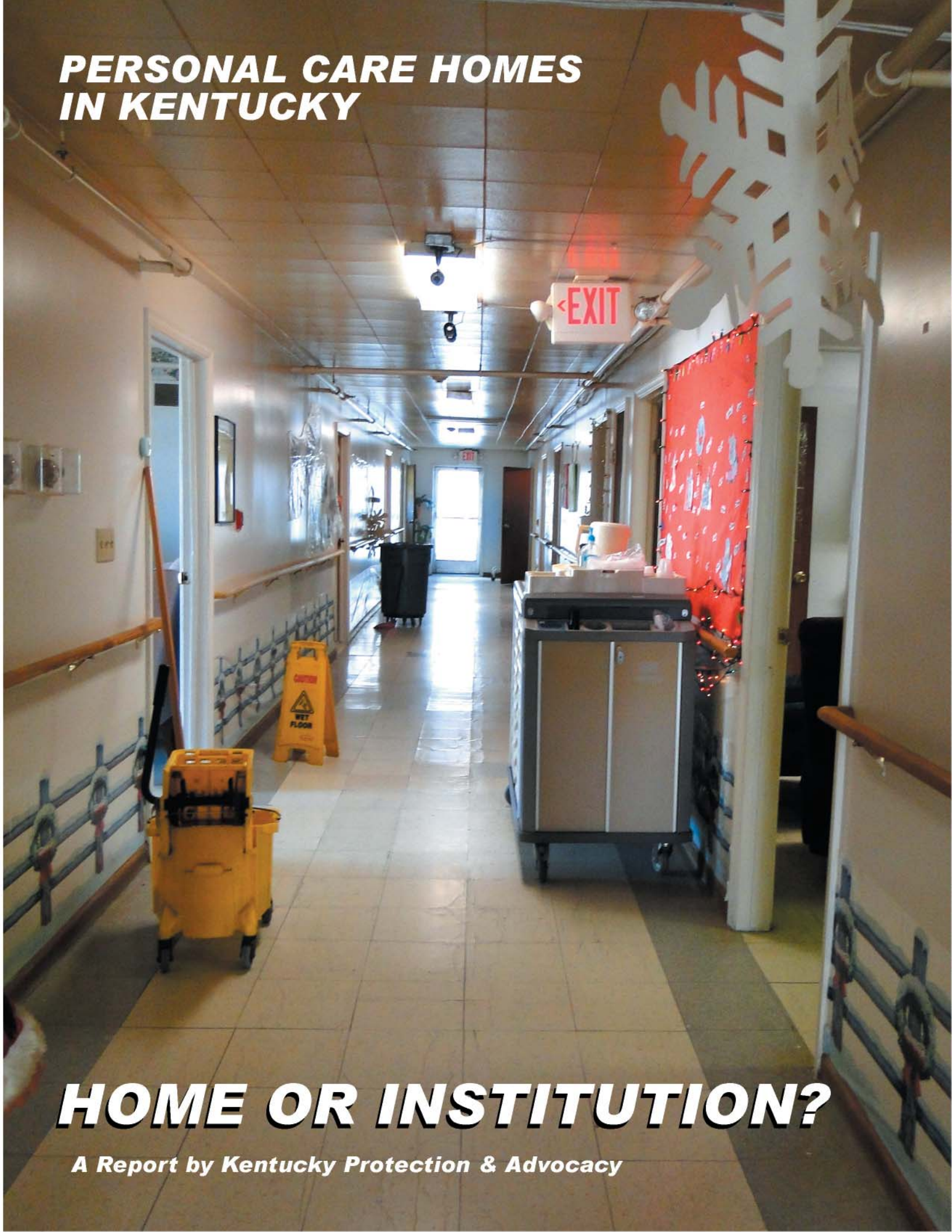
PERSONAL CARE HOMES IN KENTUCKY



HOME OR INSTITUTION?

A Report by Kentucky Protection & Advocacy

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Kentucky Protection and Advocacy (P&A) is Kentucky's protection and advocacy system mandated by federal and state law to advocate for individuals with disabilities. Kentucky P & A receives part of its funding from the Administration on Developmental Disabilities, the Center for Mental Health Services Substance Abuse and Mental Health Services Administration, the Rehabilitation Services Administration, the Health Resources and Services Administration, and the Social Security Administration. Kentucky P&A is a member of the National Disability Rights Network (NDRN), a nonprofit umbrella organization to which all 57 protection and advocacy systems belong.

Congress gave P&As the authority to access individuals with disabilities, their records and the locations where they receive services and supports to investigate abuse and neglect, monitor facilities, provide information and referral, and pursue legal and other remedies on their behalf.

To quote both the Americans with Disabilities Act (ADA) and Olmstead Decision the "most integrated setting" is defined as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." To paraphrase both the ADA and Olmstead Decision, integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities.

Upon the conclusion of reading this report, we encourage you to ask yourself: Are individuals with disabilities living in PCHs in Kentucky living in integrated settings? Do they have access to the same opportunities and access to goods and services as individuals without disabilities?

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A special thank you to those who participated in the interviews

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Kentucky Protection and Advocacy (P&A) is a client-directed legal rights organization that protects and promotes the rights of persons with disabilities. P&A is an independent state agency, and derives its authority from both federal and state law; specifically the Developmental Disabilities Assistance and Bill of Rights Act (DDAct) 42 U.S.C. § 6000 *et seq*.; the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act) 42 U.S.C. §10801 *et seq*.; and Kentucky Revised Statute 31.010 (2).

Included in both federal statutes is the mandate to monitor facilities where persons with disabilities receive services, including where they reside. Facilities are defined to include both public and private entities. Utilizing its monitoring authority, P&A focuses on the rights of individuals, abuse and neglect, transfer and discharge procedures, along with programming and integration in the community. The focus and perspective of P&A is decidedly on those policies and practices of a facility or program that impact the rights of individuals. The practice, policies and customs of a facility or program are measured against statutes and regulations that provide a statement of individual rights. P&A does not function in the same manner as the Office of Inspector General which has the statutory and regulatory power to cite for violations and to require corrective actions.

PERSONAL CARE HOMES IN KENTUCKY

Personal Care Homes (PCHs) are one of seven types of long term care facilities in Kentucky. KRS 216.750 states a personal care home is a place "devoted primarily to the maintenance and operation of facilities for the care of aged or invalid persons who do not require intensive care normally provided in a hospital or nursing home, but who do require care in excess of room, board and laundry." Kentucky Administrative Regulations define a personal care home as "an establishment with permanent facilities including resident beds. Services provided include continuous supervision of residents, basic health and health-related services, personal care services, residential care services and social and recreational activities. A resident in a personal care home must be sixteen (16) years of age or older and be ambulatory or mobile non-ambulatory, and able to manage most of the activities of daily living. Persons who are non-ambulatory are not eligible for residence in a personal care home." [1] PCHs provide services to people with mental health diagnoses, and developmental, intellectual and other disabilities.

