Jane (MD), The Home Health Agency and the Ivory Tower, *Public Health Nursing*, March 1987.

forms or, in some instances, signing forms already filled out by someone else.⁸⁵

According to Loretta Scheg of Monroe County Legal Assistance Corporation, "The service that doctors order is influenced by what is available. Doctors don't just order the service. They send the case over to be assessed by the CHHAs and approve the amount that is available, not necessarily based on the person's needs. They approve the level of service which is available."⁸⁶

"The service that doctors order is influenced by what is available. Doctors don't just order the service. They send the case over to be assessed by the CHHAs and approve the amount that is available, not necessarily based on the person's needs. They approve the level of service which is available."

**Loretta Scheg,
MCLAC**

Consumer-Directed Model

"I have more control over who changes the oil in my van than who changes my catheter."

- Monroe County Personal assistance service User

CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES are intended to meet a person's continuous assistance needs.⁸⁷ The service user is regarded as a consumer who is capable of supervising his or her own service. The Consumer-Directed Model assumes that disabled individuals are well versed in their own needs and have

⁸⁵ Koren, Mary Jane (MD), The Home Health Agency and the Ivory Tower, Public Health Nursing, March 1987.

⁸⁶ Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

⁸⁷ Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," Archives of Physical Medicine and Rehabilitation, February 1990.

the necessary ability and skills to direct, monitor, and supervise their own personal assistance services.

Personal responsibility and decision-making are at the core of the Consumer-Directed Model. Supervision of personal assistance services builds an individual's confidence and strengthens his independence. The person with a disability is in control of his life. The Consumer-Directed Model, however, does not assume that every person has the skills to manage his own personal assistance services. Instead, it provides the personal assistance service user with the training and support to facilitate this process.

Personal assistance services are vital to the people who need them. The Consumer-Directed Personal assistance service Model provides the backup personal assistance services which allow people to live independently in the community. Although a person with a disability may have prepared his own "back-up" plan, this Model realizes that not every plan is perfect and that everyone is faced with uncontrollable emergencies at some point in his life.

Two Consumer-Directed Personal Assistance Service Programs:

A FEW CITIES AND STATES HAVE FOUND INNOVATIVE ways to work within the medically-oriented Medicaid framework. They still make it possible for individuals who are disabled to maintain a great deal of control over how their personal assistance services are delivered. In Denver, Boston, New York City, and a few other areas, Independent Living Centers have been designated as Home Health Agencies. They, in turn, allow people with disabilities to hire and train their own

A few cities and states have found innovative ways to work within the medically-oriented Medicaid framework. They still make it possible for individuals who are disabled to maintain a great deal of control over how their personal assistance services are delivered.

attendants, with Center approval. Some even pay the attendant's wages directly to the consumer, who then pays his or her own attendant.

The Massachusetts Program⁸⁸

THE BASIC PREMISE UNDERLYING THE Massachusetts personal assistance service program is that many individuals with disabilities are aware of their own personal assistance service needs and do not need the degree of medical intervention common to other programs. To be eligible for personal assistance services through this program, an individual with a disability must meet with the Personal Care Attendant (PCA) evaluation team (a Registered Nurse and Occupational Therapist) to assess the need for PCA services and the number of hours of service required.

Reassessments are made at least once per year and sometimes more often, depending on the medical condition of the user. The Medicaid program reimburses need assessment services on a fee-for-service basis.

In order to qualify for this program, a person must require at least 10 hours of physical assistance with activities of daily living each week and demonstrate the ability to manage the program.

Should an applicant be lacking in any skills related to the utilization of personal assistance services, the independent living program provides training to enhance the applicant's ability to manage his own

⁸⁸ DeJong, "Attendant Care and Independent Living," Archives of Physical Medicine and Rehabilitation, October, 1979.

personal affairs. This service is also reimbursed by the Medicaid program.

The responsibility for recruiting attendants falls mainly on the consumer. After the initial assessment, the independent living program acts mainly as an intermediary in the payment process. Time sheets, signed by both the attendant and the consumer are submitted by the consumer to the independent living program, which in turn sends the bill to Medicaid for payment. The independent living program issues a check to the consumer, who in turn pays the attendant.

The hourly wage for an attendant in Massachusetts is set at \$7.85 per hour. The average personal assistance service user needs about four hours of personal assistance services per day divided between the morning and evening hours. When needed, a nighttime attendant is available and receives \$15.70 per night. Emergency PCAs receive an additional \$1.75 per hour above the regular rate and are reimbursed for travel expenses.

Funding for PCA services is secured, depending on the person's eligibility, through CommonHealth, Medicaid, The Massachusetts Commission for the Blind, or the Massachusetts Rehabilitation Commission.

In the Massachusetts Program, the responsibility for recruiting attendants falls mainly on the consumer.

The New York City Concepts Program⁸⁹

Concepts Of Independence, Inc. is a New York City based personal assistance service program developed by a group of people with disabilities in 1977. Concepts is the only client maintained personal assistance service program currently operating in New York State.

CONCEPTS OF INDEPENDENCE, INC. IS A NEW YORK City based personal assistance service program developed by a group of people with disabilities in 1977. Concepts is the only client-maintained personal assistance service program currently operating in New York State. Concepts allows clients who are eligible for personal assistance services to assume administrative responsibility for many aspects of their personal assistance service. It was designed for the client who has a stable medical condition, despite possible severe physical disabilities, and who has a strong desire to manage the delivery of his or her support services.

In 1991, Concepts served over 300 members (clients), who employ a total of over 600 attendants per year at an average cost of \$9.80 per hour. Members with various disabilities range from 21 to 94 years of age. The Board of Directors is comprised of consumers of personal assistance services and is directly responsible for the selection of the staff and the formation of administrative policies.

The program divides the responsibility for all aspects of service between an agency selected by the Human Resources Administration (the New York City Department of Social Services) and the participating clients. The contract agency is not responsible for some of the functions assumed by standard vendor agencies, such as training and recruitment,

⁸⁹ Concepts of Independence, Inc., "Living Independently: A Consumer's Guide About Personal Care Attendants," 1988.

replacement of home attendants, and supervision -- these are assumed by the client.

A person who wishes to participate in the Concepts personal assistance service program needs to complete an application. This application requires the person to provide an outline of the plans to recruit and secure attendants, orient and train them, report all time worked, and provide on-going supervision of the attendant's day-to-day activities. All applications are reviewed by Family and Adult Services (FAS)⁹⁰ to ensure adequate service delivery. The client is then interviewed in person or by telephone.

Participation is limited to cases where the client can assume the assigned managerial responsibilities; relatives or client representatives are not allowed to assume these functions. Family and Adult Services makes the decision as to who may participate in the program.

Clients who do not fulfill their responsibilities in the employment and/or payment process may be removed from the program. The Human Resources Administration investigates any complaints made regarding the participating client and makes final decisions as to whether the client should continue to receive personal assistance services under the program or under the regular vendor system. In the event that HRA/FAS decides that the client can no longer receive services under the Concepts program, the client is

Participation is limited to cases where the client can assume the assigned managerial responsibilities; relatives or client representatives are not allowed to assume these functions.

⁹⁰ Family and Adult Services is a department of the New York City Human Resources Administration, the name for the Department of Social Services there.

The Massachusetts and New York City programs illustrate how people who use personal assistance services can be empowered to manage their own services within the current system. Such programs must be universally implemented so every personal assistance service user could share in their benefits.

transferred to the regular system. Clients, however, have the right to a fair hearing on these decisions.

The Concepts program is also very cost-effective. Only 4.3 percent of the hourly Medicaid Billing rate is applied to administrative expenses. Twenty-six cents pays the cost of administrative staff (including semi-annual nursing supervision visits). Sixteen cents covers other administrative expenses. Of the \$9.87 billed to Medicaid for each hour of PCA service, \$9.45 is paid to attendants in wages and benefits.

A Simple Choice: The Consumer-Directed Model

THE MASSACHUSETTS AND NEW YORK CITY programs illustrate how people who use personal assistance services can be empowered to manage their own services within the current system. Such programs must be universally implemented so every personal assistance service user can share in their benefits.

Legislation passed in 1992 allows Long term home health care programs, Certified Home Health Agencies, AIDS Long Term Home Health Care Programs and Licensed Home Care Services Agencies under contract with such agencies to offer consumer-directed programs. Programs under contract with the Department of Social Services and exempt agencies under contract with DSS may also provide consumer directed programs. The legislation requires that the guidelines for implementing these programs shall be published by January 31, 1993. Consumer directed services may be offered as an option to home care

and personal care recipients determined to be eligible for this program.

Consumer-directed programs should supplement, not replace, existing agency-supervised services because consumer-directed services do not meet everyone's needs. We must develop a model which allows each individual to choose the system which best meets his needs. As much as possible, we should incorporate a menu of services into such a program, allowing individuals to select the supports they need while assuming the level of responsibility they want and are able to manage.

Principle 6:

Personal assistance service policies must allow maximum control over the service by its users. Personal assistance service users must have the option of managing their own service.

As much as possible, we should incorporate a menu of services into such a program, allowing individuals to select the supports they need while assuming the level of responsibility they want and are able to manage.

Empowering People with Disabilities to Reform the System

It is essential that personal assistance service users and their advocates be involved in the restructuring to ensure that the system meets the needs of those it serves.

"Building in control and choice to any service of which we are the supposed beneficiary, must be continually reinforced. Thus whether it be the designing of a health coverage system or of a building, there must be guaranteed input, perhaps even veto power, of the aging and disability community. Too many programs...give only token, if any, recognition to the role that consumers should play in their decisions.

- Irving Zola

"Aging, Disability, and the Home-Care Revolution"
Archives of Physical Medicine and Rehabilitation

THE PRINCIPLE OF PERSONAL CONTROL CAN ALSO BE applied to the overall restructuring of our personal assistance service system. People with disabilities who use personal assistance services understand best how these services impact on their lives. It is essential that



personal assistance service users and their advocates be involved in the restructuring to ensure that the system meets the needs of those it serves. While agency providers, those from the medical profession and county

administrators, can provide substantial input into this process, care must be taken to involve members of the disabled community as full participants in any redesign efforts.

Such efforts should not be limited to the initial design. The satisfaction of people using personal assistance services will provide the best measure of the effectiveness of any restructuring efforts. Regular evaluations by consumers will be used to ensure that the system provides the best possible service.

Principle 7:

Personal assistance service users and advocates for people with disabilities must have a significant role in the policy development and program design of a restructured personal assistance service system. They should also have ongoing input into review and improvement of the system.

Such efforts should not be limited to the initial design. The satisfaction of people using personal assistance services will provide the best measure of the effectiveness of any restructuring efforts.

Profile:

Patricia Carpenter

Patty volunteers as a peer counselor for the United Cerebral Palsy Association. Patty also initiated the Alternative Living Facility -- a 24-unit fully accessible housing project sponsored by the Easter Seal Society of Monroe County. In 1992, Patty was named Outstanding Developmentally Disabled Person of the Year by the New York State Developmental Disabilities Planning Council for her accomplishment in the areas of independence, productivity and integration. Patty has Cerebral Palsy and Arthritis.

***I'm thirty-seven
and I only get to
stay up until 10
pm. I know 13
year olds with
more lenient
curfews.***

Patty Carpenter



MUCH OF MY CHILDHOOD WAS SPENT IN THE NEWARK Developmental Center in Newark, New York. I was released from Newark under the Deinstitutionalization Act of 1975. Instead of moving into the community, I was sent to Monroe Community Hospital (MCH), where I spent another year-and-a-half.

When I was 20, I married another MCH resident and moved into the community. Four years later, I was divorced and having trouble with unreliable and inflexible attendants. In 1985, my personal assistance services were taken away with no explanation, and I was forced to move back to MCH. To this day, I still don't understand why my services were stopped.

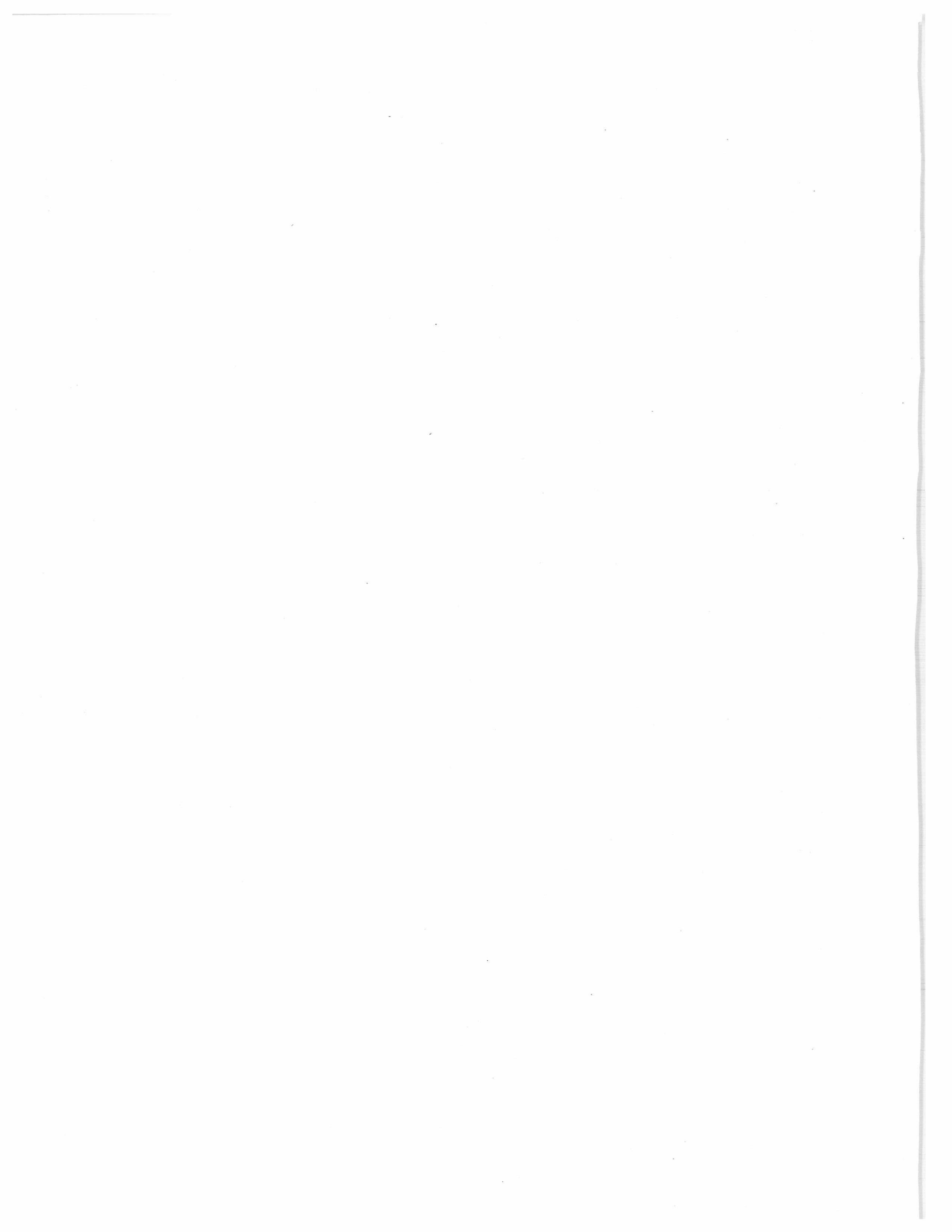
I felt like I was serving jail time at MCH. When I wanted to leave that institution, I couldn't. Monroe County refused to reinstate my personal assistance services. With my friend, John Leach, I moved out of MCH. Because the County refused to provide me with personal assistance services, we began to pay for them out of our own pockets. The Rochester **Democrat and Chronicle** reported on my situation. After the story appeared, Monroe County reinstated my services.



