HOME AND COMMUNITY-BASED SERVICES BARRIERS ELIMINATION WORK GROUP

REPORT

Pennsylvania Intra-Governmental Council on Long-Term Care

March 2002

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COUNCIL ON LONG-TERM CARE

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This document is an effort to reach as much consensus as was possible. Not all Work Group participants or their sponsoring organizations are in agreement with all aspects of this report.

HOME AND COMMUNITY-BASED CARE BARRIERS ELIMINATION WORK GROUP REPORT

I. Introduction

The concept of Home and Community-Based Services refers to all supportive services available to assist consumers in living in their home or community through public and private funding. Home and community-based care helps keep families living together. Most people incorrectly believe that Medicare and Medicaid will cover most of their needs for long-term care and services. In fact, Medicare pays for a small fraction of the costs of long-term care, and while Medicaid pays for long-term care, it does so primarily for those in nursing facilities who have exhausted their income and resources to Medicaid's impoverishment levels. Perhaps this is because people live longer and have more medical interventions and rehabilitation opportunities than existed 35 years ago, when Medicare and Medicaid were established.

In the fall of 2000, the Intra-Governmental Council on Long-Term Care formed a work group to evaluate obstacles Pennsylvania's consumers face in their efforts to obtain home and community-based care. The Barriers Elimination Work Group was charged with determining what barriers exist to receiving care and services in the home or community, researching efforts already underway to eliminate some barriers, and make recommendations for the elimination of remaining barriers.

The focus of the Work Group is on all publicly and privately funded home and community-based services (HCBS) for adult consumers with physical disabilities and cognitive impairments, excluding MH/MR services. Public HCBS includes care and services funded by Medicare, Medicaid, or state programs. Private HCBS includes care and services funded by consumer resources or long-term care insurance products.

Many of the barriers discussed herein relate exclusively to publicly funded care while some relate to both publicly and privately funded care.

The Work Group found approximately 22 barriers that relate to lack of information and knowledge about HCBS, the stigma attached to receiving publicly funded HCBS, complexities and delays in establishing functional and financial eligibility for publicly funded HCBS, insufficient services for certain geographic or functional populations, unavailability of affordable housing, shortages in the work force, and lack of quality assurance. While the barriers relate to numerous aspects of the system, the Work Group grouped the barriers in terms of those which are **procedural,** meaning those pertaining to the process for obtaining care or services, those which are **informational,** meaning those pertaining to the information necessary to understand and know about the availability of care or services, and those which are **systemic,** meaning those resulting from deeper systems problems that require policy and attitudinal changes to resolve.

The Work Group concluded that eradicating the procedural barriers to home and community-based services must be the priority. Difficulties and delays in establishing eligibility for care and services must be eliminated and care and services must be made truly available before resources are spent educating and informing the public so that consumers can understand and know about the availability of care or services. Additionally, improving the packages of services through elimination of systemic barriers is the proverbial cart before the horse if the consumer cannot make it through the procedural obstacles to obtaining care and services.

II. Background

One out of every five people in the Commonwealth is over the age of 60[1] and Pennsylvania now has the second-oldest population in the nation, trailing only Florida.[2] Medical breakthroughs have meant that each successive generation can expect to live longer than the preceding one. Those living to be over 100 years of age will spend over a third of their lives in retirement[3] and the result is a "demographic inversion." No longer will Pennsylvania have a considerable population of younger people which triangles to fewer and fewer people up the age ladder. The non-working elderly is becoming a significant portion of our population.

As we age, the likelihood of needing long-term or ongoing care increases dramatically. Pennsylvania's long-term care and services expenses increased by more than 300 percent between 1986 and 1995.[4] Over the last decade, the 85 and older population of the state increased by 61 percent,[5] and almost half of this group will suffer from Alzheimer's disease, requiring significant long-term care and services.[6] In addition to the needs of the elderly population and those with Alzheimer's, individuals with disabilities also comprise a significant population in need of long-term care and services.

Long-term care impacts more than just its recipients. Family members and friends face enormous physical, emotional, and financial burdens when needs arise. Approximately 80 percent of long-term care is provided in the home by friends and family members,[7] usually women, serving as a critical source of long-term care for persons needing assistance with activities of daily living.[8] Many people who need long-term care have been able to remain at home because of the assistance of family members. These days, however, fewer seniors live near their adult children, and women are increasingly unavailable to provide assistance because they are in the work force, juggling careers and family responsibilities.

III. Why does access to home and community-based services need to be improved in Pennsylvania?

Today, an estimated 746,000 Pennsylvanians need long term care.[9] Seniors and other people with long-term care needs in Pennsylvania usually cannot pay for the cost on their own. The costs over time are simply too large.

Long-term care insurance has not been widely utilized. Long-term care insurance has been purchased by only 2–3 percent of seniors.[10] By the time people begin to think about the need for help to pay for long-term care, they usually cannot afford long-term care insurance because the premiums for a person their age are beyond their reduced retirement income. The average persons seeking long-term care are a nearly 70-year-old couple with an annual income of less than $35,000, who cannot afford long-term care insurance premiums of several thousand dollars a year.[11]

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[1] Pennsylvania Department of Aging, *Draft State Plan on Aging* 2000–2004, p. 7.

[2] *Id.*, p. 2.

[3] *Secure Aging: The New Society Branches*, May 2000, Jewish Health Care Foundation.

[4] Pennsylvania Department of Aging, *Long-Term Care Fact Sheet*

[5] Pennsylvania Department of Aging, *Draft State Plan on Aging* 2000–2004, p. 8.

[6] National Alzheimer's Association Fact Sheet data.

[7] Pennsylvania Department of Aging, *Long-Term Care Fact Sheet*, p. 1.

[8] Merlis, Mark, *Financing Long-Term Care in the Twenty-First Century: The Public and Private Roles*, *Commonwealth Fund*, p. 4.

[9] *Assisted Living: A Choice for the Future*, Pennsylvania Intra-Governmental Council on Long-Term Care, p.3.

[10] Merlis, Mark, *Financing Long-Term Care in the Twenty-First Century: The Public and Private Roles*, *Commonwealth Fund*, p. 8. Private insurance spending for long-term care for the elderly amounted to only 1 percent of the total nationally in 1995.

[11] *Secure Aging: The New Society Branches*, May 2000, Jewish Health Care Foundation. In Pennsylvania private insurance paid for 1.95percent of nursing facility care in 1997. Source: *Long-Term Care 2000 Statistics and Information*, The Pennsylvania Association of Non-Profit Homes for the Aging, Winter 2000, p. 23.

The situation for working age adults is not much better. Most do not realize they are one serious accident or illness away from facing the same problems that seniors face when they have long-term care needs. Most of us rely on employer-based health insurance for our health care. A serious illness or injury that requires long-term care usually means the loss of one's job and its accompanying health care coverage. Just when health care coverage is really needed, it is lost because of the inability to work. Because the paycheck stops, purchasing the continuation of that coverage through COBRA is not possible. Medicare is not available until two years after Social Security Disability payments start! Once Medicare is obtained, it does not cover most long-term care needs, because Medicare was designed to cover acute care and rehabilitation. Most long-term care needs are for personal care services for chronic illness — the kind of care not covered by Medicare.[12]

As a result, persons in need of long-term care (1) depend on children for direct care or financing; (2) become impoverished to qualify for state-funded nursing facility care; or (3) do without needed services and support.[13] The majority, in fact two-thirds, of those who require long-term care will require public funding for that care at some point. With so many Pennsylvanians requiring publicly funded long-term care, it is essential to evaluate the publicly funded care that is available in Pennsylvania.

Until recent years, Pennsylvania has had a considerable institutional bias in its long-term care spending. While significant efforts have been made in the past couple years to shift resources and to focus attention to home and community-based services options, Pennsylvania has not completely purged its long history of institutional bias from its long-term care system.

Pennsylvania spends a large portion of its Medicaid dollars on long-term care, in fact two-thirds of its entire Medicaid budget is spent on long-term care. However, well over 90 percent of this long-term care expenditure is spent funding care delivered in nursing facilities.[14] While this percentage has shifted in recent years from the high 90 percentiles to the lower 90 percentiles, the number remains above 90 percent. Far too often persons needing long-term care receive it in a nursing home because of inadequate public funding for long-term care services in the community. What this report finds, is that far too often persons needing long-term care receive it in a nursing home because of difficulties and delays in obtaining it in the home or community.

