

Attendant Care  
and its Effects on  
Consumers' Lifestyle Choices

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# **Attendant Care and its Effects on Consumers' Lifestyle Choices**

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# Attendant Care and its Effects on Consumers' Lifestyle Choices

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## **Abstract**

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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.

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## **Overview of Attendant Care Services in Pennsylvania**

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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.

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## **Attendant Care and its Purposes**

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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.

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## **The impact of attendant care on consumers' quality of life**

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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.

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### **Tasks performed by attendants**

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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.

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### **Paying for attendant care in Pennsylvania**

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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.

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### **Attendant Care Waiver eligibility**

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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.

- Income does not exceed 300% of federal poverty level.
- Financial resources under \$2,000, and
- Pennsylvania residence

For a consumer who does not meet the “mentally alert” requirement because of a cognitive disability, there are additional waivers that provide for *Daily Living Services*, which are services similar to attendant care.

The following is a list of some of the waivers in Pennsylvania that offer Daily Living Services, but do not have the mentally alert requirement.

OBRA Waiver

Independence Waiver

Michael Dallas Waiver (offers attendant care services to consumers who use technology to sustain life)

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## **Service delivery models**

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In Pennsylvania, a consumer can receive attendant care services under two different methods. These methods are called *service delivery models*. They are as follows:

1. Consumer-option model, and
2. Agency-option model

Each model has a distinct manner in which they administer attendant care services. Since both models have positive and negative aspects, a consumer is able to consider each one and choose under which model he/she would like to receive services. A consumer can also switch models at any time or receive services using a combination of both models.

### **Consumer-option model**

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

- Consumer employs attendant exclusively.
- Consumer interviews, hires, trains and fires attendants.
- Consumer can hire as many attendants as needed.
- Service schedules are negotiated between consumer and attendant, and
- Consumer receives attendants' paychecks from a third party payroll agent and then gives it to the attendants.

### ***Positive aspects of consumer-option model***

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

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.

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### **Common problems with attendant care**

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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.

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### **Advocacy efforts to improve availability of attendant care**

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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.

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## Methodology

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

<b>Stage</b>	<b>Description</b>
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.

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## The Survey

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The following is the attendant care satisfaction survey that was mailed to consumers:

### *Attendant Care Satisfaction Survey*

Directions: Read each of the following statements carefully. Then, using the scale below, circle the number that best describes your response to each statement.

- 1 = strongly disagree
- 2 = disagree
- 3 = neutral
- 4 = agree
- 5 = strongly agree

This survey will take about 10 minutes to complete. Thank you for participating in this process to help make services better.

1. Many of my attendants treat me like I'm a sick person who has no life.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2. My attendant care services are not meeting my individual needs.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. Having attendant care services does not give me more control over my life.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. My attendant care services do not help me be a contributing member to society.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

| Disagree | | | | Agree |

5. I can only get attendant care services in my apartment or home.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

6. I am not getting enough service hours.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

7. I do not ask for more service hours when I need them.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

8. I do not feel comfortable explaining my individual needs to my attendants.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

9. My attendants do not properly wash, bathe or groom me.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

10. My attendants do not properly clean my apartment or house.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

11. I sometimes go hungry, even though my attendants are supposed to feed me.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

12. When an attendant is late or calls out, it ruins my plans for that day.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

13. Many of my attendants are irresponsible people who don't care about doing a good job.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

14. I do not trust many of my attendants with my money and possessions.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Directions. If you use the Consumer Option model for attendant care, then answer statements 15-20. If you use Agency Option, then answer statements 21-26. If you have both Consumer

Option and Agency Option, then answer questions 15-26. If you don't know which model you have, then you have finished the survey.

### Consumer Option Questions

15. It's not easy to find good people to hire as Consumer Option attendants.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

16. My Consumer Option attendants and I have problems agreeing on the times services should be scheduled.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

17. My Consumer Option attendants and I have a hard time handling problems because there is nobody who can help us with them.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

18. When a Consumer Option attendant calls out or doesn't show up for work, I don't know how to handle it.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

19. There are times when my Consumer Option attendants do not perform the tasks I need them to do.

1	2	3	4	5
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Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
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20. Many of the consumer-option attendants don't understand that I'm their boss, not someone else.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

**If you only have the Consumer Option service – please stop here. You are done with the survey.**

### Agency Option Questions

21. The agency does not send good people to work as attendants.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

22. The agency does not schedule my service when I want it.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

23. The agency does not help me with any problems I have with my agency-option attendants.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

24. The agency does not quickly send a replacement attendant when my regular attendant calls out or doesn't show up for work.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

25. Due to the agency's rules, there are times when my agency-option attendants don't perform the tasks I need them to do.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

26. The agency does not consider my specific, individual needs when planning my services.

1	2	3	4	5
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

**If you use the Agency Option service – please stop here. You are done with the survey.**

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**Survey statements**

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The survey is comprised of 26 statements, not questions. Each statement is about a particular attendant care issue that a consumer may find problematic. These issues were identified during the preliminary research stages as being possible areas of concern with the attendant care system.

