

Community Forum Findings  
On  
Personal Assistance Services  
In Pennsylvania

Prepared by the  
Pennsylvania Council on Independent Living  
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Dear Reader:

On behalf of the Pennsylvania Council on Independent Living (PCIL), it is with great pleasure to provide you and the Pennsylvania Developmental Disabilities Council (DD Council) with the following report.

The DD Council has identified the Commonwealth as a leader in offering home and community based services for Pennsylvanians with disabilities. Many people with disabilities, however, still fall through the cracks, either because they are not eligible for publicly supported services, are eligible for services but not the services they need, or they do not know how to access the services that do exist.

The PCIL is a 501 ©(3) not for profit statewide membership Association of Pennsylvania Centers for Independent Living (CILs) whose purpose includes to further develop and expand Independent Living options for persons with all types of disabilities throughout the Commonwealth. PCIL has responded to the DD Council's wish of exploring all methods to ensure cross-disability access to personal assistance services for Pennsylvanians who need them. The attached report reflects Phase I of III. Specifically, the activities, findings and outcomes of a series of Community Forums pertaining to personal assistance services in the Commonwealth of Pennsylvania.

In light of the Olmstead vs. L.C.,E.W. decision by the U.S. Supreme Court and the U.S. Department of Health and Human Services Center for Medicare and Medicaid Services' Real Choice Systems Change Grants, these are exciting times for the disability community. Perhaps, one of the Commonwealth's most exciting directives is the implementation of Governor Ridge's Program Policy Guidelines. This directive includes: shifting public resources from institutional to home and community based services; the development of a Home and Community Based Services Governance Structure; and a comprehensive recruitment and retention initiative to ensure a pool of qualified direct care workers for home and community based services.

The PCIL believes this cross disability, consumer-driven report is a tool for the Commonwealth to capitalize on national and state initiatives that will increase the opportunity for community living. Remember, together, we can and do make a difference!

Sincerely,

Michael A. Auer  
Executive Director

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# **EXECUTIVE SUMMARY**

## **Community Forum Findings on Personal Assistance Services In Pennsylvania**

### **Overview**

The “community forum findings” contained in this document are the Phase I outcomes of a three (3) phase project, undertaken by the Pennsylvania Council on Independent Living (PCIL), pursuant to an initiative of the Pennsylvania Developmental Disabilities Council (DD Council). The overall goal of the project is to investigate the political, administrative, financial and policy barriers in establishing comprehensive / cross-disability Personal Assistance Services (PAS) in Pennsylvania. Phase II of the project will examine the Commonwealth’s many intra/inter-departmental philosophical, regulatory and systemic barriers to comprehensive PAS, as well as research to assure maximum federal financial participation. Phase III will include stakeholder and state administrative involvement in identifying achievable PAS improvements, including strategies to overcome remaining barriers to a comprehensive PAS.

### **Background**

Pennsylvania has been recognized as a national leader in affording people with physical disabilities access to community based personal assistance services that promote consumer choice, control, management and direction. Most notable among these efforts are the Attendant Care Program and Community Services Program for People with Physical Disabilities. More recently, the OBRA, Independence and Attendant Care waivers have been developed to incorporate many of the independent living principles inherent in the original attendant care model. Like their predecessor initiatives, however, these waivers target specific types of disabilities, age groups, and support service needs. Moreover, they join a hodgepodge of other age limited, disability specific and diagnosis driven support service programs that contain little or no recipient control.

The PA DD Council has wisely noted that a patchwork of home and community based waiver programs is emerging. While these initiatives should, theoretically, provide PAS assistance to any Medicaid eligible disabled individual, the systemic problems inherent in the states fragmented approach leave far too many unserved, underserved and/or inappropriately served. The principles of personal autonomy, consumer control, risk and choice are inconsistently applied and/or arbitrarily forsaken from program to program. Those with sensory, cognitive, multiple, or more severe disabilities are the least likely to find a level of PAS assistance that meets their specific needs or desires.

