

**Final Report  
On  
Personal Assistance Services  
In Pennsylvania**

**Prepared by the  
Pennsylvania Council on Independent Living  
2002**

**For the**

**Pennsylvania Developmental Disabilities Council  
Personal Assistance Services Initiative  
Grant Number 01490014**

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## Overview

This is the final report for the Pennsylvania Developmental Disabilities Council (DDC) Personal Assistance Services Initiative for a comprehensive cross disability and consumer controlled Personal Assistance Services program in the Commonwealth of Pennsylvania, Grant # 01490014, which commenced October 1, 2000.

The goal of this project is twofold: to identify barriers from individuals, and the community of persons with disabilities; as well as those barriers inherent in government systems, and to make recommendations toward a comprehensive cross disability, consumer controlled Personal Assistance Services (PAS) to serve people of all ages. Contained herein are those barriers identified both from stakeholders and consumers of services, as well as those financial, administrative, political, and policy barriers presented by government- - the Commonwealth of Pennsylvania and the Federal system.

## Project Activities

Initially, the Pennsylvania Council on Independent Living (PCIL) had planned to conduct community forums to elicit input from persons with disabilities utilizing the Pennsylvania Coalition of Citizens with Disabilities (PCCD), a statewide membership organization as the vehicle for these forums and its Executive Director as the facilitator. At the outset of this grant, with PCCD no longer in existence, the Executive Committee of PCIL conferred and it was decided that Linda Anthony, the former Executive Director of PCCD would be engaged to conduct the community forums.

Six community forums were held during the second quarter. The locations of the forums were chosen to be representative of the diverseness of the Commonwealth, and yielded a cross disability perspective from consumers, persons with disabilities and their advocates (**See Appendix A: Community Forum Invitation and Handout Material**). Over 200 individuals participated. One-day forums were conducted in Erie (February 26, 2001), Pittsburgh (February 28, 2001), Williamsport (March 2, 2001), Harrisburg (March

6, 2001), Philadelphia (March 9, 2001) and Hazelton (March 13, 2001).

The results of the activities, findings and outcomes of Phase I—the Community Forums are detailed in Appendices of this report (**See Appendix B: Community Forum Findings Report on Personal Assistance Services in PA**).

Michael Auer, the Executive Director of PCIL, and project director for this grant, became a participating member of the Department of Public Welfare's Home and Community Based Services Project in October 2000. He was later appointed as PCIL's representative to the Home and Community Based Services Stakeholders Planning Team, (HCBS SPT), by the Secretary of the Department of Public Welfare, which was established in response to the Supreme Court's decision on *Olmstead vs. L.C., E.W.* Please see Collaborative Efforts/Recommendations below for more on the HCBS SPT.

Phase II of the project sought to gain an understanding of the barriers the Commonwealth's faces with regard to the development of a seamless system of Personal Assistance Services based on the outcomes of Phase I. PCIL determined the Virtual Governance Structure to be the entity to assist with identifying the financial, administrative, political and policy barriers to a cross disability, comprehensive PAS Program in Pennsylvania (**See Appendix C: Written Inquiry to PA Virtual Governance Structure**). At the request of the Governance Structure, following correspondence to its Executive Director and Chair and a subsequent meeting, a written survey or inquiry was prepared.

Utilizing the conclusions and issues raised in the Community Forums, and Pennsylvania's current Act 150 Attendant Care Program (PL 1477 of 1986) and the Attendant Care Program's Medicaid Waiver, a comprehensive- for- research -purposes only, definition of Personal Assistance Services, (with emphasis on the particular needs of those with sensory disabilities and cognitive disabilities, Sections 2 (iv) (v)), was set forth by PCIL (**See Appendix D: Comprehensive Cross Disability Working Definition of Personal Assistance Services**). The written inquiry, known as the Barrier Identification Survey, was developed in Quarter Four and addressed assumptions to be made

for a cross disability, comprehensive PAS in order that financial, administrative, political, and policy barriers might be identified (**See Appendix E: Barrier Identification Survey to PA Virtual Governance Structure**). The response from the Virtual Governance Structure supported the findings of the Community Forums, indicating that within the Commonwealth's community based services which provide PAS, eligibility determination, administration, and service provision are disparate from program to program (**See Appendix F: Virtual Governance Structure Response to Barrier Identification Survey**).