Although personal assistance services have improved since the early Eighties, there are still significant problems. Nursing supervision, by and large, is unnecessary for most personal assistance service users. I'm not sick; I have a disability. I don't need a nurse. The nurse only asks how I am and if there are any problems. She asks the aide if there are any problems, signs the activity sheet and leaves. We spend an outrageous amount of money on these visits. There must be a cheaper way.

There are also no emergency services. If an emergency comes up or if my transportation is late I run the risk of missing my scheduled aide.

Finally, there is no flexibility. I am the prisoner of a schedule. It's hard to live your life like that. I'm thirty-seven and I only get to stay up until 10 pm. I know 13 year olds with more lenient curfews.



Seven:

A Comprehensive Personal Assistance Service System

"I did a lot to get my independence, and it means a lot to me. I get up when I want to. I eat when I want to. I hire my own people to work for me. That is a big step, because I grew up in an institution and I never thought I would know how to live independently."

- Mary Ambo

"Speaking Out,"

With the Power of Each Breath:
A Disabled Women's Anthology

AN EFFECTIVE PERSONAL ASSISTANCE SERVICE

system for Monroe County and New York State would serve every individual who needs personal assistance services in the way that best meets his individual needs. This chapter recaps the principles of an effective personal assistance service system and then proposes a model for such a comprehensive personal assistance service system in Monroe County and New York State.



Principles for Designing an Effective Personal Assistance Service Program

CHAPTERS TWO THROUGH SIX OF THIS REPORT HAVE defined seven principles which comprise an effective personal assistance service system. In order for Monroe

County and New York State to develop a truly effective personal assistance service system, these principles must be incorporated into any proposed personal assistance service system changes.

Seven Principles of a Comprehensive Personal Assistance Service System

- Principle 1:** Personal assistance services must be redefined as a human and civil right. Such a policy is the logical extension of current deinstitutionalization and mainstreaming policies, and is consistent with the tenants of the Americans with Disabilities Act.
- Principle 2:** Personal assistance services must deal with the growing needs of our community due to societal and demographic changes.
- Principle 3:** The personal assistance service system must emphasize the professionalism of attendants and provide attendants with a reasonable wage, benefits and the opportunity for career advancement.
- Principle 4:** The personal assistance service system must coordinate the patchwork of funding streams and programs which allow people to "fall through the cracks". These services must be provided based on a person's functional need rather than diagnosis.
- Principle 5:** Personal assistance services must be available to people of all income levels. Personal assistance services must not be a disincentive to employment or marriage.
- Principle 6:** Personal assistance service policies must allow maximum control over the service by its users. Personal assistance service users must have the option of managing their own service.
- Principle 7:** Personal assistance service users and advocates for people with disabilities must have a significant role in the policy development and program design of a restructured personal assistance service system. They should also have ongoing input into review and improvement of the system.

A Comprehensive Personal Assistance Service System Model

A COMPREHENSIVE PERSONAL ASSISTANCE SERVICE model provides the level and types of services needed by people in the community. It professionalizes the role of attendants, offering them benefits, job satisfaction, and the opportunity for advancement. The Comprehensive Personal Assistance Service Model coordinates the various personal assistance services through a single county agency and offers people the option of managing their own services. Payment for personal assistance services is not tied to income maintenance programs and personal assistance services are no longer a disincentive to employment. Finally, personal assistance service users and disability advocates play a significant role in the development, monitoring, and restructuring of the system.

As people with more severe disabilities move into the community, even higher levels of individual service will need to be available.

Services Designed to Meet the Community's Needs

PERSONAL ASSISTANCE SERVICES WHICH ARE BASED ON the concepts of deinstitutionalization and mainstreaming provide the necessary support for people with disabilities living in the community. With the current trends in our society, it is clear that the amount of service needed by our community is increasing. As people with more severe disabilities move into the community, even higher levels of individual service will need to be available.

Because fewer informal caregivers are available to assist people and because people with disabilities are no longer necessarily living with their families who serve as primary caregivers, personal assistance services must

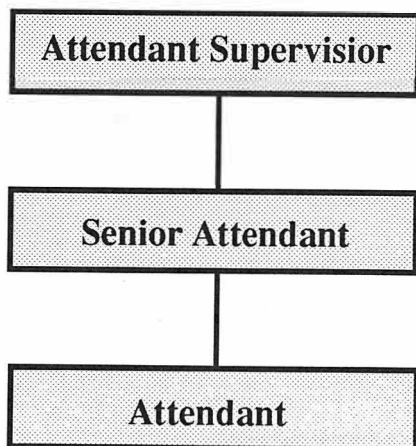
be available 24 hours a day, seven days a week. Timely emergency and backup services must also be available.

Professionalism of Attendants

ATTENDANTS, WHO NOW WORK UNDER SEVERAL different titles with markedly similar job duties and qualifications, would be reorganized on a new career ladder. This career ladder would clarify the various job titles, provide appropriately increased compensation to those working in more advanced job titles, offer

distinct opportunities for advancement, and instill a sense of professional pride.

Proposed Attendant Career Ladder



Under a revised career ladder, attendants would be certified through a uniform training program, similar to the current Home Health Aide Training Program. Training for attendants, currently provided by agencies, would be shifted to community-based organizations. The attendant would receive 70 hours of classroom training, 30 hours of supervised experience, and at least 5 supervised on-the-job

visits with a satisfactory evaluation.

This training would teach specific skills related to personal assistance services including: bed baths, transferring, and the use of a Hoyer lift. Other components would help to professionalize the role of attendants. These components would include: confidentiality, disability awareness/ sensitivity, and other issues.

This title would be certified by the New York State Department of Health and the New York State Department of Social Services. All current Home Health Aides, Personal Care Aides, and Homemakers would be automatically retitled.

Attendants could pursue additional training for specialized or complex work. Completion of this training would merit a promotion to Senior Attendant and an increase in pay by 15% when working on specialized cases. This training will allow attendants to upgrade their skills and move up the new career ladder, potentially receiving college credit and -- with additional formal education -- a nursing degree.

A new paraprofessional title would also be created in the agencies providing personal assistance services. The Attendant Supervisor would be a salaried, frontline supervisor who monitors the quality of the agency's services and offers advice on effective techniques. The Attendant Supervisor would be responsible for visiting each agency-managed case every 60 days. This position would be staffed by an experienced paraprofessional who has been given additional training and an opportunity for promotion.⁹¹

All attendants would be entitled to benefits on a pro-rated basis including vacation, sick leave, personal leave, retirement and health/dental insurance. In

A new paraprofessional title would be created... The Attendant Supervisor would be a salaried, frontline supervisor who monitors the quality of the agency's services and offers advice on effective techniques. ...This position would be staffed by an experienced paraprofessional who has been given additional training and an opportunity for promotion.

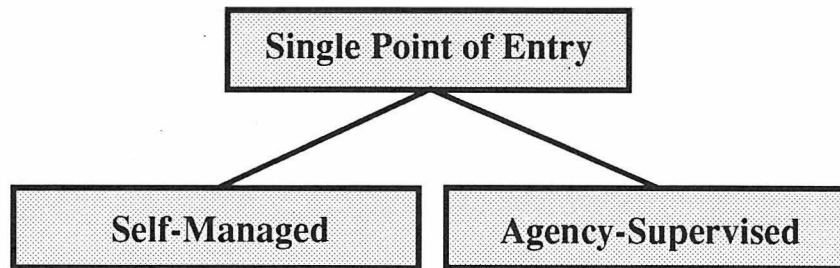
⁹¹ A demonstration project in New York City with similar positions has shown some success. Preliminary evaluations have shown that attendant positions which receive this support had fewer absences, higher staff retention, a reduction in the number of complaints filed, and more worker telephone contact with the agencies.

conjunction with Monroe Community College, attendants would also be able to get college credit for their work experience in the college's Human Services or Nursing programs.

Coordinated Services

PUBLICLY FUNDED PERSONAL ASSISTANCE SERVICES IN Monroe County would be coordinated by a single County agency; private pay individuals would have the option of using this agency's services. This agency would evaluate the needs of all prospective personal

assistance service users and serve as a vendor to approved agencies. People would be given the choice of self-managed or agency-supervised



personal assistance services. The agency would process all necessary paperwork, monitor the personal assistance service programs through a variety of statistics and recommend any needed changes. Additionally, an ombudsman would be hired to ensure that the persons who need personal assistance services receive the necessary services. This agency would also provide emergency and backup services to anyone who needs them.

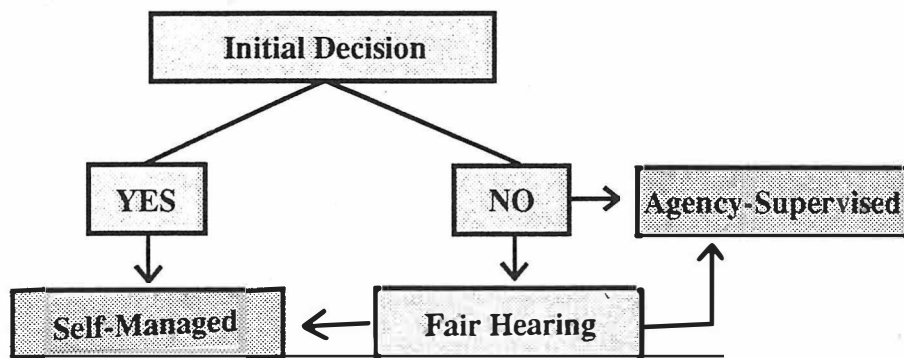
Self-Managed Personal Assistance Services

PERSONAL ASSISTANCE SERVICE USERS WHO OPT FOR self-managed services would be referred to a local consumer-directed personal assistance service

agency. Applicants would be screened using an application process similar to that used in the Concepts Program.⁹² Prospective agency clients would be required to explain their plans to recruit, orient, train, and provide on-going supervision to an attendant. As a final step in the process, a supervisor from the agency would interview prospective members to determine their suitability for the program and determine, with the prospective member, the number of hours and services needed. The supervisor would also answer any questions about the consumer-directed program.

Staff would evaluate these applications with the recommendations from the agency supervisor and decide whether to admit the person to the consumer-directed program. People denied membership would be entitled to a fair hearing as well as training on the self-management of personal assistance services.

Application/Fair Hearing Process



Training and support would also be available on an on-going basis for people interested in the program or

⁹² See Chapter 6 for a summary of the Concepts for Independence Program in New York City.

Program members would be able to hire anyone to provide their services. They might hire a neighbor, family member, a person trained in a community-based program for training attendants, or a college student who needs internship experience.

already enrolled. Training would be provided in a format to suit various learning styles. It should include videotape, group discussion, role playing, and presentations. Such training would include information on:

Assertiveness Training	Interviewing Techniques
Community Resources	Problem Solving Skills
Conflict Resolution	Self Esteem
Supervisory Skills	

Program members would be able to hire anyone to provide their services. They might hire a neighbor, family member, a person trained in a community-based program for training attendants, or a college student who needs internship experience. The agency would also have a pool of applicants from which the member might select an attendant. Similarly, the agency would also have a pool of registered nurses available for people who need that level of assistance. Ongoing supervision would be the responsibility of the personal assistance service user. People will be able to take advantage of a menu of services available through the agency, including assistance with recruitment.

If a member does not live up to his obligations, he would be recommended for removal from the program and advised of his right to an appeal which would include a fair hearing. Depending on the outcome of the hearing, he would either be given training opportunities to improve his skills or be removed from the program and provided an agency-supervised attendant. If he is removed from the program, he would be offered additional training and

the opportunity to reapply to the program at a later date.

Agency-Managed Personal Assistance Services

PEOPLE WHO USE THE AGENCY-MANAGED PROGRAM would be actively involved in the evaluation process and the development of service plans. Initially, however, the consumer would be evaluated by a County nurse to determine the level and types of services he or she needs. People who have agency managed services would also be able to exercise their own independence through the selection of the agency providing their services and maintaining as much control as they want and are able.

Once an attendant is assigned to the person, supervision would be limited to once every 60 days, unless additional supervision is requested by the attendant's supervisor, attendant or the personal assistance service user. The attendant's supervisor would meet with the personal assistance service user privately to discuss any concerns as well as actually supervise the assistance provided by the attendant. Such a reduction in the required amount of supervision would be balanced by the increased communication between the nurse and personal assistance service user and the increase in actual supervision of the services being provided.

Personal Assistance Services Facilitate Independence and Employment

PEOPLE WHO REQUIRE PERSONAL ASSISTANCE services would not be tied to income maintenance programs in order to remain eligible for these services. Changes at the State level and the inclusion of

Such a reduction in the required amount of supervision would be balanced by the increased communication between the nurse and personal assistance service user and the increase in actual supervision of the services being provided.

personal assistance services in any universal health care program would eliminate the work disincentive.

Empowerment of Personal Assistance Service Users

The County Advisory Council will be charged with monitoring the County's personal assistance service program and developing an annual plan to address the needs of our community.

PEOPLE WITH DISABILITIES MUST PLAY A POWERFUL role in the development of this comprehensive personal assistance service system. They must also serve on the design team which develops the proposed system and have ongoing input on a County Advisory Council. This Council will be charged with monitoring the County's personal assistance service program and developing an annual plan to address the needs of our community.

Additionally, people using the personal assistance service program would be invited by the Advisory Council to discuss their concerns at an annual public meeting. The public input from that meeting would be used in conjunction with the data gathered by the agency to develop this plan.



Profile:

Carmen Hernandez

Carmen is a vocal advocate for Hispanics with disabilities. She has served as co-chair of the Transportation Advocacy Group, been a member of the Monroe County/City of Rochester Council on Disabled Persons, interned for the Ibero American Action League. She currently works as an advocate for the Rochester Center for Independent Living.

When I first told my primary nurse that I was expecting a baby, she suggested that I have an abortion or place the child in foster care.

**Carmen
Hernandez**



IN 1992, I HAD A BABY -- ANDRE MIGUEL BUDD. SINCE he came home from the hospital, we have had two attendants in the apartment. One for him, and one for me.

When I first told my primary nurse that I was expecting a baby, she suggested that I have an abortion or place the child in foster care. This initial reaction was not uncommon. I have had Spinal Muscular Atrophy, a form of Muscular Dystrophy, since my early childhood. Physically, I am very weak; spiritually, however, I am very strong. I have chosen to raise my son as I have lived my whole life -- independently.