Statements 1-14 are general statements that can be applied to consumers who use either the consumer-option model or the agency-option model. Statements 15-20 are about specific issues that pertain only to the consumer-option model. Statements 21-26 are about specific issues that pertain only to the agency-option model.

Presumably, all consumers participating in this survey will respond to statements 1-14. Consumers receiving attendant care services through the consumer-option model will respond to statements 15-20, and not respond to statements 21-26. Consumers receiving attendant care services through the agency-option model will respond to statements 21-26, and not respond to statements 15-20. Consumers receiving attendant care services through a combination of both models will respond to statements 15-26. Consumers who don't know which model they use will not respond to statements 15-26.

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## **Response scores**

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*Response scores* are the numbers consumers have to choose from to describe their response to a statement. The following is the response score scale:

- 1 = strongly disagree
- 2 = disagree
- 3 = neutral
- 4 = agree
- 5 = strongly agree

Theoretically, the less a consumer agrees with a statement, the lower his/her response score will be for that statement. The more a consumer agrees with a statement, the higher his/her response score will be for that statement.

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## **Discussion**

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Approximately 750 attendant care satisfaction surveys were mailed to consumers in Southeastern Pennsylvania who receive attendant care services through an Independent Living Center. Cover letters were mailed with the surveys assuring consumers that their responses

would be kept strictly confidential. They were also told that answering the survey was voluntary and choosing to participate or not to participate would have no effect on their services. Consumers were given 2 to 3 weeks to return the surveys.

The Workplace Technology Foundation received 115 returned surveys from consumers. Not all of the returned surveys were completed as some consumers may have chosen not to respond to certain statements or did not realize that they skipped some statements.

For analysis purposes, the consumers who returned surveys were divided into 4 groups according to which statements they responded to regarding the service delivery models (Statements 15-26). The following are these 4 groups along with how many consumers were placed into each group:

1. Consumer-option only group (45 consumers)
2. Agency-option only group (27 consumers)
3. Both models group (28 consumers)
4. No specification group (15 consumers)

#### *Grouping definitions*

1. Consumer-option only group – consumers who responded to statements relating to the consumer-option model (statements 15-20).
2. Agency-option only group – consumers who responded to statements relating to the agency-option model (statements 21-26).
3. Both models group – consumers who responded to statements relating to both models (statements 15-26).
4. No specification group - consumers who didn't respond to any statements relating to either model.

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## Results

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To analyze the data collected from the returned surveys, an **overall average response score** - an average response score that encompasses *all* the data for a particular statement - was calculated for each statement. In addition to an overall response score, **average group response scores** – an average response score that encompasses *only* the data from a particular group for a particular statement – were calculated for each statement.

The following is a table displaying the overall average response scores for each statement as well as the average group response scores.

The following is the response score scale:

1 = strongly disagree  
 2 = disagree  
 3 = neutral  
 4 = agree  
 5 = strongly agree

STATEMENT #	OVERALL	CONSUMER-OPTION ONLY	AGENCY-OPTION ONLY	BOTH MODELS	NO MODEL SPECIFIED
1	1.8	1.7	1.7	2	1.7
2	2	1.9	1.9	2.3	1.7
3	1.9	1.8	1.7	2.1	1.8
4	1.9	1.9	1.7	2	2
5	2.5	2.5	2.4	2.5	2.8
6	2.7	2.4	2.6	3	2.8
7	2.4	2.3	2.2	2.3	3.1
8	1.9	1.8	2	2	1.9
9	1.8	1.9	1.7	2	1.2
10	2.3	2.2	2.5	2.5	1.7
11	1.4	1.5	1.3	1.6	1.3
12	3	2.8	3	3.2	3
13	1.9	1.9	1.7	2.3	1.9
14	2.2	2.3	2.1	2.3	1.7
15	3.5	3.4		3.6	
16	2.2	2.1		2.5	
17	2.1	2		2.4	
18	2.3	2		2.6	
19	2.3	2.1		2.7	
20	2.6	2.4		2.9	
21	2.4		1.9	2.8	
22	2.3		1.8	2.9	
23	2.3		1.8	2.7	
24	3		2.9	3	
25	2.8		2.5	3	
26	2.4		2.1	2.7	

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**Average response scores analysis: High average response scores**

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To identify areas of concern with current attendant care services as indicated by the returned surveys, the survey's statements and their average response scores must be examined. A high

average response score for a statement suggests that consumers are saying that the statement's issue is more problematic to the attendant care system.