The costs for Pennsylvania of financing a long-term care system that primarily relies on nursing home care for a rapidly increasing group of people will be prohibitive. Soon the need for long-term care and the costs of providing it primarily in a nursing home will overwhelm the ability of our work force to pay for this care. Pennsylvania taxpayers presently pay 40 percent more per capita towards the costs of long-term care than does the average taxpayer because of the Commonwealth's heavy reliance on nursing facility care.[15] Our ratio of working persons to seniors is among the lowest in the country.[16] We need to find more cost efficient means of providing long-term care and providing care and services in the home or a more residential setting in lieu of a nursing facility. The Commonwealth's own

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[12] *Secure Aging: The New Society Branches*, May 2000, Jewish Health Care Foundation. In Pennsylvania private insurance paid for 1.95percent of nursing facility care in 1997. Source: *Long-Term Care 2000 Statistics and Information*, The Pennsylvania Association of Non-Profit Homes for the Aging, Winter 2000, p. 23.

[13] *Id.*

[14] *Id.*

[15] Merlis, Mark, *Financing Long-Term Care in the Twenty-First Century: The Public and Private Roles*, *Commonwealth Fund*, p. 15. Medicaid long-term care spending per working-age adult in Pennsylvania is $254.25 as compared to a national average of $146.13.

[16] *Id.*

data supports this premise, as does the experience of multiple other states. In 1998, the average Medicaid cost for Pennsylvania to provide home and community-based services to a nursing home eligible person in her own home was $12,780/year. The same cost to provide those services in a nursing facility was $31,653.[17]

Pennsylvania is spending proportionately far more on nursing facility care than on home and community-based long-term care services.[18] Pennsylvania's taxpayers spent 40 percent more per capita on nursing home expenditures[19] and 92.6 percent less per capita on home and community-based services than the national average.[20] In actual dollars, the Pennsylvania Medicaid Program spent $160.57 per capita on nursing facility care vs. $1.20 per capita on home and community-based services for the aged and persons with disabilities.[21] There is a significant disparity that causes Pennsylvania to rely almost exclusively on nursing facility care to serve the long-term care needs of its Medicaid population.[22]

The latest statewide data shows that with regard to Medicaid long-term care funding, Pennsylvania has been spending its long-term care public funding on supporting 54,208 persons in nursing facilities (92 percent)[23] in comparison to 4,563 persons receiving home and community-based services for aged and persons with disabilities (8 percent).[24] With regard to other state funding, Pennsylvania supports approximately 11,000 non-nursing home eligible SSI recipients who reside in personal care homes through the state SSI supplement.[25] Notwithstanding, the long-term care funding for nursing home eligibles (who cannot, by law, reside in personal care homes) does not adequately meet consumer preferences or cost benefit analyses.

Consumers prefer more residential settings. Nursing facilities are not the consumer's first choice of long-term care setting. Generally, they are a last resort. A system that funds institutionalization over all other options has the effect of sometimes institutionalizing persons who require assistance with activities of daily living who could otherwise be served in their home or community. People who don't have a choice feel they are denied their independence and dignity. It is not what people want[26] or deserve. People with long-term care needs want to remain at home as long as possible. If that home represents an unacceptable health risk, they want to be in as homelike a place as possible where they will retain their independence,

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[17] Data provided to the Assisted Living Work Group of the Pennsylvania Intra-Governmental Council on Long-Term Care by the Pennsylvania Department of Public Welfare and Governor's Budget Office.

[18] Newcomer, R.J., Harrington, C., Tonner, M.C., LeBlanc, A., Crawford, C.S., Ganchoff, C., Wellin, V., *Medicaid Home and Community Based Long Term Care in Pennsylvania*, Department of Social and Behavioral Sciences, University of California, San Francisco, May 2000. Comparing non-MR HCBS waiver programs to Medicaid nursing facility ratios, in 1997 in Pennsylvania the number of waiver participants was only 4 percent of the number living in institutions. *Id.*, p. 28.

[19] Merlis, Mark, *Financing Long-Term Care in the Twenty-First Century: The Public and Private Roles*, *Commonwealth Fund*, p. 4.

[20] Newcomer, R.J., Harrington, C., Tonner, M.C., LeBlanc, A., Crawford, C.S., Ganchoff, C., Wellin, V., *Medicaid Home and Community Based Long Term Care in Pennsylvania*, Department of Social and Behavioral Sciences, University of California, San Francisco, May 2000. Comparing non-MR HCBS-waiver programs to Medicaid nursing facility ratios, in 1997 in Pennsylvania the number of waiver participants was only 4 percent of the number living in institutions. *Id.*, p. 28.

[21] *Id.*

[22] *Assisted Living: Long-Term Care and Services Discussion Sessions and Findings*, February 1999, Pennsylvania Intra-Governmental Council on Long-Term Care, p. 14, quoting the April 1999 State Long Term Care Profiles Report.

[23] *Utilization by Facility*, January 1 through December 31, 2000, PA Department of Health, Bureau of Health Statistics (Based on the number of patient days paid by Medicaid).

[24] PA Department of Public Welfare, Aging Waiver Enrollment Records for FY 1999–2000.

[25] This funding is not part of the Medicaid long-term care funding and personal care is, by definition, not considered long-term care.

[26] *Assisted Living: Long-Term Care and Services Discussion Sessions and Findings*, February 1999, Pennsylvania Intra-Governmental Council on Long-Term Care.

privacy, dignity and freedom of choice.[27] This has not been possible in Pennsylvania, except for our most affluent citizens.

Since 1997, the Pennsylvania Intra-Governmental Council on Long-Term Care has reported that Pennsylvanians overwhelmingly want to remain independent and at home as long as possible. They want respect and dignity as well as consumer choice. The Council's reports were developed from information gathered during several sets of structured discussion groups held throughout the state over four years.[28] The philosophy of **consumer choice** drove the participants' responses: people want to have control and choice concerning their long-term care needs. They believe that funding should be directed to those long-term care services they need and want, rather than to those services that have traditionally received the largest share of funds. They believe long-term care and services should include a combination of supportive services and personalized assistance services designed to respond to individual needs of those who need help with activities of daily living and instrumental activities of daily living.

In addition to the fiscal and policy reasons for improving access to quality home and community-based services options, is the 1999 U.S. Supreme Court case L.C. *v.* O*lmstead*.[29] The O*lmstead* case requires all states, including Pennsylvania, to rethink how they use the public resources available to them in providing services and supports to persons with disabilities.[30] Finding that a public funding system that offers insufficient home or community-based options has the effect of segregating persons with disabilities from the rest of society, the Supreme Court required states to eliminate the institutional bias from their public spending.[31] The O*lmstead* decision is comparable to the 1956 U.S. Supreme Court decision in B*rown vs*. T*he* B*oard of* E*ducation*.[32] It not only requires states to remedy their policies that segregate but also calls for states to do so with the same kind of "all deliberate speed" standard that B*rown* required for desegregating schools.[33] It is by this standard that states will be measured in evaluating whether they are appropriately and expediently responding by developing community-based services for persons who have been or will be inappropriately placed in medical institutions.[34]

As noted earlier, Pennsylvania has made significant strides in recent years. The situation described above has improved from where it had been just a few years ago. Some important steps that Pennsylvania has recently taken to begin to address this problem include:

- Increasing HCBS services funded through tobacco settlement funds;
- Limiting Medicaid funding for new nursing facilities, so that new funds will be used for home and community-based long-term care;
- Establishing the Bridging Program to address needs of persons with resources higher than

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[27] *Assisted Living: Long-Term Care and Services Discussion Sessions and Findings*, February 1999, Pennsylvania Intra-Governmental Council on Long-Term Care.

[28] *Id*.

[29] O*lmstead v.* L.C., 119 S.Ct. 2176 (1999).

[30] Letter to State Medicaid Directors, January 14, 2000, Department of Health and Human Services, from Timothy Westmoreland, Director of Center for Medicaid and State Operations, HCFA, and Thomas Perez, Director, Office for Civil Rights, HHS.

[31] The decision was grounded in the 1990 Americans with Disabilities Act.

[32] T*he* Olmstead D*ecision*: I*mplications for* M*edicaid*, Kaiser Commission on Medicaid and the Uninsured, March 2000.

[33] More recently, President Bush has announced the New Freedom Initiative: Fulfilling America's Promise to Americans with Disabilities. Goals of this initiative are to: "Ensure that existing federal resources are used in the most effective manner to swiftly implement the Olmstead Decision and support the goals of the ADA" and evaluate "policies, programs, statutes, and regulations to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities." http://www.hhs.gov/newfreedom/

[34] T*he* O*lmstead* D*ecision*: I*mplications for* M*edicaid*, Kaiser Commission on Medicaid and the Uninsured, March 2000.

the Pennsylvania Medical Assistance Program permits;
- Hosting the Home and Community-Based Services Fall Planning Series and establishing a HCBS Stakeholders Planning Team;
- Expanding medical assistance for workers with disabilities;
- Implementing a nursing home transition grant;
- Developing and promoting a Long-Term Care Helpline and Web site;
- Developing a brochure for Medicaid waiver-funded HCBS;
- Developed estate recovery regulations and a brochure for the general public.