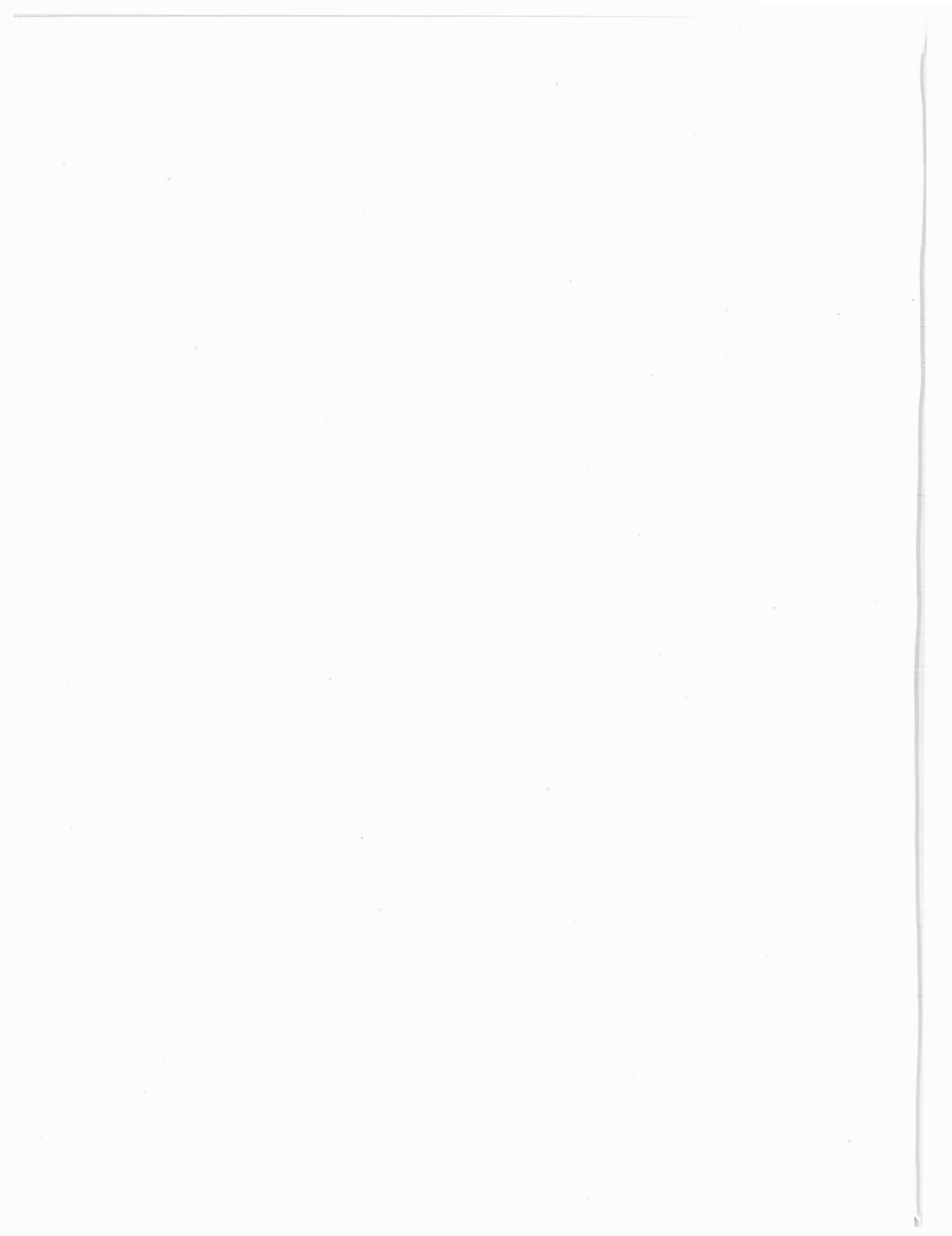
As a child and young woman, my mother and sisters provided my personal assistance services. I have used publicly funded community-based personal assistance services since I moved to Rochester from Puerto Rico in 1984. There is a world of difference between using community-based personal assistance services and being cared for by family. Paid attendants do things my way; my family often assisted me in their own way.



The personal assistance service system, however, still must be improved. People with disabilities must have even greater control over their personal assistance services. I can train an attendant better than any agency. Often the agency will tell a new attendant to listen to me because I know what I am doing.

Communication is very important. I must clearly express my needs, and the attendants must be willing to listen. The agency must also be willing to listen to my concerns.

Now that I have Andre, I am even more concerned that we receive quality services. If an attendant does not fulfill her responsibilities, I don't want her in my house again.



Eight:

Recommendations

"Our liberation will be everyone's victory."

- Debra Kent,
"In Search of Liberation"
With Wings: An Anthology of Literature
by and about Women with Disabilities

**These
recommendations
are based on the
principles
summarized in
Chapter 7 of this
report.**

THIS CHAPTER PROVIDES SPECIFIC RECOMMENDATIONS to Monroe County and New York State which will create an effective and comprehensive personal assistance service system. These recommendations are based on the principles summarized in Chapter 7 of this report.

Recommendations to Monroe County

"Home care as practiced today is not valued and has little to do with the home. Those who buy the service -- insurers, government, and businesses -- see it as a low-cost service, little above domestic care level, and as something that could be done by people and families themselves if they were not so lazy and inefficient."

- Elsie Griffith
"The Changing Face of Home Health Care,"
Public Health Nursing

MONROE COUNTY MUST MAKE SIGNIFICANT CHANGES in the way personal assistance services are delivered in order to meet the growing and changing needs of our community during the next decade. The County has

an opportunity, once again, to take the lead both in the State and across the nation in this arena. We should not let such an opportunity pass us by.

The County has an opportunity, once again, to take the lead both in the State and across the nation in this arena. We should not let such an opportunity pass us by.

1. Monroe County must develop an advisory board on personal assistance services with a majority of members being people who use those services.

In order to effectively meet the needs of people with disabilities, the Monroe County Personal Assistance Services Advisory Board must re-evaluate the role of community based personal assistance services utilizing the suggestions of persons using personal assistance services in the restructuring of personal assistance services. The advisory board should appoint a design team to develop the specific details of a Monroe County personal assistance services plan. Using the principles developed in this report and the guidance of the advisory board, the design team will develop the specifics of a restructured personal assistance service system for Monroe County. When necessary, Monroe County would apply for waivers or status as a pilot project to implement these plans. At a minimum, the plans developed by this committee would include mechanisms for:

- a) designating a single agency to be primarily responsible for the administration and coordination of personal assistance services;
- b) specifying a single point of entry into the Monroe County Personal assistance service Program;
- c) describing the mechanisms which will assure that adequate and appropriate assistance, assessment, training, referral, quality assurance, and management services are established;

- d) minimizing the impact of conflicting New York State regulations affecting personal assistance services; and
- e) creating the option of consumer directed services.

2. Monroe County must have an independent organization undertake an evaluation of its contract with Tender Loving Care (TLC).

This evaluation should be completed by an organization familiar with the needs of people with disabilities and the complexities of the personal assistance service system. The evaluation must have significant input from those using the services of the agency, as well as from professionals. It should describe the impact of the contract on the reliability of TLC's services, the impacts of these changes on people with disabilities using TLC's services and any changes which could improve the quality and consistency of their services.

In order to gather data on unfilled services, every TLC personal assistance service recipient must be informed of his or her right to contact the County if TLC is unable to provide services. Many personal assistance service users we spoke with were unaware of the TLC contract and have gone without services without contacting the County.

The results of this evaluation should be made available to the Monroe County Personal Assistance Services Advisory Board for use in developing the County's plan. The information gathered from this evaluation should be incorporated into the next RFP for providing services through the County's preferred contract.

In order to gather data on unfilled services, every TLC personal assistance service recipient must be informed of his or her right to contact the County if TLC is unable to provide services. Many personal assistance service users we spoke with were unaware of the TLC contract and have gone without services without contacting the County.

3. Monroe County must provide the option for self-directed persons currently receiving home health services to shift their services to Department of Social Service Personal Care Services.

If one Home Health recipient were transitioned to the Medicaid PCA program, Monroe County would save \$2,174.67 per year. If 50 clients were transitioned, the County would save over \$108,000.00 per year!

Many self-directed Home Health recipients could receive their services through a Department of Social Services PCA program, rather than through the costly Home Health Services system. The transferral from HHA to PCA could save the County a great deal of money.

Assuming an individual receives 6 hours of service each day, the Medicaid billing for that client would be decreased by \$21,746.70 per year if that client were transitioned to a PCA program. Monroe County would save \$2,174.67⁹³ per year. If 50 clients were transitioned, the County would save over \$108,000.00 per year!⁹⁴

⁹³ Home Health Services : \$42,551.70
(\$19.43 per hour x 6 hours per day x 365 days per year)

Personal Care Aide Services: \$20,805.00
(\$9.50 per hour x 6 hours per day x 365 days per year)

$\$42,551.70 - \$20,805.00 = \$21,746.70$ Total Medicaid Savings

$\$21,746.70 \times .1 = \$2,174.67$ Monroe County Savings.

⁹⁴ $\$2,174.67 \times 50 = \$108,733.50$ Potential savings by transitioning 50 HHA clients to a PCA program

4. Monroe County must fund the development and implementation of programs to train persons with disabilities in the selection, management, and dismissal of attendants.

Some people may question the ability of people to manage their own services without any support or training. The County could fund an organization to develop a training program which would ensure that these individuals are able to effectively manage their own personal assistance services. Even if the County set aside \$25,000 to provide this training, it could still save over \$80,000.00 in the first year⁹⁵ and over \$108,000.00 annually.

Even if the County set aside \$25,000 to provide this training, it could still save over \$80,000.00 in the first year.

The availability of the training and the option to use PCA services must be widely publicized to people with disabilities, personal assistance service users, and providers. People should also be given an opportunity to appeal the decision if they are denied the option of PCA level services.

5. Monroe County must develop, with assistance from representatives of the disabled community, a program similar to Concepts of Independence in New York City.

This program would allow people with disabilities the option of managing their own personal assistance services. It returns control to people whose lives have been misunderstood and over-medicalized. These programs return to people the fundamental right to

⁹⁵ \$108,733.50 - \$25,000.00 = \$83,733.50

decide who touches their bodies and gives them the flexibility that able-bodied people take for granted.

Attendants in that program must be paid a competitive wage. This program might be set up within an existing agency. However, personal assistance service users must be involved in the management of the program.

If the nursing supervision were reduced to the 60 day requirement for 400 Home Health recipients, the County could save nearly \$60,000.00 annually.

6. Monroe County must decrease supervision of home health aide cases to once every 60 days, where allowable under the regulations, from the current practice of bi-weekly supervision.

Monroe County needlessly spends Medicaid funds on the supervision of Home Health Aide cases. By decreasing the nursing supervision from once every two weeks to once every 60 days, the County could eliminate 20 unrequired visits. At the County CHHA billing rate of \$73.97 per visit the County may decrease the Medicaid billing per individual by \$1,479.40 per year.⁹⁶

Although the County would save only one-quarter of that figure per person, if the supervision were decreased on 400⁹⁷ Home Health recipients, the County could save nearly \$60,000.00 annually.⁹⁸

⁹⁶ $\$73.97 \times 20 \text{ visits} = \$1,479.40$ Savings to Medicaid each year

⁹⁷ This figure represents about one-half of the Monroe County CHHA's caseload.

⁹⁸ $\$1,479.40 \times .1 = \147.94 County savings per HHA client

$\$147.94 \times 400 = \$59,176.00$ Total County savings per 400 clients

Further, the County could easily expand this practice so that only the most needful cases receive this level of nursing supervision. If this practice were expanded to nearly all Medicaid Home Health recipients in Monroe County, the savings would be even more substantial.⁹⁹

7. Monroe County must redefine the supervision of attendants so that an attendant is supervised if the attendant is unfamiliar with the task rather than the specific person.

Actual savings from this recommendation are difficult to determine. Even two additional visits per month, however, increase the Medicaid bill by \$1,775.28 per year.¹⁰⁰

By changing this policy for only 400 clients, the County's Medicaid billing could be decreased by \$710,112.00 each year. Monroe County could save \$71,011.20 annually.¹⁰¹

By changing this policy for only 400 clients, the County's Medicaid billing could be decreased by \$710,112.00 each year. Monroe County could save \$71,011.20 annually.

⁹⁹ The 400 case figure is only one-half of the Monroe County CHHA's caseload; this is only one of five Certified Agencies.

¹⁰⁰ $\$73.97 \times 2 \text{ visits per month} \times 12 \text{ months} = \$1,775.28$

NOTE: The figure of two visits per month was based on the personal experiences of those who attended the focus groups.

¹⁰¹ $\$1,775.28 \times 400 = \$710,112.00$ Total Medicaid Savings

$\$710,112.00 \times .1 = \$71,011.20$ Monroe County Savings

8. Monroe County must maximize the billing of Medicare in order to minimize the cost of personal assistance services to County taxpayers.

Many personal assistance service users have Medicare as well as Medicaid. Most providers are unaware that their services may be billable to Medicare as well as Medicaid. By billing Medicare for these services the County reduces its share of the cost of these services.

Many personal assistance service users have Medicare as well as Medicaid. Most providers are unaware that their services may be billable to Medicare as well as Medicaid. By billing Medicare for these services the County reduces its share of the cost of these services. For example, a personal assistance service user (with both Medicaid and Medicare coverage) receives 5 hours of home health services each day from the Monroe County Certified Home Health Care Agency. The Monroe County CHHA bills Medicaid \$35,459.75 per year. ($\19.43×5 hours per day $\times 365$ days per year) Monroe County pays ten percent of that amount, \$3,545.98 per year.

The Monroe County CHHA could bill Medicare for a portion of those services: 25 hours per week, Monday through Friday. During a year, Medicare would pay the entire cost of those services \$25,259.00 in Medicare eligible billing. Deducting the \$25,259.00 from the overall billing leaves only \$10,200.75 which is billed to Medicaid. Monroe County pays only \$1,020.08 of that, **reducing the County's costs by \$2,525.90 per year.** ($\$3,545.98 - \$1,020.08$)

The savings to Monroe County could be substantial. If only 50 such personal assistance service users were

billing this level of their services to Medicare, the County would save \$126,295.00 each year.¹⁰²

If the County allocated \$500 per client in advocacy fees to get the Medicare approvals, it would still save \$101,295.00 during the first year. If this policy were extended to 200 personal assistance service recipients, the County would save over one-half million dollars annually¹⁰³ (\$505,180.00).

9. Training programs for attendants must be made available to individuals not working for specific agencies.

Currently, agencies are unwilling to describe their payscales and benefits outside of orientation seminars. The current system requires an attendant to attend orientation after orientation in order to find the best offer. Attendants are also required to work for the agency that provided their training for a specified period of time.

By offering this training through a college, attendants will be able to seek out the best financial offer, rather than be indentured to a specific agency. Attendant training, when combined with experience, should qualify attendants for college credit at Monroe Community College. Attendants could use Student Loans to cover the cost of their training and intern with different agencies in order to get the experience they need. Such a training system would allow aides to seek

The savings to Monroe County could be substantial. If only 50 such personal assistance service users were billing this level of their services to Medicare, the County would save \$126,295.00 each year.

¹⁰² $\$2,525.90 \times 50 = \$126,295.00$

¹⁰³ $\$2,525.90 \times 200 = \$505,180.00$

out the best offer, rather than indenturing themselves to a specific agency before they are trained.

10. Monroe County must explore the creation of the attendant career ladder proposed in this report.

Although Medicaid pays the Monroe County CHHA over \$19.00 per hour for Home Health Services, the aides providing the services may get only five or six dollars an hour.

The turnover and loss of attendant seems to be one of the biggest problems facing the personal assistance service system. Although Medicaid pays the Monroe County CHHA over \$19.00 per hour for Home Health Services, the aides providing the services may get only five or six dollars an hour. Until attendants are given a decent wage and are valued as professionals, the rapid turnover of attendants will continue.

The Monroe County Personal Assistance Services Advisory Board, Attendants, Personal Assistance Service Providers, the Monroe County Health Department, and Monroe Community College could work together to implement the proposed career ladder.