The services provided to residents of personal care homes are:

- room accommodations
- housekeeping, including laundry
- maintenance services
- three meals a day, and snacks between meals and before bedtime
- soap, clean towels, washcloths, and linens
- planned individual and group activities
- recreational room or space
- reading materials, radios, games, and television sets [2]

Per Kentucky Revised Statutes, "all residents shall be encouraged and assisted throughout their periods of stay in a long-term care facility to exercise their rights as a resident and a citizen, and to this end may voice grievances and recommend changes in policies and services to facility staff and to outside representatives of their choice, free from restraint, interference, coercion, discrimination, or reprisal." [3] KRS 216.515 (6) states that "all residents shall be free from mental and physical abuse."

Other rights of individuals in a personal care home include, but are not limited to:

- the right to be safe
- the right to be treated with respect and dignity
- the right to privacy
- the right to receive and send unopened mail
- the right to access the telephone for making and receiving calls
- the right to participate in social, religious, and community groups of choice
- the right to go outdoors and leave the premises as you wish unless the PCH documents why this should not occur
- the right to be free from chemical or physical restraints
- the right to keep and wear your own clothing [4]

Personal care homes are licensed by the Office of Inspector General (OIG), within the Cabinet for Health and Family Services. The Office of Inspector General is Kentucky's regulatory agency for licensing all health care, day care, long-term care facilities, and child adoption and child-placing agencies in the Commonwealth. Prior to licensure, long term care facilities must obtain a certificate of need . According to the OIG, there are 6,128 Personal Care Home beds in Kentucky. Of those, there are 81 free-standing PCHs with 4,371 beds which are not part of a nursing facility. Most residents at PCHs

who are recipients of Supplemental Security Income (SSI) use their monthly benefits checks plus a state supplement to cover costs. As of January 2012, the PCH receives $1,218 for each resident ($698.00 from the resident's SSI and $520.00 from the state supplement). Each resident is allowed to retain $60.00 a month for personal spending.

RIGHTS TRAINING 2009 AND 2010

During 2009 and 2010, P&A staff and members of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory Council (PAC) provided information and training to individuals living at 44 personal care homes across the state. Information was provided about guardianship, and review and modification of guardianship, including complete or partial restoration of rights. Staff also provided information about individual rights as a resident at a PCH. The PAIMI grant mandates that each P&A system have an advisory council to guide the system in the priority setting process and keep the system in touch with issues of importance for the disability community at large.[5] Per Federal law, sixty percent of the membership of the advisory council must be comprised of individuals who have received mental health services or are family members of such individuals. In addition, members of the PAC include service providers.[6]

In 2009, 313 residents of personal care homes attended the training and 540 residents attended in 2010. The residents were asked to complete an evaluation of the training and were also asked to list issues that they would like for P&A to address in the future.

The issues identified were:

- modification of guardianship, including restoration of rights
- living arrangements for both independent and supportive housing
- lack of transportation and access to the community
- the quality and amount of food served
- the lack of cleanliness at the personal care homes
- theft and loss of possessions
- negative staff attitudes
- the inability to access the community either due to lack of transportation or due to the location of the PCH to the community
- boredom and lack of activities
- isolation and loneliness
- the lack of enough money
- the inability to smoke often (designated smoke breaks)
- the inability to leave the PCH during the day due to staff restrictions

Following the trainings, P&A received calls and complaints from residents and other agencies that provide services to residents living at PCHs. The complaints included restrictions on the freedom of movement (including some residents wearing monitoring trackers, locked doors and locked fences), poor conditions of the physical building, the quality of food served, threats of hospitalization for refusing to take medication, lack of staffing, alleged sexual abuse, lack of activities, inability to access services at the local mental health center, and inability to transfer to another PCH.

Monitoring Project 2011:

Based on these complaints and using our monitoring authority, P&A staff along with members of the PAC interviewed 20% of the resident population in 20 PCHs throughout the state in 2011. A total of 218 residents were interviewed. Sixteen out of the 20 PCHs are certified by the OIG to receive the Mental Illness /Intellectual Disability supplement. These are PCHs that are receiving an additional supplement over and above the state supplement discussed previously. Over 35% of the residents of the PCH must have a mental illness or an intellectual disability for the facility to receive the supplement.[7] Over 85% of the residents residing in the PCHs visited either had a mental health diagnosis or an intellectual disability. One requirement of the PCHs that receive this supplement is to provide group and individual activities to meet the needs of these residents.

Personal Care Homes Visited in 2011

Table 1: Personal Care Homes Information

	Licensed Number of Beds	Census on Day Visited	Number of Individuals Interviewed	Percent of Overall Interviews	Specialized Rate
Bluegrass Personal Care Home	40	36	7	3.2	Yes
Carrollton Manor	32	32	6	2.8	Yes
Colonial Hall Manor	57	54	12	5.5	Yes
DAVCO Rest Home	92	80	17	7.8	Yes
Dishman Personal Care Home	49	45	8	3.7	Yes
Dry Ridge Personal Care Home	64	47	12	5.5	Yes
Falmouth Nursing Home	28	28	6	2.8	Yes
Fern Terrace of Mayfield	140	127	25	11.5	Yes

Generations Center of Middlesboro	67	61	11	5.0	Yes
Golden Years Rest Home	84	59	12	5.5	No
Hamilton's PCH	22	22	6	2.8	Yes
Harper's Home for the Aged	27	25	6	2.8	Yes
Henderson Manor	64	49	11	5.0	No
Highland Homes	100	93	18	8.3	Yes
The Laurels	82	66	13	6.0	Yes
Regency Manor	59	57	12	5.5	Yes
Shady Lawn	75	62	15	6.9	Yes
Sunny Acres	32	25	6	2.8	No
Valley Haven Rest Home	45	37	9	4.1	No
Waynesburg Manor	28	28	6	2.8	No
Total:	1187	1033	218	100.00	

METHODOLOGY

In January 2011, P&A developed an interview tool to be used during our monitoring efforts at PCHs throughout Kentucky. Question formats included Yes/No, Likert Scale, and open-ended questions. The tool was field-tested in February 2011 after which modifications were made to assist staff and PAC members in administering the interview by including all possible responses by individuals. Possible responses were chosen based on staff experience and feedback from past monitoring visits.

The twenty PCHs that we visited were chosen for a variety of reasons, including: complaints received from the Long-term Care Ombudsman, complaints that P&A received directly from individuals living at PCHs, and observations made by staff during visits to PCHs. Additionally, PCHs where we had not had a presence historically were also chosen.

Training prior to implementation of the Monitoring Project:

Prior to implementation of the Monitoring Project at PCHs, P&A staff and members of our PAIMI Advisory Council were provided training on interviewing individuals with disabilities, including how to administer the interview to control for reliability. Interview bias was also discussed to control for validity. The training included tips on how to interview individuals, such as: the need be consistent, and the need to ask questions exactly as written and in the order written. It was stressed during the training the importance to not ask leading questions and to remain objective.

Process:

Starting in May 2011 through August 2011, P&A staff and PAC members together made unannounced visits to the twenty PCHs throughout Kentucky that accounted for a total of 1,187 licensed beds. We interviewed 218 individuals. Prior to the unannounced visit, staff were provided a packet of information including P&A materials, directions, and census information. They were instructed to interview 20% of the total daily census. Individuals, at random, were asked if they were interested in being interviewed and participating in the project. They were informed of the purposes of the interview and provided written and oral information about the mission and role of P&A.