However, we will not realize the potential of all this important work, or work towards a paradigm change in how we pay for and provide long-term care services, if we do not also aggressively eliminate the barriers that consumers face when they attempt to use publicly funded HCBS services in lieu of publicly funded nursing facilities.

IV. What barriers do consumers face in trying to obtain services in their home or community?

For the last year, the Barriers Elimination Work Group of the Pennsylvania Intra-Governmental Council on Long-Term Care has worked to identify barriers that consumers face in accessing home and community-based services. As described in the Introduction, the 22 barriers identified fell into several groups: 1) procedural, 2) informational, 3) systemic, etc.

The procedural barriers include the problems consumers face applying for and becoming eligible for services. The applications all differ, the processes all differ, and the information required by funding sources differs. The need for long-term care services is immediate, but the approval process is lengthy and complicated. Those who need services are not able to immediately obtain services under most programs and this is a barrier. These are the barriers that the Work Group recommends be eliminated first.

The informational barriers include the lack of understanding about existing home and community-based services, the lack of publicity about home and community-based services, the multitude of different programs, and the welfare stigma of receiving services from the Department of Public Welfare.

The systemic barriers include the lack of uniformity of services available under the programs, the lack of services available until one has deteriorated to "nursing home eligible," the lack of coverage of certain services, the narrow categories of coverage under some programs, and the lack of financial support for housing costs where inability to pay those costs would cause unwanted institutionalization.

A. Procedural Barriers

It can take months and months for persons needing publicly funded home and community-based services to establish their eligibility and begin to receive services, despite their best efforts. Most nursing home eligible people cannot exist for that period of time without these critical services. Nor can their families take time off from work to fill the gap until verification information is amassed, applications are finally processed, and services are arranged. Nursing facilities are able to and permitted to assume the risk that a person will not be found functionally or financially eligible for publicly funded services and, consequently stand ready and willing to provide immediate bundled services, assist in the MA application process, and receive retroactive MA payment. The lengthy procedural barriers for both MA and HCBS eligibility mean that HCBS are not truly an option for most eligible people who are instead forced to seek the more immediate admission to a nursing facility. Tobacco Settlement funds have created significantly more HCBS, but until this barrier is eliminated, waiver services may go unclaimed and nursing facility occupancy will remain high. It is for this reason that the Work Group feels this problem deserves the highest priority to resolve.

The process for applying for and establishing eligibility for state or federally funded home and community-based services programs is unduly

burdensome at best. The application for services differ from program to program, the process for applying for services differs from program to program, and the information required by funding sources differs from program to program. Even if one follows all steps necessary to qualify for services, it is challenging to obtain services because the portals to the system are fraught with miscommunication, misunderstanding, and other problems. Merely completing the application process can often be so cumbersome that applicants fail to get needed services solely because they were unable to understand or swiftly produce what is needed. No applicant is able to obtain prompt services, making home and community-based services an infeasible option for most being discharged from a hospital or other healthcare institution.

Barrier 1: The process for determining eligibility and arranging for and starting services takes too long.

In order for home and community-based services to be a meaningful alternative to placement in a nursing facility, they must be a practical alternative. When it takes months to apply for and implement services under a home and community-based services waiver program, the waiver services cannot be part of a discharge plan from a hospital or rehabilitation facility. Few can dispute that when people are in need and/or in a crisis they'll use and choose the quickest, most accessible, and readily available solution to their problem, even if they would not have otherwise selected that option.

Another factor that makes getting services in a nursing home far more swift and hassle-free is the surplus of available beds in the state's licensed facilities.[35] By considerable contrast, there have been persistent (although declining) waiting lists for obtaining home and community-based services in one's home. In the fall of 2000, it was estimated that approximately 1,670 nursing home eligible persons age 60 or over were on waiting lists for receiving services in their homes.[36] Some 4,800 other persons age 60 or over were not nursing home eligible but were on waiting lists for supportive services in their homes.[37] The Work Group hopes that the influx of PDA waiver slots due to the Tobacco Settlement funds will help improve the availability of this waiver.

As stated above, nursing facilities are often able to provide immediate access, through a form of presumptive eligibility. The facilities assume the risk that the person will not be found Medicaid eligible or have a family member do so. The effect is that those who appear like they will be eligible are treated as eligible and services are started immediately. Nursing homes subsequently complete all the necessary paperwork to ensure that they receive retroactive payment. This is not presently possible for those who wish to remain in and receive services in home or community-based settings. Even though CMS has authorized states to make interim services available, Pennsylvania is not doing this.[38] Additionally, many HCBS providers are not permitted or not able to assume the risk that the applicant will be found ineligible.

Attached as Exhibit A is the chronology of a real-time example of the lengthy process for applying for home and community-based services. In this case, it took almost 12 months for a

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[35] Although Pennsylvania's licensed beds per 1,000 persons aged 65 and older are 51.2, just below the national average of 53.1, the homes are generally not filled to capacity. On the whole, the supply of beds in facilities, even the more residential settings, is at a surplus, making these settings far more accessible to a person with an immediate need for services. Pennsylvania's licensed personal care beds per 1,000 persons aged 65 years and older is above the national average. Pennsylvania has 31.7 beds per 1,000 persons aged 65 and older vs. a national average of 24.3. Personal Care Homes are, on average, only at a 65 percent capacity.

[36] Current information provided by the Pennsylvania Department of Aging.

[37] *Id.*

[38] *Dear State Medicaid Director Letter #* 4 in the Olmstead series.

woman who wanted to remain at home and was clearly eligible to obtain HCBS with the help of an attorney. On average, it can take anywhere from 3–4 months to 10–12 months to get from needing or wanting HCBS to actually having HCBS. The example case, however, is illustrative of the delays faced by far too many applicants for HCBS.[39]

***Work Group Recommendations*:**

- Processing of completed MA applications for HCBS must be expedited. Interim MA coverage of HCBS as authorized by CMS must be provided within three days of submission.
- The CAO, or some more consumer-friendly entity, must advise applicants of what is still needed to complete incomplete applications within three business days of submission *and assist consumers to obtain that information.*
- State funds or Olmstead interim funding (the federal government will pay up to 180 days) should be used to provide interim presumptive eligibility services for HCBS.
- Functional eligibility must be done more expeditiously or allow the draft care plan to be used to start services under the presumptive eligibility model, with AAA to do follow-up to verify.

Barrier 2: There is nothing simple or seamless about it: applying for services is too convoluted.

Presently "waiver programs" are identified as discreet, distinct "programs." This makes applying for home and community-based services a complicated process. First, a consumer must try to determine which waiver program to try to apply for. Procedurally, locating the appropriate application to complete and the appropriate agency through which to complete and submit it is difficult. The burden is on the consumer to identify his/her needs and the costs of providing those services (to demonstrate that the costs are less than receiving those services in a nursing facility) and then to locate the agency through which to apply for services and funding. This is particularly true for under 60 years old waiver applicants.

The system must become simple, seamless, and much, much easier to apply for. The consumer and/or family know that long-term care services are needed for the applicant to remain in the community. Initially that should be all the consumer should need to know. The consumer's articulation of this need should trigger an application for available services from appropriate programs. Application should be made through a single, simple application — available on the Web, through the Hotline, or from a variety of other sources. The state should then determine what program or programs would be most appropriate for the applicant and should assist the consumer in obtaining any additional information that is necessary. This would eliminate a present problem that an individual who mistakenly applies for services through one waiver program must apply anew to a different waiver program, if the first waiver program is found to be inappropriate.

***Work Group Recommendations*:**

- Home and community-based services should be generally advertised and promoted without demarcating different waiver programs that cover different services for different populations.[40] Consumers should simply apply for available services and an overall benefits/programs check should be completed.
- A single, simple, seamless application should be used for all long-term care services, health care and the PACE/PACENET Program.

[39] Although a small part of the delay was due to the family having trouble finding and amassing the voluminous documentation that is necessary, the lion's share of the delay was due to miscommunication or non-communication by the CAO.

[40] Some of the programs are exactly the same in terms of who they serve and what they offer, with funding streams and eligibility requirements differing.

Barrier 3: The requirements for making a Medicaid application "complete" are overwhelming.