11. Monroe County Departments of Health and Social Services must continue their dialogue on conflicting regulations and increase the coordination of personal assistance services in Monroe County.

Coordination of personal assistance services should be handled through a single County department, as specified in the Monroe County Personal assistance service Plan. Although there are clearly conflicts within State regulations, the County should seek out ways to avoid these conflicts within the current structure, where possible.

Recommendations to New York State

"...nothing has worked against home care the way the drive for profits has. In a country where we pay \$800 to have a wart removed, we consider it exorbitant to pay \$15 an hour to have a health aide in our home caring for a sick family member."

- Elsie Griffith

"The Changing Face of Home Health Care,"
Public Health Nursing

SIGNIFICANT CHANGE ON SOME ISSUES, HOWEVER, must be made at the State level. Dialogues among advocates have revealed that the types and availability of services throughout the State vary greatly. It is essential that personal assistance services be available consistently throughout the State. Some legislation and changes in State regulations may be required to implement the model we have proposed.

1. New York State legislation must be developed defining personal assistance services.

As the first step in an effort to meet the changing needs of our State, legislation should be passed which defines personal assistance services. This legislation should describe the components of the personal assistance service system, list specific programs, and define the philosophy behind the delivery of personal assistance services in New York State.

Dialogues among advocates have revealed that the types and availability of services throughout the State vary greatly. It is essential that personal assistance services be available consistently throughout the State.

2. New York State must coordinate the delivery of personal assistance services by developing uniform eligibility criteria, types of services, rules, and policies.

A Personal Assistance Services State Plan must be developed by the New York State Department of Health, New York State Department of Social Services, New York State Office of Aging, the New York State Office of the Advocate for the Disabled, the Association of Independent Living Centers, and other representatives of the disabled community.

To do this, a Personal Assistance Services State Plan must be developed by the New York State Department of Health, New York State Department of Social Services, New York State Office of Aging, the New York State Office of the Advocate for the Disabled, the Association of Independent Living Centers, and other representatives of the disabled community.

This plan should provide specific timetables and make recommendations on:

- a) designating a single agency to be primarily responsible for the administration and coordination of personal assistance services;
- b) specifying a single point of entry into the New York State Personal Assistance Service Program;
- c) creating a uniform Bill of Rights and appeals procedure for personal assistance recipients;
- d) describing the mechanisms which will assure that adequate and appropriate assistance, assessment, training, referral, quality assurance, and management services are established uniformly throughout the State;
- e) eliminating differences in regulations affecting personal assistance services in the State; and
- f) creating the option of consumer-directed personal assistance services in every county.

The New York State Personal Assistance Services Plan will require every County to write and implement its own Personal assistance services Plan, similar to the one suggested for Monroe County.

Both the State and individual County Plans will be evaluated and updated annually.

- 3. New York State must develop mechanisms for gathering data on the need for personal assistance services throughout the State and how the State's personal assistance service program must change to meet those needs.**

As part of a comprehensive personal assistance service legislation, the following mechanisms should be developed to ensure that the New York State Personal Assistance Service Plan is effectively meeting the needs of the State's Personal assistance service users:

- a) an advisory board primarily of persons using personal assistance services;
- b) regional public forums ; and
- c) workshops and conferences on varying aspects of the personal assistance service issue.

The State must also keep accurate statistics on how persons with disabilities receive personal assistance services. Statistics collected should include: number of clients, type of disability, source of personal assistance service, type of services provided, level of client satisfaction, and documentation on clients with unmet personal assistance service needs.

The State must also keep accurate statistics on how persons with disabilities receive personal assistance services.

4. New York State must develop and fund programs that train persons with disabilities in the selection, management, and dismissal of attendants.

If only 1,000 clients were transitioned from Medicaid Home Health to the PCA Program throughout the State, the State would save over \$8.6 million annually.

Personal Care Aide services are more cost effective than Home Health Aide services. It is in the best interest of the State to maximize the numbers of people who receive PCA services, as shown in the Monroe County recommendations.

Based on an individual receiving 6 hours of service each day, the Monroe County Medicaid billing for that client would be decreased by \$21,746.70 per year if that client were transitioned to a PCA program. The County would save \$2,174.67¹⁰⁴ per year. Because the State pays 40 percent of the total cost, it would save over \$8,000.00 annually. Based on that data, if only 1,000 clients were transitioned throughout the State, the State would save over \$8.6 million annually (\$8,698,680.00).

The State could allocate a training allowance of \$500.00 per person. Even at the cost of \$500,000.00, the savings generated from the transition would be

¹⁰⁴ Monroe County costs:

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\$42,551.70 - \$20,805.00 = \$21,746.70 Total Medicaid Savings

\$21,746.70 x .1 = \$2,174.67 Monroe County Savings.

\$21,746.70 x .5 = \$8,698.68 New York State Savings

substantial. The State might pilot such a training program in several Counties to study the effectiveness of transitioning Home Health Service recipients to the PCA program.

The training must emphasize the self-determination of people with disabilities and the rights of both those providing and receiving personal assistance services.

6. New York State must implement consumer-directed personal assistance service programs throughout the State and make them available to every personal assistance service user.

Consumer direction of personal assistance services empowers self-directed persons to manage their own lives. Many self-directed PAS recipients are restricted by the rigid, medical-model systems which currently support them in the community. Consumer-directed services must be consistently available throughout the State.

5. New York State must maximize Medicare billing for Personal assistance services.

The State must explore the maximization of Medicare billing as a means of minimizing the cost of personal assistance services to the State. By billing Medicare where appropriate, the State shifts a significant portion of the cost of those services to the Medicare program and the Federal government.

Based on Monroe County figures, Medicaid may pay \$35,459.75 per year for 5 hours of personal assistance services each day. ($\$19.43 \times 5 \text{ hours per day} \times 365 \text{ days per year}$) Medicare billing could cover at least 25 hours per week, Monday through Friday. During a

By billing Medicare where appropriate, the State shifts a significant portion of the cost of those services to the Medicare program and the Federal government.

If only 1000 such personal assistance service users were billing this level of their services to Medicare, the State would save \$10,103,600.00 each year. If the State allocated \$500 per client in advocacy fees to get the necessary Medicare approvals, it would still save over \$9.6 million in the first year.

year, Medicare would pay \$25,259.00 in Medicare eligible billing. Deducting the \$25,259.00 from the overall billing leaves only \$10,200.75 which is billed to Medicaid. The State pays \$4,080.30 of that, reducing its costs by \$10,103.60 per year by billing Medicare. (\$14,183.90 - \$4,080.30)

If only 1000 such personal assistance service users were billing this level of their services to Medicare, the State would save \$10,103,600.00 each year. If the State allocated \$500 per client in advocacy fees to get the necessary Medicare approvals, it would still save over \$9.6 million in the first year (\$9,603,600.00).

6. Any legislation for Universal Health Care enacted in New York State must include personal assistance services as a covered expense.

Current plans for Universal Health Insurance in New York State do not include long term, personal assistance services. Generally, it has been thought that these services are far too expensive to be included in such a Plan.

If currently proposed legislation passes, personal assistance service users will be required to spend down to Medicaid levels in order to get the coverage they need. No other group of people will be required to do this.

Universal Health care advocates should estimate the cost of including long term personal assistance services in proposed programs. They should include maximized Medicare billing for covered services, as well as the funds which currently cover the administration and implementation of the State's many personal assistance service programs (i.e. EISEP, Older Americans

Act funds, Medicaid, OMRDD). Based on these figures we can make an informed decision on the feasibility of including long term personal assistance services in a Universal Health Insurance package.

7. New York State must develop and fund innovative programs to find and train qualified attendants.

The shortage of qualified attendants is a critical issue to reforming the attendant service system. Funding innovative programs to address this shortage is imperative. Such programs could include:

- a) developing courses to train and graduate qualified attendants in order to provide greater access to this profession and raise the perceived status of the job;
- b) providing attendants with the opportunity to use their work experience to further their education in health and other related fields;
- c) encouraging personal assistance service internships and practicums for students in Rehabilitation Counseling, Nursing, and other related fields; and
- d) utilizing funds designed to get people off Home Relief as a means for increasing the pool of available attendants;
- e) using vocational rehabilitation and supportive employment programs as a means of allowing persons with disabilities to work as attendants.

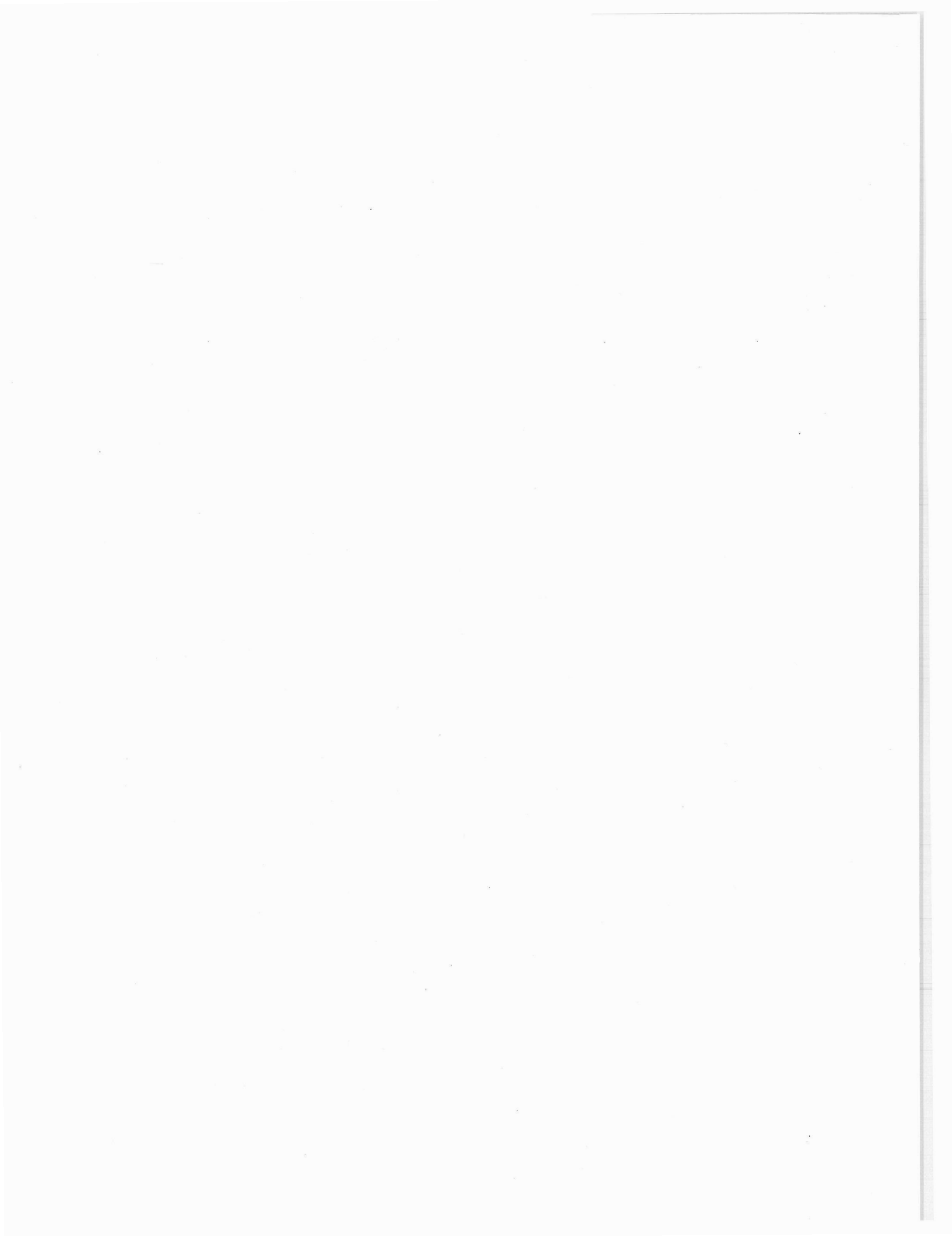
Universal Health care advocates should estimate the cost of including long term personal assistance services in proposed programs. They should include maximized Medicare billing for covered services, as well as the funds which currently cover the administration and implementation of the State's many personal assistance service programs (i.e. EISEP, Older Americans Act funds, Medicaid, OMRDD).

8. New York State must adopt the Attendant Career Ladder proposed in this report and implement it in the regulations governing personal assistance services.

Attendants receive only a fraction of the Home Health dollars spent by Medicaid in Monroe County. Wages are not much higher in other areas. We must seek ways of minimizing the administrative costs, increasing the wages paid to attendants, and improving their benefits.

The shortage of attendants will continue to be a chronic problem facing personal assistance service users until the system recognizes their expertise and skill. Attendants must receive appropriate compensation and benefits in order to stay in this field. Attendants also must have the opportunity to advance.

Currently, attendants receive only a fraction of the Home Health dollars spent by Medicaid in Monroe County. Wages are not much higher in other areas. We must seek ways of minimizing the administrative costs, increasing the wages paid to attendants, and improving their benefits. Any efforts to improve the personal assistance service system, must improve the working conditions of the attendant and the development of a professional career ladder.



Profile:

Teresa Carroll

In January, 1985, Teresa was living in Florida. One night while she was driving home from work, a man ran a red light and hit her car from behind. The fourth and fifth vertebrae in her neck were fractured and dislocated. Two weeks after her surgery, she enrolled in the Miami Project for rehabilitation. In October of 1985, she moved to Rochester. She attended the University of Rochester and graduated from there in May 1991. She lives independently with her service dog, Achilles, in downtown Rochester. Currently she is a law intern at Nixon, Hargrave, Devans, and Doyle.

...my home life has turned into a virtual bus stop with the high turnover of attendants. During a two month period, over 49 different strangers were dispatched to my home to assist me.

Teresa Carroll



I'M TIRED OF THE UNCERTAINTY.

Is it a man or a woman? What is his or her name? Will this person steal from me? Will he or she be able to read? Will they know I have a service dog? Will they understand why I have him and that he is not a pet? Is this person scared of dogs? Am I the first quadriplegic this aide has worked with? Can they operate a Hoyer lift? And finally, will this person return tomorrow? These are questions which should be answered during an interview -- not when I am waiting to get out of bed.

While at the University of Rochester, I took 18 credits per semester, served as a member of the Student Senate, and organized major fundraising events, but was forced to go to bed at 8:30 PM. I continue to be an active member of my community. I have served on boards of directors, coordinated disability awareness programs, and organized a benefit concert. But today, I still have no control over who assists me.



Since moving to Rochester and getting aide services, my home life has turned into a virtual bus stop with the high turnover of attendants. During a two month period, over 49 different strangers were dispatched to my home to assist me. Over 26 aides assisted me in the mornings. Ten different aides assisted me at night. Thirteen different nurses performed my bowel program. I should be able to interview and orientate these people ahead of time.

Most people don't understand that I view those who assist me in my home as my employees. They are in my home to assist me. When I explained this to my primary nurse, she told me that I should simply accept the services I am given and be grateful for them. She told me that I should also be grateful to **her**. She pays the taxes which provide my health coverage.

My personal care has been overmedicalized and taken out of my control. There are many places throughout the United States and the State of New York where you can have control over the people who assist you. These places allow people with disabilities to interview, hire and fire their own attendants and nurses. Rochester is not one of them.