A preliminary interview by the Project Director with the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), Americans with Disabilities Act (ADA)/Olmstead Workgroup during quarter five yielded the recommendation that a partnership be formed with state government so that a Medicaid State Plan Amendment, under which PAS would be an entitlement, might be considered (**See Appendix G: Summary of Interview with US Department of Health and Human Services ADA/Olmstead Workgroup**). PCIL began developing its own body of knowledge regarding Medicaid statutes/regulations. Toward this end, a review of PAS initiatives in other states was suggested as well as collaboration with the Home and Community Based Services Stakeholder Planning Team.

As conceived originally, Phase III was to have been a Policy Summit to consider the establishment of a comprehensive cross disability PAS network in Pennsylvania, based on the needs, desires, and suggestions of its consumer participants. In quarter six, following discussion with the DDC Project Officer, the work plan was revised to redirect project activities toward examining barriers to a comprehensive PAS, with Federal Financial Participation (FFP) coming under Medical Assistance. The Pennsylvania Health Law Project was engaged to analyze options for financing PAS through Medical Assistance. This report, which evaluates existing Medicaid PAS, also defines services allowed under Medical Assistance, and a comparison of a State Plan Amendment, Section 1915© Waivers and the Section 1115 Independence Plus Demonstration Project (**See Appendix H: PA Health Law Project Report – Options for**

## **Financing Personal Assistance Services through Medical Assistance).**

### **Barriers to a Comprehensive Personal Assistance Program**

Specifically exempt from the findings toward barrier identification were nursing facilities, ICF/MRs, ICF/ORCs, group homes, assisted living facilities, personal care homes, and state institutions.

### **Consumer Perspective**

The findings from the Community Forums were based on participants' individual perceptions of PAS weaknesses derived from personal experience. The salient issues, which impede the promulgation of a cross disability, comprehensive PAS program, are cited below. The Community Forum Findings Report is contained in **Appendix B**.

- Numerous PAS programs exist within various state departments and/or offices with no coordination of effort. These programs are systemically, organizationally, philosophically and programmatically dissimilar.
- PAS program eligibility varies widely and is based on different requirements i.e., type of disability, mental alertness, age, specific support needs and most notably, the Commonwealth's infrastructure.
- Current PAS is fragmented and inconsistent.
- Inconsistencies in PAS delivery methodologies.
- Access to PAS programs is time intensive, bureaucratically driven, intrusive, regulated by governmental oversight and non-responsive to applicants.
- Ancillary services are precluded absent the need for more medically oriented services.
- Workforce development issues, and those disincentives to employment i.e., training, wages, benefits, travel for attendants need to be addressed.
- Traditional administrative/contractor/provider relationships and "health and safety" issues present conflicts to the philosophy of Independent Living.

- PAS is not available for people with sensory disabilities unless they qualify secondarily by age, other disability, employment status, and intellectual capacity.

## **Commonwealth's Perspective**

The Department of Public Welfare's response to the PCIL Personal Assistance Survey was submitted by the Virtual Governance Structure. The Response was coordinated by the Office of Policy Development with input from the Office of Medical Assistance Programs, Office of Social Programs, the Office of Mental Retardation, Office of Mental Health and Substance Abuse and the Department of Aging. The Survey was aimed at soliciting the financial, administrative, political and policy barriers to a cross-disability, consumer controlled, comprehensive PAS in Pennsylvania. The Survey is contained in **Appendix E**. The Response is contained in **Appendix F**.

The five most noteworthy inter/intra departmental administrative obstacles were identified as follows:

- The current structure for the provision of community based services for persons with disabilities varies from program to program. The eligibility assessment, service plan and administration of the programs are housed and coordinated differently by county or region or centralized.
- A central location for PAS services may pose problems for consumers, depending on their functional need, and their needed supports, as certain programs offer different services, currently necessitating administration by multiple entities (county and regional).
- The restructuring of current PAS programs will require administrative changes to the managing entities. The restructuring will involve costs and time to effect the changes.
- Current consumers may oppose the new PAS program, as it may not be seen as better than the current provision of PAS they receive.