Presently, the applicant is required to compile extraordinary amounts of documentation and verification to prove their functional and financial circumstances. They generally have to do so without assistance, as the CAO staff will not assist them, instead denying the application if the documentation is not produced. (See Appendix A.) Many who need services are denied eligibility due to inability to meet the paperwork requirements. Many of those end up, instead, in nursing facilities, which have staff to assist in the documentation necessary to secure MA payment for their facility.

Much of the verification necessary to qualify for HCBS could be more simply and swiftly obtained by the CAO or could be directly obtained electronically by the state from other state and federal agencies with which the state already has arrangements. For example, the face and cash surrender values of life insurance policies could more simply and swiftly be obtained by a county assistance office caseworker with direct connections and repeated relations with an insurance company than by a consumer who has no idea of how to do so. Similarly, when the state already has access to Social Security Administration resources to verify an applicant's income, the state can more simply and swiftly obtain this information on its own than by placing the burden on the applicant to locate the source of the information, make a request, await a response, and submit the response to the state.

***Work Group Recommendation*:**

- The procedural barrier of substantiating financial status must be eliminated by reducing the burdensome verification requirements (to the extent permissible under federal law), by requiring CAO personnel to verify all information that is independently verifiable, and by providing personnel to assist consumers and families in getting documentation and information necessary to apply.

***In the works since the Barriers Elimination Work Group began*:**

The Department of Public Welfare has made available a uniform on-line application for healthcare for children and pregnant women (COMPASS). It is anticipated that within 6–18 months, consumers will be able to complete and submit MA eligibility applications over the Internet. Whether this will be on a shorter, more simplified application form for which less verification is required is unknown. The application for long-term care, but not waiver programs, is to be included by 2002. This, however, does not address the income and resource verification needed for long-term care.

Barrier 4: The amount of time to obtain functional determinations must be reduced and clear eligibility criteria must be established.

The timeframes for obtaining face-to-face functional assessments are impracticable if home and community-based services are going to be a real alternative to nursing home care. Presently an assessing agency has two weeks to do its assessment after it has received a referral with the doctor's paperwork (the MA-51). Getting the MA-51 back from the doctor's office can alone take weeks. As a result, the time lapse from the date of referral to the date of assessment can be a good six weeks or more. Once the assessing agency is done assessing functional needs, the application goes to the state for its determination as to whether the applicant meets the particular waiver's functional requirements. There is no deadline for the state to respond and, consequently, applicants can wait months to receive a decision on whether they will be functionally eligible for a specific program.

The explicit admission criteria for a given program are often not articulated. The state or contracting agency has discretion to determine who will be served. Thus a person with a disability needing attendant care, who is otherwise financially and functionally eligible, must wait to

see if the state's contracting agency will determine that s/he can safely be served in the community (a CMS waiver requirement), can self-direct their care, etc. These agencies do so, however, without explicit criteria to make these determinations. Although appealable, this determination can be critical for consumers and can impact how much further delay may result.[41]

***Work Group Recommendations*:**

- There must be prompt timeframes for state and contracting agencies to evaluate applicants and render decisions on providing services. Existing timeframes must be shortened to insure swift entry into home and community-based services programs.
- There must be formalized criteria, developed with stakeholders input, to determine whether a person who is functionally and financially eligible, should be able to receive services at home.
- Distinct timeframes for initiating services must also be articulated as part of care planning. Delays in arranging services are often incurred after a consumer is finally found financially and functionally eligible and approved for HCBS.
- The state should be maximizing the possibilities of interim services as described in the CMS' Dear State Medicaid Director letter on O*lmstead*, instructing states to use up to 180 days of interim funding to begin implementing available services while locating providers for unavailable services.

B. Informational Barriers:

In order to access home and community-based services, a consumer must be informed of what services are available and how to get them.

Barrier 5: There is a significant lack of information and clear understanding by the consumer about what HCBS are, how to access them.

Too many consumers who need long-term care and services are unaware that:

- those services are available in the home or community in a variety of settings;
- there are people available to assist them in obtaining those services; and/or
- for many, those services are partially subsidized or free.

It is no wonder that people are either confused or unaware of their long-term care options. The types of services a person can receive depend on their level of care needs and the setting in which they would receive them.[42] There are multiple funding sources for long-term care services: Medicare, Medicaid, state funds, personal funds, and private insurance. There is no uniformity of benefits, coverage limits, medical necessity requirements, or terminology among the third-party payers of long-term care. Those with long-term care insurance are often unaware of coverage limits and those without it are often unaware that other funding sources are available.

The options for long-term care are many, but they are confusing and often unknown, and once known, are often overwhelming. This is exacerbated when there is a sudden need for long-term care after an unexpected hospitalization. Families are anxious, emotional, and under intense pressure to immediately arrange long-term care because of an imminent discharge. Trying to understand options in such a situation is extremely difficult. This problem is made worse by the fact that too many social workers, discharge planners, hospital administrators,

[41] For example, where the state finds that the existing level of care an applicant is receiving by existing providers is inadequate, the time it takes to staff up for additional hours or challenge whether additional hours should be imposed can be great.

[42] For instance, Medicare will only pay for very limited skilled nursing facility care, but Medicaid will pay for lengthy nursing facility care if the person is "nursing facility eligible." Medicaid will pay for HCBS in the home, but generally not in a personal care home or assisted living residence.

health plan case managers, and others in positions to direct consumers to services in the home are also unaware of the existence of a broad array of services available through public and private funding. If they are aware, they know that these services often take months to arrange, and hospital or rehabilitation center's payment systems cause intense economic pressure to discharge the patient. The quickest place to discharge a patient is to a nursing facility.

Work Group Recommendations:

- Pennsylvanians of all income levels need to be educated and informed of all their options *at critical decision points*, e.g. during a hospital stay prior to discharge, when they request NF, by physicians, at Senior Citizen Centers, etc.
- Information should be targeted to consumers not only before they need long-term care, but also at those crisis points when they suddenly need long-term care services. The Council focus groups of consumers consistently said the most critical time for this information is when someone has suddenly been hospitalized, needs long-term care, and the hospital is putting pressure on the family to move the consumer out. It is critical that this information be available at all hospitals and doctors' offices.
- Not only consumers need to be educated but also *discharge planners and other essential staff at healthcare institutions need to be informed*. The primary message should be: "When you need long-term care, you have choices. Here they are. Here is how to access services."
- I*nformation needs to be available in a variety of formats*: written, web-based, newspaper, radio, television, bus signs, etc. To change the paradigm, we need a media blitz such that the public no longer automatically associates the need for long-term care services with nursing facilities. This will take a sustained, multimedia effort.
- I*nformation needs to be simple and understandable*.
  - With regard to private pay consumers, the Insurance Department should work to require standardized long-term care insurance policies, similar to the standardized Medicare Supplement policies. This would permit consumers to better understand coverages, durations, caps, and gaps and to feel more comfortable about purchasing such coverage.
  - With regard to publicly funded care and consumers, the Commonwealth should have a single, seamless waiver application process to apply for all long-term care services. The information needed from the consumer must be clearly and understandably stated in the application.
  - The TV *portion of the media campaign* should model itself after the very successful CHIP/MA commercials, running with very popular programming watched most by the target group and prominently promoting a toll-free informational and assistive hotline. It should be done statewide.
  - *The Commonwealth should have a dynamic web page*, which permits the user to enter data on needs and county location and receive customized information on how and where to apply for available programs for which the consumer appears eligible. The inputted information should flow into the single, simple application to permit consumers to apply online. (This could be similar to the Commonwealth's COMPASS initiative.) Courteous trained staff should follow up with consumers to help them complete unfinished portions and obtain needed verification information.

In the works since the Barriers Elimination Work Group began:

As of December, 2001, the state has launched the Long-Term Care web site and has staffed the Long-Term Care Toll-Free Helpline. These tools are means to provide answers to questions about what services are available. They do not provide assistance beyond information and referral. The Helpline staff members don't assist in applying for services. The web site is not interactive and does not yet include online applications. This has been a joint effort to PDA, DPW, PID, and DOH. It is a good first step, but needs to be expanded. The Department of

Health is conducting a large media outreach campaign to publicize the availability of the web site and the hotline.

Additionally, the Department of Public Welfare has published and posted on its web site considerable information about the home and community-based waivers. These materials, however, refer readers to the long-term care helpline, where they may have additional questions answered and eventually be referred further for instructions on application for services.

Barrier 6: There is a lack of knowledge about how to access home and community-based services.

The current piecemeal approach to home and community-based services reflects the state's continued interest in adding services and plugging coverage gaps. However, the result is a convoluted and perplexing system that is mystifying for most consumers. There is a significant lack of knowledge about how to access waiver programs, where to apply, how to apply, what the criteria are, etc.