## **Parameters/Limitations**

This investigation involves a review of Pennsylvania's home and community based services for all citizens with all types of disabilities and/or comparable functional needs. It is inclusive of all PAS and PAS-type services, regardless of program designation or funding source. Those programs or waivers with multiple components are considered as to their PAS and/or PAS-type components exclusively.

There is currently no generally recognized definition of Personal Assistance Services. Accordingly, the broadest possible interpretation of PAS has been utilized for this examination. Examples of PAS or PAS-type services include attendant care, daily living / home support, routine wellness, personal assistance, homemaker, mobility aid, EPSDT supports, health maintenance, family caregiver supports, non-personal "ancillary" services, respite, non-skilled nursing, certain clustered/shared living arrangements, etc. , and to a lesser extent state Medicaid plan services. Specifically exempt from this inquiry are nursing facilities, ICF/MRs, ICF/ORCs, group homes, assisted living facilities, personal care homes, state institutions, mental health residential settings, etc.

The "respondents" in the community forums based their observations on their individual perceptions of service weaknesses derived from personal experience. Participants were hampered by numerous factors including the absence of a precise definition of PAS, systemic variations in philosophic approaches to PAS delivery, inconsistent conceptualization of consumer management/control, and a multitude of other known and unknown variables. While the community forums generated extremely valuable information on existing problems that warrant corrective measures, the Phase I Findings are generally reflective of the above noted limitations and should be interpreted accordingly.

## **Conclusions**

A description of the methodology utilized in conducting the Phase I Community Forums, and the specific findings summarized therefrom, are contained in the body of this report. Generally, the forum participants highlighted numerous personal issues that require serious consideration in formulating a more comprehensive (ie. seamless, inclusive, responsive) PAS system in Pennsylvania. The conclusions drawn from the Community Forum findings are summarized as follows:

- Community based PAS and PAS-like programs for people with disabilities in Pennsylvania are systemically, organizationally, philosophically, and programmatically dissimilar.
- Eligibility, for state PAS programs, is needlessly dependent upon factors such as age, diagnosis, arbitrary measures of mental acuity, disability type, economic status, varying assessment standards and, most notably, state system infrastructure needs.

- Workforce development issues such as training, wages, benefits, advancement, travel, etc., need to be addressed within the confines of comprehensive home and community based PAS assistance.
- The barriers to uniform PAS for all persons with disabilities, or those of comparable functional need, which arise from existing bureaucratic structures, intra/inter-governmental jurisdictions, and traditional administrative/contractor/provider relationships need to be eliminated.
- PAS alternatives for individuals with sensory disabilities, and those whose sensory impairment(s) results from (or coexists with) another disability, need to be developed.
- The barriers to providing comprehensive PAS assistance in a manner that eliminates disincentives to employment and equitably assures service regardless of economic status need to be addressed.
- The barriers to providing “ancillary” type assistance as a primary function of PAS need to be identified and eliminated.
- The PAS model(s) utilized to provide services should empower the recipient/consumer of services to the maximum extent possible.
- Regulatory intrusion into recipient/consumer utilization of PAS assistance, including changes in utilization frequency, should be decentralized and minimized.
- The state’s prospective and retrospective payment system(s) for PAS need to be equitably uniform throughout the Commonwealth, should be consistent with PAS workforce development initiatives, should promote adherence to specified philosophical principals, should encourage service provision to traditionally disenfranchised populations, should invite innovative approaches, and should be prompt.
- Methods to identify prospective recipients/consumers of comprehensive PAS prior to (and, when necessary, immediately following) any type of institutional placement should be developed and implemented, as should a streamlined eligibility determination process to include presumptive eligibility.
- The state’s formula for calculating the “aggregate cost containment cap” on PAS assistance should be reevaluated based on the expanded population of potential service recipients inherent in comprehensive PAS delivery.
- The identification of specific PAS delivery strategies within an overall consumer managed/empowerment based program structure, particularly as relating to traditionally unserved, underserved and/or inappropriately served populations, must be community based with systemic incentives for development.