In addition to interviews with individuals, P&A staff completed a tool to reflect observations of both the inside and outside of the PCH (facility tool). P & A staff also conducted an interview with the PCH administrator (or the designee). While at the PCH, P&A staff reviewed, when posted, the schedule of activities and the most recent survey conducted by the Office of Inspector General (OIG).

Information collected on both the individual interview tool and the facility tool was then entered into the Statistical Package of the Social Sciences (SPSS). SPSS, developed by IBM, is often used by the social sciences to manage data and to perform various statistical analyses. This information, part of an observational study, was collected to be able to provide information to P&A about individual's perspectives of living in PCH on a a daily bais.

We assert that the information collected and mentioned forward was collected in a manner that is consistent with research practices that would assume the information collected is valid and reliable.

INDIVIDUAL INTERVIEWS

Individuals interviewed were observed by staff both prior to and after the interviews. Sixty-six (66) percent of individuals were observed to be sitting alone, smoking, walking the halls, or to be doing nothing. Others were watching television, eating snacks, taking medicines, or sitting with peers.

Demographics:

P&A staff and PAC members interviewed 218 individuals living at PCHs throughout Kentucky (Table 1). The average age of residents was 51 years of age and ranged from 20 to 77 years of age. Fifty percent (50%) of responders were male and 50% were female. Eighty-seven (87) percent of responders identified themselves as White/Non-Hispanic and 12% identified themselves as black (Table 2). Seventy-eight (78) percent of individuals identified themselves as being a person with a mental illness only, 10% as an individual with intellectual and/or developmental disability (ID/DD) only, 8% as a person with a mental illness and ID/DD, and 4% as being a person without mental illness or an intellectual and/or developmental disability (Chart 1). Forty-eight (48) percent of individuals interviewed had been appointed a legal guardian through the court system. Of those with a guardian, 92% had a full guardian. Both disability and guardian data were verified by P&A staff through chart review with permission from the individual.

Individuals were asked to self-report the number of years they have lived in a Personal Care Home settings, with 39% reporting they have lived in a PCH for five or more years (Chart 2).

Table 2: Demographic Information

	Number of Responses	Percent
Gender		
Male	109	50.0
Female	109	50.0
Total	218	100.0
Race/Ethnicity*		
White/Non-Hispanic	187	86.6
Black	26	12.0
Asian	2	.9
White/Hispanic	1	.5
Total:	216	100.0
*Excludes missing data		

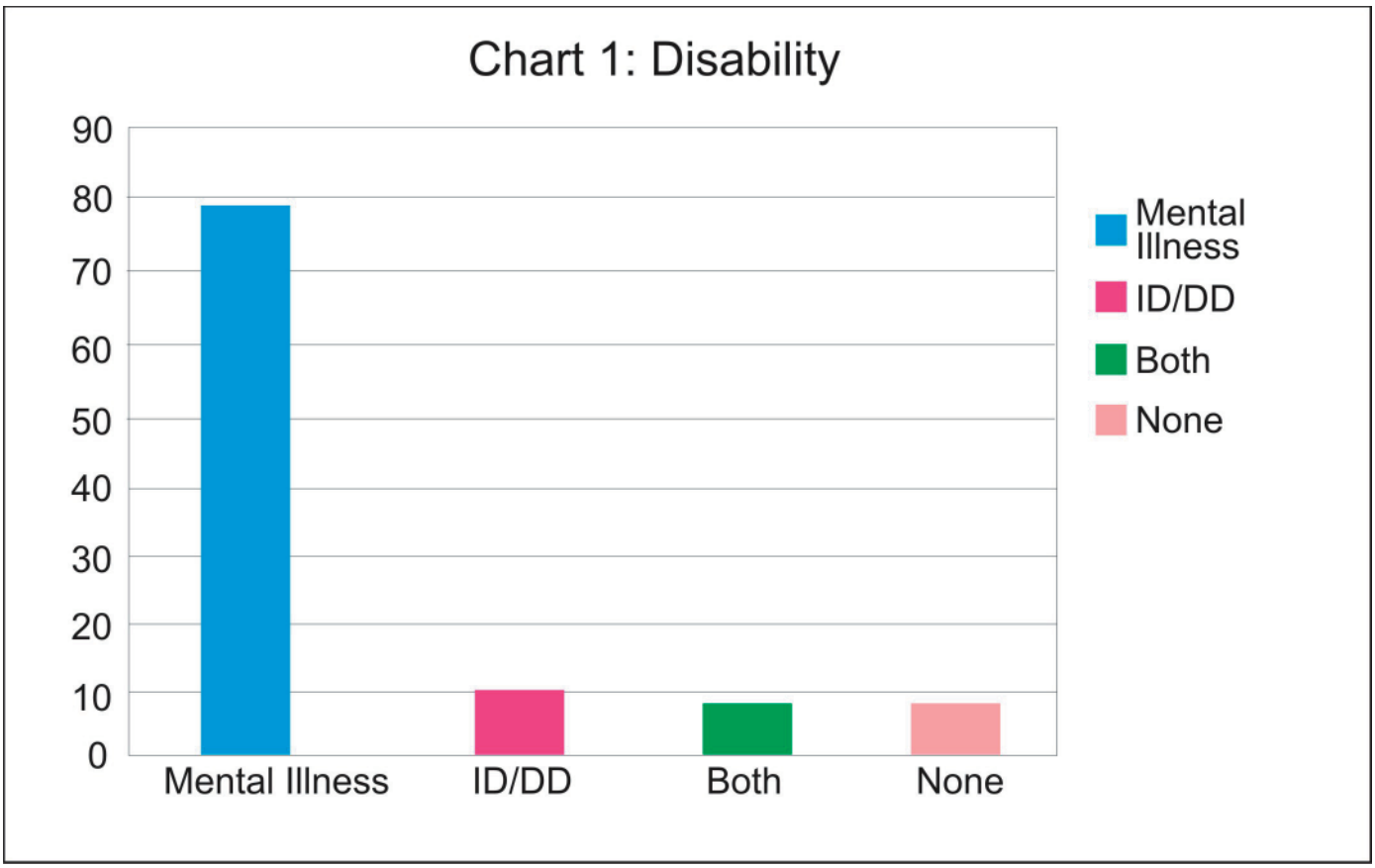


Chart 1: Disability
90
80
70
60
50
40
30
20
10
0
Mental Illness
ID/DD
Both
None
Mental Illness
ID/DD
Both
None