***Work Group Recommendation*:**

- The state should embark on major education and outreach campaign on HCBS generally. This should include development of a glossy, attractive, non-DPW-looking information packet that gives HCBS options that are community-specific and could be used by the AAAs, discharge planners, CAOs, providers, DPW to MA and Health Choices plan to help inform consumers of their long-term care options. This packet should describe all programs and how to apply, using the single, simplified uniform application suggested above. This packet should be used with the media campaign and the hotline described above.

***In the works since the Barriers Elimination Work Group began*:**

The newly launched Long-Term Care web site and Long-Term Care Toll-Free Helpline are designed to help inform consumers of their long-term care options and how to apply for services. An attractive HCBS waiver pamphlet has been produced by DPW describing the various waiver programs. While the Long-Term Care web site and Toll-Free Helpline as well as the brochure provide information about services and programs available, they do not provide step-by-step details on getting through or assistance with the application process.

Barrier 7: There is a considerable amount of stigma surrounding the home and community-based services programs.

HCBS waivers are part of the Medicaid Program, which until recently has been closely tied with welfare. Our historic approach to welfare programs has included the goal of dissuading use of welfare programs. Since the 1500s, it was common for applicants to be given meager benefits, required to go through a lengthy and demeaning application process, and made to feel badly about using the services. While no longer the goal, the system remains one in which consumers feel dissuaded, demeaned, and embarrassed.

Older persons needing long-term care services have spent their entire lives trying to be self-sufficient and avoid welfare. They have no qualms about getting health care through Medicare because they feel they have earned it. They've paid their taxes for years and years so that Medicare would be there for them when their employer-based insurance ended. There needs to be a similar feeling about using Medicaid-funded HCBS. People have paid their state and federal taxes and used their private resources to provide for their long-term care needs. As their resources/income become reduced and their long-term care needs increase, these Medicaid programs funded by their tax dollars exist to assist them to remain at home just as Medicaid would assist them to live in a nursing facility. Considerable attention is needed to shift attitudes so that shame is not a barrier to care and services.

Presently, we identify Medicaid "waiver programs"

or state-funded programs as discreet, distinct "programs." By contrast, we should be advertising and promoting home and community-based services and not demarcating different programs that cover different services for different populations. Some of the programs are exactly the same in terms of who they serve and what they offer; the only difference is funding streams and corresponding financial eligibility requirements. In other words we create a "waiver program for the poor" and then wonder why people don't want to participate. Years ago the PDA began the Aging Block Grant as a way of combining the funding streams at the state level and offering "services for the elderly" at the local level. For all intents and purposes, a person who gets services from the AAA doesn't know and may not care what the funding stream is. Yet, they also do not want to be labeled or stigmatized as participating in a program for the poor. Because perception of many essential services as "welfare" poses a serious barrier to accessing care, the state must work to eliminate the stigmatizing aspects of the home and community-based services systems.

***Work Group Recommendations*:**

- The program must be renamed and repackaged and all vestiges of the demeaning stigma of needing "welfare" need to be removed from the program.
- The program must have less apparent identification as "welfare" program and efforts must be made to minimize contact with "welfare" offices.
- The application, the brochures, and the media campaign all must be glossy, attractive, non-bureaucratic-looking, such as has been done with the CHIP Program.
- Language and terminology must be reassigned. Terminology such as "nursing home eligible" is a turn-off to many eligible consumers. Many individuals would never consider themselves "nursing facility eligible" even if they meet the clinical criteria. Instead, use "in need of long-term care services." We also need to rid vocabulary of the term "waivers;" instead call it a program, or a menu of services.
- Use focus groups to test the renaming, repackaging, applications, brochures, and program name and lingo used.
- Use focus groups to test the consumer friendliness and helpfulness of all groups that come into contact with an applicant/family member: the Hot Line Staff, Intake Workers, AAA staff, etc. Use consumer satisfaction surveys thereafter.
- Funding streams should be seamless with one application.
- The entire thrust of the program must change to one that is consumer friendly, helpful, encouraging, and non-bureaucratic, etc.

C. Systemic Barriers

There are 10 different Medicaid home and community-based services waiver programs. There are at least six different state-funded programs that also provide home and community-based services. These programs are all designed to meet the needs of different populations. They offer different service packages, have different caps on services, and their services are not available statewide. Another major systemic barrier for most of these programs is that one cannot access services until one has deteriorated to the point of meeting the clinical measure of "nursing home eligible," a point many who meet the criteria would never want to believe themselves to be in. Another systemic barrier is the virtual lack of financial support for housing costs where a person's inability to pay those costs would cause his/her unwanted institutionalization.

Barrier 8: The lack of uniform availability of a comprehensive package of HCBS across the state.

There are three problems with the availability of a comprehensive package of HCBS across the state for consumers needing long-term care services:

- Not all the waivers contain comprehensive services or have been updated to add new needed services. For instance, the AIDS waiv-

er is very outdated. Some waivers contain service caps, others do not.
- Some services are not available in some counties. For example, Adult Day Care is not available in all counties. This is a critical service available through the PDA Aging Waiver. For many, this is an essential service component necessary to support consumers in their homes rather than in a nursing facility.
- In other counties, some services on the waiver menus are available but with such limited capacity that there are long waiting lists, effectively making that particular home and community-based service unavailable.

Comprehensive waiver programs are not truly available statewide unless the services available through those waivers are also available in all counties. It is essential that efforts be taken to insure that the services available through a waiver actually be equally available across the state and throughout the different counties. There should not be counties where certain waiver programs are effectively not available. There should also be more comparability among the waivers for long-term care services needed by all consumers.

***Work Group Recommendations*:**

- Counties should be surveyed to determine the existence and availability of services through all the long-term care programs.
- Waiver programs should be analyzed to determine whether additional services should be added to make waivers more uniform and to better meet consumers' needs. Programs should be modified and improved.
- Where service gaps or capacity exits, the Commonwealth should work with counties to address this problem.

***In the works since the* Barriers Elimination *Work Group began*:**

The Department of Public Welfare has been studying several of the waiver programs to evaluate the equity of access to services within the service areas.

Barrier 9: More services needed for those not yet nursing home eligible.

While it is understandable for the state to want to target its funding on service for those with the greatest care needs, it is counterproductive to do this without also funding the services that would prevent others from deteriorating to the point of having great care needs. While personal care homes are available and the lottery funded OPTIONS program provides services to persons over 60 who are not yet nursing home eligible, this is not enough. Lottery funds are insufficient to meet the needs for these services by older Pennsylvanians and are not available for younger persons. Personal care homes are not paid to meet great personal care needs of residents.

By way of example, consider a 59-year-old woman who requires assistance with medication self-administration and monitoring her blood sugar levels and health status, but who is not quite nursing home eligible. The failure to provide her with the assistance she requires will, in time, cause her health to deteriorate to the point where she will require even greater assistance and meet the standard of being "nursing home eligible." This is just not sound fiscal policy. A continuum of long-term care services needs to be provided for those without the income and resources to pay for them. Where possible, the state should leverage as much federal funding as possible to do so.

***Work Group Recommendations*:**

- Personal care services, subject to prior authorization should be added to the Medicaid state plan. This would permit the state to provide services with cost controls to people of all ages with limited income and resources to prevent unnecessary deterioration. By adding this to the state plan, the federal government would pay for more than half the costs.[43]

[43] Twenty-six states offer personal care services through their state plans.

- The Medicaid state plan should also be amended to permit more than the present limit of 15 home health visits/month, to permit a higher number that meets the needs of those needing long-term care but not qualifying for Medicaid HCBS, and to prevent unnecessary institutionalization. Soon most of the state will be in HealthChoices and the HMOs can appropriately manage the number of home health visits.
- Adequate dedicated funding should be provided for persons with long-term care needs, and limited means who do not qualify for lottery, Medicaid, or waiver services.

Barrier 10: Misunderstanding and dislike of estate recovery program.

Until Fall 2001, Pennsylvania did not have clear regulations implementing the federal Medicaid estate recovery requirements. The old system was misunderstood and strongly disliked by consumers. While the regulations clarify how estate recovery will work, consumers will need to understand how estate recovery works. They are currently concerned that the receipt of home and community-based services will force them to lose their homes during life or prevent any family from inheriting the home. And, even though the regulations do not call for loss of house or preclude certain people from inheriting the house, estate recovery continues to remain a significant reason for some to reject needed services. Even with an understanding of estate recovery, there are those consumers who will reject needed services.

