
Emails Submitted to

ra-LTCCommission@pa.gov

in

May

Greater Harleysville and North Penn Senior Services



Board of Directors:

- Andrew Santana, President
- Deb Santoro, 1st VP
- Joann Barnak, Treasurer
- Mary Metz, Secretary
- Sheri Strouse, NP Liaison
- Linda Bean
- Anna Crouse
- Katie Farrell
- Mark Hoffman
- Robert Iannozzi
- Jason Klaskin
- Dan McKee
- Hervey Schofield
- Robert Schoen
- Louise Shaheen
- Tammy Towers

Greater Harleysville and North Penn Senior Services is a 501(c)3 nonprofit corporation as determined by the IRS. Greater Harleysville and North Penn Senior Services operates two senior center facilities: Encore Experiences at Harleysville and The PEAK Center in Lansdale.

Encore Experiences at Harleysville and The PEAK Center in Lansdale are supported in part by funding received from Montgomery County Office of Aging and Adult Services. We are participating agencies of the North Penn United Way and the United Way of Southeastern PA & Northern NJ. Other sources of support include grants, wills & bequests, corporate donations, foundations, special events and individual contributions.

The official registration and financial information of Greater Harleysville and North Penn Senior Services may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.



Pennsylvania Long-Term Care Commission
 PO Box 2675
 Attn: OLTL POLICY
 Harrisburg, PA 17105.

ra-LTCCcommission@pa.gov

This letter is in support of fully funding senior centers in Pennsylvania.

Please allow for flexible funding for infrastructure, AAA services, including senior centers and other services to defray early admission to nursing homes.

Research shows that older adults who participate in senior center programs can learn to manage and delay the onset of chronic disease and experience measurable improvements in their physical, social, spiritual, emotional, mental, and economic well-being.

Approximately 70% of senior center participants are women; half of them live alone. The majority are Caucasian, followed by African Americans, Hispanics, and Asians respectively. **Compared with their peers, senior center participants have higher levels of health, social interaction, and life satisfaction and lower levels of income.** The average age of participants is 75. 75% of participants visit their center 1 to 3 times per week and depend upon the services they receive there.

Senior centers serve as a gateway to the nation's aging network—connecting older adults to vital community services that can help them stay healthy and independent. More than 60% of senior centers are designated focal points for delivery of OAA services—allowing older adults to access multiple services in one place.

A recent cost analysis showed that on average it costs \$345.00 a year for each participant to be served by a local community based senior center. In Pennsylvania, it nursing home costs average \$261.00 a day or \$95,265.00 a year. **We can save over \$94,000.00 per person per year by investing in home and community based services and avoiding or delaying the need for institutionalization.**

- Senior centers offer a wide variety of programs and services, including:
- * Meal and nutrition programs
 - * Health, fitness, and wellness programs
 - * Public benefits counseling
 - * Volunteer/civic engagement opportunities
 - * Educational and arts programs
 - * Information and assistance
 - * Transportation services
 - * Employment assistance
 - * Social/recreational activities
 - * Intergenerational programs

We are hopeful that our input will be included in the development of the final plan that will set priorities and guidelines in improving the current long-term care system.

Thank you,

 Robin Burstein
 Executive Director

Alexander, David A

From: Missy Wyatt [REDACTED]
Sent: Sunday, May 04, 2014 12:58 AM
To: AI, LTC-Commission
Subject: Comments and Feedback LTC



Hello and thank you for giving us the opportunity to comment and have a voice for the long term care. I started out as a CNA working at a local nursing home and graduate in December with my RN. I could never go back to long term care to work. Its sad. I health coach and went to see a patient in the hospital who states she was being sent to a facility to die.

We work so hard to have a good retirement but how can anyone in todays economy afford that. ~~More options need to be available and affordable for people to stay at home.~~ Patients that I currently have in the nursing homes - I have to call them for updates and reports. There is a lack of communication - everywhere in healthcare but for this its bad.

I have also noticed from experience that if they are not the nicest to deal with whether it be they are upset at family, in a lot of pain or just a rough life, no one wants to deal with that person.

1. Staffing in any medical facility needs to be improved. Patient to nurse ratio (good quality care) not sure that has ever happened as a mandatory setting
2. State visits? WHY are they announced? We all know when the state is coming. The halls are cleared, the residents are out of bed and dressed, everything looks so nice. There is more staff there on the days the state is there then there is the whole month. I have always thought that was the silliest thing -
3. Prevention of long term stays at nursing facilities after surgical procedures - good care of a pt is the best prevention - whether its bed sores, DVT prevention, dehydration, broken bones, or anything as severe as sepsis.
4. We all have family - I think as a nurse these things come easy. I think of how I would want my own family treated - if I were in a situation, how would I want it to be handled? We, one could never afford to put them in a nursing home and you hear so many horror stories, because they aren't monitored properly -

Again thank you for letting me voice my opinion. Our healthcare is awful. Patients saying to me ' I cannot afford my medications - we need to eat.'

Thank you again.

[REDACTED]
[REDACTED]
[REDACTED]

Sent from Windows Mail

Senior Life

I have received many benefits from Senior Life including being put in the hands of Dr. Kahn. She diagnosed me as having diabetes right away which I had not previously been treated for. She started me on my meds & supplies right away. She is keeping an eye on my blood pressure & other problems I have. She has taken a very sincere interest in me.

My nurses Audrey & Shannon have given me much love & care making sure of my every need, and keeping a close watch on me. Shannon comes to my home & checks my meds & see if I am O.K. She also was a great comfort to me as I have lost both of my sisters in February & March.

I love to go to physical therapy where Amber & Corine are. They heat they give me & using the bike have made a big improvement in my back & the way I move around. Corine fixed up my bathroom for me & Amber gave me slippers & a walker right away when I began having problems with my feet. They are always so pleasant to be around.

②

Cindy, the dietitian taught me many things about food & eating portions. She has always been willing to talk about my eating habits & helps me to loose weight.

Marsha does a great job at keeping people entertained with crafts, games, exercise, bingo & scrabble. She along with Debbie Kaitlan keep a watchful eye on people in the dining room & hurry to their aid if needed. Marsha always makes holidays special.

Jamie & Megan, social workers are there to answer any questions I may have.

William, our cook, I think he does a wonderful job. The food is very good. He works very hard at trying to please everybody.

Cindy, the receptionist always greets me with a smile & is very courteous when you call in.

Carrie in charge of transportation does a great job of making arrangements for buses to pick you up. Also she makes arrangements to get me to my doctors visits.

Marcie, what a great job she did to get me my hearing aids. No words can express my appreciation. She is so happy for me. Many employees were happy for me. I don't know when I've been around so many beautiful people. Senior Life surely is full of them.

The bus drivers Jay, Liz, Jim, Terry & Shaun always greet me with a smile. It's amazing how they handle all these people with walkers & wheel chairs. They are so kind. What a job that is.

Cindy - manager - what a lovely woman she is & what a good job she does keeping an eye on everything.

Sara - the wonderful person that came to my home & worked hard doing all the paperwork to get me into Senior Life.

I am very thankful I have entered Senior Life in Greensburg. My life has been changing. It's a great feeling to know people who care about my physical & mental well being. They are very special people in what

they do to serve others. They make my Tuesdays & Fridays days to look forward to. I have met many new people & have made some new friends.

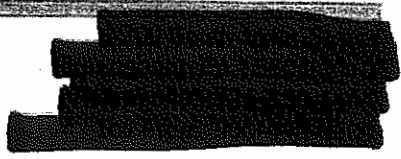
There is always someone to greet me when I arrive at Senior Life. I do not know everybody's names. Eventually I will learn them.

I am very grateful for Senior Life. I appreciate all they do for me.

Jois

Ray R. DuCoeur
Administrator

Commissioners: Charles W. Anderson, Chairman • R. Tyler Courtney • Ted Kopas



May 8, 2014

PA Long-Term Care Commission



To The Long-Term Care Commission:

The Westmoreland County Area Agency on Aging has served as a pioneer in the field of Care Transitions from acute care hospital settings to community-based and nursing home settings for over five years. As such, we have learned, on a first-hand basis, the tremendous benefit to our older citizens of Area Agencies on Aging providing a stronger transition from the hospital to the community. We have facilitated hospital readmission reductions at a rate of over 30 percent among the persons we have worked with. Overall cost-savings for these outcomes are tremendous and the quality of life improvements are immeasurable and, at times, live-saving. We have also seen clearly through this work that the Area Agency on Aging is perceived by the public as a highly trustworthy and credible provider of assistance and that this perception, in itself, reinforces the successes of the service. We want to recommend that Care Transition programs should be replicated and expanded across the State via the Area Agencies on Aging.