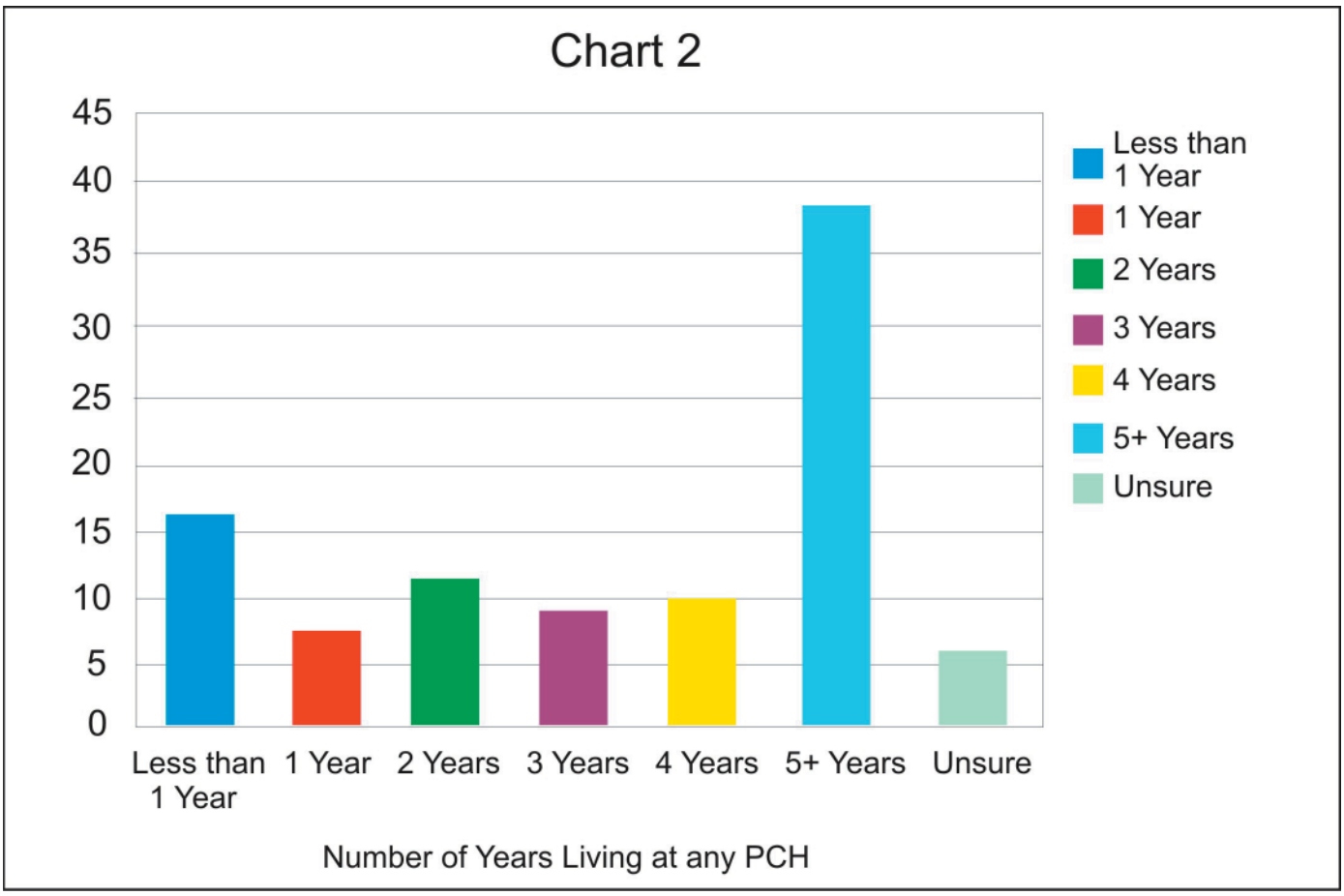


Chart 2
45
40
35
30
25
20
15
10
5
0
Less than 1 Year
1 Year
2 Years
3 Years
4 Years
5+ Years
Unsure
Less than 1 Year
1 Year
2 Years
3 Years
4 Years
5+ Years
Unsure
Number of Years Living at any PCH

SEGREGATION FROM THE COMMUNITY

The Americans with Disabilities Act (ADA) and Olmstead decision define the "most integrated setting" as "a setting that enables individuals with disabilities to interact with non-disabled person to the fullest extent possible." [8] "Integrated settings are those that provide individuals with disabilities opportunities to live work and receive services in the community, like individuals without disabilities. By contrast, segregated settings often have qualities of an institutional nature. Segregated settings include, but are not limited to: congregate settings populated exclusively or primarily with individuals with disabilities; congregate setting characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or settings that provide for daytime activities primarily with other individuals with disabilities." [9]

Residents living in a personal care home are segregated from the community in which they reside. For the vast majority there is virtually no meaningful interaction with individuals who do not have a disability. Persons living in personal care homes in Kentucky expressed isolation, loneliness, boredom, and hopelessness. The structure of living in a personal care home affords little opportunity for integration in the community.

Personal Care Homes in Kentucky segregate individuals from the community by:

- the location (many times located miles from the nearest community)
- locked doors
- chain link fences with padlocks
- lack of transportation
- lack of planned community activities

- having a doctor visit the PCH
- designated times when the individual can leave the facility
- the requirement of a sign out sheet
- separation of the individual from family and friends
- lack of opportunities for individuals with disabilities to interact with individuals who do not have a disability
- discouragement of employment

Many PCHs are located in rural communities, making it difficult to walk to stores, restaurants, libraries, or churches (Table 3). Others are located on busy highways or roads that do not have sidewalks. PCH staff feels they are protecting residents from injury, therefore restricting their access to the community. Some staff restrict residents from access to their communities by locking the doors to PCHs, therefore, preventing individuals from entering or exiting. In other PCHs, there are large chain link fences with a locked gate surrounding the properties. Some PCHs have staff assigned to the grounds to ensure that residents do not leave.

Table 3: Community Access Information		
	Number of Responses	**Percent**
How do you get into the community the majority of the time? *		
PCH Transports	33	15.2
Local Transportation	23	10.6
Walk	93	42.9
Doesn't Go into the Community	39	18.0
Family	13	6.0
Other	16	7.4
Total:	217	100.0
Are there places in town or around here you can't go? *		
Yes	71	33.3
No	112	52.6
Sometimes	5	2.3
Unsure	25	11.7
Total:	213	100.0
Why don't you get out? *		
Guardian Restriction	14	10.9
Staff Restriction	15	11.6
No Transportation	25	19.4
No Money	26	20.2
Too far to walk	14	10.9
Choose to Not get out	11	8.5
Unsure/I don't know	6	4.7
Other	18	14.0
Total:	129	100.0
*Excludes missing data		

Public transportation is non-existent for most individuals living at the PCHs in rural communities visited by P&A. Some residents stated they were not allowed to cross the street or could only walk as far as the railroad track. Most of the residents access the community by walking. Very few PCHs have a vehicle capable of transporting residents to the community. One PCH census was 127 residents. The van for the PCH was a six passenger van. In another PCH residents who use a walker or wheelchair stated they cannot go on outings because the van is not accessible. A common complaint that residents made was that the PCH rarely planned an outing. One PCH takes the residents out once a year to go shopping if the resident has any money. Residents stated church groups come to some of the PCHs weekly. Bookmobiles visit from the local library in several PCHs instead of individuals going to the public library. Many residents remarked that they only went on outings into the community if they attended Therapeutic Rehabilitative Program (TRP) (Table 4). This program is offered by the community mental health centers to provide a day program to individuals who have mental illness. Many residents expressed interest in attending the TRP and the community mental health center for counseling or case management services; however, the staff at the PCH would not arrange it (Tables 5 and 6) even though 85% of the individuals interviewed have a mental health diagnosis. In many PCHs, residents reported that instead of going into the community for appointments with their doctor, the doctor visits the PCH. This arrangement mimics how services are delivered at psychiatric hospitals. Some PCHs have set times that residents may come and go from the PCH with the permission from staff or the administrator. Many PCHs have a sign-out sheet. Residents of one PCH stated they have to be back at the PCH by 3 p.m. and residents of another PCH stated they are not allowed to leave on Sundays (Table 7). As noted above, one PCH had a chain-link fence locked with a padlock. The residents were not allowed to leave the PCH unless the administrator is at the PCH and unlocks the gate. As one resident stated, “I have to stay inside the fence.”

