

Attendant Care
and its Effects on
Consumers' Lifestyle Choices

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Attendant Care and its Effects on Consumers' Lifestyle Choices

Abstract

The purpose of this white paper is to explore the attendant care system in Pennsylvania and measure its effects on lifestyle choices for consumers who use these services. This paper contains an overview of Pennsylvania's attendant care system. Additionally, current advocacy efforts geared to increase the availability and improve the quality of attendant care will also be discussed.

To measure the effects of attendant care on consumers' lifestyle choices, approximately 750 attendant care satisfaction surveys were mailed to consumers who receive these services. Analysis of the data collected from the returned surveys will also be included in this paper.

This paper will conclude with observations based on the analyzed data and recommendations on how to improve the attendant care system that would benefit consumers who use these valuable services.

Overview of Attendant Care Services in Pennsylvania

This white paper is being written from the perspective of the Independent Living (IL) philosophy. IL promotes self-determination, equal rights and access for all persons with disabilities. Any type of institutionalization, segregation or confinement is vehemently opposed by this philosophy. Unlike a "medical-model" view on disability, IL does not see people with disabilities as sick patients who need healing. Rather, we are consumers who have the right to take control and make choices about our own lives.

People with disabilities having access to community-based, consumer-oriented attendant care is essential to the IL philosophy. The amount and type of services received should be based on a consumer's functional needs, not diagnosis of disability. Likewise, a consumer should be able to choose the services that are available to him/her. This gives the consumer more control over the attendant care services and ultimately, more control over his/her own life.

Attendant Care and its Purposes

Attendant care is a type of long-term care, community-based service that assists persons with disabilities who need significant help with *Activities of Daily Living* (ADLs). ADLs are bathing, dressing and eating. The person providing this service is called an attendant. Attendants are often unskilled workers who perform medical and non-medical tasks for the consumers who employ them.

Attendant care can be given any time of the day or night. It commonly occurs in the consumer's home, but the service can also be in other places like the workplace or school if needed by the consumer.

One of the main purposes of attendant care is to offer an alternative to institutionalization for people with disabilities. With attendant care services, a consumer can live in any community he/she chooses and actively participate in it.

Another purpose of attendant care is that a consumer using it is less dependent on family and friends for daily activities. This eliminates the stress and strain on a relationship when one person is dependent on a loved one to function. Also, having attendant care allows for a level of privacy that a consumer may want to have between his/her family and friends.

The impact of attendant care on consumers' quality of life

The preliminary research shows that attendant care services have a positive impact on consumers' quality of life. In other words, consumers are able to participate in activities and contribute to society with the assistance of attendant care.

The following is a list of activities identified by the preliminary research that consumers are able to do because of attendant care:

- Go to work and travel for work.
- Go to school.
- Go shopping, and
- Go to cultural events

Having attendant care services also has a positive impact on a consumer's health and living environment.

The following is a list of examples identified by the preliminary research of how attendant care impacts consumers' health and living environment.

No institutions or other confined settings
No bedsores or infections.
Good personal hygiene.
Live in a clean environment, and
Easier for consumer when attendant does the cooking.

Tasks performed by attendants

The following is a list of non-medical tasks typically performed by attendants:

- bathing and hygiene
- dressing and grooming
- wheelchair transfers
- meal prep, eating and clean-up
- travel
- housekeeping, laundry
- shopping
- errands

The non-medical tasks are not limited to the above list.

The following is a list of medical tasks typically performed by attendants:

- bowel and bladder routine
- G-tube feeding
- decubitus care
- trachea cleaning
- pill administration

The medical tasks are not limited to the above list.

Paying for attendant care in Pennsylvania

The following points support the claim that there is an "institutional bias" when it comes to paying for long-term care.

- 75% of Medicaid's long-term care funds go to institutions, while only 25% go to community-based services.
- Every state's Medicaid program provides for institutional services like nursing homes, while paying for community-based services is only optional.

Medicaid Waivers

To overcome this bias, the federal government's Department of Health and Human Services "waives" its Medicaid requirements so that states can fund alternatives to institutions for low or medium income individuals with disabilities. This is called a "Medicaid Waiver". A Medicaid Waiver is a diversion of services not usually covered by Medicaid. They are paid for by a combination of state and federal monies. The state and federal government contribute 40 and 60 cents respectively for every dollar spent on a waiver.

In Pennsylvania, consumers who have Medicaid get attendant care services for free because they are eligible for Pennsylvania's Attendant Care Waiver. The Department of Public Welfare, Office of Social Program administers the Attendant Care Waiver.