Also, the Commonwealth of Pennsylvania needs to more aggressively pursue ~~opportunities that will re-balance spending within the long-term system, emphasizing the non-institutional preference of seniors and their loved ones -- an approach that is both most-desired and most cost-effective.~~ Pennsylvanians should not be allowed to fall behind other states in a re-balancing in the direction of the more cost-effective home and community based services.

In addition, the Commonwealth should work to guarantee that the Pennsylvania Lottery remains fully dedicated to senior programs and services, including senior community centers, while pursuing reasonable efforts to generate additional revenues for home and community-based care.

The Area Agencies on Aging remain steadfast and dedicated to the mission of ~~maintaining our older citizens in their homes and in their communities at the highest possible levels of quality of life.~~ We do so in a neutral and conflict-free manner and have developed a trustworthy reputation in this regard. Our gatekeeping assessing, protective and other functions should be maintained on this basis so as to best benefit the welfare of the senior citizens that we serve.

PA Long-Term Care Commission
Page 2

Thank you for the ability to provide input for your consideration on this very important matter that truly affects all of us.

Respectfully,



Ray DuCoeur
Administrator

[Redacted]

Alexander, David A

From: Jennifer Marasco [REDACTED]
Sent: Thursday, May 08, 2014 2:40 PM
To: AI, LTC-Commission
Subject: LTC commision comments

I am emailing related to the PA LTC Commisions desire to seek public opinion on issues related to prevention and caregiver support, Accessibility, Provision of Service, and Quality Outcomes and Measurement.

I am a social worker for Presbyterian SeniorCare in Oakmont, PA. I work specifically with older adults with dementia at Woodside Place which is a secure personal care home and adult day program. Some issues I consistently find working with this population and their family is that there is ~~lack of awareness of resources in the community~~. There also is an issue about when is the right time to reach out to the those services.

I'm grateful to work for an organizaation that has such a wonderful reputation in the community and we provide an excellent array of services; however, I still encounter many referrals or inquiries from families who are in emergency need or are beyond the point where my services at Woodside Place could help them. They will often comment that they didn't know these services existed before. We are working internally at our organization to help promote the various services we offer so the community is aware, but in communicating with other organizations and county funded entities, there is lack of awareness of programs or the requirements in a general sense.

One main example is Adult Day services. I've reached out to the Area Agency on Aging for Allegheny and Westmoreland county along with the Alzheimer's Association for information on this service. We have found many families do not know what Adult Day services are or the cost saving benefits these programs offer. Adult Day programs help with reliable and consistent support and respite for the family, socialization and security for the participant and can lead to a smoother transition to a long term setting if and when that is needed. It also can prolong the ability for that participant to remain in the community since there is such a consistent support.

I think we all have to remember we are a referral source for those in need so I think it is important to educate as many as we can about the available services for older adults and funding sources to help pay for those services. We may not have all the answers individually, but if we know the right professionals and programs to refer to, that is a step in the positive. Aging is something we all have in common so it would benefit ourselves and others to become ~~educated and proactive related to the aging community~~.

Jennifer Marasco, LSW
Social Worker, Woodside Place

Presbyterian SeniorCare



Positively Living

Jennifer Marasco, LSW
Social Worker

Long Term Care Commission
 May 8, 2014, Mercer, PA
 Carl Berry, Community Resources for Independence, Inc.

Members of the Pennsylvania Long-Term Care Commission, members of Pennsylvania's office of the Governor, other members of government, service providers, participants, and other interested persons:

I thank you for the opportunity to speak today regarding Pennsylvania's Long Term Care Support Services. This is a time of great change, and the decisions that the state makes now will have significant and long-lasting effects on Pennsylvanians for years, possibly generations, to come.

It has been generally accepted that home and community based services can be less expensive than institutional placement, yet still meet the needs of many Medicaid participants. So much so that the federal government, particularly the Center for Medicare and Medicaid Studies, is providing a financial incentive to states that rebalance their long term support services and increase their use of home and community based services. However, there are several factors that can jeopardize the benefits of home and community based services.

Rates to Providers

It has been 4 years since a rate increase for service provision companies. That increase did not keep up with inflation. I believe the increase before that was about four years earlier. It too did not keep up with inflation. A network of once-robust providers have been weakened, slowly starved by the state's inattentiveness. Additionally, many "unfunded mandates" have been imposed over the years - from state licensing to the federal Affordable Care Act - that, along with increasing wage pressures and inflation, have eroded the financial stability of the provider network that supplies the most cost effective long term support service for Pennsylvania's elderly and people with disabilities.

When the state government puts out a bid for a highway bridge, the state chooses the bid based on reasonable materials, workmanship, and timetables, and pays accordingly. The state doesn't

want substandard scrap metal to be used in bridges, it wants quality materials and is willing to pay for it. Why can't this be for other services like Personal Assistive Services to Pennsylvania's citizens?

With the impending onset of managed care for long term support services, the financial viability of the support network is further at risk. Managed care companies make money by taking on as many participants as possible, then squeezing the subcontractors' rates. I would encourage the commonwealth's administration to consider specifying a minimum rate to be paid by the managed care organizations to the providers, a rate that adequately covers current expenses now and into the foreseeable future.

Managed care

As the state is contemplating its foray into managed care for long term support services, I am sure that the magnitude of this change is not lost on this governor's administration. This is a Herculean undertaking that will impact many people in ways that may not be fully understood at this time or for quite some time to come.

I encourage the state to have truly meaningful stakeholder involvement, and to craft a plan that represents all stakeholders' best interests. A listening session such as this is a great opportunity to gather diverse viewpoints on a complex problem. The administration would do well to consider what it learns in these sessions. However, it would also do well to actively seek multiple, diverse, expert opinions, both pro-managed care and con. Converse. Listen. Ask questions of all involved. And be prepared to accept answers the administration likes as well as those the administration does not. Most importantly, make an informed decision based on the wants and needs of those citizens you represent, before you take a plunge down that rabbit hole.

Clear and open communication during the plan formulation phases

In addition to soliciting and listening to multiple stakeholders' inputs, communication from the administration to the stakeholders is vitally important. Those who receive the long term support services deserve to know what is Pennsylvania's plan for those services, and deserve to know how they will receive their services under a managed care long term support service

environment. Those that provide the services also deserve to know. As do those citizens and entities that pay for those services.

Any change is scary. Change shrouded in uncertainty is terrifying to a person who depends on long term support services for their independence and health. Open and transparent communication, ready information, and education will help participants to overcome that anxiety and ease the transition. I dare you to over-communicate.

Adequate Planning and Implementation Timeframes

An adequate lead time until implementation, during which stakeholders are kept updated and informed, will be essential. Kansas recently changed to a ~~managed care environment~~, and the change came as a surprise to many stakeholders, including the state's Centers for Independent Living and services providers, resulting in consumers experiencing unnecessary confusion and anxiety, and unnecessary disruption in services when the agencies that supported the participants for so many years suddenly were out of work and closing their doors. Worse, the managed care companies weren't fully ready yet the state went ahead anyway. Of course, it is in Kansas' and the MCOs' best interests to say everything went off without a hitch, but it didn't. A change of the magnitude of a managed care environment is not like ripping off a Band-Aide; fast and sudden to 'get it over with' is not applicable.

Have clearly stated and defined goals and expectations of managed care organizations. Have readiness milestones set in advance. Have readiness reviews throughout the lead-in period. And be prepared to -- have the guts to -- postpone implementation if all is not ready to go. Think of this as a space launch to the moon: if not all is right before launch and we aren't willing to abort the countdown and launch another day, we can have an epic disaster on our hands.

Consider the Range of Long Term Support Services

The state contract with the managed care organizations should include nursing home placement in the covered services. After all, if nursing home care is a significant portion of the state budget, and one of the state's reasons for managed care is to contain costs, it makes sense to include nursing home placement under managed care. Furthermore, some states that have not

included nursing homes under the managed care contract experienced a number of participants being moved (or "turfed") into nursing homes from home and community services, ultimately increasing the state's overall nursing home expenses – resulting in exactly the opposite of what the state wanted from a strategy of cost containment via managed care. Conversely, states can and should include nursing home placement in the MCO contracts, and build in goals for home and community based services, placing financial and quality incentive on the MCO's to keep the participant in the community and receiving comparatively less expensive care.

Participant choice of MCO's, Participant Choice of Providers.