The following is a table displaying the highest overall average response score, the highest average group response scores and their statement numbers.

<b>Group</b>	<b>Statement Number</b>	<b>Highest average response score</b>
Overall	Statement #15	3.5
Consumer-option only	Statement #15	3.4
Agency-option only	Statement #12	3
Both models	Statement #15	3.6
No specification	Statement #7	3.1

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Statement #15 is about finding good people to be hired as consumer-option attendants.

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Statement #12 is about when an attendant is late or calls out, it ruins the consumer's plans for that day.

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Statement #7 is about the consumer not asking for more service hours when he/she needs them.

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### **Average response score analysis: low average response score**

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To identify the positive aspects of the attendant care system as indicated by the returned surveys, the survey's statements and their average response scores must again be examined. A low average response score for a statement suggests that consumers are saying the statement's issue is less problematic to the attendant care system.

The following is a table displaying the lowest overall average response score, the lowest average group response scores and their statement numbers.

<b>Group</b>	<b>Statement Number</b>	<b>Lowest average response score</b>
Overall	Statement #11	1.4
Consumer-option only	Statement #11	1.5
Agency-option only	Statement #11	1.3
Both models	Statement #11	1.6
No specification	Statement #11	1.3

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Statement #11 is about the consumer going hungry, even though the attendant is supposed to feed him/her.

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## **Conclusions**

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The premise of this research is that good, reliable attendant care increases a consumer's lifestyles choices. Based on the data generated from the satisfaction surveys, consumers are saying that their services are supporting their choices in lifestyles.

The two statements that address quality of life issues, statements #3 and #4, both received the same overall average response score at 1.9. This is a relatively low overall average response score, which means that consumers are saying that their attendant care services improve their quality of life.

According to the data, consumers are indicating that their attendants are responsible people who treat them with respect. This is based on the relatively low overall average response score for statement #1 at 1.8 and statement #13 at 1.9.

Consumers are also saying that they are comfortable explaining their individual needs to their attendants. This is based on the relatively low overall average response score for statement #8 at 1.9.

Another positive finding from this research is that consumers are satisfied with the way their attendants groom and feed them. This is based on the relatively low overall average response scores for statements #9 and #11 at 1.8 and 1.4 respectfully. However, consumers are less satisfied with the way attendants clean their living areas as the overall average response score for statement #10 is 2.3.

The above conclusions demonstrate that consumers are satisfied with some of the most important elements of their attendant care services. Having these elements work effectively helps the consumer live life the way he/she wants.

However, the data also suggests that there are some aspects of the attendant care system that consumers are less satisfied with and may need improvements.

According to the data, consumers are saying that when an attendant is late or calls out, it ruins their plans for that day. This is based on the relatively high overall average response score for statement #12 at 3.

Consumers using the consumer-option model are expressing that it's not easy to find good people to hire as consumer-option attendants. This is based on the overall average response score for statement #15 at 3.5, the highest overall average response score.

Consumers using the agency-option model are saying that the agency does not quickly send a replacement attendant when the regular attendant calls out or doesn't show up for work. This is based on the relatively high overall average response score for statement #24 at 3.

Consumers using the agency-option model are also saying that due to agency's rules, there are times when the agency-option attendants don't perform the tasks the consumers need them to do. This is based on the relatively high overall average response score for statement #25 at 2.8.

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## **Recommendations**

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Although having a perfect attendant care system in Pennsylvania may not be attainable or realistic, there are changes that could be made to the system that may improve the effectiveness of attendant care services.

The following are recommended changes to the attendant care system that may improve the effectiveness of attendant care. These recommendations are based on the information gathered during the preliminary research stages and the analyzed data.

Higher wages for attendants, along with medical insurance and other benefits. This would attract better workers to the profession.

Better ways of introducing consumers to people whom want to be hired as consumer-option attendants.

Passing MiCassa will increase the availability of attendant care services to all Americans with disabilities.

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## **Closing**

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In closing, this research has shown that attendant care services are succeeding in supporting consumers' lifestyle choices in Southeastern Pennsylvania despite some flaws to the system. These flaws cannot be overlooked, but through education, advocacy and legislation they can be corrected making a better system for all Pennsylvanians with disabilities.



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