## **Phase II**

As noted previously, the respondents at the Community Forums based their input on their respective experiences with the various types of PAS and/or PAS type assistance currently available in the Commonwealth. While many philosophical, programmatic and systemic problems were identified, the current Attendant Care Program, absent many undesirable components, appears to be the closest existing initiative that meets the varying identified needs of citizens with disabilities. This is evidenced by the significant attention given to attendant care services at the forums. Accordingly, PCIL will use the state's Attendant Care Program, its enabling legislation, and its medicaid waiver component as the "benchmark" for inquiry into the further identification of the political, financial, administrative and policy barriers inhibiting the development of comprehensive PAS services in Pennsylvania. Specific strategies for conducting this inquiry are currently under development.

# **COMMUNITY FORUM FINDINGS**

**on**

## **PERSONAL ASSISTANCE SERVICES IN PENNSYLVANIA**

### **INTRODUCTION**

“There is nothing in the world greater than freedom.” These words were uttered by one of our country’s greatest civil rights leader, Dr. Martin Luther King. The freedom that Dr. King spoke of is yet to be realized for many people with disabilities.

Freedom is a word that much of society takes for granted. Yet it is this freedom that is the very fabric of this country’s creation. It is this freedom that drove men and women to flee their native land and seek out a new country, a new life and new hope. It is this freedom that people of color, and those from other nations, continue to leave their homelands and come to America. It is this freedom for which many people lost their lives. It is this freedom that people with disabilities now seek.

People with disabilities seek the freedom to live, grow and prosper in their communities. They seek the freedom to pursue opportunities to fulfill their life dreams, whatever those dreams may be. Like much of society, people with disabilities want to feel they are needed, that they are contributing and that their voice matters. Some people just want to live where they choose, how they choose, and with whom they choose. Nothing more, nothing less. For people with disabilities who need some form of assistance to accomplish life’s daily tasks just to stay alive, freedom and opportunities take a back seat to the more pressing issues like “will someone show up to get me out of bed in the morning?”

The following report and testimonies reflect the frustrations, the joy, and the overall lack of understanding that exists in our current service delivery systems for people with disabilities, their families, advocates and providers. Through a grant from the PA Developmental Disabilities Council, the PA Council on Independent Living (PCIL) held a series of forums across PA, in order to solicit input from the community of people with disabilities regarding the real and perceived barriers to expanding personal assistance services in the Commonwealth.

### **PROCESS**

Six community forums were held throughout Pennsylvania to acquire input from consumers, people with disabilities, their families and their advocates from all areas of the state, from all walks of life, and with all types of needs. One-day forums, hosted by Centers for Independent Living (CILs), were conducted in Erie, Pittsburgh, Williamsport, Harrisburg, Hazleton and Philadelphia. One agenda was followed for each of these forums, to assist in the consistency of information gathering and coverage. Over 200 individuals participated.

There was representation from the community of people who have physical disabilities, those who are blind or deaf, those with head injuries, people with mental retardation and/or mental health disabilities, as well as advocates, family members, providers, organizations that serve people with disabilities, and local media in some cases. The facilitator is an individual with a physical disability, a former user of personal assistance services, a former employee of one of the attendant care program providers, and current Secretary of the PA State Attendant Care Advisory Committee.

Participants first interacted in a discussion regarding current state programs, such as the Attendant Care Program (ACP), the Community Services Program for People with Physical Disabilities (CSPPPD), the Family Caregiver Support Program, etc. Local providers of the services offered an overview of these programs and answered questions from participants regarding the particulars of each. Following this information, the facilitator spoke of each of these programs' relationship to Federal Financial Participation such as Medicare, Medicaid, and discretionary funds available to each state. A brief history of disability programs and services created a natural segue to a closer examination of Pennsylvania's program development, past and present.

While the afternoon's activity focused on soliciting input from those in attendance, the morning's interactions created the interest and desire to openly and constructively discuss views, share experiences, and express thoughts or suggestions. Many of the participant's comments were about their own individual situation and/or needs, but were actually reflective of bigger, more complex problems that may require significant systems change. These individual testimonies are the basis of the findings contained in this report.