Consumers who do not have Medicaid are charged a weekly fee to pay for attendant care services. Their income and other financial resources are used to determine the fee.

Office of Vocational Rehabilitation

Another source of funding for attendant care is the Office of Vocational Rehabilitation (OVR). OVR will pay for an attendant to do *only* job-related tasks for the consumer.

It should be emphasized, however, that OVR has strict rules and guidelines for sponsoring attendant care services at work. For example, OVR requires that the consumer's employer pay for much of the attendant care costs. Aggressive advocacy by the consumer and his/her advocates may be needed before OVR will pay for these services.

Attendant Care Waiver eligibility

The following is a list of eligibility requirements to receive attendant care services through Pennsylvania's Attendant Care Waiver:

- Physical impairment that is expected to last not less than 12 months.
- Eligible for nursing facility services
- Cannot perform ADLs independently.
- Between ages of 18 and 59.
- Mentally alert
- Able to hire, supervise and fire attendants
- Able to manage legal and financial matters.

Consumer can hire anyone he/she wants (other than close family members) to work as an attendant.

An agency or other third party doesn't interfere with service schedules. This makes services schedules less regimented and the consumer is free to have services whenever he/she wants it as long as the attendant is agreeable.

Since a consumer can hire as many attendants as he/she wants, he/she has more back-up attendants when needed, and

Attendant does not have to follow an agency's rules and regulations regarding which tasks can be performed for the consumer. The attendant and consumer agree upon the tasks performed without an agency's interference.

Negative aspects of consumer-option model

The following are negative aspects of the consumer-option model identified by the preliminary research:

Difficult for a consumer to find people interested in working as attendants especially when the following is true:

Social isolation – when a consumer doesn't have a network of people he/she can asked to work as attendants or refer him/her to potential attendants, and

Geographic isolation – when consumer lives in an area where there are few people who are interested in working as attendants.

No quality assurance from an agency.

No agency to mediate between a consumer and attendant when there is a problem, and

Attendant not understanding that the consumer is the only employer. Attendants sometimes think that the payroll agent employs them.

Agency-option model

The following are the main features of the agency-option model:

Agency employs attendant.

Agency assigns an attendant to work for a consumer.

Consumer negotiates service schedules with agency.

Attendant receives some general training before being assigned to a consumer, and

Agency pays attendant directly.

Positive aspects of agency-option model

The following are positive aspects of the agency-option model identified by the preliminary research:

Agency provides back-up attendant when regular attendant can't work.

The process of recruiting, interviewing and hiring attendants is eliminated for consumer, and

When there is a problem between a consumer and attendant, they can ask the agency for intervention to help solve the problem.

Negative aspects of agency-option model

The following are negative aspects of the agency-option model identified by the preliminary research:

Agency and their attendants may have preconceived, medical notions about the consumer and/or having a disability in general. Agency's policies may reflect a "medical model" view on disability.

Attendant must abide by agency's rules and regulations, so the attendant is limited in what tasks he/she can perform for the consumer.

In most cases, the consumer can't choose the attendant the agency is assigning them.

To have a service schedule changed or cancelled, consumer must inform agency. The agency will tell the attendant about the change. A consumer cannot clear it with his/her attendant directly.

Agency personnel doesn't always respond to consumers' phone calls in a timely manner or the consumer gets no response at all.

Agency doesn't always tell consumer the time services have been scheduled or may not schedule services when the consumer wants them.

Agency doesn't always fire untrustworthy attendants. Agency may just assign them to a different consumer, and

Agency doesn't always reprimand attendants who act irresponsibly.

Common problems with attendant care

Although there are consumers who are very satisfied with their attendant care services and have had the same attendants for years - even decades - there are still some common problems with the attendant care system that span both the consumer-option and agency-option models. These problems effect the lifestyle choices of consumers because they limit the effectiveness of attendant care.

The preliminary research has identified 4 main categories of attendant care problems. They are as follows:

1. Attendant's wages and benefits
2. Attendant's personal and professional characteristics
3. Attendant care back-up system, and
4. Consumer passiveness

Attendant's wages and benefits

Attendants are often paid low wages, get few or no benefits and receive no sick or vacation leave.

The following is a list of results identified by the preliminary research that come from attendants not being paid adequately:

Attendant care workforce is unstable; high turnover.
Doesn't attract good workers.
Difficult to find people willing to work as attendants, and
No financial incentive to do good work.

Attendant's personal and professional characteristics

Even though there are many good attendants who are responsible and professional workers, there are still others who have personal and professional characteristics that prevent a consumer's attendant care services from running successfully.