***Work Group Recommendations*:**

- Focused educational outreach and consumer education materials need to be developed to explain estate recovery to potentially eligible waiver applicants.
- AAAs should systematically monitor the take-up rate of HCBS slots and track why eligible consumers refuse waiver services. This should be analyzed to determine if estate recovery or other policies are deterring eligible consumers from using needed services and should be modified. Those who reject HCBS should be tracked to determine how they met their need for long-term care services.

***In the works since the* Barriers *Elimination Work Group began*:**

The final regulations on Estate Recovery have been published. Additionally, educational materials on estate recovery developed by the IGCLTC Estate Recovery Work Group are being printed.

Barrier 11: There is an entitlement to nursing facility care but no entitlement to home and community-based care.

For years, many counties have had a shortage of home and community-based services. In recent months, waiting lists for entering waiver programs have declined. However, waiting lists do remain. Missouri has recently made the commitment to provide home and community-based waiver services to every eligible consumer, so that all consumers can choose between community-based services vs. those received in a nursing facility. Massachusetts is considering legislation to do the same. Oregon and Maine have also tried to ensure that there were more waiver services available than were needed. The results have been gratifying. Most consumers choose waiver services, at far less cost to the state.[44] There is no overflow to keep nursing facility beds filled. Maine, for instance, has served far more people, and spent less on long-term care, by ensuring a more than adequate supply of waiver services. This is a win-win-win situation. Consumers receive services where they want to, the state saves money, and the state eliminates its institutional bias for long-term care in compliance with the O*lmstead* decision. Adequate funding of community-based services will

[44] Federal waiver requests will not be granted unless the state can demonstrate that the cost of providing waiver services is equal to or less than that of serving consumers in a nursing facility. The Pennsylvania Department of Aging (PDA) waiver costs are about half of the cost of serving the same consumer in a nursing facility.

also foster the growth of these community services and an adjustment in nursing facility beds.

***Work Group Recommendations*:**

- Pennsylvania should pass legislation similar to Missouri's that would ensure that qualifying consumers could choose between having their long-term care needs met in the community or in a nursing facility.
- Pennsylvania should seek approval for an adequate number of waiver slots to meet the demand for those services from qualified consumers.

***In the works since the Barriers Elimination Work Group began*:**

In June legislation was passed which permits the use of Tobacco Settlement funds to pay the state cost of Medicaid home and community-based services through PDA. Although the funding can only be used for this waiver, it will substantially increase the number of waivers available through that program. For the most part, the waiting lists for most HCBS programs are presently very low or non-existent. However, efforts must continue to insure the availability of HCBS especially as the option is made more readily and easily available through implementation of these recommendations.

Barrier 12: Unavailability of funding for housing.

Remaining at home with adequate services will not be practicable where the home has not been modified to meet the changing needs of the consumer. It will also not be practicable where the consumer's income no longer covers the housing, taxes, and utilities. This often occurs when one spouse predeceases the other and the income is cut in half. What was once affordable housing, is no longer.

The lack of affordable housing is a considerable obstacle to remaining in the home or community. Historically, unmet needs for safe and affordable housing have led to unwanted institutionalization. Medicaid will not pay for shelter and food costs in the community, but they will in a nursing home.

Several states have begun to work with local housing authorities to set aside Section 8 vouchers specifically for this population. Others have begun to provide state subsidies to assist with housing costs for those residing at home and receiving waiver services. Even with the state housing subsidy these states are finding that the total state costs are less than paying for that consumer in a nursing facility.

The Commonwealth of Pennsylvania does provide housing subsidies for those lower income individuals residing in community-based residences like domiciliary care homes or personal care homes. No similar subsidy is available to those who wish to remain at home.

In order to prevent unwanted institutionalization and to insure that home and community-based services, in practice, is an alternative to nursing homes, the state must recognize the importance of available and affordable housing.

***Work Group Recommendations*:**

- The Departments of Public Welfare and Aging must collaborate with the PHFA to increase affordable housing options for persons with long-term care needs. Dedicated funding and programs should be devoted to this purpose.
- The state should also evaluate creative solutions to making services accessible on a 24-hour basis to those choosing to reside at home. For example, one creative idea to be explored might be clustering residents in housing units in close proximity to each other and hire a shared 24-hour aide to circulate amongst them.
- The state should pay for a housing subsidy to keep a consumer who qualifies for waiver services in his/her home if the total state cost is less than the state cost of paying for that consumer in a nursing facility.

***In the works since the Barriers Elimination Work Group began*:**

The 2001–2002 Budget funded a housing coordinator to act as a liaison between housing authorities and other housing resources and

sources of home and community-based services.

Barrier 13: Lack of publicly funded options for eligible waiver consumers needing the availability of 24-hour services.

In order to keep under the cost caps required by Medicaid-funded waivers[45], it may not be possible to have services available in the home on a 24-hour basis. Without the availability of 24-hour services, it may not be feasible for waiver-eligible consumers to remain at home. A typical case is a woman in her 80s or 90s who cannot walk without assistance and needs to go to the bathroom several times a night. Because of falls or fear of falling, the consumer and/or family may feel that she cannot be left alone for periods of time. She cannot go to an assisted living residence or personal care home and continue to receive her Medicaid-funded waiver services. In order to receive waiver services, one must be nursing home eligible. However, under Pennsylvania law, one may not be nursing home eligible and live in a personal care home or assisted living residence where 24-hour services are available. The only alternative for the woman is to go a nursing facility.

***Work Group Recommendations*:**

- Assisted Living Legislation is needed that would permit consumers to receive waiver services in a PCH or ALR and live in their own units and have the availability of 24-hour services.
- Pennsylvania should obtain amendments to waivers to take cost caps to the maximum permitted by federal law so that needs can be better met. (See discussion of Barrier #18).

Barrier 14: There is an inadequate work force available to staff the service needs of consumers who want home and community-based services.

Not unlike the situation in other long-term care and healthcare settings, home and community-based services providers are struggling these days to find the staff to provide the services. There are even occasions where available funding goes unused and needy people go unserved because there are not workers to staff their cases. Addressing the work force issues is a high priority for the state. The Council's work force issue work group has been studying this problem. They have recently produced two detailed reports documenting and quantifying the problems in the healthcare and homecare work force arena. This must remain a high priority in order to insure that consumers in any setting are able to receive the services they need.

In addition, however, the work force disparities that face home care workers must be addressed. There are disincentives, like lack of pay for time in transit between patients' homes and lack of reimbursement for mileage, that dissuade a healthcare worker from choosing home care over facility-based care. In this arena, home and community-based services work must be made competitive with nursing facility work.

***Work Group Recommendation*:**

- The recommendations of the IGCLTC Report on Work Force issues should be followed.

***In the works since the Barriers Elimination Work Group began*:**

This year's state budget includes a direct care worker initiative. Included was:

- $3.4 million for improving recruitment-retention of direct care workers. These dollars will be used by providers at the local level to address areas such as bonuses, training, benefits, and image of direct care workers;

[45] Cost must not exceed nursing facility costs, but some of Pennsylvania's waivers have even lower cost caps, e.g., the PDA waiver is 80 percent of nursing facility costs.

- funds to bring agencies together to share best practices; and
- funds for the development of apprenticeships for direct care workers.

In addition, $1.5 million of IGT funds are designated to implement the recommendations of the IGCLTC Work Force Issues Work Group. Discussion continues with a national foundation regarding the work force issue.

Barrier 15: There is no coordinated system of quality assurance and quality improvement in place for all home and community-based services.

HCBS consumers are frequently nursing facility eligible, and their very lives may depend on being able to receive quality home and community-based services. Because the services are provided in their homes, in a relatively isolated situation, the potential for neglect, abuse and substandard care exists. Since consumers are so reliant on these services, and work force shortages exist, services may be provided in and consumers may be more willing to accept services provided in a "take-it-or-leave-it manner," without regard to consumer's preferences, independence or dignity.

It is important that services be provided in a manner that is responsive to the needs and concerns of the participants. It is also critical that there are quality assurance and quality improvement systems for home and community-based services. There must be a coordinated system for monitoring and insuring the quality, courtesy, professional manner, reliability, etc. of the care providers and the consumer satisfaction across HCBS as a whole. Further, the process and its results must be incorporated into a public commitment to insuring consumer satisfaction.