Choice is independence, choice is dignity. Person-centered planning is deeply rooted in participant choice. The Olmstead Act revolves around participant choice. Features of the Affordable Care Act and the Rebalancing Incentive are designed specifically to enhance participant choice. "This is your only option, take it or leave it" is not a choice.

I encourage the administration to ~~design its managed care long term support service contract to mandate that the managed care organizations utilize all local providers.~~ When I say "local" I mean those Pennsylvania companies – for-profit and non-profit – who are currently providing long term support services, such as the home and community based services. These local providers have a history with the participants; the providers are the participants' neighbors; the participants are comfortable with their providers and they know what they are getting.

Participants should have the choice of managed care companies, and choice of provider organizations. By have a choice, managed care companies and providers are at risk of losing their customers to competitors. This option encourages the MCOs and providers to provide higher quality services and additional support services, in order to keep the participant and the state happy.

Pennsylvania in recent history chose to ~~outsource parts of its personal assistive services to large out-of-state government contractors.~~ As a result, thousands of Pennsylvanians have lost their jobs. I know: I had to tell many of my own employees, face-to-face, that I am sorry but I was laying them off. And the state's transitions to these mega-marts of government contractors were

not without problems during the changeover and after. Monopolies do not belong in social services any more than they belong in other aspects of a free market. Choice does.

MCO contract with service coordination entities.

~~HCBS is a social service model. It is a non-medical model.~~ Services in the home and in the community consist of more than just vital signs and yet another pill to take. Community inclusion, interaction with others, independence of thought and action, and even having the freedom to fail, are essential to a person with a disability's quality of life. Pennsylvania's current service coordinators understand this perspective, and understand the differences from a medical model. Current service coordinator providers also understand the other local support services available in the local community. Most importantly, current service coordinator providers are an advocate for independent living. This isn't to say that medical case management isn't important – it is. But medical case management is notorious for not fully "getting it" when we're talking about independent living.

Thank you

I thank you for taking the time to listen to the various viewpoints today, including my own. Please take back the many comments, questions, requests, suggestions, and words of caution to the governor and his administration. Please encourage them to plan completely, communicate constantly, implement carefully, and most of all, set up a system that supports independence and choice.

I encourage the administration to take to heart the Center for Medicare and Medicaid Studies' report "Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs," which echoes many of my points, presents more, and does a much better job than I. Thank you.

Alexander, David A

From: Kathleen P. Kleinmann [REDACTED]
Sent: Wednesday, May 14, 2014 4:24 PM
To: AI, LTC-Commission
Subject: Recommendations on LTC Policy
Attachments: LTC Position Paper.pdf



For the Commission deliberations

--
Kathleen Kleinmann [REDACTED]
[REDACTED]

This message from TRIPIL may include confidential information and further distribution may be strictly prohibited. If you are not the intended recipient, please notify the sender by replying to this message and then delete this message.



Recommendations for Future Policy Changes in Medicaid Long Term Care Services from the Disability Community

Prepared for Bev Mackereth, Secretary of Public Welfare
Authored by Kathleen Kleinmann & Shona Eakin, April, 2013,
based upon the input of the Pennsylvania Disability Community

The Disability Community of Pennsylvania asks that you be the Visionary Leader. One who will actually re-balance the utilization of long term care expenditures under Medicaid. All the changes made to the HCBS system during the last 3 years have had little impact on re-balancing. Furthermore, the changes have made home-based long term care services more difficult to obtain and sustain and far less consumer responsive.

From OUR point of view, the goal of Re-Balancing has been "lip service" only from OLTL. Starting in 1985, HCBS was designed and implemented by OLTL and the disability community represented by Centers for Independent Living. Over the last three years, OLTL has withdrawn from the planning table and has instituted unilateral changes without regard to the impact on program participants.

Table of Contents:	Page
Introduction	1
Action Steps	2
Obstacles	7
CIL's in PA	10
Community Choice Directive 2003	Attachment

(10)

ACTION Steps for Secretary Mackereth and OLTL:

1. Bring the disability community and consumers back to the planning table. We want the same outcome that you want. We want reliable, quality home care services that enhance independence and community life and help to avoid nursing home placement. We want cost effective programs that allow the state to serve more people and maximize the use of Federal funds instead of state tax payer funds. We want providers held to high standards. We want consumer-operated programs. Surely, we can get there together, and rebalance the expenditure of long term care funds.

2. Re-balance Pennsylvania's use of Medicaid long term care dollars and do not continue the practice of merely spending more both nursing homes and HCBS. Pennsylvania has not been approved by CMS to participate in the Balancing Incentive Program created by the Affordable Care Act of 2010 (Section 10202) which holds a funding pot of 3 BILLION dollars towards re-balancing worth of enhanced funding. Work with advocates to establish specific benchmarks, including annual objectives that identify the number of people and amount of funding that shift from nursing facilities and institutions to home and community-based services. ADAPT has developed a document that can serve as the basis for developing both the plan and the individual benchmarks. Publicly report on its progress in meeting these benchmarks to assure transparency in these efforts. Give us a system to track denials of community services, including those in nursing homes that are denied.

3. Recognize an emerging model of service called the "Consumer Delegated Employer" to fill the gap in service supports created by revamping FMS to single statewide

provider with no local presence. Under this emerging model, the Agency is the employer of record but consumers have control of hiring and directing their attendants. Consumers are essential to the employment of the attendant and cannot be switched to other homes to provide care arbitrarily. The agency and the consumer are seeking to create a long term employment match that mirrors that of the "Consumer Employer" model. Currently, the PA Health Department rules impose hardship on this new model, and attendants under this model will require exemption from rules that govern the traditional, short-term care givers in home health agencies.

4. Initiate a campaign to update the Nurse Practice Act to provide exemptions for attendants under the "Consumer Delegated Employer" Model.

<http://www.pacode.com/secure/data/049/chapter21/chap21toc.html>

Allow the consumer (with support of a provider) to teach an attendant to perform those same tasks that were allowable under the "Consumer Employer" model. This will require DPW to approach the PA Department of Health for collaboration and regulatory changes to provider waivers to provisions of the law.

5. Recognize the unique and dedicated partnership that exists between OLTL, Centers for Independent Living and Area Agencies on Aging. We are sponsored by tax dollars from Pennsylvania and the Federal Government as special partners and not your typical provider agency. We are actively a part of our community and the long range planning of services for our community. We can be invaluable sources of information and cost effectiveness for the programs that you administer.

6. Reorganize OLTL as an agency and fiscal monitoring and planning agency and NOT as "Case Managers." Issue policy directives that will give broader discretionary levels to the local level and to the consumer level. Plan for a program that can truly meet the needs of hundreds of thousands of consumers in the community so that hiring of new State Employees is not the default solution to re-balancing long term care in PA.

7. Resurrect the Community Choice Demonstration Project as it was envisioned under the POLICY AND QUALITY ASSURANCE DIRECTIVE dated December 2, 2003, Number: 2003-01. Under this program, consumers received services within 72 hours of request and nursing home diversion was a reality. We proved that it worked but some issues remained to be resolved before it was statewide. We must get back to the planning table. Attached Directive of 2003.

8. Apply for the funding available for the Community First Choice Option under the Affordable Health Care Act.

<https://www.federalregister.gov/articles/2012/05/07/2012-10294/medicaid-program-community-first-choice-option>

Pennsylvania advocates worked harder than the advocates of most other states to win inclusion of this section of the law. We are shocked and dismayed that our efforts will go to benefit other states instead of bringing an estimated \$85 million dollars of funding dedicated to the diversion of people from nursing home placement under Medicaid. Pennsylvania already has the infrastructure in place to implement this portion of the law.

9. Resolve the legal dispute regarding frozen funds to providers under Consumer Employer model currently locked in provider owned bank accounts. Providers were harmed by the redefinition of the consumer employer reimbursement rate prior to the reorganization of the actual service delivery system. Providers are under tremendous pressure from auditors and bankers to recover costs for services delivered in good faith. Obstacles to resolution are arbitrary and unfair. The 37 providers should not be held hostage to each other's ability to cooperate with the state to resolve the issues that prevent settlement.

10. Work with the Consumer Workforce Council incorporated in 2011 to plan a strategy for development of the attendant care workforce. After decades of neglect of the reimbursement system, consumers and providers have now turned to Unions for help. Reimbursement rates and service delivery systems must include provisions requiring health care insurance and a basic benefit package for employees intended to be LONG TERM employees, and not just temporary help. Recognize that many "Consumer Employers" and "Consumer Delegated Model" consumers are now encouraging their employee attendant workers to join unions and to negotiate collective bargaining agreements.