The following is a list of attendants' characteristics – both personal and profession – identified by the preliminary research that are problematic to the attendant care system:

Immature and irresponsible
Poor work ethic
Don't clean consumer's living area properly.
Don't understand the needs of the disabled; insensitive
Dishonest; attendant steals money and possessions.
Health problems; attendant not able to fulfill duties because of his/her poor health.
Takes away control from the consumer by doing the following:
 Provides services when the attendant wants to, not at the time when the consumer wants services, and
 Does only the tasks the attendant wants to do, not doing the tasks the consumer wants the attendant to do.
Can't read at a functional level

Attendant care back-up system

When an attendant calls out or does not show up at all, a consumer's lifestyle choices may be effected.

The following is a list of circumstances identified by the preliminary research that may occur for a consumer when his/her attendant is absent:

Rearrange schedule for that day.
Cancel plans for that day.

Not use bathroom for a long period of time, and
Sleep in wheelchair all night

There are numerous ways in which a consumer can cope with an absent attendant. A consumer using the consumer-option model can ask another attendant to fill-in that day. A consumer using the agency-option model may rely on the agency to send them a back-up attendant. However, there is no guarantee that the agency will send an attendant in a timely manner. If these back-up systems fail, a consumer may handle this situation by having a family member, a friend or a neighbor assist that day.

Consumer passiveness

There are many consumers who are quite comfortable with explaining their individual needs to their attendants. However, there are some consumers who have difficulty establishing themselves as their attendants' employer.

The following is a list of reasons identified by the preliminary research why a consumer may not assert him/herself with an attendant:

- Attendant is being paid a low wage.
- Attendant intimidates consumer.
- Friendship develops between consumer and attendant.
- Consumer doesn't want to be seen as being difficult, and
- Consumer believes that he/she is helpless and unable to take control of his/her life.

Advocacy efforts to improve availability of attendant care

All across the nation, there is a push by the disability community for a national attendant care program that would provide attendant care services in areas where they are lacking or non-existent. Part of this effort is a bill in the United States Congress that proposes a national attendant care program that is consumer-directed and community-based. This bill is known as MiCassa which stands for Medicaid Community-based Attendant Services and Supports Act of 2003 (S. 971/HR. 2032).

Making attendant care services available to every American with a disability is the primary goal of MiCassa. Under this legislation, a consumer eligible for various types of institutions can choose community-based services as an alternative to institutionalization. Attendant care services would be provided in the most integrated setting appropriate to the consumer's needs. Services and their delivery models would be selected and controlled by the consumer receiving them. Back-up and emergency attendant care services would be offered. Additionally, costs for a consumer transitioning out of an institution would also be covered under MiCassa.

MiCassa was drafted by Americans Disabled for Attendant Programs Today (ADAPT), a national group that focuses on rights for people with disabilities using advocacy and activism. Senators Arlen Specter of Pennsylvania and Tom Harkin of Iowa introduced MiCassa, a bill that receives bipartisan support.

As stated earlier, every state’s Medicaid program provides for institutional services like nursing home care, while paying for community-based services is only optional. Moreover, only 25% of Medicaid long-term care dollars are spent on community-based services while 75% goes to institutions.

MiCassa eliminates this institutional bias by redirecting 25% of what Medicaid currently spends on institutional care to attendant care programs.

In the long run, MiCassa will be more cost effective than institutional care, as not all persons with disabilities require the round-the-clock care that an institution provides. Paying for just a few hours of attendant care a day is cheaper than paying for 24 hours of care.

Another benefit of MiCassa is that people who would normally be the recipients of government programs, like Supplemental Security Insurance (SSI) or Social Security Disability Insurance (SSDI), would be able to become taxpayers because they will have the supports and services needed to be educated and achieve gainful employment.

Methodology

To research the effects of attendant care on consumers’ lifestyles choices, the following process was conducted:

Stage	Description
1	Search the Internet for information on the attendant care system in Pennsylvania.
2	Interview the following individuals about the attendant care system and its effects on consumers’ lifestyle choices: Consumers with attendant care services in Southeast Pennsylvania, and Professionals employed by an Independent Living Center who have daily contact with consumers who have attendant care.
3	Develop attendant care satisfaction survey (and its cover letter) based on information gathered in the first 2 stages, the preliminary research stages.
4	Mail survey to consumers who receive attendant care services from an Independent Living Center in Southeast Pennsylvania.
5	Captured data from returned surveys.
6	Analyze data from returned surveys.

