

Pennsylvania Developmental Disabilities Council
Personal Care Homes Position Paper

General Philosophy/Values

The Pennsylvania Developmental Disabilities Council (Council) believes that people with disabilities have the right to safe and affordable housing as well as quality services and supports which will enable them to lead full lives. Council believes that people with disabilities have the right to live in their own homes where they can be integrated into their communities and exert choice and control over their lives. Council believes that all people with disabilities have the right to be treated with dignity and respect.

The Scope of this Position Paper is Personal Care Homes

In Pennsylvania, Personal Care Homes are defined in law as residences that provide meals, shelter, supervision, and assistance with personal care tasks for four or more unrelated adults. The Department of Public Welfare (DPW) has oversight responsibility. Currently, Personal Care Home regulations apply to all Assisted Living Facilities as there is no separate licensure for Assisted Living Facilities in this state. This position paper does not address the issue of creation of an assisted living level of care in Pennsylvania, an issue which raises different or additional policy concerns. A separate Developmental Disabilities Council Briefing Paper on Personal Care Homes contains more detailed information on licensure, oversight and funding of PCH level of care, as well as demographics about the facilities and the people who live in them.

Statement of Concern about Personal Care Homes

Council believes that current Personal Care Home regulations are inadequate and are inadequately enforced to ensure a safe and appropriate housing and service setting for people with disabilities. Council believes that new housing and service models should be developed to provide for individuals' long term care needs. Council is particularly concerned with the lack of housing and service options typically experienced in the current system by over 9,000 low-income residents of Personal Care Homes and by the risk of abuse and neglect vulnerable residents may face.

Issues and Recommendations for Personal Care Homes

Council recognizes that Personal Care Homes have existed for many decades and have become a large industry in Pennsylvania. The development of appropriate alternative options for people with disabilities will take time. Until other housing and service options become viable, the following recommendations regarding the current system are offered:

1. Personal Care Home residents do not have control over the services they receive or the state funding that supports the arrangement. Use of the Supplemental Security Income (SSI) PCH State Supplement is currently contingent upon a person residing in a licensed facility. The funds are paid directly to the PCH provider by the State.
Recommendation: That the Department and stakeholders use demonstration project results to implement mechanisms that allow residents to move to an integrated community setting of their choice and take the supplement with them.
2. Many years of inadequate public funding and lack of administrative focus on licensing, inspection, and complaint investigation have resulted in inadequate enforcement of Personal Care Home regulations. There has also been an unwillingness to fully enforce the regulations in light of the lack of adequate resources to deal with the consequences of licensing actions, e.g., complaint investigations and the relocation of residents due to a closure. We acknowledge and support the Department's recent shift of focus to increased enforcement activities, and we support the use of risk management teams to begin to address this concern. **Recommendation: That the Department implements relocation policies and procedures for closures, enforces the regulations using best practices, and secures adequate resources for effective PCH oversight comparable with other licensed systems.**
3. Oversight of quality in personal care homes over the years has been inadequate. Independent measures for quality used in other settings such as Independent Monitoring for Quality (IM4Q) or Community Satisfaction Teams are not in place for residents in Personal Care Homes. There are no state or county program offices monitoring facilities' quality measures such as adherence to residents' rights or consumer satisfaction. **Recommendation: That an entity responsible for quality improvement measurement in Personal Care Homes is identified and given adequate resources to be effective.**
4. Many PCH residents do not have an agreement or contract with the provider which would give them enforceable rights or access to due process. Examples are the terms

under which a resident can be evicted, what services are to be provided, and what standards can be expected. The absence of a contract makes the resident vulnerable and has a chilling effect on raising grievances or complaints. **Recommendation: That the Department develops and enforces the use of a standard minimum contract between the resident and the facility. The Department must ensure that residents and providers are educated about residents' rights.**

5. Many low-income residents do not receive the help which they need to secure other housing, services or treatment. While some residents do meet the criteria to receive Intensive Case Management from the mental health system, others are not eligible to be served by a case manager or supports coordinator. Some are not aware of assistance they may be eligible to receive from the mental health, mental retardation, or aging services system. We support the transition of persons with mental retardation to more appropriate settings. We support the effort of the Office of Mental Health and Substance Abuse Services (OMHSAS) to determine housing needs and preferences of people living in Personal Care Homes and to ensure that their needs are included in county specialized and generic housing plans. **Recommendation: That the Department ensures that each PCH resident is connected to the service system for which he/she is eligible and that all residents who want to move from the personal care home get the assistance they need to be successful.**
6. Personal Care Home residents on SSI receive only \$60 per month out of the State Supplement for all personal items including prescription co-pays. The Personal Needs Allowance (PNA) has not been increased in many years to keep pace with inflation, nor to off-set the impact of rising co-pays. Providers recently received an increase in the State Supplement payment, but the PNA was not changed. **Recommendation: That the Department increases the Personal Needs Allowance to keep pace with inflation and that residents with excessive prescription co-pays be given relief.**
7. Advocates are concerned with the placement of individuals released from prison with a history of violent or sexual offending behaviors in Personal Care Homes that also house vulnerable populations. There is an absence of public policy regarding safeguards for such situations. **Recommendation: That the Department with stakeholder input develop guidelines and appropriate monitoring mechanisms for violent and sexual offenders and, for those offenders with developmental disabilities, safe and appropriate housing alternatives.**

8. There is currently no functioning stakeholder advisory body for personal care homes and no official structure for systems advocates to give input and receive information. An external group, the Personal Care Home Coalition, currently informally fills this role for low income residents and people with disabilities. **Recommendation: That the Department establishes a mechanism to solicit input from stakeholders. Any advisory body must be balanced to include 51% residents of Personal Care Homes and their advocates.**
9. Because of a lack of other options, some individuals have been moved from state institutions or nursing homes into Personal Care Homes, or found them to be their only affordable place to live. Some of these homes have more than a hundred residents in them. Even those that house smaller numbers of people generally fail to provide for a connection to the community or a homelike environment. Personal Care Homes are institutions and have inadequate regulations for persons with disabilities. **Recommendation: That policymakers work with stakeholders to develop new housing options which are safe, affordable, accessible, homelike and integrated. Options and models to be considered should include, but not be limited to: in-home supports and services, home ownership, Fairweather Lodges, etc. Public policy must be developed to ensure that only safe and appropriate settings are used to transition people from one level of care to another.**

In conclusion, the PA Developmental Disabilities Council urges action which will ensure that all Pennsylvanians with disabilities have homes where they can live in the least restrictive setting of their choice with appropriate services over which they have control. Currently over 9,000 PCH residents who are aging or have a disability have limited options due to their income. We must ensure that individuals who are currently living in Personal Care Homes in Pennsylvania receive protection of their rights and good quality of services. We must increase the availability of support services and housing options for individuals who want to move to a more independent, integrated setting. All stakeholders must work together to address the systemic barriers that perpetuate the problems in the current system. In addition all stakeholders must work together to develop new and better models for the future.

Approved March 29, 2007