Table 4: Did you or will you go to town today?*		
	Number of Response	Percent
Yes	40	18.4
No	171	78.8
Unsure	6	2.8
Total:	217	100.0
*Excludes missing data		

Table 5: Do you attend the Therapeutic Rehabilitation Program?		
	Number of Responses	Percent
Yes	29	13.3
No	189	86.7
Total:	218	100.0

Table 6: Do you go to the local CMHC or Comprehensive Care?*		
	Number of Responses	Percent
Yes	54	24.9
No	152	70.0
Unsure	11	5.1
Total:	217	100.0
*Excludes missing data		

Table 7: Can you leave go into the community when you want? *		
	Number of Responses	Percent
Yes	129	59.4
No	70	32.3
Sometimes	9	4.1
Unsure	9	4.1
Total:	217	100.0
*Excludes missing data		

Many residents no longer have contact with family and friends for various reasons. Due to numerous placements, either in a PCH or psychiatric hospital, friendships are difficult to maintain. The residents who do maintain these relationships live in PCHs that are located hours from their family and friends. This places a financial strain on both the residents and family members. One resident stated that he had not seen his family in ten years. Other residents want to live closer to their families and indicate they miss their children. Some residents mentioned they have yearly visits from family members and they looked forward to these visits (Tables 8 and 9). One resident stated that the visit from P&A was the first visit that he had in six years. He shared with P&A staff, “I am a lonely man. I spend my time sitting on a milk crate in the shade.”

Residents also stated they spend most of their time with either other residents or stay to themselves (90%) (Table 10). Most residents indicated they wanted to participate in the same activities as individuals without disabilities. They wanted to go shopping, to restaurants, to movies, to the gym, to church, to the library, go fishing, go to school, spend time with family and friends, and seek employment. Some residents do work at the PCH by helping out with janitorial chores. There are very few opportunities for a person living in a PCH to be employed in a non-segregated work place. One of the individuals interviewed stated, “I just want to enjoy life.”

Table 8: How often do you have visitors?*		
	Number of Responses	Percent
Weekly	26	12.0
Twice a Month	21	9.7
Once a Month	42	19.4
Couple of Times per Year	39	18.1
One Time per Year	14	6.5
Never	74	34.3
Total:	216	100.0
*Excludes missing data		

Table 9: How often do you see friends or family not living at the PCH? *		
	Number of Responders	Percent
Weekly	37	17.1
Monthly	50	23.1
Few Times per Year	49	22.7
Never	80	37.0
Total:	216	100.0
*Excludes missing data		

Table 10: Who do you spend your free time with the majority of the time?		
	Number of Responders	Percent
Residents	148	67.9
Staff	11	5.0
Family or Friends not Living at PCH	8	3.7
No One	48	22.0
Both Friends and Family at PCH	2	.9
Unsure	1	.5
Total:	218	100.0

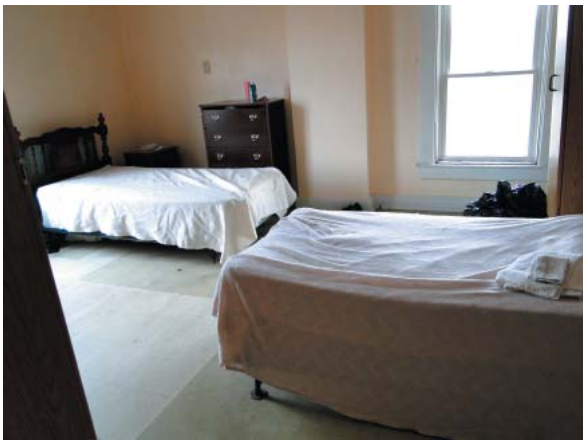
CONGREGATE SETTING

Individuals who live in personal care homes are living in congregate settings. The majority of the individuals have a disability and, because of this disability, they are placed at a PCH. The 20 PCHs visited by P&A are licensed by the OIG ranging from 22 to 140 beds. The physical structures of these PCHs often make them appear identifiable as institutions and are not natural housing arrangements. Many PCHs are located in areas that are not easily accessible to the community. Many PCHs are not within a reasonable distance to stores, restaurants, place of worship, jobs, healthcare providers, and family and friends.

Individuals who reside in PCHs:

- have multiple roommates
- are not able to choose their own roommate
- are subjected to loss of personal property due to theft
- eat their meals at the same time
- are not able to choose what food they would like to eat
- all take their medication at the same time
- are not able to have private phone conversations
- have regimented smoke breaks
- have designated bedtimes
- have times where they cannot watch television
- are provided activities that are not age appropriate
- do not perform tasks such as cooking, laundry or shopping for clothes

In the personal care homes visited by P&A, the majority of the residents do not have a private room. They are assigned anywhere between one and three roommates and are not provided with the choice of roommates (Table 11). Almost all of the residents interviewed stated they do not have a key to their room. Residents state that often times their personal possessions are missing. Twenty-five percent of the residents reported they have been hurt at the PCH. The most often reported reason for injuries was resident-to-resident fighting (Tables 12 & 13). Over 30% of the residents stated that they have witnessed another resident hurt at the PCH.



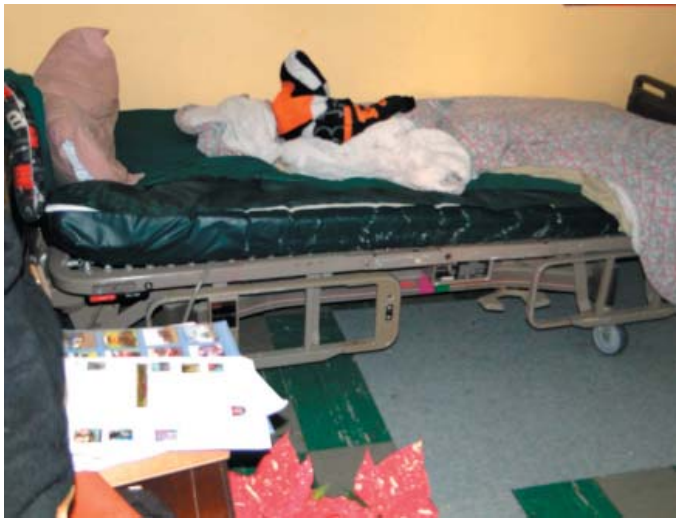
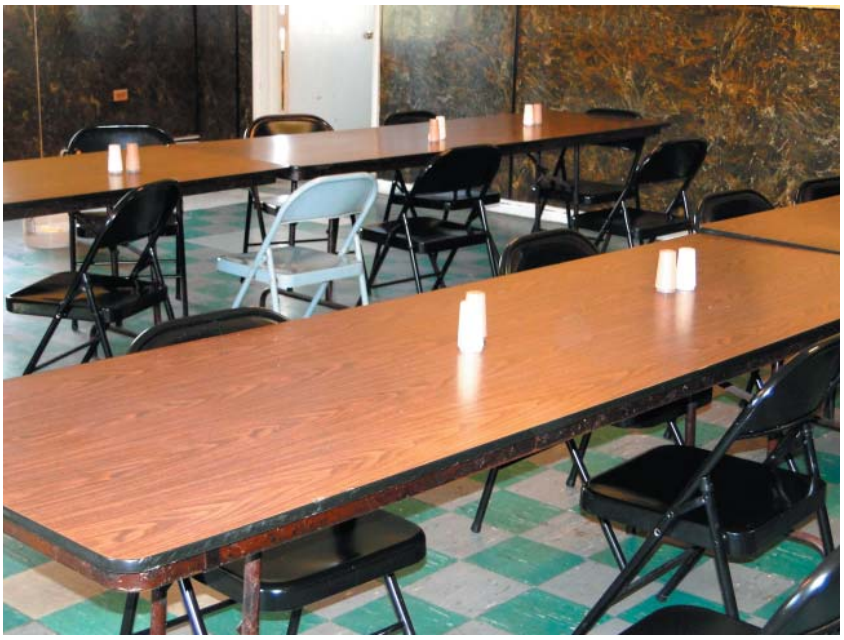