The five most noteworthy barriers to the use of Federal Medicaid Funds in a comprehensive PAS program are described below:

- Financial. A broadened definition of PAS will result in a wide array of services requiring significant financial commitment from the State. Such a financial commitment on behalf of Pennsylvania is most likely not possible, given the current budgetary constraints.
- Medicaid Rules on Consumer Control. Both the state and Federal government require qualified providers. The question becomes a proper balance between consumer control and quality assurance.
- Use of Medicaid money. Rules do not allow for Medicaid dollars to be utilized for the payment of family members in the provision of PAS, except in exceptional circumstances.
- Quality Assurance/Monitoring. The Department of Public Welfare is the designated state Medicaid agency that assures the quality of delivery of services. This may preclude regional control of monitoring and quality assurance of services.
- Model of Service. The provision of service under Medicaid is essentially based upon “medical” necessity. As such, the policy question is whether or not Medicaid, as a health care program, should be the vehicle to fund all of the services as proposed by the PCIL definition of PAS.

The major financial, administrative, and political and policy barriers to a comprehensive PAS Program are:

- Financial. With the assumption that persons of all incomes would be eligible for PAS within the proposed structure, this would necessitate government involvement. A detailed budgetary and financial analysis to assure the creation of a fair cost share system for only those who truly could not pay would need to be generated. This would require the Commonwealth to make a significant commitment to establish the cost-sharing system and administer services.
- Administrative. To change from the current multiple program system, which provides for the delivery of PAS based on a person’s disability and age, to a regional approach to delivery/administration for all populations, may produce consumers’ opposition to a new structure, and thus administration of the program would be difficult.

- If consumers were able to chose to remain with their current program or elect the proposed PAS program there may be duplication of efforts and additional costs to the system.
- Policy. It may not be possible for all persons to have consumer control of their PAS as a matter of policy and quality assurance. The method of determining who could apply the concept of consumer control to their PAS would be difficult and controversial.
- Liability Issues. Under the consumer directed model, employer/employee issues of who would be responsible and liable for different circumstances would need to be clarified.
- Nurse/Medical Practitioners Act. Under the consumer directed model one could choose an individual and direct that individual to complete a task, which may fall within the scope of practice of a professional license. It would be contrary to law for that task to be performed within the Commonwealth's current professional practice laws.
- Policy. A structure for managing waiting lists, should they become necessary due to lack of funding and or direct care workers, would need to be developed to reflect the criteria for the priority of those most in need of PAS based on functional and/or financial factors.

### **Independent Analysis Perspective**

The barriers, according to the analysis undertaken by the Pennsylvania Health Law Project, on the options for financing PAS through Medical Assistance are, utilizing the definition of PAS as defined by PCIL:

#### **Current Medicaid State Plan PAS Barriers**

- Financial. Individuals must qualify to receive any Medical Assistance service. Income limits for persons between the ages of 18 and 64 and those between the ages of 6 and 18 and over 64 and those who are working between ages of 16 and 64 are regulated and vary.
- Should Pennsylvania increase financial eligibility limits, more individuals would become eligible thus increasing the amount of money the state would have to expend on Medical Assistance.
- PAS is not a mandatory service for adults. However, home health is a mandatory service. Assistance with daily living activities is

being provided under this category under the sub-division of home health aide.

- Limitations in covering PAS under Federal Home Health category of services. Regulations stipulate services must be ordered by a physician, with a written review of the plan of care every 60 days.
- Pennsylvania's restriction to providing home health services to only the "homebound."
- Pennsylvania's regulation that specific services must be provided by home health aide determined by a Registered Nurse (RN).
- DPW service limits payment to one fee per visit. So that if an individual needed multiple hours of home health care, payment would be the equivalent of only one hour's need for service.
- DPW limits payment of home health care to 15 visits per month after first 28 days.
- Early Periodic Screening, Diagnosis and Treatment (EPSDT) only vehicle for PAS under age 21.
- PAS for persons under age 21 is not consumer (or family) controlled and is provided primarily using nursing agencies.