## **FINDINGS**

These findings reflect testimony and/or comments received throughout the forums. It in no way reflects all of the problems brought to the forums and is not intended to do so. It is intended to show that these problems, real and perceived, exist in the minds and lives of people trying to remain in the community. These problems highlight some barriers to expanding personal assistance services in Pennsylvania. These are the issues that cause people with disabilities to check into an institutional setting, like a nursing home, because it becomes their only guarantee of services.

The issues identified below are listed in no particular order of priority or frequency. Throughout the document the term "consumer" is used to identify people with disabilities who use the services. "Family members" are used to identify individuals who serve as primary caregiver, home companion or decision-maker for individuals with various types of disabilities, particularly those with cognitive difficulties.

## **AVAILABILITY OF PERSONAL ASSISTANTS**

Personal assistance services, in one form or another, exist within the Department of Aging and several disability specific administrative offices within the Department of Public Welfare, including the Office of Mental Retardation and the Office of Social Programs. The type of services delivered, the eligibility criteria, and the provider

network is different for each of these forms of personal assistance type services. However, all of these programs provide the daily assistance one requires to correctly address their daily activity needs. Overwhelmingly, no matter which system was being referenced, the consumers for people with physical disabilities or the family members of children getting assistance under the MR waiver, workers are often not available to provide these services.

At every forum we heard of the unavailability of personal assistants and the strain this was putting on the well being of consumers and their families. Without continuous daily assistance, the consumer's physical and/or emotional health can deteriorate to the point of hospitalization, often followed by institutionalization. Leaving the institution becomes too difficult and quickly seems insurmountable to the consumer or their family.

If providers are not able to find workers for consumers enrolled in some programs, they are still paid administrative costs for serving that individual, even if they do not send an attendant five days out of seven. There appears to be no incentive for providers to remedy this situation. Consumers are told to use their emergency back-up, but for people with disabilities who do not get around in the community, finding people to serve as a personal assistant in an emergency situation is sometimes impossible. Family members of a person with a disability can sometimes be just as isolated or unsuccessful at recruiting help. Some individuals simply do not get out of bed on the days that a worker does not show up. Families of children or adults with disabilities can become confined to the home and limited in their opportunities. Moreover, the current system is fraught with confusion regarding provider versus consumer responsibility for back up services. This confusion is a health and safety issue for the state and an area of great practical concern for consumers who need services, particularly with those in employment situations.

Across all disability types, consumers overwhelmingly felt that family members should be able to be paid to provide personal assistance.

## **WAGES AND BENEFITS FOR PERSONAL ASSISTANTS**

Personal assistant wages are an issue in all of the Commonwealth's programs. At each of the six forums we heard unanimously the need for better wages and benefits for attendants employed in the DPW Attendant Care Program. Consumers questioned the rates per hour paid to providers vs. the low hourly wage (\$6.50 to \$8.50/hour) paid to agency employed attendants. Attendants employed by consumers under the "consumer model" receive no health benefits. Many attendants leave to work at jobs that provide benefits and better wages per hour, such as fast food restaurants and factories.

Many expressed the need for a health insurance "pool" for personal assistants hired by the consumer, allowing them to buy into a health benefits package. The availability of health care coverage would greatly enhance the appeal of becoming a personal assistant to an individual (or several individuals) within a community, and promote this profession as a career opportunity. While these jobs demand minimal education, they require compassionate, ethical people who understand the need to maintain control of services with the consumer and/or their family.

Another problem for personal assistants in rural areas, where there is no public transportation, is the distance traveled between consumer's places of residence. Many times, in order to be paid for a full 8-hour day, a personal assistant needs to assist multiple consumers. The personal assistant actually works a 12 hour day because they do not get paid for travel between consumer's places of residence, nor do they get any compensation for the use of their vehicle. This scenario, in some cases, applies to the urban area where public transportation is available. Realistically, it can take 1 to 2 hours to cross town using public transportation.