Nine:

Implications for Organizers: Building a Coalition and Common Agenda

"...the 'Rights Revolution' began many years ago. This movement was broadly-based and generated rising expectations that expressed a demand for dignity and participation on the part of millions of people who saw themselves as voiceless and powerless. The African-American civil rights movement, whose tactics were themselves spawned by the earlier labor movement, later created the impetus for the modern women's movement and the disabilities movement. The common thread of these other historic efforts is their attempt to remove barriers from the lives of certain groups of people and to establish a meaningful voice in shaping their own destinies."

- David Richart and Stephen Bing
Fairness is a Kid's Game

THIS CHAPTER SERVES AS A GUIDE FOR DISABILITY rights advocates working on the personal assistance service issue. It describes resistance from service providers and some members of the disabled community to reforming the personal assistance service system, ties the personal assistance service issue to other social movements, and suggests other communities with whom disability rights advocates can begin to build a coalition.



Resistance From Within

Many people fear that if they speak out against the system, they will lose the service that keeps them in the community. They accept marginal or inappropriate service.

"If I complain, I may lose the service I've already got."

- Monroe County Personal assistance service User

AS DISABILITY RIGHTS ADVOCATES WORK TO restructure personal assistance services in Monroe County and New York State, both service users and providers may be resistant to change. Many service users are fearful of speaking out against a system upon which they rely for everyday survival. Some providers may perceive people with disabilities as childlike and



helpless, needing professionals to supervise their service. These providers may also reinforce the dependent behavior of some personal assistance service users.

Personal assistance

services frequently are the only support a person with a severe disability has to prevent him or her from being institutionalized. Many people fear that if they speak out against the system, they will lose the service that keeps them in the community. They accept marginal or inappropriate service.

Such fears were detailed in the Habilitation article :
"Fear and Retribution".

"Fear and retribution.

Those were the words that cropped up again and again as we interviewed people who had lived in institutions for years but now live in the community.

Fear and retribution.

Those were the words we heard again and again as we interviewed people who still live in institutions but desperately want to live in the community.

So what did they have to fear by telling their stories? Some said they feared they'd be sent back to the institution, while others feared they'd never get out. Some said they feared their communication devices would be taken away; others said they feared their attendants wouldn't show up in the morning to get them out of bed.

Now, if you believe even some of the myths about people with disabilities -- that they are childlike, not really in touch, unable to assess their experience -- you might think they were being paranoid. Now while it may be true in some cases (just as it is for all of us), it only takes a quirk of fate -- a small twist in a story -- to make one see how real (and how subtly encouraged) those fears are."¹⁰⁵

So what did they have to fear by telling their stories? Some said they feared they'd be sent back to the institution, while others feared they'd never get out. Some said they feared their communication devices would be taken away; others said they feared their attendants wouldn't show up in the morning to get them out of bed.

¹⁰⁵ Habilitation, May, 1991.

Some people with disabilities, who have never had control over their lives or have constantly received criticism about their abilities, have become apathetic and helpless. They may not accept responsibility for their lives or their personal assistance services because any attempt to achieve such control seems futile.

Many able-bodied people have a "caretaking" attitude which portrays people with disabilities as people who need to be taken care of -- helpless and unable to make their own decisions. This attitude focuses on the disability people may have and ignores the many skills they possess or may achieve. It also dehumanizes them, dismissing their ability to make the decisions which allow them to control their lives.

Some people with disabilities, who have never had control over their lives or have constantly received criticism about their abilities, have become apathetic and helpless. They may not accept responsibility for their lives or their personal assistance services because any attempt to achieve such control seems futile. Some persons with disabilities have relied on other people for so long that they fear independence and responsibility.

Only when persons with disabilities believe that they can regain control over their lives -- and their personal assistance services -- will they be motivated to accept responsibility. We must realize that people with disabilities may have learned helpless and dependent behavior. As we work to reform the personal assistance service system, we must address this issue.

Related Social Movements

THE DISABILITY RIGHTS MOVEMENT AND THE Consumer-Directed Personal assistance service Model presented in this report are indebted to the contributions of other social movements -- most notably the consumer, the self-help, and the demedicalization movements. Our Consumer-Directed Personal assistance service Model incorporates the values and

assumptions that characterize each of these movements.

According to the **consumer movement**¹⁰⁶ the consumer, not the provider, is best able to judge the adequacy of services and products. Having personal experience with their own disabilities, individuals best understand their own personal assistance service needs. Thus, as consumers of personal assistance services, they are best able to monitor the quality of the assistance they receive.

The **self-help movement**¹⁰⁷ assumes that the individual is not only capable of evaluating service quality, but that he or she is also able to manage and direct the services. Likewise, the Consumer-Directed Model presumes that the disabled individual is best able to manage and direct his or her own personal assistance services.

The **demedicalization movement**¹⁰⁸ asserts that there is too much unnecessary medical intervention into various life conditions which are social and economic rather than medical. In the case of physical disability, the movement argues that a continuous medical presence is unnecessary once an individual is medically stable. Disability Rights Advocates must

**Disability Rights
Advocates must
realize the
importance of
linking our advocacy
efforts to these
larger movements.
We can capitalize on
the momentum and
acceptance.**

¹⁰⁶ DeJong, Attendant Care and Independent Living, Archives of Physical Medicine and Rehabilitation, October, 1979.

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As the primary users of personal assistance programs and a strong political force, seniors represent the strongest partner in any coalition to improve these services.

Disability rights advocates should seek the political support of the Gay and Lesbian Community in our efforts to reform the personal assistance service system.

realize the importance of linking our advocacy efforts to these larger movements. We can capitalize on the momentum and acceptance of these movements to bring about significant change in the provision of personal assistance services.

Building A Coalition

IN ORDER TO PRESS FOR THE DEVELOPMENT OF AN effective personal assistance service system in Monroe County and New York State, it is necessary for the disabled community and disability rights advocates to build a broad-based coalition supporting this reform. Senior Citizens, AIDS and Gay Rights organizations, African-Americans; Latinos, and the Women's Movement all have a stake in personal assistance service issues. The sections which follow detail the specific issues pertinent to each community.

Senior Citizen Action Groups

ABOUT ONE THIRD OF PEOPLE OVER 75 NEED SOME type of assistance. The provision of personal assistance services has been and continues to be a key issue for senior citizen action groups. As the primary users of personal assistance programs and a strong political force, seniors represent the strongest partner in any coalition to improve these services.

AIDS Advocates: The Gay and Lesbian Community

IN RESPONSE TO THE AIDS CRISIS, THE GAY AND Lesbian community has built a vast service structure to meet the needs of People with AIDS. AIDS activists have successfully pressed for reforms at both the local and State levels. In fact, during the State's 1991 and

1992 fiscal crises, organizations and programs serving People with AIDS have generally been spared tremendous cuts.

The disabled community has many programs, including personal assistance services, to offer people with AIDS. As people with AIDS live longer due to improved treatments, a variety of secondary disabilities begin to surface -- most notably visual impairments. The wide range of services in the disabled community can supplement current resources available to people with AIDS.

Appropriate personal assistance services for people with AIDS, however, must become a priority in order to support people with AIDS in the community. Disability rights advocates should seek the political support of this community in our efforts to reform the personal assistance service system.

African-American and Latino Communities

ALTHOUGH THE INCIDENCE OF SEVERAL disabilities, including Stroke and AIDS, is higher in the African-American and Latino communities, the disability rights community has lacked significant involvement from African-Americans and Latinos with disabilities. A disproportionate number of attendants are African-American and Latino. Both personal assistance service users and providers will benefit from such a coalition. The disabled community must include African-Americans, Latinos, and other ethnic groups in the coalition to improve personal assistance services.

A disproportionate number of attendants are African-American and Latino. Both personal assistance service users and providers will benefit from such a coalition. The disabled community must include African-Americans, Latinos, and other ethnic groups in the coalition to improve personal assistance services.

The Women's Movement

THE DISTRUST OF PROFESSIONAL DOMINATION IN medicine is most apparent in the Women's Movement. Feminists claim that women are denied the right to participate in medical decisions by doctors who are reluctant to share information or take women seriously.

Both the disabled community and the Women's Movement are struggling to be allowed to make the choices affecting their own bodies.

Both the disabled community and the Women's Movement are struggling to be allowed to make the choices affecting their own bodies. The philosophy that people should be allowed to choose who provides their personal assistance parallels feminist ideas. In addition, attendants continue to be predominantly women -- often single mothers. The disabled community and the Women's Movement must work to improve personal assistance services.

A Common Agenda for Change

THIS PAPER IS A WORKING DOCUMENT WHICH MUST be used to build a common agenda for personal assistance service reform in Monroe County and throughout the State. The work, however, must be done by each of the constituencies represented in this report. Senior citizens, AIDS activists, ethnic groups, women and disability rights advocates have a significant contribution to make to this effort. Together, we can assure that the vision of a coordinated, community-based personal assistance service system is available in Monroe County and New York State.

Appendix A:

Definitions of Terms

ACTIVITIES OF DAILY LIVING

Any of the activities which must be performed in the course of daily living. These activities include dressing, bathing, grooming, getting around, eating, preparing meals, shopping, cleaning house, and engaging in work, school, community service or recreation.

ACUTE CARE

Immediate, emergency or scheduled medical/surgical care, required for a worsening medical condition, generally provided in a hospital or in an outpatient setting (clinics, doctor's offices.)

ADULT CARE FACILITY

A family-type home for adults, a shelter for adults, a residence for adults or an adult home, which provides temporary or long-term residential care and services to adults who, though not requiring continual medical or nursing care, are, by reason of physical, mental or other limitations associated with age, physical or mental disabilities, or other factors, unable or substantially unable to live independently.

ADULT DAY CARE

Provision during the day, on a regular basis, at a site outside of the home, of health, medical, psychological, social, nutritional, educational and other services that a person with a disability needs in order to remain in the community.

ADULT HOME

An adult care facility established and operated for the purpose of providing long-term residential care, room, board, housekeeping, personal care and supervision to five or more adults, unrelated to the operator.

AREA AGENCY ON AGING (AAA)

The local planning and service units designated by the Department of Aging to administer a program of comprehensive community services for

the elderly. AAA's can be a part of county government or a private non-profit agency.

CASE MANAGEMENT

Coordination of a number of services, provided by various agencies, which are needed by a single individual. It includes assessment of client need, development of an individualized service plan, arrangement of services; and reassessment. The goal of case management is both to avoid service duplication and to facilitate an individual's receiving all needed services.

CERTIFIED HOME HEALTH AGENCY (CHHA)

A public, voluntary, or private proprietary agency, certified by the federal government and the State. It can be sponsored by a home care service agency, a residential health care facility, or a hospital authorized under State and federal law to provide care in the home. Monroe County has five: Genesee Region Home Care Association (GRHCA), HCR, Kimberly Quality Care, Monroe County Department of Health (MCDH) and the Visiting Nurse Service (VNS). All provide services to clients. Certified Home Health Agencies are certified to receive direct Medicare reimbursement.

CHORE SERVICES

Infrequent tasks related to home maintenance such as repairs and yard work. Under Title XX, personal care activities and other domestic services such as shopping and housecleaning are included in this definition as well.

COGNITIVE ASSISTANCE

Assistance with life management activities such as money management, planning and decision making.

COMMUNICATION ASSISTANCE

Interpreting for people with hearing or speech disabilities.

COMMUNITY-BASED SERVICES

Services provided in a disabled person's home or other settings (e.g. work, school, recreation) which enable the person to function in those settings. Community Health Nurse (CHN)A Registered Nurse with a Bachelor's Degree and further special training.

CONGREGATE HOUSING

Multiple unit housing with shared common space and shared services for those disabled people who are not totally independent but who do not need institutional care.

CO-PAYMENT

Used as part of Medicare and other insurance programs, (also called co-insurance). The amount the policy holder must pay directly per visit or per prescription.

COST SHARING

An arrangement allowing individuals with incomes above a certain minimum to receive services and pay a portion of the cost of those services according to a sliding scale based on income.

DEDUCTIBLE

Amount the policy holder must pay before insurance benefits begin.

DISINCENTIVES TO EMPLOYMENT

Provisions of entitlement programs (such as SSI, SSDI and Medicaid) which discourage their beneficiaries from seeking and/or holding employment because to do so would result in loss of income and/or benefits. (See Chapter 5.)

DISABILITY

A person with a disability is any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

DISCHARGE PLANNING

The process of planning for the provision of care that will be needed after discharge from the hospital or other level of care. Usually done by nurses and social workers with special training, working with the patient and family and with physician's agreement. A discharge plan must be completed, prior to discharge, which adequately spells out how the patient will be cared for at home. When in a hospital, if an adequate

plan is not in place, a patient may protest his or her discharge and gain extra hospital days while the case is reviewed.

DISINCENTIVES TO EMPLOYMENT

Provisions of entitlement programs (such as SSI, SSDI and Medicaid) which discourage their beneficiaries from seeking and/or holding employment because to do so would result in loss of income and/or benefits.

E.I.S.E.P. (EXPANDED IN-HOME SERVICES for the ELDERLY PROGRAM)

For frail persons, age 60+, living at home, who do not qualify for Medicaid. Provides case management, personal care aide and housekeeper/chore services. Fees are on a sliding scale based on income. Administered by the Monroe County Office of the Aging. Intakes and case management are coordinated by Catholic Family Center.

ENTITLEMENT

Eligibility for a benefit based upon membership in a particular designated category, for instance, age, health status (blind, disabled) or income.

ESCORT

Accompanying and/or assisting a client while traveling to necessary activities, such as medical appointments, shopping, school, etc. Many attendant programs limit escort services to medical appointments only.

FUNCTIONALLY DISABLED

An impaired ability to perform activities of daily living.

HEALTH CARE PROXY

A formal document delegating the authority to make health care decisions under the requirements of Article 29-C of New York Public Health Law, for another person in the event that person lacks capacity to make decisions (Effective 01/18/91.)

HOME DELIVERED MEALS

Meals prepared at a central location and delivered on a daily basis or less frequently to homes of people who are old or disabled.

HOME HEALTH AGENCY - See HOME HEALTH SERVICES

HOME HEALTH AIDE

Person who, under the supervision of a home health or social service agency, assists older, ill or disabled persons with household maintenance and personal maintenance and hygiene tasks, and paramedical tasks. Home health aides are usually trained by the Home Health Agency or by outside training programs

HOME HEALTH SERVICES

Home health services are services and items furnished to an individual in his or her home by a home health agency. The services are furnished under a plan established and periodically reviewed by a physician and include: part-time or intermittent skilled nursing care; physical, occupational, or speech therapy; medical social services, medical supplies and appliances (other than drugs and biologicals); home health aide services; and homemaker services.

HOMEMAKER

Person who, under the supervision and training of a home health or social service agency, assists older, ill, or disabled persons with household maintenance tasks and child care.

HOSPICE

A medically directed program providing a continuum of home and inpatient care for the terminally ill patient and the family. The program provides palliative and support care to meet the special needs arising out of physical, emotional, spiritual, social and economic stresses which are experienced during the progressive stages of illness, during dying and bereavement. Such programs are usually provided in patients' homes but are also offered in hospitals, residential health care facilities (Nursing Facilities), or in freestanding units.

HOUSEHOLD MAINTENANCE TASKS

Cleaning, shopping, meal preparation, laundering, heavy cleaning, and repairs.

INTELLECTUAL DISABILITY

Mental Retardation

INDEPENDENT LIVING PROGRAM (ILP)

A community-based non-profit organization, usually controlled by disabled people, which provides a variety of services directed at enabling disabled people to live independently. Among these services are peer counseling, personal assistance/attendant referral, benefits counseling, Independent Living Skills training, housing referral, and advocacy to remove social, economic, and environmental barriers.