11. Reduce and combine the number of CMS approved waivers but also resurrect the plan to adopt the Personal Care Option under the Medicaid State Plan. Home care must be the preferred, cost saving solution to individuals identified as nursing home eligible. Institutional care is the solution of last resort. CILs will work creatively and strenuously with the State on this approach. Preserve the special role of the Act 150 Attendant Care as a sliding scale matched to income for those

seeking employment and independence. Eliminate all waiting lists.

12. Employ workers with disabilities and expand their participation in the States efforts to keep people out of institutions. CILs have successfully trained disabled community members and survivors of institutional care to be competent with enhanced knowledge due to their personal struggles to maintain and sometimes recapture freedom from institutional care. Prior administrations have accommodated this type of worker and defended them against attacks from professional groups calling for formal education. Again, we need you to value these workers who frequently can obtain success where professionals fail.

13. Bring us to the table to design and implement the provision of HCBS to dual eligible persons under both Medicaid and Medicare. Four years ago we began planning process and demonstration project but our efforts were set aside due to a lack of a Medicaid computer billing system to accommodate the program. Solve the technical issues and assure us of consumer-controlled options in the service models to this category of program participants.

Obstacles to Consumer Responsive HCBS:



- 1. OLTL implementation of complicated system changes have dramatically slowed down and often halting the progress being made to transition of people out of nursing homes.** In 2010, DPW terminated providers of OLTL Waiver services in favor of a single provider, Maximus. The process took four months before anyone requesting services received a response. Waiting lists were established for the first time since the second year of the Governor Ridge Administration. Rebalancing of long term care dollars in the community verses institution had become much more difficult since the start of the Corbett Administration. People on waiting lists are NOT being diverted from nursing home care.
- 2. The change to a single statewide provider of the "Consumer Employer" Model has eliminated the Consumer Employer model as a resource for those consumers who require day-to-day, agency-based support.** The Independent Living Philosophy embraces the individual's right to make both good and bad choices as they learn skills to maintain themselves in community life. We call this the "Dignity of Risk" and support people who value independence balanced against safety concerns. For example, there are increased risks for people with severe disabilities who choose to live alone rather than in group homes or institutions. Many professionals concerned about liability will create barriers to prevent these consumers from having the choice to live the community by refusal to be satisfied by support plans and refusal to accept the

individual's right to make the choice with a well understood level of risk. This judgmental attitude is often directed towards people who are unable to read or write, require assistance with day to day decision making, live alone for the majority of the night or day, or have no support for internment problem solving. Individuals often severely disabled since a young age that do not have a strong family support network are struggling to find a replacement service. Many Centers for Independent Living filled this program gap by using the "Consumer Employer" model as partners with DPW. FMS was wrapped in an Agency-type support model. Using creative methods on a case by case basis, enhanced services were provided in the community where the family network had deteriorated due to long term institutional care, rural settings or the death/disability of a primary care giver.

Traditional provider rates for "Consumer Employer" model consumers were similar to an agency-employer model and included a significant administrative cost which was established to pay for the significantly higher support levels. Prior to the full establishment of FMS, funds dedicated to those costs are now frozen in specialized accounts pending resolution of a legal dispute. Non-profit, provider organizations and CIL's were forced to borrow money until the funds are released.

- 3. Consumers switching to an agency-based model have lost the advantage available under the "Consumer Employer" Model to delegate skilled tasks to long employed attendants that they have trained themselves to provide their personal care.** The Nurse Practice Act reserves the job responsibilities of RN's any task

defined as "invasive" to the body, such as administering of medication, assistance with catheter and bowel care, and other tasks regarded as "skilled". The majority of long term care consumers receive at least one of these tasks as part of their service care plan. "Agency employer" model services governed by the PA Department of Health are NOT a viable option for a large portion long term care consumers in the community unless they are supplemented by RN services for any skilled task. Consequently, there is no longer a low cost, effective service for consumers with a high level of skilled care needs and community service support. Also, consumers are resorting to accepting additional risk or advising attendants to perform the task without informing their agency employer.

- 4. The State has established a complicated system of oversight comprised of State Employees in Harrisburg that oversees the smallest details of service plans for people in remotes parts of the state.** As these programs grow, are you as Secretary planning to increase the number of State workers by thousands? At what point will you realize that these costs are untenable and will vastly diminish the anticipated savings of community care over institutional care? OLTL has approved Provider agency of "Service Coordinators." These are established as intermediaries pursuing permission for the minutest of changes to each and every person's service plan. Provider "Service Coordinators" have no time to address consumers concerns outside of the realm the OLTL world. This is an unresponsive and costly system which stifles community life and quality community service. There is a GAP in service model because the new single provider for the "consumer employer" model provides for no clear view into the working

relationship between the worker and the consumer at the local level. Without scrutiny from informed local sources, incidents of fraud and abuse evidenced by attendant time sheets are far more likely to go undetected for local intervention and correction.

Centers for Independent Living (CIL's) in PA

Reforms of 2010 - 2012 have devastated small community service systems known as Centers for Independent Living Centers that serve the most "at risk" people with disabilities.

There are 18 CILs in Pennsylvania, and each was called into existence with seed funding from the Federal Rehabilitation Act of 1979 or Pennsylvania Independent Living Services Act 139 of 1994. The intention of the laws was to foster the creation of local self-help, non-profits nonresidential organizations, owned and operated by local people with disabilities to promote a philosophy of independent living and to provide services that enhanced independent living. Also, each CIL is unique as it is a reflection of the leadership and vision of the local disability community.

Since the 1980's, many CILs have built their organizations service delivery system primarily on the Consumer-Employer Model of service and have used the Agency model of service delivery only as a "back-up" or contingency. Consequently, the State's reorganization of the funding formula has the most dramatic effect on CILs as PA providers than any of the home care agencies.

Pennsylvania Centers for Independent Living (CIL) have been unique service providers of home and community based services for over 30 years.

In Pennsylvania, CILs are a true solution to empower people to become more self-sufficient and work to make people with disabilities less reliant on "the system." CILs recognize "the culture of disability" that arises as an individual learns to survive in the American culture. CILs also strongly promote that recipients of program services be involved in the planning of those services and believe that process is critical to the success of any service delivery.

Many Pennsylvania CILs draw funding from Department of Public Welfare and Department of Aging programs to deliver direct services under "consumer-controlled" models. In fact, CILs believe that other states and CMS have "copied" the models that were first delivered in Pennsylvania in the mid 1980's. Pennsylvania CILs generally work with individuals who are regarded as too severely disabled by many other service organizations. CILs employ and have on their boards of directors individuals who actually use the services. Service delivery is extended beyond traditional "professional boundaries" to ensure needs are met in a style using a self-reliant philosophy and normally avoiding admission to institutional-type services. CILs often are the first to find and use new assistive technology to enhance independent living. Advocacy, Skills Training, Peer Support, and Information and Referral are core services. CILs have no age or disability boundary and will work with individuals of all ages and disability types, under definitions within the law.

CIL's have pioneered, created, and promoted the "Consumer Employer" model of delivery of Personal Assistance Services since

the first demonstration grants conducted by DPW in 1984. The Pennsylvania State Legislature had created a state budget line item at the urging of the 4 existing CILs to create an attendant care program to help with employment and avoidance of nursing home placement. This history is the foundation of all Consumer-Employer models used by all DPW and Aging programs and was established as the Attendant Care Act 150 of 1987.



NGA Health Care Sustainability Task Force Report

Approved February 22, 2014

Submitted to LTC Commission by Kathleen Kleinmann
May 14, 2014

52
10

The History of Act 150 in Pennsylvania

In December, 1987, Pennsylvania passed the ATTENDANT CARE SERVICES ACT (P.L. No.150). This was in many ways the great climax of a concerted effort of people with severe disabilities, human service agencies, and legislators across the Commonwealth to create a community-based alternative for long term care services.

Attendant Care had actually started through budget funding by the legislature in 1984 which was followed by the actual supporting legislation of 1987. The PA budget line enabled demonstration grants to provide services and to test models of service, including the Consumer Employer Model. Until the demonstration grants and later Act 150, families and friends were stressed to the breaking point to provide care for individuals with disabilities who were trying to survive in the community in a personal living situation. At the breaking point, these individuals were swept into group living situations, such as nursing homes and personal care homes. These individuals gave up privacy, independence, personal possessions, and self-determination in exchange for personal care: a sudden and profound change to those critical components to quality of life in the American society. Some individuals fared well in the exchange. Others suffered greatly from the loss.