Individuals with disabilities who travel overnight, can face a lack of personal assistance that can make the trip a nightmare. Persons who hire their own personal assistants can take the employee with them, however, the personal assistant will not get any hours from other consumers while they are on the trip. The alternative means going to a strange city and trying to line up personal assistance through an agency in the yellow pages. This can be costly and unreliable.

### **QUALITY OF SERVICES**

Personal assistant workers and consumers alike complained that many times personal assistants are sent out by the agency and they are told nothing about the individual they will be assisting. This is sometimes a very awkward situation for all parties involved, leaving everyone uncomfortable. The consumer may never see that individual again, so they will have to explain what is to be done for them each time the agency sends a new employee.

Others felt strongly that those who do the assessment for community services needed to be consumer controlled organizations knowledgeable in the capacity of people with disabilities (including those with the most severe disabilities) to live in the community. If a more progressive provider, like a Center for Independent Living does not perform the assessment, people are sometimes seen as incapable of community living.

Some people have experienced problems with the caliber of the personal assistants being sent to the consumer's home. Many complained of being robbed of their possessions and money; others spoke of the apathy of their personal assistant in doing a thorough job. Some demonstrated a pattern of provider problems that strongly suggests training, education, and a commitment to principles of consumer control are lacking in the current provider system.

Some consumers stated that they have been "black listed" by a provider or agency because they are assertive in communicating their displeasure regarding the quality of services. Consumer choice in the selection of their Attendant Care "Act 150" provider was voiced as a need.

### **ATTENDANT CARE PROGRAM RESTRICTION OF "MENTALLY ALERT"**

In several forums, people expressed their concern that the attendant care program is too restrictive because of the requirement that the individual be mentally

alert and able to direct their own services. Many felt that this program could benefit other consumers and families who need the range and control of service delivery offered. However, the consumer is not always mentally alert, or is not able to direct a personal assistant, and therefore is not eligible for the Attendant Care Program. The “mentally alert” requirement is arbitrary, it is at the discretion of the assessing service coordinator, and is without written guidelines.

Consumers with mental retardation and their families complained that personal assistance services within the MR system are still very medically oriented. Families are forced to use an agency model of care, which means they must rely on the agency to send them a personal assistant. Unlike consumers in the Attendant Care Program, families do not have the option of hiring and training the individual themselves. Many reported that they sometimes go several months without assistance and without any movement by the agency to remedy the situation.

### **TIME TO ACQUIRE SERVICES**

Some felt that the length of time it took to apply for and finally receive services was much too long. The delay prevents those in emergency or temporary situations from receiving the personal assistance they need, when they need it. People with disabilities expressed concern that, while not needing personal assistance services at this point in their disability, the time will come when they absolutely will need assistance to remain in their homes. This eventuality may come rather quickly, as in the form of an injury or sudden illness. Some expressed concern that even enrollment in the Attendant Care Program would not prevent some of them from going into a nursing home, even if it were only for “a little while.”

This is particularly true for people who require hospitalization. Those with a developmental disability benefit from a tracking system to assure that they are offered community services as an alternative to any institutional care. Community services for these individuals can be put into place before their discharge from a rehabilitation facility, although this does not usually happen.

People whose disability does not meet the “developmental” requirement are not assured information about community services prior to hospital discharge or institutional admission. Providers report that these individuals are sometimes identified in the course of serving others. Many can and do benefit from relocation assistance and community services, provided that they are eligible for “non-developmental disability” waiver services.

Many of those already enrolled in the Attendant Care Program complained that the Department of Public Welfare’s Office of Social Programs insists on approving, or more-often disapproving, all changes in service hours. This means that each time one of the over 3,000 people being served on the program needs a change in their hours, even temporarily, they must seek the approval of their provider, who must, in turn, get permission from DPW in Harrisburg. All of this takes time and it robs the individual of dignity and control over their lives and services.