INDIVIDUAL PROVIDER

An attendant hired and supervised by a recipient.

LONG TERM "CARE"

The whole spectrum of services potentially needed by disabled and ill people of all ages. The range includes health care, social services, housing, transportation, income security, and jobs.

LONG TERM HOME HEALTH CARE PROGRAM (LTHHCP)

(Also known as the Nursing Home Without Walls Program or Lombardi program.) - Is a program utilizing community-based services under waivers to Medicaid recipients and other individuals assessed as eligible for health related or skilled nursing home care. The program features case management of long-term care services, with per capita expenditures limited to 75% of the local average annual Medicaid cost for maintaining patients at a comparable level in a nursing home. LTHHCP's are licensed by the State after undergoing a Certificate of Need application process. LTHHCP's in Monroe County are run by the Monroe County Home Health Agency (MCD), the VNS, St. John's Home, Park Ridge Nursing Home and the Rochester General Hospital (Independent Living for Seniors.) For certain patients (e.g. Alzheimer's disease) expenditures may be 100% of institutional average cost

MEDICAID

Joint federal-state program, created in 1965 by Title XIX (Medical Assistance) of the Social Security Act. It is administered by the states and pays for health care services for people with very low income. In some states it also pays for personal maintenance/hygiene services or attendants.

MEDICAID COST SHARING

The amount of a Medicaid recipient's monthly income which must be spent on medical care or services before Medicaid coverage will assume payment for additional monthly medical expenses.

MEDICARE

Federal program, created in 1965 by Title XVIII (Health Insurance for the Aged) of the Social Security Act. It provides health insurance benefits primarily to persons over the age of 65 and others who are eligible for Social Security Benefits.

MENTAL DISABILITY

Psychiatric illness

MOBILITY

Ability to move from one place to another.

NURSING HOME PRE-ADMISSION SCREENING

A process conducted prior to entry into a nursing home to assess a person's functional abilities and service needs in order to determine whether the individual can remain living in the community rather than enter a nursing home.

NUTRITION CENTERS FOR SENIOR CITIZENS

Various locations where a balanced meal is provided for a suggested donation of \$1.75 per meal and an opportunity to socialize is also made available. Donations by meal recipients are used to defray meal costs or for other programs of centers when possible. Van transportation is available to most centers.

PATIENT'S BILL OF RIGHTS/GRIEVANCE PROCEDURE

Statutory or regulatory "bill of rights" setting forth the rights and privileges of patients within a system of care (acute care, nursing home care, home health care, etc.) primarily to insure the protection of these citizen's rights. Should be given and explained to the patients. Now required for all CHHA's and LHCSA's as well as hospitals and nursing facilities.

PERSONAL ASSISTANCE SERVICES

Assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. These tasks include: personal maintenance and hygiene tasks, mobility tasks, household maintenance tasks, infant and child care related tasks, cognitive tasks, security related services, and communication services.

PERSONAL MAINTENANCE AND HYGIENE TASKS

Dressing, grooming, feeding, bathing, respiration, equipment maintenance, and toilet functions such as bowel, bladder, catheter and menstrual tasks.

PROTECTIVE SERVICE

Activities to assist individuals who, because of mental or physical disability or family situation, are unable to protect themselves from neglect, hazardous situations or abuse without assistance from others.

RESPIRE SERVICES - See SHORT-TERM SERVICES

SECTION 1619 OF THE SOCIAL SECURITY ACT

See footnote 4, page 7.

SECURITY-RELATED SERVICES

Daily monitoring by phone, special alarm systems, etc.

SHORT-TERM SERVICES

Intermittent attendant services replacing family members or other assistance on a scheduled basis which enable the individual with a disability to receive the assistance needed and be independent of the family for brief periods while allowing the family members to leave the home for anywhere from a few hours to several weeks. Short-term services are part of the continuum of personal assistance services ranging from daily service to assistance for very short periods.

SUPPLEMENTAL SECURITY INCOME (SSI)

A federal income maintenance program which provides a flat monthly grant to people who are poor, disabled, or old, whose resources and other income fall within certain strict limits.

SOCIAL SECURITY DISABILITY INCOME (SSDI)

A federal income maintenance program for people who become disabled after they have worked a minimum period of time depending on age at onset of disability. Payment amounts are determined by the duration and level of a recipient's prior earnings. There are no limits on a recipient's resources or other non-work related income.

STATE AGENCY ON AGING

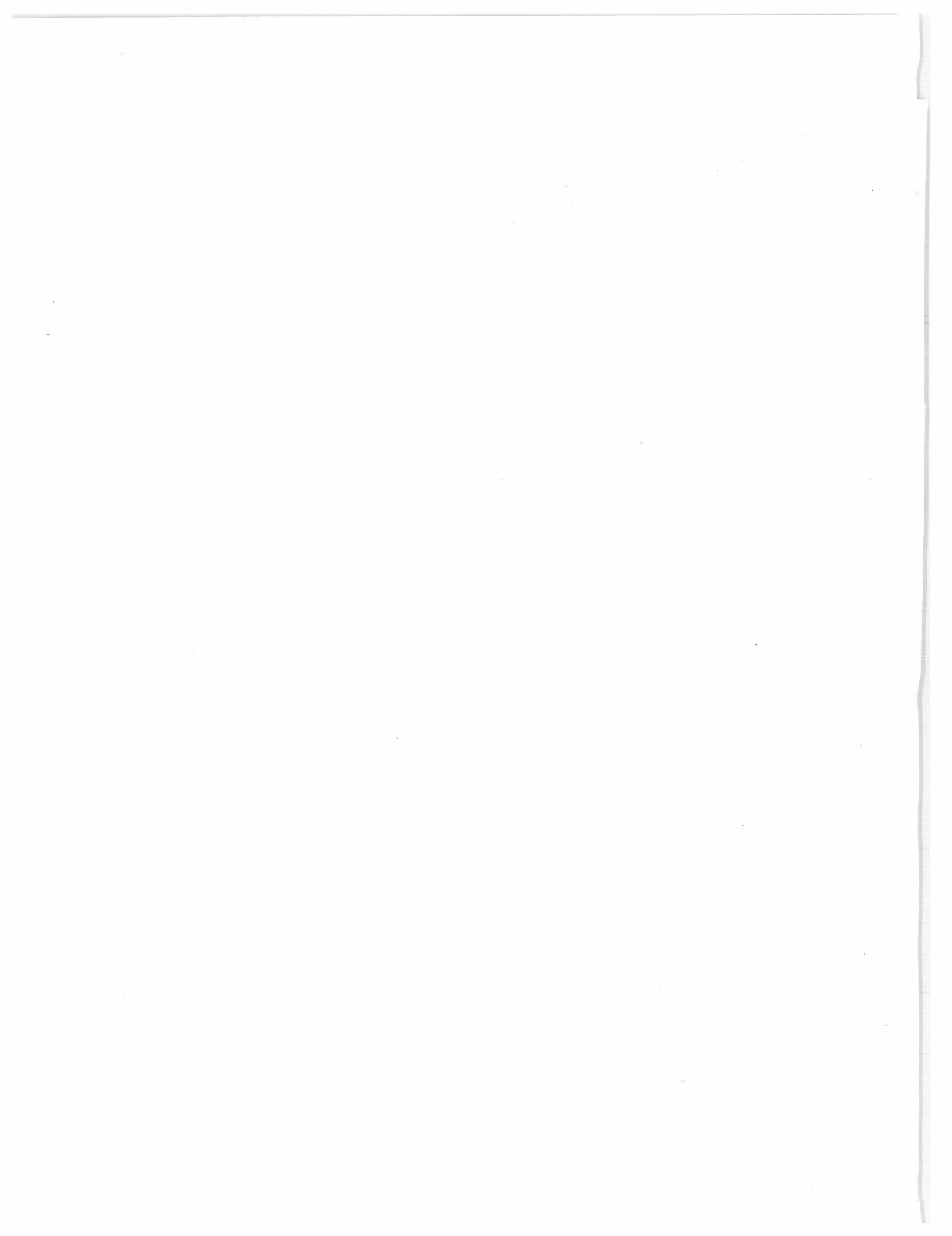
The state-level agency that oversees the work of the Area Agencies on Aging in each state.

TEACHING AND DEMONSTRATION

Instructional services which enable recipients of attendant services to perform some or all of those services themselves.

TELEPHONE REASSURANCE

Daily or regularly scheduled telephone calls made by family, friends or volunteers to check on those who are homebound.



Appendix B:

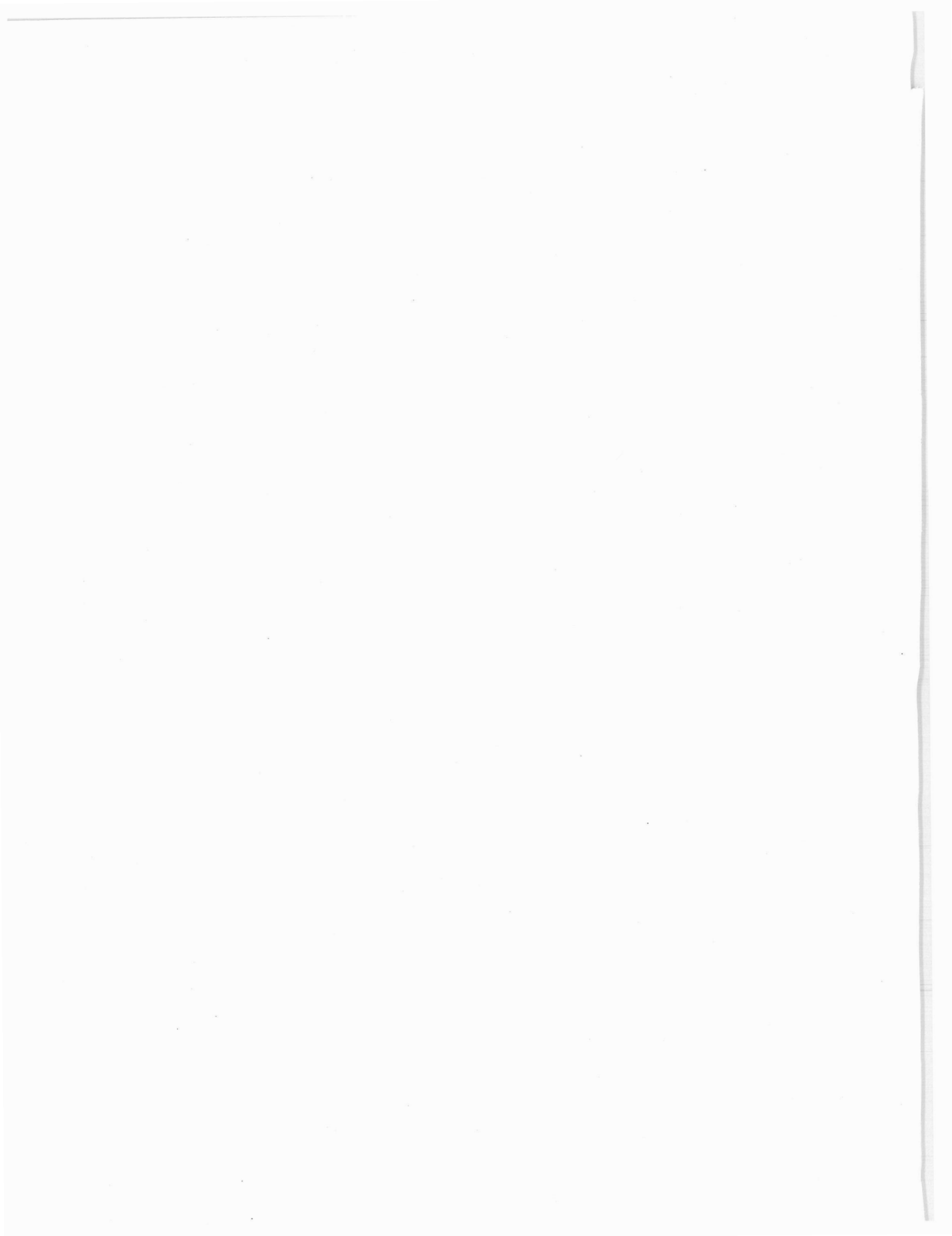
Methodology

CDR Public Policy committee members began to research the problems of the attendant service system. To identify these problems, we relied heavily on tapes and a transcript of a Speakout held on the issue about a year-and-a-half earlier -- in February 1990 -- hosted by the Action Center for the Disabled, a local service and recreation program serving people with disabilities. About 50 people attended the speakout and discussed the problems that they saw with the current systems.

People who use attendant services complained about a system which did not recognize their ability to direct their own lives. They spoke about being treated as children. They drew a distinction between the "care" required by sick people and the "assistance" they needed with their basic activities of daily living. They complained about the County's requirement that they be given nursing supervision every two weeks when the State only requires such visits twice a year for many people. They expressed their frustration with the system which discourages them from seeking employment, and they talked about how it felt to be an adult who is put to bed at 8:00 PM.

The Policy Committee then conducted an exhaustive search of reports and articles on these issues. We used the research work of the World Institute on Disability which had prepared reports and policy analysis of federal attendant service programs. We also conducted interviews with local providers and advocates working on attendant service issues across the nation. From this information, the Center outlined the maze of services which comprise the attendant service system and compiled a series of recommendations to improve this system. The basic proposal included changes at the County, State, and Federal levels.

These recommendations were presented to focus groups of about 30 people with disabilities who rely on attendant services. From these groups, the Center modified the basic recommendations and developed profiles of attendant service users and providers. The revised paper was finally distributed to 22 expert readers from various backgrounds and areas of expertise. In all, five lawyers, two doctors, a Registered Nurse, four Disability Advocates, eight people with disabilities and two technical editors reviewed the report. The suggestions and comments from these readers were incorporated into the final document during the Winter and Spring of 1993.



Appendix C:

Bibliography

"Aide Shortage Limits Home Health Delivery," *Hospitals*, May 5, 1988.

Attendant Services Speakout Transcript, Action Center for the Disabled, February 1990.

Bell, William G. PhD, "Community Care for the Elderly: An Alternative to Institutionalization," *The Gerontologist*, Autumn, 1973.

Benson, K. and Crane, Lavinia, "Home Care -- Why the Hesitancy?", *Canadian Journal of Public Health*, July 1966.

Bernstein, Lawrence H., M.D., "The Role of the Physician in Home Care," *Public Health Nursing*, March, 1987.

Carey Ione, "Training and Use of Home Health Aides," *American Journal of Nursing*, August 1966.

Center for Governmental Research, "Toward an Improved CHHA in Monroe County," 1989.

Concepts of Independence, Inc., "Living Independently: A Consumer's Guide About Personal Care Attendants," 1988.

DeJong, Gerben, and Wenker, Teg, "Attendant Care as a Prototype Independent Living Service," *Archives of Physical Medicine and Rehabilitation*, October, 1979.

The Disability Rag, "Personal Care," January/February 1989. Griffith, Elsie I., "The Changing Face of Home Health Care," *Public Health Nursing*, March, 1987.

Hutchinson, Lisa L. and McAlister, James C. III, "Home Health Care: The Patient's Perspective," *American Journal of Hospital Pharmacy*, June, 1986.

Kane, Nancy M., "The Home Care Crisis of the Nineties," *The Gerontologist*, No. 1, 1989.

Koren, Mary Jane, M.D., "The Home Health Agency and the Ivory Tower," *Public Health Nursing*, March, 1987.