The Act was carefully crafted to create a choice for those individuals for whom self-direction and autonomy was most important. The opening policy statements of Act 150 include from Section 2:

1. The increased availability of attendant care services for adults will enable them to live in their own homes and communities.

2. Priority recipients of attendant care services under this act shall be those mentally alert but severely physically disabled who are in the greatest risk of being in an institutional setting.
3. Recipients of attendant care have the right to make decisions about, direct the provision of and control their attendant care services. This includes, but is not limited to, hiring, training, managing, paying and firing of an attendant.

These policies set the stage for a program design unlike anything the Commonwealth had ever experienced. Within the Department of Public Welfare, the Commonwealth turned to those community based organizations most committed to personal empowerment and freedom of choice for people with severe disabilities for implementation of Act 150. Centers for Independent Living took the lead as contractors in the urban areas. United Cerebral Palsy took the lead in the more rural communities where there were no strong Centers.

With more philosophy than well-tested models to start from, the Act 150 Attendant Care Program began as a demonstration project. Bidders for the state contracts were encouraged to experiment within the policy guidelines in the design of the local program. Some projects took the matters of consumer-control to the absolute limits. Other projects followed more the traditional lines of structured regularity with a great deal of agency control. The contractor's meetings were exciting times to compare notes and learn how risk-taking had succeeded or had failed. The local community advisory groups had much to debate and to study. Individuals with severe disabilities who benefited from attendant care services became very obviously more secure in their family and community life.

In an on-going process of evaluation, it became necessary to standardize the program requirements so that there was a uniform array of program options statewide. Available options could no longer be related to geographic residence and which agency was the service provider in that geographic region. It was determined that both the consumer-control option and the agency-control option had benefits to different types of people. People are individuals with differences, and one "size" does NOT fit all.

True consumer empowerment was now recognized to happen only when the provider offered the full spectrum of consumer-control and agency control model options with every shade in between. Those agencies that tended to be comfortable with one model over the other were forced to come to grips with the true meaning of consumer choice. It was no longer just a "catch-phrase." Independent Living Centers and other providers of the program learned more about their consumers. The individual programs became more complex. As more choices became available, consumer demand increased and the statewide waiting list for services grew.

The Focus on the Most At-Risk:

The Independent Living providers of attendant care services continued to become more focused and educated about people with the most severe disabilities. Over time, the population most frequently served by centers for independent in Pennsylvania were no longer the typical employment-seeking clients of the Office of Vocational Rehabilitation. Instead, the most active independent living centers in PA were now working most closely with the group of individuals who had started the nationwide independent living movement in the 1970's: those persons who were the most severely disabled and who were the most threatened with institutionalization.

Act 150 clearly directs the Department of Public Welfare in the selection of providers under Section 4:

"©Proposal selection criteria.--Proposals shall be selected based on service priorities developed by the department; however, priority shall be given to proposals that will serve the severely disabled and those at greatest risk of being institutionalized as defined by the department."

and

"(e) Participation of eligible clients.--Providers, where appropriate, shall include eligible clients in the planning, start-up, delivery and administration of attendant care services and training of personal care attendants."

In conjunction with this process, the centers for independent living also became providers of services under a new, innovative program within the Department of Public Welfare. It was called the Community Services Program for Persons with Physical Disabilities (CSPPPD) and was based upon the Federal OBRA '87 legislation requiring deinstitutionalization services for people with developmental disabilities that were segregated in nursing homes for services when a more integrated setting was more appropriate.

This new program took Independent Living Center staff into the nursing homes. In these institutions, they found those individuals who had slipped into an institution before the advent of the Attendant Care Program. Since many of the managers and independent living center staff and board members are also persons with severe disabilities, the full impact of the absence of attendant care services hit a VERY PERSONAL CHORD. Every day independent living staff with disabilities had to face and struggle to undo the devastation to individual lives caused by the absence of community options. In an URGENT effort to prevent that devastation from happening to others (like themselves), the attendant

care waiting list became the "all-consuming agenda" of the independent living movement in Pennsylvania.

ADAPT OR PERISH

The fact that the elimination of the attendant care waiting list was a "personal issue" and not a academic or agency budget issue provoked the independent living centers to discount the risks of powerful systems advocacy. Time was of the essence. The methods of ADAPT were studied and employed. This included training and organizing "at risk-individuals" to work in letter writing campaigns, intense meetings with state officials, rallies, demonstrations, civil disobedience, and sleep-ins at the Capitol. As a direct results of these efforts and the responding efforts of Governor Ridge and his administration, the waiting list for the attendant care program that began in 1985 was eliminated in the State Budget for 1998/99.

Expansion to the Attendant Care Waiver

Another part of the evolution of the Pennsylvania Attendant Care Program has been the move by the state in conjunction with attendant care providers to seek Federal Waiver funding under Title XIX. During the 1980's, the Federal Waiver programs could not permit the consumer-control emphasis that the Pennsylvania Act 150 program required. However, the Health Care Finance Administration had been pressured by the independent living movement nationwide (most notably ADAPT) to offer the states greater flexibility and to move away from strictly medically oriented definitions of long term care.

When the Federal policy relaxed, a court order interpreting the language in Act 150 forced the State and the attendant care providers to revisit the issue of seeking Title XIX Waiver money to expand the program. This directive is clear in Act 150 in Section 5:

10

"(b) Federal and private funds.--Programs for attendant care services, under this act, shall use federal funds, wherein possible. The department shall apply for and use, subject to specific appropriation by the General Assembly, all federal funds which become available to carry out a program of attendant care services under this act. The department shall use any private funds which become available to carry out a program of attendant care services under this act."

The preparation, submission, and enrollment process in the Attendant Care Waiver was laborious and complicated for all parties. Great effort was taken to make the Waiver as similar as possible to the Act 150 program. But there are subtle differences that affect the state, the providers, and the consumers. The mastery and marriage of the two programs has been an exercise in frustration and complexity. Once again, providers had to reach deeply into their understanding of consumer's needs in order offer them acceptable service options that would also expand attendant care services to more people statewide. The fact that more individuals could be served through the dual program became the over riding justification for the effort to work toward full implementation of both programs statewide.

The Unique Nature of Attendant Care:

Many policy makers and potential providers fail to grasp the distinction of attendant care from otherwise available home health services. Attendant Care, as defined by the World Institute on Disability, is "one person assisting another with tasks the individual world normally do for him/herself if he or she did not have a disability."

These tasks include:

- personal maintenance and hygiene, such as dressing, bathing and catheter care;

- mobility needs, like getting in and out of bed or wheelchairs;
- household responsibilities, including cooking and cleaning;
- cognitive tasks, like money handling and budget planning; and
- communications access, such as interpreting and reading.

Attendant Care aims at maintaining well-being, personal appearance, comfort, safety and positive interactions with the community and society with maximum direction from the consumer. Attendant Care differs from traditional home care and homemaker service in several ways:

- Attendant Care is available when the consumer needs it seven days per week, twenty-four hours per day; where as traditional services are available only during traditional service hours.
- Attendant Care provides long term service where as traditional services are short term.
- In Attendant Care, the consumer's right to determine the extent to which he/she control and direct his/her own service is paramount; whereas in traditional home health care and homemaker service, the provider agency selects and supervises the care giver, designates the duties and sets the schedule.

According to the research and training Center on Public Policy and Independent Living at the World Institute on Disability, in the U.S. alone, it is estimated there are 9.6 million persons who need Attendant Care. Of these 7.8 million people live in the community, 1.5 million live in nursing homes.

The story of the Attendant Care Program continues in Pennsylvania. It is a continuous struggle for all involved,

state officials, advocates and service providers. But, the historical momentum is clear: Consumer control and the reversal of the institutional bias in the provision of long term care services will continue to shape public policy and service implementation in Pennsylvania's.

Essay by Kathleen Kleinmann, April 1996

January 14, 2000

10

Dear State Medicaid Director:

The recent Supreme Court decision in *Olmstead v. L. C.*, 119 S.Ct. 2176 (1999), provides an important legal framework for our mutual efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The Court's decision clearly challenges us to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services.

This decision confirms what this Administration already believes: that no one should have to live in an institution or a nursing home if they can live in the community with the right support. Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.

The Department of Health and Human Services (DHHS) is committed to working with all affected parties to craft comprehensive, fiscally responsible solutions that comply with the Americans with Disabilities Act of 1990 (ADA). Although the ADA applies to all State programs, Medicaid programs play a critical role in making community services available. As a consequence, State Medicaid Directors play an important role in helping their States comply with the ADA. This letter conveys our initial approach to *Olmstead* and outlines a framework for us to respond to the challenge.