## **LACK OF PROGRAM INFORMATION**

Often, people with disabilities and their families do not know that home and community based services are available. Public and provider education is needed if people are to find services when needed. Some people spoke about the outreach efforts that use to be done by attendant care providers. Many of the outreach activities were free of charge. Some worked with the local papers to run public interest stories about people living in the community. Others used free public bulletin boards and cable networks to run ads continuously so that family members and people who suddenly find themselves facing their long term care needs knew there were alternatives to nursing homes. None of this is being done currently, and very little public information about the Olmstead right to stay in your own homes is being conveyed to the public.

Many people were surprised to hear about the Commonwealth's waiver programs or recent amendments that might allow a family member eligible to receive more comprehensive services. Consumers were equally unaware of the Toll Free Hotlines, offered by the Office of Social Programs, allowing consumers a method to voice concerns, problems, and suggestions directly to program staff in Harrisburg.

## **LACK OF ASSISTANCE WITH PARENTING/SERVICES FOR CHILDREN WITH DISABILITIES**

People with disabilities who are raising children are unable to receive assistance with parenting under the existing personal assistance structure. This sometimes results in families splitting up or may cause some people to permanently lose custody of their children. Spouses use the argument that the disabled parent is less capable of providing for a child, and therefore should not have a right to help make decisions for that child. Many people indicated that even though their disability causes them to require assistance, they still can care for and know what is best for their children. Still others end up losing employment because they put the needs of their children above the need to bring in a paycheck.

Parents of children with disabilities, who are ages 3 – 18 and without mental retardation, have a great deal of stress. This stress would be lessened if their child could receive regular personal assistance service. Parents need more than respite services for their children. Many parents may need to have a job outside of the home to support their family and attend to other needs.

## **BLINDNESS, DEAFNESS, AND COMMUNICATION DISABILITIES**

Applying for, or even learning about, services and programs sometimes becomes a nightmare for people with sensory disabilities. Consumers report that providers, who are responsible for intake and assessments, will not get an interpreter for those who are deaf. Nor will they put materials in Braille or other languages, until threatened. Even then, many people, regardless of sensory disability, stated they were ignored and their calls to the administration were ignored.

Communication must be considered a basic service, not just an ancillary service for people with blindness, deafness, and communication disabilities. Personal assistance services are needed by these disability populations in order to communicate in the community, orient themselves with a new area, apply for employment, go to medical appointments, etc.

## **HEALTH AND SAFETY**

The issue of the health and safety of individuals with severe disabilities came up in several of the forums. The capacity of a person who is blind or mobility impaired to live alone in their own home is sometimes challenged. All agreed that the degree of “safety” of the individual trying to live in the community must be left up to the individual needing the services, or their family member. While most agreed that things could and do “go wrong” for people in these circumstances, things also “go wrong” in nursing homes and other institutions.

Should an existing consumer or their family choose to move from their current community, the inability to rely on the same degree of services from a different provider in the state may stop them from moving altogether. This, coupled with the lengthy delay in acquiring services, can hinder people from moving into the state, or even from moving from one county to another.

When consumers are receiving services from the attendant care program and enter the hospital, their service hours are limited to 5 hours per week for retrieving mail and preparing for the discharge home. This is perceived as a loss of control of the consumer’s dignity. The hospital does not always perform specialized services that an attendant may do for a consumer. In some cases, a consumer does not receive assistance in repositioning, grooming, showering, etc., because the nursing staff does not have time, expertise, or assistive technology.

Some consumers stated that the “use it or lose it” policy is not administered constructively or fairly by all attendant care contractors throughout the Commonwealth. In some instances, consumers are not even asked why they are not using their approved amount of service hours. There are legitimate reasons why consumers do not use all of the services hours, for example, personal assistant turnover.

The contractors’ interpretation and implementation of the attendant care program requirements differs across the state. Consumers who have experienced a particular philosophy of service in one part of the Commonwealth report a much different philosophy of personal assistance upon relocation to another region of the state.

Consumers are calling for personal assistance services to be based on functional needs. Services currently regarded as “ancillary” may be the only thing holding back some consumers from true independence. For example, there are differing interpretations on whether meal preparation or grocery shopping is a basic or ancillary service. Some attendant care providers do not allow consumers to receive services, through the attendance care program, if they only need meal preparation or grocery shopping assistance as a basic need. If a consumer does not have food, how are they to live healthy independent lives?

