

Position Paper of The Arc of Pennsylvania in Regards to Personal Care Homes
Approved- September 29, 2007

BACKGROUND

A Personal Care Home (PCH) is a human service facility that provides meals, shelter, supervision, and assistance with personal care tasks for four or more unrelated adults. Residents of a PCH typically need assistance or supervision in activities of daily living (e.g. dressing, bathing) or instrumental activities of daily living (e.g. laundry, cleaning). There are over 1700 licensed PCHs in Pennsylvania, and over 50,000 Pennsylvanians residing in them. Some PCHs are quite large (hundreds of beds), while some are as small as four beds. PCHs typically cater to one of two population categories; either low-income individuals who are elderly and/or have physical or mental health issues and who pay with their SSI or SSI Supplement, or a population that is wealthier and elderly who generally are private-pay clients. It is estimated that approximately 1300 people with intellectual disabilities live in PCHs, but good data does not exist that captures both individuals with intellectual disabilities known to the system and those not known to the system. People with intellectual disabilities who live in PCHs do so largely because waiting lists for community supports and services are extremely long, and county MH/MR programs have come to rely on PCHs when a person is in crisis and no other service options are available. Base funds and Person-Family Directed Services (PFDS) waiver funds are currently permitted to support individuals with intellectual disabilities who reside in a PCH. Consolidated waiver funds are not permitted to support individuals with intellectual disabilities living in a PCH.

PCHs are regulated by the state, which enforces licensing (health and safety) regulations. The regulations, found at 55 PA Code Chapter 2600, include requirements for fire safety; staff training and education; nutrition and meal preparation; resident health and medical care; personal care service delivery; physical site conditions; and other factors effecting the health, safety and well-being of residents. If an entity meets the definition of a PCH, then it must hold a license to be legally operating in Pennsylvania. The state has historically done an inadequate job enforcing PCH licensing rules, as evidenced by admissions in 2007 by Secretary of Public Welfare Estelle Richman that a majority of PCHs are operating with expired licenses. PCHs are not nursing homes, nor are they Medicaid funded; thus they are not governed by federal rules or laws. In recent history, PCHs have often been referred to or marketed as “assisted living” facilities. A new law passed in 2007 in Pennsylvania that defines assisted living for the first time, enables the public to distinguish between a PCH, assisted living, and a nursing home. However, licensing regulations governing assisted living are not expected to go into effect until 2008. Lastly, licensing regulations applied to programs funded by the Office of Developmental Programs (formerly OMR) do not govern PCHs, even when a person with an intellectual disability is placed in a PCH and is supported with county “base” funds or PFDS-waiver funds.

POSITION

General - It is the position of The Arc of Pennsylvania that Personal Care Homes are not the most appropriate settings for persons with intellectual disabilities and their use by people with intellectual disabilities should be permitted only in exceptional circumstances. Many PCHs in operation today are reminiscent of large and segregated institutions, and serious concerns exist as to whether sufficient or appropriate health and safety measures exist or are enforced to adequately protect residents in PCHs who have intellectual disabilities. PCH licensing regulations are not tailored specifically to address issues associated with individuals with intellectual disabilities. The need for PCHs would not exist if sufficient capacity in housing and community supports were made available by county and state government programs. However, The Arc of Pennsylvania recognizes that, due to the lack of available community programs, a PCH placement is sometimes the only thing keeping an individual with an intellectual disability from being placed in an institution or becoming homeless. The Arc of Pennsylvania believes therefore that, in order to avoid institutionalization or homelessness, it is appropriate for an individual with an intellectual disability to live in a PCH as long as the individual wants to live in the PCH, the individual's needs can be met by the PCH, the PCH meets or exceeds health and safety standards (see below), the PCH's core services are supplemented with community-integration services if the individual needs them, the individual's supports coordinator (SC) actively and regularly monitors the individual's living situation, and the SC continues to plan for the person to live in a community setting other than a PCH.

In those exceptional circumstances when a person with an intellectual disability resides in a PCH, The Arc of Pennsylvania believes the following:

Health & Safety – State mandated health and safety protections must be in place and enforced for PCHs.

- No person with an intellectual disability should ever reside in a PCH that is not able to meet the person's needs or is illegally operating or substantially out of compliance with state mandated health and safety standards. **People with intellectual disabilities should never reside in a PCH that houses sexual offenders and other known criminal populations.** Whenever such situations are discovered, state or county MR program staff must take immediate action to remove the individual and relocate them to an appropriate community setting.
- Licensing regulations for PCHs must take into consideration the needs of all potential residents, including individuals with intellectual disabilities. Regulations must be enforced in a timely manner by state government, and immediate actions must be taken when PCHs fail to meet operating standards, including licensure revocation, state-ordered closures, and publicly-funded relocation of residents to appropriate community locations. In addition, every PCH's current licensure status should be posted online.

Personal choice & control – Individuals with intellectual disabilities – whether or not supported with public funds – should be able to exercise personal choice and control;

have the right to move freely, travel with appropriate supervision, and have control over their money and other life decisions.

Relationships & community integration – Individuals with intellectual disabilities should be afforded opportunities to develop friendships and relationships with people with or without disabilities in their communities; they should have access to supports and services within and outside the PCH to enable them to work, play, shop, worship, and visit family/friends in their community.

Public funding – To achieve community integration, base funds and PFDS waiver funds should be made available for people with intellectual disabilities living in a PCH. Such funds should only be used if the PCH is 8 beds or fewer (individuals living in larger PCHs and are happy living there should be “grandfathered” so that they too can access community-integration services). In no case should a PCH receive or control base of PFDS funds; rather, an independent third party should do so. The individual’s supports coordinator must monitor and re-evaluate the person’s needs and living situation at least twice each year if base funded and three times per quarter if waiver funded. Community-integration services funded by base or PFDS-waiver funds should be portable so that the person can take the services with them if they choose to leave the PCH in the future.

In addition, The Arc of Pennsylvania believes the following:

Housing & Community Supports Capacity – PCHs would not be needed whatsoever if sufficient housing and community service capacity existed. The state, in collaboration with self-advocates, families and other stakeholders, should develop a plan that would commit sufficient public funds to build sufficient service capacity to serve all individuals with intellectual disabilities who need community-based services.

Identification & Transition – The state should identify all residents of PCHs who have an intellectual disability (both those known and not currently known to the system), connect them with a local supports coordinator, and develop and implement an appropriate ISP that would include community-integration services and/or a transition plan for the person to move out of the PCH and into another community home by a certain date.

Studies & Reports – Should a legislative body or other entity commission a study to examine PCHs and/or public policy issues surrounding PCHs, such research or studies should not be limited to issues of cost or cost impacts. Rather, impacts on health and safety, community integration, and the ability of PCH residents to have meaningful relationships with others in the community ought to be considered and included as well.