The Olmstead Decision

The *Olmstead* case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate. The *Olmstead* decision interpreted Title II of the ADA and its implementing regulation, which oblige States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." (28 CFR 35.130(d)). In doing so, the Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that "Unjustified isolation . . . is properly regarded as discrimination based on disability." It observed that (a) "institutional placement of persons

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (1 of 11)4/11/2006 4:11:59 PM

who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Under the Court's decision, States are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the State's treatment professionals reasonably determine that such placement is appropriate; (b) the affected

persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings. Moreover, the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

Under the ADA, States are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." (28 CFR 35.130(b)(7)). The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how the provision of services affects the ability of the State to meet the needs of others with disabilities. Significantly, the Court suggests that a State could establish compliance with title II of the ADA if it demonstrates that it has:

- a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and
- a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

Olmstead and the Medicaid Program

Olmstead challenges States to prevent and correct inappropriate institutionalization and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate. Medicaid can be an important resource to assist States in meeting these goals. We want to work closely with States to make effective use of Medicaid support in your planning and implementation of Olmstead. As an example of the interface between Olmstead's explanation of the State's ADA obligation and your Medicaid program we would point to the State's responsibility, under Medicaid, to periodically review the services of all residents in Medicaid-funded institutional settings. Those reviews may provide a useful component of the State's planning for a comprehensive response to Olmstead.

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (2 of 11)4/11/2006 4:11:59 PM

States must also be responsive to institutionalized individuals who request that their situation be reviewed to determine if a community setting is appropriate. In such a case the State has a duty to redress the situation, subject to the limits outlined by the Court and the ADA. As another example, States may choose to utilize their Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

Comprehensive, Effectively Working Plans

As we have noted, the Supreme Court in Olmstead indicated that a State may be able to meet its obligation under the ADA by demonstrating that it has a comprehensive, effectively working plan for placing qualified persons with disabilities in the most integrated setting appropriate, and a waiting list that moves at a reasonable pace not controlled by a State's objective of keeping its institutions fully populated. The Department believes that comprehensive, effectively working plans are best achieved with the active involvement of individuals with disabilities and their representatives in design, development and implementation.

The Court's Olmstead decision regarding the integration requirement applies to all individuals with disabilities protected from discrimination by title II of the ADA. Although Olmstead involved two individuals with mental disabilities, the scope of the ADA is not limited only to such individuals, nor is the scope of Olmstead limited to Medicaid beneficiaries or to services financed by the Medicaid program. In addition, the requirement to provide services in the most integrated setting appropriate applies not only to persons already in institutional settings but to those being assessed for possible institutionalization.

The enclosure to this letter offers some recommendations about key principles and practices for States to consider as they develop plans. We recognize that there is no single plan that is best suited for all States, and accordingly that there are many ways to meet the requirements of the ADA. We certainly hope States and people with disabilities will expand and improve on these ideas. Although these plans encompass more than just the Medicaid program, we realize the important role played by State Medicaid Directors in this area. As just one example, Federal financial participation will be available at the administrative rate to design and administer methods to meet these requirements, subject to the normal condition that the changes must be necessary for the proper and efficient administration of the State's Medicaid program. Because of your significant role, we have taken this opportunity to raise these issues with you.

The principles and practices contained in the accompanying technical assistance enclosure also serve as an important foundation for the DHHS Office for Civil Rights' (OCR) activities in this area. As you know, OCR has responsibility for investigating discrimination complaints involving the most integrated setting issue. OCR also has authority to conduct compliance reviews of State programs and has already contacted a number of States to discuss complaints. OCR strongly desires to resolve these complaints through collaboration and cooperation with all interested parties.

Next Steps for the Department of Health and Human Services

Consultation: We have begun consultation with States (including State Medicaid Directors and members of the long term care technical advisory group, who share responsibility for Medicaid) and with people with disabilities. We look forward to building on this start. Many States have made great strides toward enabling individuals with disabilities to live in their communities. There is much that we can learn from these States. We are interested in your ideas regarding the

methods by which we might accomplish such continuing consultation effectively and economically.

Addressing Issues and Questions Regarding Olmstead and Medicaid: As we move forward, we recognize that States may have specific issues and questions about the interaction between the ADA and the Medicaid program. In response to the issues and questions we receive, we will review relevant federal Medicaid regulations, policies and previous guidance to assure that they (a) are compatible with the requirements of the ADA and the Olmstead decision, and (b) facilitate States' efforts to comply with the law.

Technical Assistance: In response to any issues raised by the States, the DHHS working group will develop a plan to provide technical assistance and information sharing among States and stakeholders. Responses to questions and technical assistance materials will be published on a special website. We are also funding projects in a number of States to assist with nursing home transition. Finally, we seek your ideas on the additional forms of technical assistance you would find most helpful for home and community-based services and conferences for State policy makers. We will use your suggestions to facilitate the implementation of the integration requirement. We invite all States and stakeholders to submit questions and recommendations to our departmental workgroup co-chaired by the Director of HCFA's Center for Medicaid and State Operations and the Director of the DHHS Office for Civil Rights. Please send such written correspondence to:

DHHS Working Group for ADA/Olmstead
c/o Center for Medicaid and State Operations



Conclusion

The Administration and DHHS have a commitment to expanding home and community-based services and offering consumers choices in how services are organized and delivered. Over the past few years, DHHS has focused on expanding and promoting home and community-based services, offering support and technical assistance to States, and using the flexibility of the Medicaid program. The Olmstead decision affirms that we are moving in the right direction and we intend to continue these efforts.

We recognize that this interim guidance leaves many questions unanswered; with your input, we expect

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (4 of 11)4/11/2006 4:11:59 PM
to develop further guidance and technical assistance. We recommend that States do the following:

Develop a comprehensive, effectively working plan (or plans) to strengthen community

service systems and serve people with disabilities in the most integrated setting appropriate to their needs;

Actively involve people with disabilities, and where appropriate, their family members or representatives, in design, development and implementation;

Use the attached technical assistance material as one of the guides in the planning process;

Inform us of questions that need resolution and of ideas regarding technical assistance that would be helpful.

We look forward to working with you to improve the nation's community services system.

Sincerely,

/s/ Timothy M. Westmoreland Director Center for Medicaid and State Operations Health Care Financing Administration

/s/ Thomas Perez Director Office for Civil Rights

Enclosure

cc: All HCFA Regional Administrators All HCFA Associate Regional Administrators, Division of Medicaid and State Operations American Public Human Services Association National Association of State Alcohol and Drug Abuse Directors, Inc. National Association of State Directors of Developmental Disabilities Services National Association for State Mental Health Program Directors National Association of State Units on Aging National Conference of State Legislatures National Governors' Association

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (5 of 11)4/11/2006 4:11:59 PM

Enclosure

Developing Comprehensive, Effectively Working Plans

Initial Technical Assistance Recommendations

In ruling on the case of *Olmstead v L.C.*, the Supreme Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The Supreme Court indicated that a State can demonstrate compliance with its ADA obligations by showing that it has a comprehensive, effectively working plan for placing qualified

persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

We strongly urge States to increase access to community-based services for individuals with disabilities by developing comprehensive, effectively working plans for ensuring compliance with the ADA. There is no single model plan appropriate for all States and situations. In developing their plans, States must take into account their particular circumstances. However, we believe there are some factors that are critically important for States that seek to develop comprehensive, effectively working plans. Our intent in this enclosure is to identify some of the key principles, including the involvement of people with disabilities throughout the planning and implementation process. These principles also will be used by the Office for Civil Rights as it investigates complaints and conducts compliance reviews involving "most integrated setting" issues. We strongly recommend that States factor in these principles and practices as they develop plans tailored to their needs.

Comprehensive, Effectively Working Plans

Principle: Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings. When effectively carrying out this principle:

The State develops a plan or plans to ensure that people with disabilities are served in the most integrated setting appropriate. It considers the extent to which there are programs that can serve as a framework for the development of an effectively working plan. It also considers the level of awareness and agreement among stakeholders and decision-makers regarding the elements needed to create an effective system, and how this foundation can be strengthened.

The plan ensures the transition of qualified individuals into community-based settings at a reasonable pace. The State identifies improvements that could be made.

The plan ensures that individuals with disabilities benefit from assessments to determine how community living might be possible (without limiting consideration to what is currently available

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (6 of 11)4/11/2006 4:11:59 PM

in the community). In this process, individuals are provided the opportunity for informed choice.

The plan evaluates the adequacy with which the State is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings (such as State institutions, ICFs/MR, nursing facilities, psychiatric hospitals, and residential service facilities for children) to determine the extent to which they can and should receive services in a more integrated setting.