Table 11: Roommate and Room Information		
	Number of Responses	Percent
Do you have a roommate?		
Yes	182	83.5
No	36	16.5
Total:	218	100.0
Number of Roommates*		
One	123	67.2
Two	29	15.8
Three	31	16.9
Total:	183	100.0
Did you choose your roommate?*		
Yes	30	16.2
No	151	81.6
Don't Know	4	2.2
Total:	185	100.0
Do you have a key to your room?		
Yes	7	3.2
No	211	96.8
Total:	218	100.0
*Excludes missing data		

Table 12: Have you been hurt at the PCH?		
	Number of Responders	Percent
Yes	55	25.2
No	163	74.8
Total:	218	100.0

Table 13: If you were hurt at the PCH, how were you hurt? *		
	Number of Responders	Percent
Resident on Resident	28	45.2
Staff on Resident	6	9.7
Verbal Abuse by Staff	4	6.5
Sexual Abuse by Resident	1	1.6
Accidents, Seizures or Falls	15	24.2
Other	8	12.9
Total:	62	100.0
*Excludes missing data		

At meal times, residents eat all at the same time and many have assigned seating. Other residents are required to eat at a separate time or at another dining area because they either have a physical disability or have "been disruptive" to the other residents. At one PCH, P&A witnessed six out of 26 residents eating at children's school desks with their faces turned toward the wall. At another PCH, residents with physical disabilities were referred to as "the feeders" and ate their meals separate from other residents. While most expressed they liked the food served, they mentioned they did not get enough to eat and were not allowed seconds. When asked if there was an alternative to the menu items, residents often reported they could have either a sandwich or cereal. Two-thirds of the residents stated that they did not get anything else to eat if they missed the meal served because they were out of the PCH, were in their room, or simply chose not to eat at the set time (Table 14). According to PCH regulations, a snack is supposed to be served between meals and before bedtimes; however, this is often not the case.



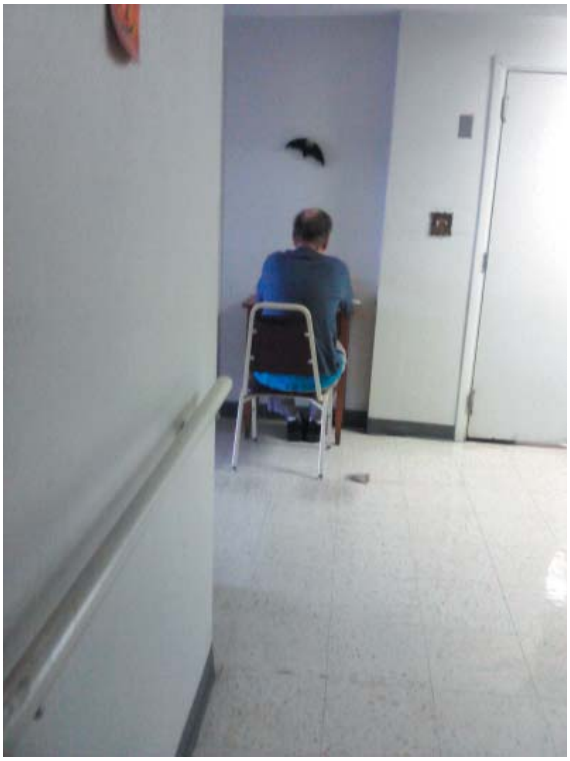


Table 14: Eating Information		
	Number of Response	Percent
Does everyone eat at the same time?*		
Yes	187	86.2
No	27	12.4
Sometimes	3	1.4
Total:	217	100.0
Do you choose where to sit?*		
Yes	120	55.3
No	93	42.9
Sometimes	4	1.8
Total:	217	100.0
Do individuals with special eating needs eat at different times? *		
Yes	65	30.8
No	143	67.8
Unsure	3	1.4
Total:	211	100.0
What happens if you don't eat at designated times?*		
Given an Alternative	26	14.9
Saved for Later	6	3.4
No food, Staff yell, or Other	140	80.0
Don't Know	3	1.7
Total:	175	100.0
*Excludes missing data		

Medications are given out at approximately the same time (Table 15). Residents either line up by the medication room or their names are called out over a loud speaker. Telephones are available for residents, although in most PCHs there is only one phone for residents to use. Private conversations are difficult because either staff or residents are nearby. In one PCH, the only phone available is a payphone located outside of the building. Some PCHs do not provide long distance service, making it difficult for residents to keep in contact with family and friends. The majority of the PCHs have designated visiting hours (Table 16). Many residents stated they do receive mail monthly. When asked about it, they stated it was mail issued by Social Security Administration. Twenty-two percent of the residents stated they rarely or never receive mail.

Table 15: Does everyone take medicines at the same time? *		
	Number of Responders	Percent
Yes	151	69.6
No	45	20.7
Sometimes	19	8.8
Unsure	2	.9
Total:	217	100.0
*Excludes missing data		

Table 16: Times that individuals can have visitors.*		
	Number of Responders	Percent
Anytime	75	37.7
Visiting Hours	122	61.3
Unsure	2	1.0
Total:	199	100.0
*Excludes missing data		

Most residents stated that while they were able to smoke whenever they wanted, many PCHs had regimented smoke breaks (Table 17). In one case, a facility allowed 8 smoke breaks a day (8 cigarettes). Another PCH allowed residents to smoke on the hour during waking hours (8am-9pm). P&A observed residents lining up by a wall for smoke breaks.

Table 17: Can people choose when to smoke?*		
	Number of Responders	Percent
Yes	158	73.8
No	42	19.6
Sometimes	4	1.9
Total:	214	100.0
*Excludes missing data		

Some PCHs have curfews and about one half of the residents stated that the doors are locked after the curfew (Table 18). There are some PCHs that state a resident has to be back by a certain hour (usually before the evening meal). One third of the residents stated they are restricted from going into the community. This was either due to restrictions placed on them by their guardian or staff at the PCH. Most PCHs allow the residents to leave, but require the residents fill out a sign-out sheet (Table 19). The majority of the residents stated they tell staff where they are going when they leave the PCH. Some PCHs have a designated bedtime while other PCHs have a designated time for residents to be in their rooms (Table 20). Some residents complained about the noise in the PCH at night caused by other residents and indicated they had difficulty sleeping. Most PCHs have one television and there are times when the residents are not allowed to watch television, which is when they are supposed to be in their rooms (Table 21).