The Nurse Practices Act is sometimes cited to limit the consumer's control over what assistance can be received. For example, assistance with clipping toenails.

### **TRANSITIONAL SETTING NEEDED**

Many people felt there should be a place for individuals, moving out of institutional settings or their families home, where there is some assurances of service availability. It was felt this was needed until these individuals acquire the skills they need to advocate for themselves and their services, while providers in the community prepare reliable, consistent services.

### **AGING SERVICE DELIVERY**

Forum participants discussed the inconsistency between the personal assistance available to people with disabilities through the DPW Attendant Care Program, and the theoretically similar services provided by the Department of Aging. While provisions have been made to remedy inconsistencies for people who transition from DPW to the Department of Aging, individuals who are not receiving DPW attendant care, or who acquire their disability after age 60, face a distinctly different service environment.

Aging services were described as medically oriented, non-consumer directed and not adequate to fulfill the needs of older consumers. Those aging citizens who attended the forums complained that because they now need assistance getting around their homes, services will be supplied to them when the provider agency is able to serve them. There is no consideration given to the person, their family, their schedules or their lives. As in all other programs, personal assistants providing services to the elderly are paid very little, and often move on to private duty or facility-based programs like Assisted Living.

### **EMPLOYMENT**

Consumers receiving services under the Act 150 Attendant Care Program are subject to a fee determination for services. The fee is determined on a sliding scale that takes into consideration the total family income, size, medical expenses, and expenses that are unique to the consumer's disability.

The sliding fee scale, and the method of fee calculation in its current format, can create a sizable fee for consumers who are becoming competitively and gainfully employed. In effect, a disincentive obtaining and maintaining employment has been created. Some consumers feel penalized for trying to succeed and often wonder if they would be "better off" to rely on government programs for their livelihood.

Contractors and Department staff are questioning the legitimacy of medical expenses and whether expenses are unique to a consumer's disability. Presumptive characterizations of consumer's disability(ies) or economic status seem to impact whether or not an expense is eligible.

## OUTCOMES

Attached as an appendix to this report, are written testimonies from Community Forum participants regarding the need to expand the quality and availability of Personal Assistance Services in Pennsylvania. Also included in the appendices section are the names and affiliations of the forum participants. While participants “consumers” were not asked the specific nature of their disability, a broad cross-section of disabilities were represented, as were family members, providers and advocates. The final appendix to this document is a definition of PAS currently recommended by the federal Health Care Finance Administration (HCFA) for state implementation of the Ticket to Work and Work Incentives Improvement Act of 1999 (PL No 106-107). Although this definition is somewhat lacking in its scope, and was not utilized in the community forums, it is offered as an indication of federal financial participation in the development of comprehensive PAS for citizens with a broad array of disabilities.

The forum participants highlighted numerous issues that point to the need for a simpler, more comprehensive, and universal version of PAS in the state. Most notable among these issues are:

- PAS workforce problems need to be addressed in a proactive manner.
- The current PAS system (or lack thereof) is fragmented, inconsistent, and excludes meaningful service utilization by far too many.
- Inconsistencies in PAS delivery methodologies are rampant and arbitrary.
- Many PAS-type programs exist within various state departments and/or offices with no coordination of effort.
- Access to most current PAS and PAS-type programs is unduly time intensive, is bureaucratically driven, is poorly coordinated, and is generally non-responsive.
- PAS and PAS-type program eligibility varies widely and is based on arbitrary requirements such as disability-type, perception of mental acuity, age, need for certain supports, etc.
- Eligibility requirements of most PAS programs preclude vital “ancillary-type” supports, absent the need for more medically-based services.
- PAS recipient/consumer “health and safety” issues are in conflict with the philosophical constructs of many existing programs.
- PAS for people with sensory disabilities are largely non-existent, except in cases where the individual is otherwise categorically eligible by virtue of a secondary qualification such as age, employment status, intellectual capacity, etc.
- Without exception, disincentives to employment exist in current PAS and PAS-type initiatives.