### **Medicaid State Plan Amendment - Personal Care Services Option Barriers**

- Financial. See Current Medicaid State Plan Barriers above.
- PAS would need to be provided to everyone on Medical Assistance who needs PAS.
- State Plan Amendment services must be made available to all people who are "categorically needy."
- Eligible individuals cannot be limited by type of disability; this would include short term PAS for persons without disabilities.
- "Reasoning" is beyond the scope of traditional PAS. With the exception of money management and medication management, Federal regulation recognizes PAS as assistance with physical tasks as.
- Sign-language interpretation could be covered, but Medical Assistance is payer of last resort.
- "Escort" service is not covered per se, but may be provided with other "basic" needs, such as mobility assistance.
- "Making decisions" except as it relates to money management is beyond the scope of coverable PAS.

- Liability issue regarding consumer management of agency employees.
- The state must develop provider qualifications to assure quality of service.
- Some individuals would not meet financial income or asset limits.
- State Plan Amendment must be statewide.
- Services would be funded for all eligible individuals.
- Limited ability to control costs.
- Most expensive option for financing PAS through Medical Assistance.
- Additional funding sources would need to be identified. Federal monies in Title XX and Federal Medicaid could not be used.

### **Section 1915 © Waivers under the Social Security Act Barriers**

- Section 1915 © Waivers require that the cost to the State of Waiver services do not exceed costs of Medical Assistance for Waiver eligible persons in applicable institutions.
- Pennsylvania utilizes higher income limits for its Waivers, but this requires the State to place a cap on the number of persons who can be served under a particular Waiver.
- Federal restriction on cross-disability Waivers. Services are restricted to persons with no more than one category of disability in the same Waiver. There are three (3) distinct categories of persons who can be served: persons who have no Developmental Disability (DD) and aged; persons who have Mental Retardation and other DD; and persons with mental illness. However, the PAS component can be included in any 1915 © waiver. A waiver template or menu of services that can be provided under a 1915© waiver is the starting point in the development of any waiver. States choose which services from the template they want to include in any particular waiver.

### **The Advent of Section 1115 Independence Plus Demonstration Project**

On May 9, 2002 Secretary Tommy Thompson of the US Department of Health and Human Services (HHS) announced the Independence Plus programs to assist states to achieve the goals established in President Bush's New Freedom Initiative. The President's initiative is

intended "... to ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment and to promote community life." - President George W. Bush, Executive Order 13217.

Recognition of the strengths, preferences and desired outcomes of families of persons with disabilities and persons with disabilities themselves is essential in the development and delivery of effective and meaningful services. By allowing individuals with disabilities, or their families, to direct the design and delivery of their own health care services, they will experience higher levels of satisfaction, avoid unnecessary institutionalization and use resources more effectively.

- Delay institutional or other high cost out-of-home placement by strengthening supports to families or individuals, permitting the individual with a disability to live in their family's or own home.
- Recognize the essential role of the family or individual in the planning and purchasing of health care services and supports by providing control over an agreed upon resource amount.
- Facilitate cost effective decision-making in the purchase of supports and services.
- Increase family and individual satisfaction by facilitating control and choice, concepts voiced by many persons participating in a National Listening Session - New Freedom Initiative.
- Facilitate the states' abilities to meet legal obligations under the Americans with Disabilities Act (ADA) and the Supreme Court Olmstead decision.

Sections 1115 and 1915© of the Social Security Act provide states two options to establish family or individual directed community supports; however, the 1115 Demonstration option provides optimum flexibility. The 1115 Demonstration Template must be used if the State wishes to:

- Establish a program serving multiple populations, such as persons with mental retardation and persons with physical disabilities or;
- Establish a program making cash directly available to demonstration participants or;

- Cover an eligible population other than those who meet an institutional level of care.

Other facts on the Section 1115 Independence Plus Demonstration Project are as follows:

- Eligible individuals must have received services from home health agency for 12 months. However, this can be modified as necessary to address each demonstration's eligibility criteria.
- State determines the total number of individuals that can be enrolled.
- State can target service to one or more specific populations.
- Costs of demonstration project must not exceed the costs for Medical Assistance for the eligible population had there been no demonstration project.
- Demonstration Project must be budget neutral. CMS to compare actual per capita costs of community-based "long term care" services within the demonstration project to the projected per capita costs of providing same services to same population in a pre-demonstration "base year."