***Work Group Recommendations*:**

- Ombudsman and Protection and Advocacy programs must be extended and funded to cover home-based care. Consumers must be provided information about these programs when they are approved for HCBS and on a periodic basis thereafter.
- A mechanism for consumer/family feedback on the manner and reliability of home and community-based services must be developed to monitor consumer satisfaction and obtain information on the quality of those services.
- Other outcome-based measurements and standards should be developed and the quality of the HCBS provided should be regularly assessed and quality improvement efforts should be undertaken when services are found to be substandard.
- A 24-hour/day hotline should be established for HCBS consumers for filing complaints and obtaining an immediate response in emergency situations. (Such a hotline is available for nursing facility residents and will soon be extended to personal care home residents. It is perhaps even more needed for HCBS consumers.)
- A certification program and registry should be established for HCBS agencies, so that consumers could be assured that someone coming into their home to provide personal care services has demonstrated competency and has had and passed the appropriate background checks.
- A HCBS quality review advisory board should be established to review and work on remedying evolving issues, reviewing quality outcome data and helping to insure the safety and consumer satisfaction of those who receive home and community-based care, whether privately or publicly funded.

***In the works since the* Barriers *Elimination Work Group began*:**

CMS has issued new guidance on Quality Assurance Monitoring for Medicaid-funded HCBS. The CMS Protocol is designed for evaluating states and their compliance with CMS requirements. This Protocol calls on states to have quality assurance monitoring processes and tools. Each of Pennsylvania's HCBS waivers has since developed a quality assurance and quality improvement team. However, there is no coordinated system for monitoring and insuring

the quality, courtesy, professional manner, reliability, etc. of the care providers or of consumer satisfaction across HCBS as a whole.

Barrier 16: The distribution of waiver services across populations needs to be proportional.

Most of the existing home and community-based services waiver slots are for consumers with mental retardation.[46] Despite this, there are waiting lists for MR slots. Because this Work Group did not focus on MH/MR care and services, these facts bear mention but not discussion. Many other waiver programs have limited slots to serve the number of individuals in the needs population. And, some of the waivers are virtually unavailable in certain areas of the state.

***Work Group* Recommendations:**

- A needs assessment by geographic area should be conducted to determine the number of persons needing long-term care services and the type of services and public resources needed.
- The state should develop a plan to equitably add publicly funded waiver services by geographic area and type of disability and to quickly meet the demand for those services statewide and by waiver category.

***In the works since the* Barriers Elimination *Work Group began*:**

The state is conducting a study of several of the waivers to determine the adequacy of the waivers across counties and across populations.

Barrier 17: Many people needing waiver services cannot obtain them because they do not meet the narrow categories of disability for the existing waivers.

Notwithstanding the fact that Pennsylvania presently has 10 different waiver programs, there are many people who cannot get home and community-based services because they do not fall within one of the narrow definitions of populations served by one of the 10 waivers.[47] As written, those with a physical disability that is not a developmental disability and that developed after age 22, cannot be served in any existing waiver program if they are under 60. Nor can persons who have had strokes or suffered from another form of traumatic brain injury if they are under 60 even if they are nursing facility eligible. They must go to a nursing facility to receive comparable Medicaid-funded services.

***Work Group* Recommendations:**

- A complete study of needs and service gaps is needed to reveal who could be, but is not presently served under the current waivers. As indicated by the study, additional waivers should be sought from CMS.
- DPW should also explore with CMS if a generic waiver can be applied for, for those nursing home eligibles that do not fit any of the existing waivers.

***In the works since the* Barriers Elimination *Work Group began*:**

The state has expanded the Michael Dallas waiver to include persons 21 years and older. DPW also applied to CMS without success for a waiver for persons with autism and traumatic brain injury. CMS denied the waiver because of the grouping of the two disability groups. Since that time DPW has been trying to serve persons

[46] According to the Office of Medical Assistance Programs Statistical Report for Fiscal Year 1998–1999, the Commonwealth has 17,208 home and community-based services waiver slots with 10,864 of those being for the MR Waiver.

[47] The most extreme example of a narrow waiver is the Elwyn Waiver that is for persons over age 40 who are deaf and/or blind and live in Delaware County. http://www.dpw.state.pa.us/omap/geninf/statreport/omapsr9899medwav.asp

with autism and traumatic brain injury through existing waivers.

Barrier 18: Waiver services need to be more comparable and the scope and eligibility for waivers needs to be maximized.

One of the requirements waived under a home and community-based services waiver is the federal Medicaid comparability requirement. This is waived so the state can provide more services to nursing facility eligible persons served in the community than it does to other Medicaid recipients. In seeking federal approval for the various waivers, DPW had to demonstrate to CMS that the group of persons for whom the waiver was sought could be served in the community at a cost equal to or less than that of serving them in a nursing facility. Because this was uncharted territory, limits to services were established to ensure that the cost caps would be met.

Now that Pennsylvania has had experience with the waivers, it is clear that this has led to some disparity between waiver programs and a denial of essential services for some groups. Limiting services to selected age groups and capping dollar amounts at different percentages is no longer justified.

For instance, the Aging waiver is capped at 80 percent of the cost of caring for the participant in a nursing home, whereas other waivers are capped at 100 percent of that cost. Maximizing the scope and services available under the waiver programs would insure that needs are met while still meeting the federal cost caps. For example, setting the cost cap for all waivers at 100 percent of the cost of nursing home care for that applicant would insure that none of the applicant's needs would go unmet because of cost caps. However, because the cost caps are linked to the applicant's needs, they would inherently be different. Thus, 100 percent of the cost of care for an Aging waiver participant would be approximately $40,000 whereas 100 percent of the cost of care for a Michael Dallas waiver participant would be approximately $240,000.

The Attendant care waiver program is administered with a maximum of 45 hours of attendant care a week, even where more is needed. Forty-five hours of attendant care is far below the cost of care in a nursing facility. Waiver programs must be flexible to meet the needs of the individual participants and not capped in an arbitrary manner for some groups far beyond what is required by federal law.

There was no clarity on whether the existing dollar caps were established to account for administrative costs incurred in implementing the waiver. The Work Group believes that administrative costs must be exclusive of the waiver caps and should not be used to limit the amount of services a person can access. The cost of care in a nursing home is not calculated to include the administrative costs.

***Work Group Recommendations*:**

- The state should review the limits on existing waivers and seek waiver amendments from CMS to put all waivers at 100 percent of the cost of nursing facility care and to eliminate unnecessary service caps.
- The state should review service limits and eliminate those that are not justified by a reason other than cost.
- The state should determine if additional services should be added to waivers.

***In the works since the* Barriers Elimination *Work Group began*:**

The Work Group has learned that for all the existing waivers, the Department of Public Welfare is obtaining CMS approval to shift to aggregate cost caps. This would allow the waiver programs to serve those individuals with needs that would exceed the cost of serving that person in a nursing home provided the overall costs to the state do not exceed the overall costs of serving all participants in nursing homes.

Barrier 19: Personal Care Homes/ Assisted Living Residence standards and enforcement need to be improved before they can house waiver recipients.

Presently, state law does not permit a nursing home eligible person to receive services in a personal care home/assisted living residence. Yet, because of the lack of affordable housing and the need for some consumers to have access to 24-hour-a-day care, these community-based residential options are an integral part of the long-term care continuum. DPW is operating a pilot project in Philadelphia to determine the feasibility of permitting a nursing home eligible person to receive HCBS in a personal care home. However, the conditions in some of the state's personal care homes make them totally inappropriate settings for nursing home eligible individuals. Inadequate training standards, quality assurance, services, and maintenance issues all raise concerns about the use of personal care homes for waiver recipients. Yet, when a consumer can no longer live alone, a personal care home offers the availability of 24-hour services. However, until standards and enforcement are significantly upgraded, personal care homes/ assisted living residences should not be used for nursing facility eligibles.

***Work Group Recommendations*:**

- The Council's Assisted Living Report recommendations should be implemented.
- Legislation is needed to license assisted living residences pursuant to the recent Stakeholders' recommendations.

***In the works since the Barriers Elimination Work Group began*:**

DPW is reviewing and proposing new personal care home regulations. The Auditor General has completed a review of enforcement activities and has made recommendations for improvement. An Assisted Living licensure bill has been passed in the House of the General Assembly.

Barrier 20: Inability to obtain public funding for services in assisted living residences.

As was discussed with Barrier #12, only those eligible for the SSI Supplement can receive public funding for personal care services in a personal care home. However, nursing home eligibles may not be served there and one must be nursing home eligible to receive Medicaid-funded HCBS. Also, as discussed in Barrier #19 above, the present training, staffing, and enforcement standards for PCHs are inadequate for a person who is nursing facility eligible.

Over 30 states have passed legislation to license assisted living residences.[48] Many of these same states are using Medicaid-funded HCBS to serve consumers living in assisted living residences (ALRs). ALRs can provide a residential setting where one can age in place, with services changing in accordance with needs.