The plan establishes similar procedures to avoid unjustifiable institutionalization in the first place.

Plan Development and Implementation Process

Principle: Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up. When effectively carrying out this principle:

The State involves people with disabilities (and their representatives, where appropriate) in the plan development and implementation process. It considers what methods could be employed to ensure constructive, on-going involvement and dialogue.

The State assesses what partnerships are needed to ensure that any plan is comprehensive and works effectively.

Assessments on Behalf of Potentially Eligible Populations

Principle: Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities. When effectively carrying out this principle:

- The State has a reliable sense of how many individuals with disabilities are currently institutionalized and are eligible for services in community-based settings. The plan considers what information and data collection systems exist to enable the State to make this determination. Where appropriate, the State considers improvements to data collection systems to enable it to plan adequately to meet needs.

1 The State evaluates whether existing assessment procedures are adequate to identify institutionalized individuals with disabilities who could benefit from services in a more integrated setting.

2 The State also evaluates whether existing assessment procedures are adequate to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting.

3 The plan ensures that the State can act in a timely and effective manner in response to the findings of any assessment process.

Availability of Community-Integrated Services

Principle: Ensure the Availability of Community-Integrated Services. When effectively carrying out

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (7 of 11)4/11/2006 4:11:59 PM

this principle:

The plan identifies what community-based services are available in the State. It assesses the extent to which these programs are able to serve people in the most integrated setting appropriate (as described in the ADA). The State identifies what improvements could be accomplished, including in information systems, to make this an even better system, and how the system might be made comprehensive.

The plan evaluates whether the identified supports and services meet the needs of persons who are likely to require assistance in order to live in community. It identifies what changes could be made to improve the availability, quality and adequacy of the supports.

The State evaluates whether its system adequately plans for making supports and services available to assist individuals who reside in their own homes with the presence of other family members. It also considers whether its plan is adequate to address the needs of those without family members or other informal caregivers.

The State examines how the identified supports and services integrate the individual into the community.

The State reviews what funding sources are available (both Medicaid and other funding sources) to increase the availability of community-based services. It also considers what efforts are under way to coordinate access to these services. Planners assess the extent to which these funding sources can be organized into a coherent system of long term care which affords people with reasonable, timely access to community-based services.

Planners also assess how well the current service system works for different groups (e.g. elderly people with disabilities, people with physical disabilities, developmental disabilities, mental illness, HIV-AIDS, etc.). The assessment includes a review of changes that might be desirable to make services a reality in the most integrated setting appropriate for all populations.

The plan examines the operation of waiting lists, if any. It examines what might be done to ensure that people are able to come off waiting lists and receive needed community services at a reasonable pace.

Informed Choice

Principle: Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings. When effectively carrying out this principle:

The plan ensures that individuals who may be eligible to receive services in more integrated community-based settings (and their representatives, where appropriate) are given the opportunity to make informed choices regarding whether -and how- their needs can best be met.

Planners address what information, education, and referral systems would be useful to ensure that people with disabilities receive the information necessary to make informed choices.

Implications for State and Community Infrastructure

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (8 of 11)4/11/2006 4:11:59 PM

Principle: Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan. When effectively carrying out this principle:

Planners evaluate how quality assurance and quality improvement can be conducted effectively as more people with disabilities live in community settings.

The State also examines how it can best manage the overall system of health and long term care so that placement in the most integrated setting appropriate becomes the norm. It considers what planning, contracting and management infrastructure might be necessary to achieve this result at the State and the community level.

FACT SHEET Assuring Access to Community Living for the Disabled

Overview:

On June 22, 1999, the U.S. Supreme Court affirmed that policy by ruling in *Olmstead v. L.C.* that under the Americans With Disabilities Act (ADA) unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination. In its ruling, the Court said that institutionalization severely limits the person's ability to interact with family and friends, to work and to make a life for him or herself.

The *Olmstead* case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs were receiving mental health services in state-run institutions, despite the fact that their treatment professionals believed they could be appropriately served in a community-based setting.

In accordance with that Court ruling, the U.S. Department of Health and Human Services (HHS) today issued guidance to state Medicaid directors on how to make state programs responsive to the desires of disabled persons to live in appropriate community-based settings. The Administration's goal is to integrate people with disabilities into the social mainstream with equal opportunities and the chance to make choices.

In addition, HHS Secretary Donna E. Shalala wrote to the governor of each state, underlining the Department's commitment to community services for those with disabilities and noting that the *Olmstead* decision applied to all relevant state programs, not just Medicaid.

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (9 of 11)4/11/2006 4:11:59 PM

The Olmstead Decision

The Court based its ruling in *Olmstead* on sections of the ADA and federal regulations that require states to administer their services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

Under the Court's ruling, certain principles have emerged:

- unjustified institutionalization of people with disabilities is discrimination and violates the ADA;
- states are required to provide community-based services for persons with disabilities otherwise entitled to institutional services when the state's treatment professionals reasonably determine that community placement is appropriate; the person does not oppose such placement; and the placement can reasonably be accommodated, taking into account resources available to the state and the needs of others receiving state-supported disability services;
- a person cannot be denied community services just to keep an institution at its full capacity; and,
- there is no requirement under the ADA that community-based services be imposed on people with disabilities who do not desire it.

The Court also said that states are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would

fundamentally alter the nature of the service, program or activity." Meeting the fundamental alteration test takes into account three factors: the cost of providing services in the most integrated setting; the resources available to the state; and how the provision of services affects the ability of the state to meet the needs of others with disabilities.

Olmstead and the Medicaid Program

The Medicaid program can be an important resource to assist states in meeting the principles set out in Olmstead. In its letter/guidance to State Medicaid Directors, the Health Care Financing Administration, which oversees the Medicaid and Medicare programs, reminds states they have an obligation under Medicaid to periodically review the services of all residents in Medicaid-funded institutions.

The letter also reminds states they may chose to utilize their Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

HCFA urges states to develop comprehensive working plans to strengthen community service systems and to actively involve people with disabilities and their families in the design, development and implementation of such plans. HCFA also encourages states to take steps to prevent future inappropriate institutionalization of persons with disabilities and to assure the availability of community-based services.

file:///F:/New%20Website%20Content/PCPG%20Files/2000/2000/smd011400c.asp (10 of 11)4/11/2006 4:11:59 PM

Next Steps

Over the past few years, HHS has focused on expanding and promoting home and community-based services, offering support and technical assistance to states and using the flexibility of the Medicaid program. The Olmstead decision affirms that we are moving in the right direction.

To help states comply with the Court ruling, HCFA and the HHS Office for Civil Rights have begun working with states and the disability community toward the goals of promoting home and community-based services; honoring individual choice in service provision; and acknowledging that resources available to a state are limited by the need to serve both community-based and institutionalized persons.

In addition to continued technical assistance to states, HHS will review relevant federal Medicaid regulations, policies and previous guidance to assure that they are compatible with requirements of the ADA and Olmstead decision and that they facilitate states' efforts to comply with the law.

Alexander, David A

From: Alan Holdsworth [REDACTED]
Sent: Monday, May 19, 2014 10:53 AM
To: AI, LTC-Commission
Subject: written comments to the Long term Care commission

Handwritten marks: a circled '11' at the top right, and a large handwritten '10/1' below it.

I believe that living in the community is a human right and a civil right not a financial conundrum.

We are not cash cows only useful if we make a profit for somebody.

Living in the community is also more cost effective than being institutionalized. If you are in a "facility" you're lying there waiting to die. But if you live in the community your attendant helps you get dressed, eat a decent meal go to work and pay taxes. You are part of the solution not the problem,

~~With Medicaid expansion and the rebalancing incentive and the Community first Choice act the state could save over 1.5 billion in 5 years which is better than the deficit we have now.~~ The only reason that I can think of for the institutional bias is prejudice stereotypes and the government's extreme resistance to change. "That's the way it is."

~~Nurse delegation is crucial especially for me.~~ I use an insulin pen so I can inject myself every day so I can be independent with my medication. If I could not I would be forced into an institution only because I couldn't inject myself. They only reason they would have an excuse to institutionalize me is that I if I couldn't inject myself. Nurse delegation means that lots of folks like me could live in the community and have their attendant perform basic health care tasks.

Consumer control can be defined as nothing about us without us. We are not criminals or little children so we don't need someone telling us what to eat what to wear etc. ~~Consumer control gives us dignity and makes us full citizens.~~ Otherwise we are marginalized in society. Consumer control makes sure that we are fist class citizens not pariahs.