Litvak, S., Zukas, H., and Heumann, J. E., *Attending to America: Personal Assistance for Independent Living*, April 1987.

Mainstream, "Attendant Care: Taking a First Look at a Critical Issue," May 1985.

Monroe County Health Department, *Community Health Assessment*, Monroe County, New York 1989.

Olmsted, Lois, M.S., "Home Care Instructions," *The Physical Therapy Review*, June 1954.

Regulatory Conflict in Home Care, April, 1988.

Rogatz, Peter, M.D., "Perspective on Home Care, Public Health Nursing," March, 1987.

Rousseau, Elaine J. R.N., M.S., "Opening the Gateway to Home Health Care," *Public Health Nursing*, March, 1990.

Steinberg, Franz U., M.D., "The Management of Patients with Spinal Cord Injury by a Hospital-Based Home Care Programme," *Paraplegia*, 1975.

Wallace, Steven P., PhD, "The No-Care Zone: Availability, Accessibility, and Acceptability in Community-Based Long-Term Care," *The Gerontologist*, 1990.

Weissert, William G., "Seven Reasons Why It Is So Difficult To Make Community-Based Long-Term Care Cost-Effective", *Health Services Research* 20:4 (October 1985).

World Institute on Disability, "Attendant Services Network," Fall 1988. World Institute on Disability, "Attendant Services: Descriptive Analysis of California's In-Home Supportive Services Program, 1987.

Zola, Irving Kenneth, "Aging, Disability, and the Home-Care Revolution," *Archives of Physical and Medical Rehabilitation*, February 1990.

Appendix D:

Personal Care Aide Functions and Tasks

The following pages list specific tasks which can be performed by level I and II Personal Care Aides.

Level I and II Personal Care Aide Functions and Tasks Scope of Practices

New York State Department of Social Services
Bureau of Long Term Care
Home Care Unit
40 North Pearl Street
Albany, New York 12243-001
3/5/92

3/5/92

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This listing indicates the full scope of practice for Level I and II Personal Care Workers. Each worker must demonstrate competency in performing the necessary skills and only perform those skills indicated on the plan of care. All Level I and II PCAs are required to observe, record and report their actions and findings when assisting the client with a specific function, task or procedure. Nursing supervision must assure that the client's needs are appropriately met and that the person providing such personal care services is competently and safely performing the functions and tasks specified in the patient's plan of care.

ENVIRONMENTAL SUPPORT

1. Make and change beds
 - a. Unoccupied
 - b. Occupied
2. Dusting and vacuuming rooms used by patients
3. Light cleaning of kitchen, bedroom, bathroom
4. Dishwashing
5. Listing needed supplies
6. Shopping
7. Laundering, mending, ironing
8. Payment of bills and other errands

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
X	X	
	X	I
X	X	
X	X	
X	X	
X	X	
X	X	
X	X	

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NUTRITIONAL SUPPORT

1. SIMPLE MODIFIED DIETS

(Defined as a change in one nutrient, amount of calories or mechanically altered.)
 Examples include: low fiber, low fat, low cholesterol, low sugar, low sodium, low calorie, high fiber, high calorie, high protein, bland, soft, liquid, chopped ground, pureed.

- a. Develop menu
- b. Prepare grocery list
- c. Grocery shopping
- d. Prepare meals
- e. Assist with feeding
- f. Measure and record intake

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
X	X	
X	X	
X	X	
X	X	
	X	I
	X	I

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NUTRITIONAL SUPPORT

2. DIABETIC, RENAL OR COMPLEX DIETS

(Complex diet defined as when a change in more than one of the following is ordered; a nutrient, the calorie amount or mechanical alteration.)

- a. Develop menu
- b. Prepare grocery list
- c. Grocery shopping
- d. Prepare meals
- e. Assist with feeding
- f. Measure and record intake

3. PREPARE NUTRITIONAL SUPPLEMENTS

4. ASSIST WITH GASTRIC GAVAGE (TUBE FEEDING)

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
		I AND II
		I AND II
X	X	
		I AND II
	X	I
	X	I
		I AND II
		I AND II

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PERSONAL CARE FUNCTIONS

1. **BATHING CLIENT**
 - a. In bed, tub or shower or sponge bath
 - b. Pour premeasured medication into bath water
2. **SKIN CARE**
 - a. Back rub
 - b. Gentle massage to unbroken skin areas
 - c. Lubricate unbroken skin with **nonprescription** powder, lotion, cream
 - d. Lubricate unbroken skin with **prescription** powder, lotion, cream
 - e. Foot and hand soaks (hot or cold)

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
	X	I
	X	I AND II
		I AND II

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PERSONAL CARE FUNCTIONS

3. GROOMING

- a. Shampoo (tub, shower, bed)
- b. Finger nails
(ONLY clean and file for NON diabetic)
- c. Toe nails
(ONLY clean and file for NON diabetic)
- d. Finger/toe nails of diabetic or PVD
(clean, file or cut)
- e. Use of pumice stone
- f. Shave client
- g. Oral hygiene
- h. Denture care
- i. Assist with dressing
- j. Apply elastic stockings
- k. Apply ace bandage

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
		I AND II
		I AND II
	X	I
	X	I
	X	I
	X	I
	X	I
		I AND II

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PERSONAL CARE FUNCTIONS

4. TOILETING

- a. Assisting with use of bedpan, urinal, commode, or toilet
- b. Apply, remove adult diapers
- c. Apply condom catheter (Texas, external)
- d. Change bed and/or leg bag of external catheter
- e. Empty bed and/or leg bag of external catheter
- f. Empty bed and/or leg bag of indwelling catheter
- g. Change bed and/or leg bag of indwelling catheter
- h. Assist with daily catheter care (routine perineal care, empty bag, measure output) of external and indwelling catheter
- i. Assist with straight catheterization
- j. Measure and record output

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
	X	I
	X	I
	X	I
		I AND II
	X	I
		I AND II
	X	I

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PERSONAL CARE FUNCTIONS

5. WALKING

- a. Assist with use of durable medical equipment (wheelchair, walker etc.)
- b. Assist inside or outside of home
- c. Use of safety belt during walking

6. TRANSFERRING , POSITIONING AND RANGE OF MOTION

- a. Transfer from bed, chair, wheelchair using proper body mechanics, sliding board or Hoyer (Hydraulic) Lift
- b. Assist to sit or stand from bed, chair, or wheelchair using proper body mechanics, sliding board or Hoyer (Hydraulic) Lift
- c. Position in bed, chair, or wheelchair using proper body mechanics, sliding board or Hoyer (Hydraulic) Lift
- d. Assist in performance of range of motion
 1. Active (client does exercises with coaching, ie. read and count exercises, support joints)
 2. Passive (exercises require another person to move joints)

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
	X	I
	X	I
	X	I
	X	I
		I AND II

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PERSONAL CARE FUNCTIONS

7. USING MEDICAL SUPPLIES AND EQUIPMENT

(such as walkers, wheelchairs, etc.)

- a. Assist with brace, splint and/or sling
- b. Assist with prosthesis
 - 1. Artificial limbs (apply, clean, store)
 - 2. Artificial breasts (apply, clean, store)
 - 3. Hearing aids (including checking and changing batteries, adjusting volume, and assisting with placement in ear)
 - 4. Artificial eye
 - a. Clean and store
 - b. Remove from eye socket
 - c. Clean eye socket
- c. Humidifiers (including adding water, adding tablets to prevent mineral buildup and washing the humidifier)
- d. TENS units (apply or adjust)
- e. Apply restraints

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
	X	I
	X	I
	X	I AND II
	X	I AND II
X	X	
		I AND II
		I AND II

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PERSONAL CARE FUNCTIONS

8. WELL BABY

- a. Bathe infant (sponge or tub)
- b. Bottle feeding (clean bottles, mix formula store formula, feed infant, burp infant)
- c. Solid food feeding
- d. Change diapers
- e. Apply **nonprescription** powder/ lotion only to **unbroken** skin on buttocks
- f. Apply **prescription** powder/lotion to **broken or unbroken** skin on buttocks
- g. Infant nail care
 1. Clean
 2. Trim (only when necessary)
- g. Apply prescription and nonprescription medication to any reddened or open areas

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
	X	I
	X	I
	X	I
		I AND II
	X	I
	X	I
		I AND II

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PERSONAL CARE TASKS AND FUNCTIONS

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This listing indicates the full scope of practice for Level I and II Personal Care Workers. Each worker must demonstrate competency in performing the necessary skills and only perform those skills indicated on the plan of care. All Level I and II PCAs are required to observe, record and report their actions and findings when assisting the client with a specific function, task or procedure. Nursing supervision must assure that the client's needs are appropriately met and that the person providing such personal care services is competently and safely performing the functions and tasks specified in the patient's plan of care.

PERSONAL CARE FUNCTIONS

9. ASSISTING WITH CHANGING A CLEAN DRESSING OF A STABLE WOUND (A "stable wound" is defined as a closed area of skin which MAY be crusted or have a scab. The wound has NO drainage, is NOT infected and is NOT red or swollen. It is the responsibility of the nurse supervisor to determine if a wound meets this criteria.)
- a. Remove old dressing
 - b. Cleanse skin around wound with soap and water
 - c. Apply prescription or nonprescription medication
 - d. Apply new dressing (bandage, gauze)
 - e. Assist with/ apply sterile dressing

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
	X	I
		I AND II
	X	I
		I AND II

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PERSONAL CARE TASKS AND FUNCTIONS

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This listing indicates the full scope of practice for Level I and II Personal Care Workers. Each worker must demonstrate competency in performing the necessary skills and only perform those skills indicated on the plan of care. All Level I and II PCAs are required to observe, record and report their actions and findings when assisting the client with a specific function, task or procedure. Nursing supervision must assure that the client's needs are appropriately met and that the person providing such personal care services is competently and safely performing the functions and tasks specified in the patient's plan of care.

PERSONAL CARE FUNCTIONS

10. **ASSISTING WITH SELF-ADMINISTRATION OF MEDICATION** ("Assisting" includes reminding client when to take medications, reading the label for the client, bringing the medication and any necessary supplies or equipment to the client, opening the container, positioning the client for medication administration, provide appropriate liquids for swallowing medication, store, clean and dispose of used supplies and equipment and store medication properly.)
 ("Self-Administration" means that a client directly swallows, applies, inhales, inserts or injects a medication into his or her own body.)
- a. Oral
 1. Remove proper amount to make available to client
 2. Place medication in client's mouth
 - b. Intramuscular/ Subcutaneous
 1. Draw up or give medication
 2. Dispose of insulin syringes
 3. Dispose of other syringes

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I
		I AND II
		I AND II
	X	I
		I AND II

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PERSONAL CARE TASKS AND FUNCTIONS

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This listing indicates the full scope of practice for level I and II Personal Care Workers. Each worker must demonstrate competency in performing the necessary skills and only perform those skills indicated on the plan of care. All Level I and II PCAs are required to observe, record and report their actions and findings when assisting the client with a specific function, task or procedure. Nursing supervision must assure that the client's needs are appropriately met and that the person providing such personal care services is competently and safely performing the functions and tasks specified in the patient's plan of care.

PERSONAL CARE FUNCTIONS

10. **ASSISTING WITH SELF-ADMINISTRATION OF MEDICATION** ("Assisting" includes reminding client when to take medications, reading the label for the client, bringing the medication and any necessary supplies or equipment to the client, opening the container, positioning the client for medication administration, provide appropriate liquids for swallowing medications, store, clean and dispose of used supplies and equipment and store medication properly.)
 ("Self-Administration" means that a client directly swallows, applies, inhales, inserts or injects a medication into his or her own body.)
- c. Vaginal and Rectal (insert)
 - d. Topical (apply prescription or non-prescription medication to a stable or unstable wound).
 - e. Eye, Ear and Nose (instill)

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
		I AND II
		I AND II
		I AND II

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PERSONAL CARE TASKS AND FUNCTIONS

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This listing indicates the full scope of practice for Level I and II Personal Care Workers. Each worker must demonstrate competency in performing the necessary skills and only perform those skills indicated on the plan of care. All Level I and II PCAs are required to observe, record and report their actions and findings when assisting the client with a specific function, task or procedure. Nursing supervision must assure that the client's needs are appropriately met and that the person providing such personal care services is competently and safely performing the functions and tasks specified in the patient's plan of care.

PERSONAL CARE FUNCTIONS

11. SIMPLE MEASUREMENTS

- a. Weigh client
- b. Temperature, Pulse, Respirations
- c. Blood Pressure
- d. Sugar and Acetone for urine
- e. Glucose test for diabetic

12. SAFETY AND ACCIDENT PREVENTION

- a. Heimlich Maneuver
- b. Artificial Respiration
- c. CPR

PERMISSIBLE LEVEL I	PERMISSIBLE LEVEL II	NONPERMISSIBLE LEVEL I AND/OR II
	X	I I AND II I AND II I AND II I AND II
<p>These are not routine aide level tasks. However, in an emergency situation and in accordance with the employing agency policies, properly trained aides may perform these tasks.</p>		

Appendix E:

About the Center for Disability Rights

The Center for Disability Rights, Inc. (CDR) is a multi-issue advocacy organization working for the full integration and civil rights of people with disabilities. CDR's mission is to improve the lives of people with disabilities through the coordination of systems advocacy activities, public commentary, research and policy analysis, information sharing, support and training for lay advocates, and technical assistance on disability rights issues. The Center, which has no paid staff, utilizes the expertise of its board and general membership.

Coordination of Systems Advocacy Activities

CDR is bringing together advocates from around Rochester and across the state to develop and implement a common agenda of reforms to improve the lives of people with disabilities.

Public Commentary

Through memoranda and commentary, CDR responds to proposed legislation, budgets, and policies affecting people with disabilities. CDR monitors local and state government activities.

Research and Policy Analysis

Detailed research and analysis are pre-requisites to effective advocacy. The Center for Disability Rights produces reports documenting the systematic problems affecting persons with disabilities. CDR recommends changes in legislation and policy to improve the lives of people with disabilities.

Information Sharing

CDR publishes a bi-monthly newsletter to keep its membership up-to-date on issues affecting the disability rights movement. CDR also distributes more frequent alerts on immediate issues affecting the disabled community.

Support and Training for Lay Advocates

CDR offers advice and technical support to people with disabilities interested in systems advocacy and disability rights issues.

Technical Assistance

Using accepted standards and knowledge of disability law, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, CDR provides consulting services and technical assistance to area businesses and agencies to help them develop fully accessible programs and buildings.

Key Accomplishments

CDR is most recognized for its success in making the Downtown Rochester Hyatt Regency Hotel accessible to people with disabilities. For over six months, CDR members attended City Council meetings, wrote letters, met with the Mayor, reviewed the plans, and generated a great deal of news coverage. Our successes include the following:

- We stopped legislation authorizing the City of Rochester to spend nearly \$200,000.00 on accessibility modifications to the poorly-designed hotel. These changes were eventually paid in full by the for-profit developer;
- We convinced the City Administration to enforce the appropriate codes. Due to our efforts the for-profit developer made over \$500,000.00 in accessibility modifications to the Hotel's entrances, public restrooms, restaurant and guest rooms; and
- We raised community awareness of the different standards for accessibility with our **Speaking Out** piece on the editorial page of the Rochester Democrat and Chronicle/Times Union newspapers.