***Work Group Recommendations*:**

- Assisted living residences should be licensed and be capable of serving most nursing facility eligible residents. Once this is done, HCBS waiver services should be available in ALRs and for those PCHs that can demonstrate capacity and competency to safely provide quality, consumer-directed services to nursing facility eligible consumers.

***In the works since the Barriers Elimination Work Group began*:**

As discussed above, DPW is operating a pilot program in Philadelphia to permit HCBS in selected PCHs.

Barrier 21: The Medicaid resource level is too low.

The income levels for HCBS are much higher for waiver recipients than they are for the same person applying for Medicaid who is not nursing

[48] In Pennsylvania, anything can call itself assisted living. However, assisted living residences are presently licensed as personal care homes.

facility eligible.[49] A single person can be eligible for HCBS and have income of about $1,610/month. However, the Medicaid resource level has not been changed for over 10 years. It remains at $2,000. There have been no cost of living adjustments. Had there been, the resource level would be over $2,800 today.[50]

The resource level is particularly important for consumers living at home and receiving HCBS. Few people feel comfortable living in a home without a small nest egg to cover the cost of maintenance and repairs. However, the resource level is so low that it permits only a few hundred dollars in the bank above the maximum monthly income level permitted under the waiver. People are reluctant to reduce their resources to such a low level and remain in their home with inadequate funds to cover maintenance emergencies, etc. Also, the resource level is lower for people receiving Medicaid-funded HCBS at home than it is for those receiving Medicaid-funded services in a nursing facility!

***Work Group Recommendations*:**

- The resource level should include a cost of living adjustment and a home maintenance adjustment. New federal policies give states the flexibility to make this important policy change.
- The spousal impoverishment rules and other rules employed in evaluating assets for nursing home applicants should be applied to applicants for home and community-based services waiver programs to insure that there is equity and no disincentive to accept home or community based care.

Barrier 22: There are no state or federal criteria for shared or negotiated risk.

To some people, avoiding unwanted institutionalization is worth taking chances. If it means not having 24-hour-a-day services available in the case of an accident or emergency, it is worth it for purposes of maintaining autonomy, dignity, and privacy. However, service providers are reluctant to serve consumers who assume risk, because they are concerned they will be sued for negligence if something should happen to the consumer. Also, under federal law, the state must ensure that Medicaid waiver recipients are provided for in a safe and secure manner. The Regional CMS office has refused to provide guidelines on how much risk a consumer may assume and still have the state meet the requirement of providing for safe and secure services. They have left it up to Pennsylvania. Therefore, at present, it is very difficult for a consumer to assume risk and receive waiver services. There are no clear and specific criteria for entry into home and community-based services programs. Reasonable minds differ on what services the consumer needs to have to be served safely in his/her home. Additionally, there is little room for consumer preference, autonomy, or dignity where the criteria are undefined and left to the state to determine in each case.

***Work Group Recommendations*:**

- In consultation with stakeholders, the Department of Public Welfare and the Department of Aging should develop assumption of risk standards for HCBS that meet federal guidelines while providing room for consumer preferences, autonomy, and dignity.
- Pennsylvania needs legislation to provide for shared risk agreements, which protects both consumers and providers.

V. Conclusion

Recently, Pennsylvania has taken a number of important steps to change the institutional bias of its long-term care funding under Medicaid. This is critical to not only comply with the O*lm-*

[49] For instance, the income levels for HCBS is 300 percent of the SSI level, which for one person is over $1,500/month, more than twice the federal poverty level.

[50] http://www.westegg.com/inflation/

stead requirements, but also in recognition of consumers' preference to remain in their homes as long as possible when they have long-term care needs. It will also be essential so that Pennsylvania can use its limited resources to provide publicly funded long-term care services to a growing number of people, without putting undue strain on taxpayers. It is clear that the state is committed to improving access to home and community-based services throughout the Commonwealth.

Although efforts have begun as noted above, most consumers do not yet have a real choice between HCBS or a nursing facility because of the barriers articulated above. Although the supply of waivers is increasing, they are not yet readily available and swiftly accessible. Most people cannot wait the months and months it takes to secure them, once they become nursing facility eligible.

It is essential that efforts to improve access to home and community-based services focus on eliminating the informational, procedural, and systemic barriers that prevent and prolong unwanted institutionalization. Attention should be paid to deinstitutionalizing those capable and desirous of living in more residential settings. (A grant has been secured to do so in limited counties, but it needs to be done statewide.) In this vein, appropriate nursing home residents should be periodically assessed and informed of options as well as assistance available for transitioning.

The Work Group asks the Council to:

1. Accept and adopt this report.
2. Make public the findings and recommendations of this report.
3. Take steps to brief the legislature on the findings and recommendations of this report.
4. Refer this report to lead agencies for follow-up, asking them to report back to the Council on what it would take to implement the recommendations, what costs and timeframes would be involved, and whether they would be willing to implement the recommendations.

EXHIBIT A

This is the chronology of a real-time example of the lengthy process for applying for home and community-based services.

August 2000

- Client calls needing services and does not want to go to nursing home.
- Refer client to AAA for assessment.
- AAA sends MA-51 to applicant's doctor for medical evaluation.

September 2000

- Calls to medical doctor to press for completion and return of medical evaluation.
- Medical evaluation finally returned.
- AAA assessment visit completed.

October 2000

- 10/3 – AAA finds level of care to be nursing facility eligible; finds locus of care to be a nursing home. AAA is not sure client really wants to be at home and thinks client is better served in a nursing facility.
- 10/12 – Client goes to a local nursing home because she could no longer wait for services.
- 10/16 – Client transferred to local hospital for medical attention.
- 10/17 – Client had surgery to have her leg amputated.

November 2000

- 11/6 – Client transferred back to nursing home.
- 11/13 – Client left nursing home and returned home because she couldn't stand to be there and wanted to be in her own home.
- 11/14 – Nursing and PT through Medicare began.

December 2000

- 12/7 – Case assessment meeting with AAA, client, and family to bear witness to client's articulation of desire to be at home, not nursing home. Certification will be changed to locus of care home. AAA submitted MA application.
- 12/15 – Call from AAA that MA Application rejected because of failure to provide information. CAO sent two separate forms indicating missing information, but each stated different items. Provided list of all items on both forms to family to obtain documents and submit. Items due to CAO within 10 days.

January 2001

- 1/3 – Family members did not amass and send documents in time.
- 1/9 – Notice from CAO that application is incomplete. Requires all items the family believes they have just sent in.
- 1/18 – Call to CAO to clarify. No response.
- 1/22 – Call to CAO to check what precisely is needed and by when. Caseworker says just received package of info from family and AAA. Will review tomorrow and call to report what was missing, if anything, and to answer questions.
- 1/23 – Call to CAO. Caseworker says hasn't reviewed information yet. Will review and will call if she needs more information. The caseworker promised she "will not deny because information is incomplete," without advising what more is needed and giving family an opportunity to submit it.

February 2001

- 2/6 – Call to CAO. No response.
- 2/7 – Call to CAO. Told case was rejected for lack of information and that notice is on its way.
- 2/8 – Call to caseworker's supervisor, who said she supported the caseworker's decision. The supervisor reviewed what was missing, all of which were on hand with her advocate and could easily have been faxed prior to rejection.
- 2/9 – Faxed all missing documents and letter to District Administrator.
- 2/12 – Call to District Administrator. Told to appeal denial. Filed second and subsequent application.
- 2/14 – Appeal filed. Hearing scheduled for 3/29.

March 2001

- 3/2 – Call to CAO. Told client needs to sign application again but not resend all documents.
- 3/5 – Call to CAO. Told reviewing.
- 3/7 – Call to CAO. Told reviewing.
- 3/8 – Call from CAO to client. Client told needs all documentation resent again.
- 3/9 – Call to CAO. No response.
- 3/12 – Call to CAO. No response.
- 3/15 – Call from advocate. Client is over resource level.
- 3/19 – Excess assets due to pay-out from AARP policy for loss of her leg.
- 3/23 – Client willing to reduce assets to pay off bill for hospital bed. Call to caseworker to verify that once verify reduction of assets to below $2,000, client will be certified for waiver.
- 3/26 – Hand-deliver verification of reduction of assets.
- 3/27 – Approved/Certified for Waiver.

April 2001

- 4/1 – 4/15 AAA conducting care planning visits.
- 4/17 – Confirmed verification of reduction of assets.

May 2001

- 5/9 – Services began in part. (Not all shifts of HHA filled.)

July 2001

- 7/25 – All shifts of HHA filled.