We need more disabled people on the long term care commission. Nothing about us without us!

Eileen Sabel
[REDACTED]
[REDACTED]
[REDACTED]

Alexander, David A

From: Alan Holdsworth [REDACTED]
Sent: Tuesday, May 20, 2014 1:16 PM
To: AI, LTC-Commission
Subject: submission to Long term Care commission

My Name is Herman Greg

I was a resident of Philadelphia Nursing home for three and a half years .from 2002 to 2006. At great expense to the state of Pennsylvania I was incarcerated theiragainst my will. I was patronized by staff who had no idea of my disability which is Cerebral Palsy.

I used to get my clothes stolen out of the 700\$ I received in Social Security they took most of it leaving me with 45 \$ a month.. Because I was in their eyes going too fast in my wheelchair they took it away from me for 2 years. When I got it back it was all messed up. Sometimes the staff would leave me butt naked on the toilet for hours during shift changes. When I tried to speak up for myself they made fun of the way I talk.

Finally I got in touch with someone from an IL center who helped me get out of that hell hole. I'm living good now. I got my own house I pay bills I got enough money although like everyone I would like more. I come down to Liberty and do volunteering help people who are in nursing homes who want to come out.. I am also a community advocate.

I don't think that anyone in a nursing home against their will should be in their. Nursing homes are infringing our civil and human rights. As a grown man why would I need a pass to go in and out of the nursing home..

~~I support the community First Choice Option and any policy that helps people like myself get out and live in the community. I would like to see more policing of institutions so that cases of abuse and infringement of our basic human rights are better documented, reported and dealt with.~~

Thank you for this opportunity to tell you what it is really like in the expensive Institutions you run.

On behalf of many people like me that who remain there supported by your current policy we say change and free our people. This is fundamentally not about your rights nurse's rights owner's rights but the fundamental rights of people with disabilities to live in the community. I do hope that your expensive and abusive system has the guts to change.



RECEIVED
2014 MAY 28 P 3:05
DEPT OF PUBLIC WELFARE

May 21, 2014

Beverly Mackereth, Secretary of Public Welfare
Long Term Care Commission
PO Box 2675
Harrisburg, PA 17105

Re: OLTL POLICY

Dear Ms. Mackereth,

On behalf of ElderNet of Lower Merion and Narberth, an agency specializing in protecting and promoting the health and well-being of low-income older adults, we would like to submit the following statement to the Long Term Care Commission.

We would like to comment on several issues.

First, we are disturbed that under existing systems and rules, it is far easier for needy older adults to obtain admission to a nursing home than to receive the services in their own homes that would enable them to stay at home and avoid institutionalization.

The present system in Pennsylvania allows easy access to nursing homes for nursing home eligible, needy older adults.

At the same time, the present system in Pennsylvania often requires nursing home eligible, needy older adults to wait months before they can receive the services necessary to keep them at home. This is a matter of process, not funding, so that many folks must go to a nursing home because it is not safe for them to remain in their own homes without services.

We urge you to work to change the current system. During the past couple of years, the time it takes to process Aging waiver applications and get services started in a consumer's home has dramatically increased. First, it is taking months for

ElderNet of Lower Merion and Narberth is a not for profit, 501(c)(3) organization that was founded in 1976. ElderNet helps older and disabled adults remain living independently in their homes by providing free, practical, volunteer services such as escort driving, grocery shopping, telephone reassurance, and odd jobs. ElderNet also provides information, referrals, and emergency aid for adults of all ages.



ElderNet is a United Way Donor Option Agency # 03022



2

13
n/def
prash
reflecter

applications to be approved and then additional months for the service plan to be approved. DPW should ensure that there is adequate staff at county assistance offices and that they are properly trained to process applications in a timely way. Once an applicant is finally approved for waiver services and an individual service plan is created, the wait continues, as services cannot start until the Office of Long Term Living approves the individual service plan. The individual service plan review process must change so consumers are not waiting for months for the Office of Long Term Living to approve the individual service plan. In addition, Community Choice or another expedited enrollment process should be restored. It is important that there be an expedited approval of waiver applications when an applicant is at imminent risk of being admitted to a nursing home. An expedited process is needed so those who are at high risk of nursing home placement can avoid being institutionalized.

We are also concerned about the low rate of payment for the AAA's for managing waiver services. We understand that a number of counties have already opted out of managing Aging waiver services, because the rate received does not cover costs, and that Allegheny County may also do so unless the rate is raised. This is a serious loss to the aging system, because the AAA's know their counties so well, and their experience working with older adults would be difficult to replace.

Finally, we are concerned about Pennsylvania's low Medicaid reimbursement rates for home and community-based service providers. Not only have many of these providers not received rate increases in years, *some of them actually had rates cut when an effort was being made to standardize costs throughout the state.* Inadequate waiver reimbursement rates are impacting access to care and have meant that it is extremely difficult to find providers for some clients. We are afraid that the fabric of home care for frail elderly people is being destroyed.

Thank you for the opportunity to voice our concerns. We look forward to changes in the current system that will drastically increase the quality of life for the needy older adult population of Pennsylvania.

Regards,

Charlotte Thurschwell

Charlotte Thurschwell
ElderNet Board Member
Chair of Advocacy Committee

Ruth M. Sperber

Ruth Sperber, MSS, LSW
Executive Director

523 (14)

Alexander, David A

From: Michelle D. Loar [REDACTED]
Sent: Wednesday, May 28, 2014 10:51 AM
To: LTCCommission@pa.gov; AI, LTC-Commission
Subject: LTC Commission testimony

Hello,

Below please find my testimony for the Long-Term Care Commission, along with the testimony of some of the folks I've spoken to:

DJ – “Put things back the way they were. Separating PAS and Service Coordination created a great deal of stress – it’s easier to deal with one person. In home care isn’t prevalent enough in nursing homes. Housing accessibility for people with disabilities is next to none.”

GW – no comment – “Everything’s going good.”

CJ – “Everything is going good.”

TF – “Attendant benefits and raise in pay for them because special bonds are made – this would help with keeping good attendants. The hassle switching from attendant hours to nursing hours was met with a resistance. Allowing attendants to do simple “medical” procedures, such as helping with glucose checks would be more cost effective. If an attendant has stayed in home health care for years, they should be able to get a raise more readily.”

DB – “Everything has been good. The providers have handled everything ok.”

My name is Michelle Loar and I am a person with a disability who receives attendant care services. I am submitting my written comments for your consideration. There are a couple of things I would like to see addressed. First, I believe that ~~attendants should be eligible for health insurance~~. They work hard and deserve it. If our attendants are sick, we are more than likely going to end up sick as well.

Therefore, if they had insurance and could afford to go to the doctor’s as needed, we could prevent the spread of disease and illness. Secondly, as a consumer-employer who utilizes the services of Public Partnership, I think the length of time it takes to hire a new attendant is way too long. As a mother of 2 young children, I agree that the checks need ran, as I would not want someone with a serious criminal record in my home. However, we should be able to start someone on a contingency basis until their record checks come back. Telling someone that you want them to work for you, but that they cannot start for another month at the least is costing us good people that cannot go a month or more without employment. Could you?

Thank you for your time and attention to these matters.

Thanks!!
Michelle Loar
Michelle D. Loar

[REDACTED]

Alexander, David A

From: Anderson, Bruce [REDACTED]
Sent: Thursday, May 29, 2014 1:59 PM
To: AI, LTC-Commission
Subject: RE: Thank you

very few people take advantage of the Pa. Partnership Plan. the requirements make it unaffordable for most moderate to middle income seniors.

millions of pennsylvanians might take advantage of more affordable guidelines. I would like to point out that by allowing more people to protect assets from the spend down process, it lessens the financial hardship on spouses.....at no cost to the state.

as millions of babyboomers retire, the welfare system would benefit because more survivors would be able to maintain self sufficiency, avoiding public assistance.

From: ra-LTCCommission@pa.gov [mailto:ra-LTCCommission@pa.gov]
Sent: Fri 5/23/2014 4:45 PM
To: Anderson, Bruce
Subject: Thank you

Thank you for registering for the public meeting to provide input on the current long-term care system.

If you are attending and providing comments you will be limited to a total of five minutes to allow others time to share their comments.

To assist the Department in accurately capturing verbal comment, individuals are asked to provide their comments in writing to ra-LTCCommission@pa.gov or mail to:

Department of Public Welfare
Attention: OLTL Policy
P.O. Box 2675
Harrisburg, PA 17105-2675.

If there are capacity limitations, priority will be given to those who have registered to attend.