Implementation of the **Americans with Disabilities Act** is a priority for the Center. Unlike many other local agencies, we taught people with disabilities about their newly-won rights. We co-sponsored a forum on the ADA and public transportation and held an educational program on the Employment section of the Act. For professionals, we provided a training session for architects, developers, and building code inspectors on the ADA's impact on New York State Building Code. We continue to provide information and referral for individuals who are concerned about their rights. The Center is currently working with the United Cerebral Palsy Association in order to educate people with disabilities and covered entities about the ADA.

Appendix F:

The Personal Assistance for Independent Living Act of 1989

A DRAFT BILL

To establish a program of
Personal Assistance for Independent Living
for all people with disabilities

Prepared by
The World Institute on Disability

August 1990

SECTION 1. SHORT TITLE

This act may be cited as the "Personal Assistance for Independent Living Act of 1989."

SECTION 2. FINDINGS AND PURPOSES

(a) Findings. Congress finds that --

- (1) The present "system" for delivering personal assistance services is fragmented among different funding sources and different sets of administering and regulatory agencies, inefficient, overly regulated, burdensome to providers and recipients, inequitably distributed among the states, and inappropriately structured to meet the PAS needs of the nation.
- (2) Personal assistance services complement other Congressional efforts aimed at increasing financial and personal independence for disabled people.

- (3) Establishment of a uniform national program of personal assistance is necessary in order to --
 - (A) correct the enormous inequities that currently exist in the provision of personal assistance services across the United States.
 - (B) ensure that every individual who needs personal assistance services receives the full range of services which he or she needs in order to live independently in comfort and safety.
 - (C) ensure that personal assistance services are provided in a manner which best suits each individual's needs, abilities, and circumstances.

b) Purpose. --It is the purpose of this Act--

- (1) to establish a program of personal assistance for people of all ages who have one or more functional limitations in order to promote their ability to live independently and assure quality of service by either:
 - (A) Requiring state to coordinate all existing PAS programs so that there exists a single point of entry for potential PAS recipients and to modify programs as necessary to conform with the standards described below:or
 - (B) Requiring state to create a new program of PAS (or consolidate existing programs) with a single administration which would have a single point of entry for all potential PAS recipients and would conform with the standards described below.
- (2) to make a wide range of service options available and that choices among these options be made on basis of an individual's needs and desires, since people vary widely in their abilities and circumstances.

SECTION 3. The following definitions shall govern the construction of this Bill:

- (a) "Functional impairment" means a temporary or permanent disability (resulting from injury or sudden trauma, aging, disease, or a congenital condition) which limits a person's ability to perform one or more activities of daily living, including, but not limited to, dressing, bathing, grooming, getting around both inside and outside the home, eating, preparing meals, shopping, cleaning house, communicating, and performing cognitive tasks such as solving problems and processing information.
- (b) "Personal assistance services" means the following services furnished by a personal assistant,
 - (1) PERSONAL SERVICES, including, but not limited to, assistance with bathing and personal hygiene, bowel and bladder care (including catheterization), dressing and grooming, transferring, feeding, giving medications and injections, menstrual care and operating and maintaining respiratory equipment and other assistive devices.
 - (2) HOUSEHOLD SERVICES, including, but not limited to, assistance with meal preparation, shopping, cleaning, laundry, heavy cleaning, repairs and maintenance;
 - (3) CHILD AND INFANT CARE ASSISTANCE for disabled parents;
 - (4) COGNITIVE SERVICES, including, but not limited to, assistance with money management, planning and decision making;
 - (5) COMMUNICATION SERVICES including, but not limited to, interpreting, reading, letter writing;
 - (6) SECURITY-ENHANCING SERVICES, including, but not limited to, monitoring alarms and making or arranging for periodic contact in person and/or by telephone;
 - (7) MOBILITY SERVICES IN AND OUT OF HOME, including, but not limited to, escort and driving;

- (C) "Countable income" means the income remaining after all disability-related expenditures, including, but not limited to, purchase and repair of durable medical equipment and assistive devices, disability-related medical and dietary expenses, therapeutic services and special transportation devices and services, have been deducted from the individual or family net income.
- (D) "Personal Assistance Services Registry" means a brokerage mechanism which makes information about people needing personal assistance services, and individuals and organizations desiring to provide such services, available to each other.

SECTION 4. State Plan

- (a) By (DATE), each State shall prepare and submit to the Secretary of Health and Human Services a state plan for a program providing personal assistance services which complies with the provisions of this section and Sections 5, 6, 7 and 8 below. Each plan shall--
 - (1) designate a single agency as being primarily responsible for the administration and coordination of all programs in the state which provide personal assistance services;
 - (2) specify a single point of entry and intake procedure to be used by all applicants for personal assistance services, regardless of the programs(s) and/or funding source(s) for which they are eligible;
 - (3) describe the mechanisms--
 - (A) to be used to provide adequate and appropriate personal assistance, assessment, training, referral, quality assurance and management services equitably throughout the state;

- (B) for ensuring that persons who use personal assistance services have a substantial role in developing the State plan;
- (4) provide assurances that--
- (A) the needs assessment process and service delivery mechanisms are such that applicants for and recipients of services are, to the maximum extent possible, treated uniformly throughout the state, and that variations are permitted only to the extent necessary to accommodate differences in local conditions;
 - (B) a management information system for the program is established and collects, at a minimum, such data as the Secretary shall prescribe; and
 - (C) people with disabilities are employed at all management levels of the program, and that there is an affirmative action plan for the recruitment, employment, and promotion of persons with disabilities.
 - (D) an advisory board, a majority of whose members are recipients of services under the program, is established on a permanent basis. Within days after submittal of a State plan, the Secretary shall either approve it or specify what changes are necessary in order to obtain approval.
- (b) Each state shall specify whether implementation of the plan will be achieved by;
- (1) coordinating existing programs;
 - (2) consolidating existing programs;
 - (3) establishing a new program; or
 - (4) a combination of the above.

- (c) Each state shall put the program into operation, as set forth in its State plan, within one year after submitting the plan to the Secretary

SECTION 5: RANGE OF SERVICES REQUIRED. --Every state shall establish a system which has the following components:

- (a) NEEDS ASSESSMENT AND SERVICE PLANNING shall be the responsibility of a government or non-profit agency (which does not provide personal assistance services) designated in each locality by the state. This agency shall --
 - (1) Perform assessments of prospective or current recipients (relying on those individuals' or their agents' - self-assessments to the maximum extent possible) in order to determine;
 - (A) their eligibility for services;
 - (B) the extent to which they are able to perform each activity of daily living;
 - (C) the extent to which they will be capable of managing their own personal assistance services; and
 - (D) if there are special circumstances which affect their need for personal assistance;
 - (2) Work with each recipient (or his or her legal agent) to prepare a mutually agreed upon written Individual Service Plan for that recipient using the information from the assessment. The Individual Service Plan shall specify--
 - (A) the number of hours and types of service needed;
 - (B) the number of hours and types of service to be provided by the program;
 - (C) the number of hours and types of service to be provided by alternate resources;

- (D) the number of hours and types of service that will not be provided (i.e., the unmet need);
 - (E) whether or not the recipient is capable and desirous of exercising total responsibility for services and, if not, whether the recipient can acquire the necessary management skills through training pursuant to Section 5(c)(3)(E) below; or whether management assistance will be provided by an outside agency pursuant to Section 5(c)(2) below;
 - (F) whether the services will be provided by individual providers or (in cases where a recipient is not capable or desirous of exercising total responsibility for managing her or his own personal assistance services) agency employees;
- (3) Give full consideration to the opinions and desires of the recipient or his or her representative during the assessment process and preparation of the Individual Service Plan.
- (b) DIRECT SERVICES shall include all of the services listed in SECTION 3 above. These services shall be available--
- (1) 24 hours a day, seven days a week in every locality;
 - (2) from a range of types of service providers including
 - (A) individual providers, including family members, employed and supervised by a recipient; and
 - (B) workers who are employed and supervised by a private or public agency; and
 - (3) on a visiting or live-in basis;
 - (4) on a respite, emergency or short-term basis; and
 - (5) in a recipient's place of residence, in educational, employment or recreational settings, and during travel.

(c) ANCILLARY SERVICES shall include--

(1) SCREENING, REFERRAL AND OUTREACH SERVICES--

- (A) Each state shall contract with Independent Living Centers, Senior Programs, Community Colleges or other organizations to screen individuals and organizations desiring to provide personal assistance services, to establish and maintain personal assistance services registries, and to conduct outreach efforts to inform potential recipients of the services available.
- (B) The nature of the screening process and the types of information contained in the listings maintained by their personal assistance services registries shall be as specified by the Secretary.
- (C) The agency shall develop effective outreach centers, area agencies on aging, rehabilitation centers, hospitals, discharge planners, and others, not only to inform people with disabilities of the availability of the services, but also of benefits that can be derived from receiving personal assistance services, the management training and assistance programs available and the options recipients have to chose the types of services, hours and times of service, types of provider, and degree of recipient control.
- (D) There shall be a minimum of one screening, referral and outreach service in each city of _____ population or more, and a minimum of one per county in rural areas.
- (E) Everyone in the state who has a functional limitation and needs the assistance of another person to perform any of the tasks listed in Section 3(b) above may receive referral services at no charge.

- (2) MANAGEMENT ASSISTANCE to the recipient or his or her family in all aspects of managing personal assistance services including--
 - (A) recruitment,
 - (B) screening,
 - (C) interviewing,
 - (D) hiring,
 - (E) training,
 - (F) supervision,
 - (G) payment,
 - (H) termination,
 - (I) case management,
 - (J) self-advocacy, including self-protection and abuse reporting procedures.

- (3) TRAINING--
 - (A) Each state shall contract with Independent Living Centers, Senior Programs, Community Colleges or other organizations to provide training for recipients, families and personal assistants.
 - (B) There shall be a minimum of one training program in each city of ____ population or more, and a minimum of one per county in rural areas.
 - (C) Requirements pertaining to training personal assistants shall be as follows:
 - (i) formal training programs--
 - (I) shall be guided by the principles of the independent living movement

and shall involve substantial participation by recipients;

(II) shall include, but not be limited to, training in--

(a) hygiene;

(b) infectious diseases;

(c) first aid and CPR;

(d) body mechanics and lifting techniques;

(e) rights of disabled people to autonomy and self-determination;

(f) rights of penalties pertaining to abuse of recipients; and

(III) may include training in--

(a) methods of delivering personal, household, child and infant care, cognitive, security and communication assistance; and

(b) training for those assisting people with mental, intellectual, or brain injury-related disabilities, children and people with AIDS.

(ii) Personal assistants who are employed and/or supervised by public or private agencies shall complete a training course satisfying the requirements of (i) above.

(iii) Individual providers shall undergo formal training to the extent desired by their respective individual employers/recipients.

- (D) A training manual shall be developed and produced with the involvement of qualified recipients and providers and shall be used as the basis for all formal training conducted pursuant to this section. This manual shall cover the topics set forth in (C) above and shall be made available to recipients who desire to train their own personal assistants in whole or in part.
- (E) Training in the topics specified in Section 5(c)(2) above (relating to management) and Section 5(c)(3)(C)(i) (relating to personal assistance) shall be made available to recipients and their representatives at their option.

(4) SUPPORT SERVICES AND DEVICES--

- (A) The personal assistance program may award to a recipient a one-time grant of assistance of not more than \$3,600.00 for architectural renovation, other capital expenditure or purchase of special equipment to improve or facilitate services to and general living conditions or access of a person with a disability.
- (B) A maintenance stipend of up to \$500.00 per year shall be granted to recipients of equipment grants.
- (C) Any money received under this section shall be exempt from federal income tax.

SECTION 6.

ELIGIBILITY. Those eligible for services shall be any person, regardless of age and employment status, who:

- (a) has a functional limitation as defined in section 3(a) above, including, but not limited to, people with a --
 - (1) physical disability;
 - (2) brain injury;
 - (3) mental or psychiatric disability;

- (4) intellectual or cognitive disability or mental retardation;
 - (5) hearing disability;
 - (6) visual disability;
 - (7) infectious or progressive terminal disease;
 - (8) uncontrolled seizure disorder;
 - (9) communication disorder; and
- (b) has a countable income below the qualifying level or contributes a share of the cost of personal assistance services according to a sliding fee scale.

SECTION 7. PROVIDER WAGES AND BENEFITS --

- (a) The starting wage for personal assistants, including family members, shall begin at the Prevailing Community Wage Rate (PCWR) for positions with comparable duties and responsibilities, as established by the Department of Labor. PCWRs should be updated at least annually and compensation shall include health insurance. There should also be periodic increases to reflect growth in experience and qualifications.
- (b) Benefits for personal assistants shall include paid sick leave, vacation, group health insurance, workers' compensation, social security and unemployment benefits;

SECTION 8. QUALITY ASSURANCE MECHANISMS ---

- (a) A Personal Assistance Recipient's Bill of Rights shall be promulgated which shall recognize the following as rights of personal assistance recipients and which may be asserted by the recipient or his or her representative:
- (1) To receive courtesy, respect and full recognition of one's dignity as an individual capable of knowing one's needs, making decisions, managing the assistance one needs, and controlling one's household and lifestyle to the fullest extent possible and desired.
 - (2) To receive assistance from individuals who are properly trained and competent to perform their duties.

- (3) To receive services in compliance with all State and local laws and regulations without discrimination in the provision or quality of services based on race, religion, gender, age, creed or disability.
- (4) To be free from mental and physical abuse, neglect, and exploitation.
- (5) To confidentiality and privacy while receiving services regarding communications, personal thoughts, values, beliefs, relationships, activities, and personal and financial records.
- (6) To security for one's living quarters, personal possessions, food, medication and financial assets.
- (7) To have the option to interview, screen and select the type and adequate number of assistants needed.
 - (7.1) To have the option to elect and assign the specific duties with which assistance is needed.
 - (7.2) To have the option to train assistants in using methods which are safe, efficient and which the consumer prefers.
 - (7.3) To schedule assistants around a time structure that enables educational, career, leisure and other timely responsibilities of the full life the consumer chooses.
 - (7.4) To maintain quality and dependability of assistance received.
 - (7.5) To live life to its fullest in the manner and degree of social mainstream and independence one chooses.
 - (7.6) To fire and replace assistants who do not respect the rights of the recipient.
- (8) To exercise fully one's civil and due process rights and to be assisted in doing so when assistance is needed.
- (9) To receive all decisions regarding eligibility and amount and kind of services and the reasons therefore in

writing, in language understandable to the recipient, along with the fair hearing procedure.

- (10) To receive promptly written notice, in language understandable to the recipient, of reductions, terminations, or other significant changes in services, along with assistance to assure a smooth transition in services consistent with the recipient's welfare, and along with the fair hearing procedure.
 - (11) To avail one's self of an appeals process through which disputes regarding eligibility determinations, needs assessment, or service provision can be resolved through impartial hearings.
 - (12) To receive written information, in language understandable to the recipient, on the quality and type of services recipients can expect, appeals procedures, and recipient rights;
 - (13) To have as few personal assistants entering one's home as possible.
 - (14) To not be placed in a nursing home or other institution unless a finding has been made that one cannot live at home even with personal assistance.
- (b) Recipients shall participate in the program evaluation process as well as in administration, management and policy development.
 - (c) Public, private and government agency administrators and staff shall receive training regarding independent living and personal assistance, with qualified personal assistance recipients playing a significant role in the training.
 - (d) Programs shall be developed to enhance the provider-recipient relationship.
 - (e) There shall be strong penalties for abuse.

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