Table 18: Are PCH doors ever locked?*		
	Number of Responders	Percent
Yes	103	47.5
No	101	46.5
Unsure	13	6.0
Total:	217	100.0
*Excludes missing data		

Table 19: Leaving Facility		
	Number of Responders	Percent
Can you leave and go into community whenever you want?*		
Yes	129	59.4
No	70	32.3
Sometimes	9	4.1
Unsure	9	4.1
Total:	217	100.0
If you responded no, why? *		
Guardian	17	22.7
Staff	46	61.3
Other	12	16.0
Total:	75	100.0
Do you have to tell staff when you leave?*		
Yes	181	83.4
No	18	8.3
Sometimes	1	.5
Unsure	17	7.8
Total:	217	100.0
Do you have to tell staff where you are going? *		
Yes	160	73.7
No	37	17.1
Unsure	20	9.0
Total:	217	100.0
Can staff tell you, you can’t go somewhere you want to go? *		
Yes	76	35.3
No	96	44.7
Sometimes	14	6.5
Unsure	29	13.3
Total:	215	100.0
*Excludes missing data		

Table 20: Bed Time		
	Number of Responders	Percent
Does everyone go to bed at the same time?		
Yes	72	33.0
No	138	63.3
Sometimes	7	3.2
Unsure	1	.5
Total:	218	100.0
Who tells you to go to bed?*		
Staff	60	27.6
No One	155	71.4
Unsure	2	.9
Total:	217	100.0
*Excludes missing data		

Table 21: Are there times you can't watch television?		
	Number of Responders	Percent
Yes	77	35.3
No	121	55.5
Sometimes	10	4.6
Unsure	10	4.6
Total:	218	100.0

The PCH is required to offer activities and to post an activities schedule. The activities offered are games, including bingo, puzzles, or coloring. P&A did not observe much difference in the activities offered by the PCHs that receive the MI/MR supplement than PCHs that do not receive it (Table 22). Other requirements to receive this certification from the OIG is that the PCH has verification on file that the staff receive training, and a licensed nurse or certified medical technician must be on duty for at least four hours during the first or second shift. The nurse must demonstrate knowledge of psychotropic drug side effects. The PCH must also provide group and individual activities to meet the needs of persons with mental illness or intellectual disability.

Some PCHs have church groups that visit occasionally. When residents were asked if the PCH ever planned an outing, one-fourth of the residents stated daily, weekly or monthly. Over one-third of the residents stated that the PCH never plans an outing (Table 23).

Table 22: Does the PCH plan organized activities for you at the PCH? *		
	Number of Responders	Percent
Frequently	99	47.1
Sometimes	84	40.0
Rarely	14	6.7
Never	13	6.2
Total:	210	100.0
*Excludes missing data		

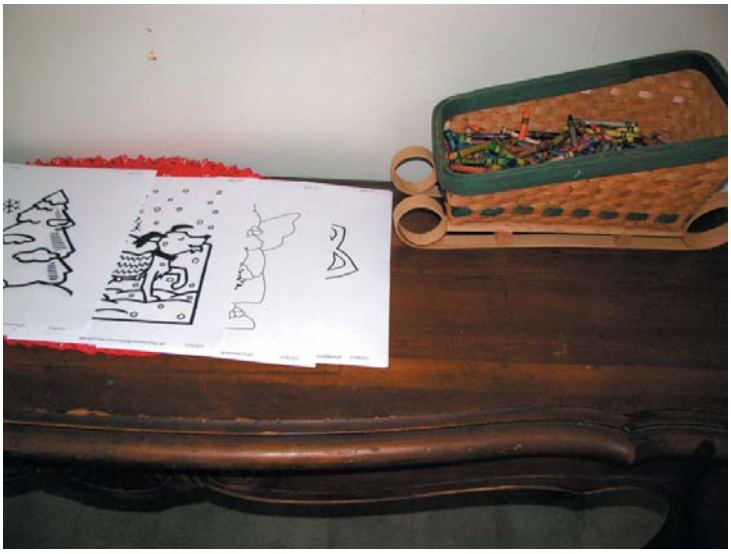
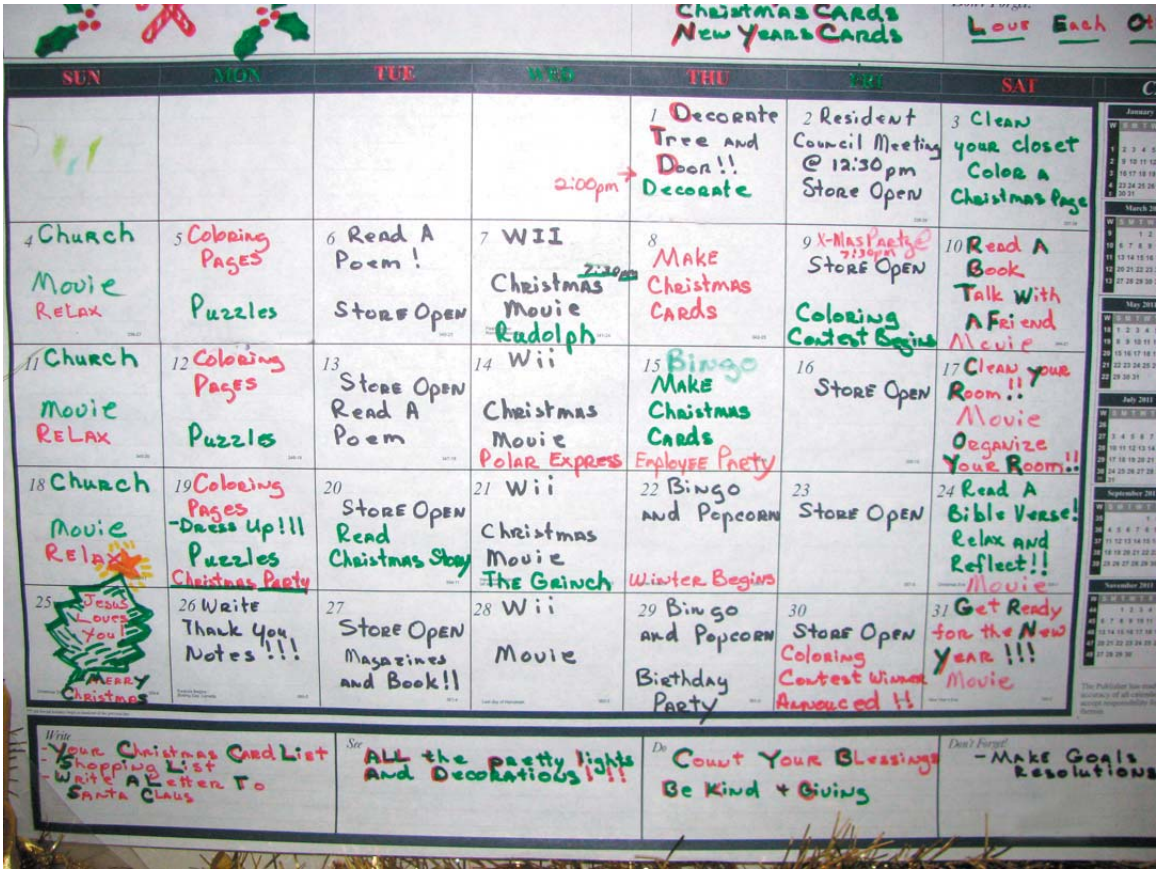
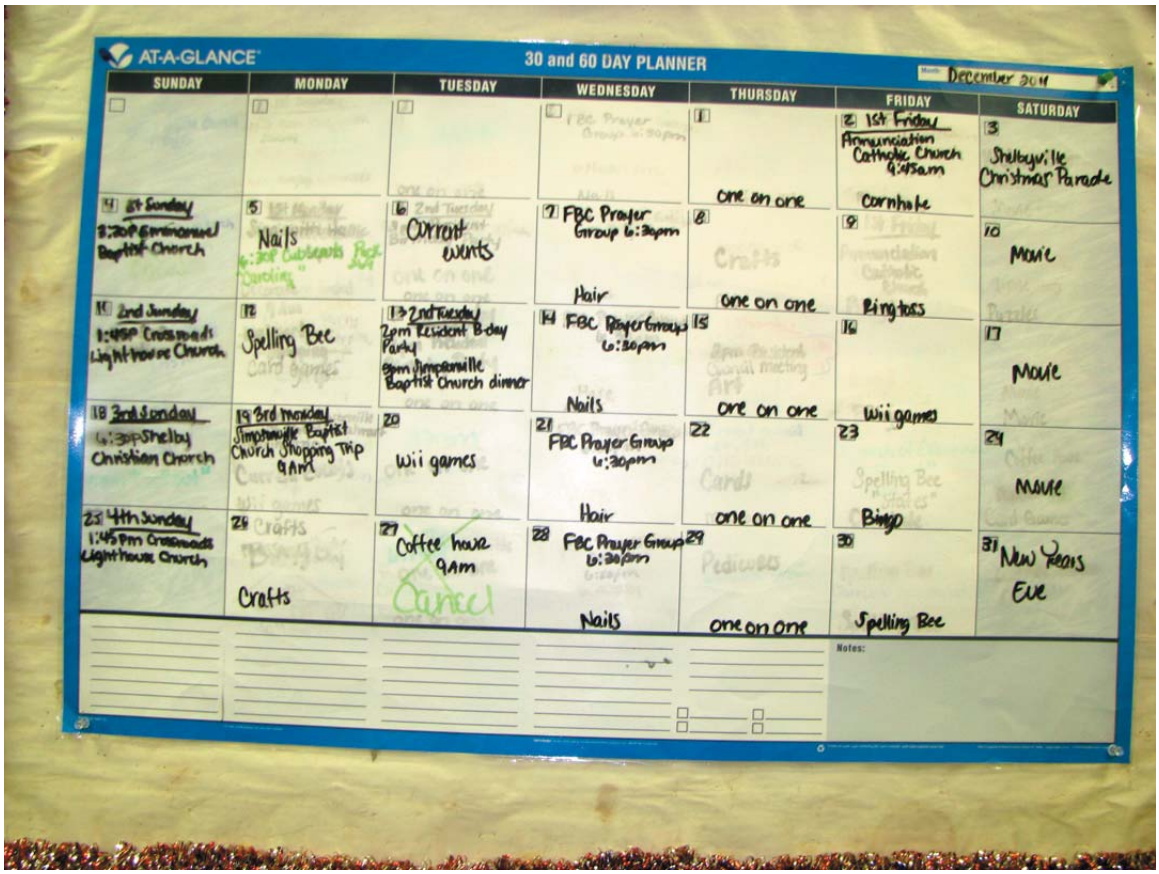