Despite the many existing barriers to comprehensive PAS delivery in the state, current recipients/consumers expressed a strong preference for community-based alternatives to their respective institutional alternatives. Family members expressed their joy in having a relative with a disability at home, but their weary and exhaustive efforts to keep their family together was consistently expressed. While people with physical disabilities are concerned that consumer control in current PAS is eroding toward nonexistence, family members expressed the desire for more direct involvement in the services afforded children with mental retardation.

The overall need to “re-think” all PAS and PAS-type service delivery methodologies, within the framework of uncompromising philosophical principles, is without question.

Abundantly apparent is the need to involve current and future PAS consumers/recipients in program development and quality evaluation.

**This report was completed by Michael A. Auer, Pennsylvania Council on Independent Living (PCIL) Executive Director and Project Director under the Personal Assistance Services Project funded by the PA Developmental Disabilities Council, in conjunction with Linda Anthony as a private consultant for the PCIL.**

## **APPENDIX I**

## Personal Assistance Services

### Personal assistance services sufficient to enable individuals to work:

For full eligibility under this grant program, entitling a State to receive multiple year funding, a State must offer personal assistance services statewide within and outside the home to the extent necessary to enable an individual to be engaged in full-time competitive employment. For purposes of this grant program, “*personal assistance services*” means:

A range of services, provided by 1 or more persons designed to assist an individual with a disability to perform daily activities on and off the job that the individual would typically perform if the individual did not have a disability. Such services shall be designed to increase the individual’s control in life and the individual’s ability to perform activities on and off the job. [Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, § 203 (b)(2)(B)(ii)]

Offering personal assistance services to the extent necessary to enable individuals with disabilities to remain competitively employed is defined as the following:

Personal assistance services must be offered statewide through:

- (a) the optional Medicaid personal care services benefit under the State Medicaid plan as defined in 42 CFR 440, 167, or
- (b) a section 1115 and/or section 1915(c) waiver and/or 1915(b) waiver which substitutes for statewide personal care coverage sufficient to support employment under the State Medicaid plan as defined below, or
- (c) a combination of State Plan personal care option (or personal care within a Home Health State Plan service) and Medicaid waiver which collectively meet the statewideness and other criteria described below, and which is not substantially different for employed and unemployed individuals.

For purposes of the TWWIIA grant program, personal assistance services are those as defined under Medicaid law that include a range of assistance provided to persons with disabilities and chronic conditions of all ages. Such assistance most often relates to performance of ADLs and IADLs. A State’s personal care benefit must be sufficient in amount, duration, and scope such that an individual with a moderate to severe level of disability would be able to obtain the support needed to live, get to and from work, and perform at the worksite. This does not mean, however, that a State is responsible for providing personal assistance services at the worksite to the degree that they go beyond the scope of the Medicaid program and subsume an employer’s responsibility under the ADA. States should base determinations of need for PAS on the worksite on an individual basis as documented in a plan of care for that individual. Evidence must be available that the State has the ability, through mechanisms including

individualized assessments, to match need for personal assistance services with the quantity of services delivered. Establishing caps on the number of days or the number of hours per day that services are available without regard to individual need will not satisfy this requirement. A State must have criteria for reviewing and responding to requests from qualified employed individuals with disabilities who believe they require more services than determined at their individual assessment, or a different type of physical or cognitive assistance that which has been made available. Such criteria should be developed in consultation with individuals with disabilities who use personal assistance services and are competitively employed.

Workers receiving personal assistance services must be able to receive personal assistance services outside their home.

Workers receiving personal assistance services must be able to receive personal assistance services at times during both the day and night, seven days a week, subject to a finding of individual need.

Unless an individual needs only assistance with activities of daily living, medical necessity definitions used by a State must not preclude the availability of personal assistance services for instrumental activities of daily living such as cooking, cleaning, or shopping if such assistance is required for an individual to remain competitively employed.