Please see further information on the Independence Plus Demonstration Project in "**Recommendations**" below.

### **Collaborative Efforts/New Developments**

There have been ongoing developments since the outset of the DDC/PCIL PAS Grant, whose focus has been to enhance and strengthen community based supports and services for persons with disabilities.

Concurrent with the U.S. Supreme Court's ruling on *Olmstead vs. L.C., E.W.*, which determined that a person with a disability has the right to receive services in the least restrictive setting, efforts by ADAPT and other advocates have led the emphasis away from an institutional bias toward a structure of home and community based services. With Governor Ridge's Disability Agenda directives as a backdrop, and in response to the *Olmstead* ruling, the Secretary of

the Department of Public Welfare appointed 25 members to the Home and Community Based Stakeholders Planning Team (HCBS SPT). The HCBS SPT was designed to assist the Department in directing system wide changes to better serve persons who need home and community based supports and services. An initial goal of the HCBS SPT is to develop a transition plan which will provide some short term recommendations to the outgoing administration as well as longer range guidance to the incoming administration so that the recent momentum on initiatives can continue with minimal delay. The Virtual Governance Structure was established, and in collaboration with the HCBS SPT, will investigate the barriers and develop a “best practices”, “seamless” full range system of home and community based services for persons with disabilities.

To this end, The Department of Public Welfare, Office of Social Programs has been formulating changes to the existing system of administering its Home and Community Based Waivers (Request For Proposal due on or around August 9, 2002). Preliminarily, the Commonwealth seeks to consolidate and ease the access to PAS. Previously only available from a multitude of programs, including but not limited to the Community Services Program for Persons with Physical Disabilities, (CSPPPD) its associated Waivers, and the Attendant Care Program and its Medicaid Waiver; there will be a single point of entry, based regionally, called a Community Resource Center (CRC). In order to provide choice and quality assurance for consumers, the CRC will develop and monitor a network of service providers, thus removing the possibility of conflict of interest. The actual provision of service will be separated from the assessment for eligibility and the creation of the service plan.

In September, 2001, Tommy Thompson, U.S. Secretary of the Department of Health and Human Services (HHS), Centers for Medicare and Medicaid Services (CMS) announced that money would become available in the form of Real Choice Systems Change Grants. These grants will be available to states to design and implement effective and enduring improvements in community long-term support services. The Centers for Medicare and Medicaid (CMS) is the agency designated to oversee these grants. In February 2001 President Bush announced the New Freedom Initiative as part of a continuing nationwide effort to remove barriers

to community living. Additionally, borne from Section 203 of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), HHS was directed to establish a grant program to enhance employment options so that persons with disabilities can obtain and maintain competitive employment in integrated settings. The Medicaid Infrastructure Grant seeks to support state efforts to develop and implement core elements of the TWWIIA so as to modify the health care systems to meet the needs of people with disabilities who want to work. To meet this goal, Pennsylvania will review the HCBS PAS Waiver programs as to how and/or if they are supporting persons who are working or who want to work. The Advisory Committee on Employment (ACE), comprised of consumers and advocates, was established to advise, provide oversight and provide input on components of this grant. Further, PCIL was appointed to serve on the ACE. A by-product of the Medical Assistance Infrastructure Grant is Medical Assistance for Workers with Disabilities (MAWD), which raised income eligibility and allowed for increased assets so that individuals can pay a premium and still receive their health coverage – a so-called Medicaid Buy-in.

The collaborative efforts of State government, the Virtual Governance Structure, the Medicaid Infrastructure Grant, the Home and Community Stakeholders Planning Team, the Pennsylvania Health Law Project studies and the work of the DDC/PCIL PAS grant combined to help craft Pennsylvania's May 2001 response to the Real Choice System Grant. Pennsylvania's response to the RFP includes an examination of the feasibility, under Section 1115 of the Social Security Act, to establish an Independence Plus PAS Demonstration Project. Likewise, the DPW via the ACE is exploring the practicability of offering PAS through a Medical Assistance Medicaid State Plan Personal Care Services Option Amendment, as well as, supporting the efforts of the Real Choice Systems Change Grant in relation to the Section 1115 Independence Plus Demonstration Project. Furthermore, two demonstrations, one rural and one urban as well as recommendations for an effective policy for "emergency" back-ups when there is a lack of an attendant or the attendant is unavailable to work are proposed.

Lastly, a Recruitment and Retention Initiative for Direct Care Workers or Attendants has been evolving and developing over several

months. Providers of HCBS have been given funding to develop localized plans for developing the capacity of personal assistants/attendants. Local plans have included the use of funds for bonuses are working for established benchmarks of time; increase in hourly wage; and local recruitment strategies for personal assistants.

Alike, a more recent development includes a statewide Apprenticeship / Journeyman initiative that is funded with Temporary Assistance for Needy Family (TANF) funds. Persons representing people with both physical and mental disabilities are working to develop statewide programs that:

- To provide for the establishment and furtherance of Standards of Apprenticeship within the HCBS Industry in order to enhance the training of Apprentices.
- To aid in providing maximum opportunities for unemployed and employed persons to improve and modernize their work skills.
- To contribute to a healthy economy by aiding in the development and maintenance of a skilled labor force, sufficient in numbers and quality, to meet the expanding needs of the HCBS Industry in the Commonwealth of Pennsylvania by the above mentioned Standards.
- To provide a program which will encourage individuals to work within the HCBS Industry on a full time career basis. This will help ensure the industry's continued strength and ability to perform its essential function of providing quality home and community-based services and supports for our citizens.
- To perpetuate the skills, technique, and pride of service within the trade, which is necessary to the successful continuation of the HCBS Industry.
- To provide links to Apprentice opportunities between the HCB Services Industry and appropriate candidates for the program.

## Recommendations

The PCIL/PAS grant posits the following recommendations for a comprehensive cross-disability; consumer controlled PAS in Pennsylvania.

- ❑ Strategies need to be developed to ensure that a comprehensive PAS Program is designed with consumer advisement and delivered within the framework of maximum consumer empowerment, and control.
- ❑ Bureaucratic structures, inter/intra governmental jurisdictions must be folded into a seamless system of PAS.
- ❑ Workforce development issues affecting recruitment, disincentives to employment and retention must be continue to be addressed.
- ❑ The PAS service model must utilize consumer control and direction to the maximum extent possible.
- ❑ Methods to identify prospective consumers of comprehensive PAS prior to and, when necessary, immediately following any type of institutional placement should be developed.
- ❑ The concept of presumptive eligibility should be implemented so that consumers receive needed supports and services in a timely manner.
- ❑ EPDST advocacy – Given the mandatory legal requirement to cover personal care for persons under 21 and the flexibility available to the State in structuring the coverage to approximate a comprehensive, cross-disabilities PAS program, PAS for persons under 21 using the personal care services option is an area that deserves additional advocacy.
- ❑ An expanded PAS Program or alternatives for PAS, to include the needs of individuals with primary cognitive and sensory disabilities, as well as those who have sensory disabilities that result from or coexist with another disability, such as cueing and decision making, sign-language interpretation, and escort service. How to provide these services under coverable Medical Assistance services needs to be explored and developed.
- ❑ Public and provider education about service options, contact information and where/how to address problems is needed.
- ❑ Outreach efforts must be enhanced and targeted to un-served and under served individuals.

- The Commonwealth should be urged to consider utilizing Section 1115 of the Social Security Act Medicaid Independence Plus Demonstration Project as the model and funding source for a comprehensive PAS Program, as It alleviates barriers uncovered, presented and faced by Commonwealth.

The Section 1115 Independence Plus Demonstration Project:

1. Allows for cross disability and consumer control.
2. Allows for more than one of the Federal eligible groups to be served.
3. Provides for significant cost controls in capping number of eligible individuals.
4. Avoids requirements of institutional level of care
5. Allows for setting medical necessity criteria not based on medical necessity for institutions.
6. Individuals need not be able to direct caregiver.
7. Family members who provide PAS can receive payment.
8. Allows for pilot project in a limited geographical area.
9. Allows for flexibility in income limits for eligibility.