Table 23: How often does the PCH plan an outing? *		
	Number of Responders	Percent
Daily	5	2.3
Weekly	30	13.9
Monthly	25	11.6
2-3 Times a Month	7	3.2
Couple of Times a Year	30	13.9
Once a Year	9	4.2
Never	67	31.0
Unsure	43	19.9
Total:	216	100.0
*Excludes missing data		


Christmas Cards
New Years Cards
Love Each
SUN MON TUE WED THU FRI SAT
1 Decorate Tree and Door!! Decorate
2 Resident Council Meeting @ 12:30pm Store Open
3 Clean your closet Color a Christmas Page
2:00pm
4 Church Movie Relax
5 Coloring Pages Puzzles
6 Read A Poem! Store Open
7 WII Christmas Movie Rudolph
8 Make Christmas Cards
9 X-Mas Party 7:30pm Store Open Coloring Contest Begins
10 Read A Book Talk With A Friend Movie
11 Church Movie Relax
12 Coloring Pages Puzzles
13 Store Open Read A Poem
14 Wii Christmas Movie Polar Express
15 Bingo Make Christmas Cards Employee Party
16 Store Open
17 Clean your Room!! Movie Organize Your Room!!
18 Church Movie Relax
19 Coloring Pages -Dress Up!!! Puzzles Christmas Party
20 Store Open Read Christmas Story
21 Wii Christmas Movie The Grinch
22 Bingo and Popcorn Winter Begins
23 Store Open
24 Read A Bible Verse! Relax and Reflect!! Movie
25 Jesus Loves You! Merry Christmas
26 Write Thank You Notes!!!
27 Store Open Magazines and Book!!
28 Wii Movie
29 Bingo and Popcorn Birthday Party
30 Store Open Coloring Contest Winner Announced !!
31 Get Ready for the New Year !!! Movie
Write -Your Christmas Card List -Shopping List -Write A Letter To Santa Claus
See ALL the pretty lights And Decorations!!!
Do Count Your Blessings Be Kind + Giving
Don't Forget -Make Goals Resolutions


AT-A-GLANCE
30 and 60 DAY PLANNER
December 2014
SUNDAY MONDAY TUESDAY WEDNESDAY THURSDAY FRIDAY SATURDAY
1 one on one
2 1st Friday Annunciation Catholic Church 9:45am Cornhole
3 Shelbyville Christmas Parade
4 1st Sunday 2:30pm Emmanuel Baptist Church
5 Nails
6 Current events
7 FBC Prayer Group 6:30pm Hair
8 one on one
9 Ringtoss
10 Movie
11 2nd Sunday 1:45pm Crossroads Lighthouse Church
12 Spelling Bee
13 2nd Tuesday 2pm Resident B-day Party 6pm Simpsonville Baptist Church dinner
14 FBC Prayer Group 6:30pm Nails
15 one on one
16 Wii games
17 Movie
18 3rd Sunday 6:30pm Shelby Christian Church
19 3rd Monday Simpsonville Baptist Church Shopping Trip 9AM
20 Wii games
21 FBC Prayer Group 6:30pm Hair
22 one on one
23 Bingo
24 Movie
25 4th Sunday 1:45 Pm Crossroads Lighthouse Church
26 Crafts
27 Coffee hour 9am Cancel
28 FBC Prayer Group 6:30pm Nails
29 one on one
30 Spelling Bee
31 New Years Eve
Notes:

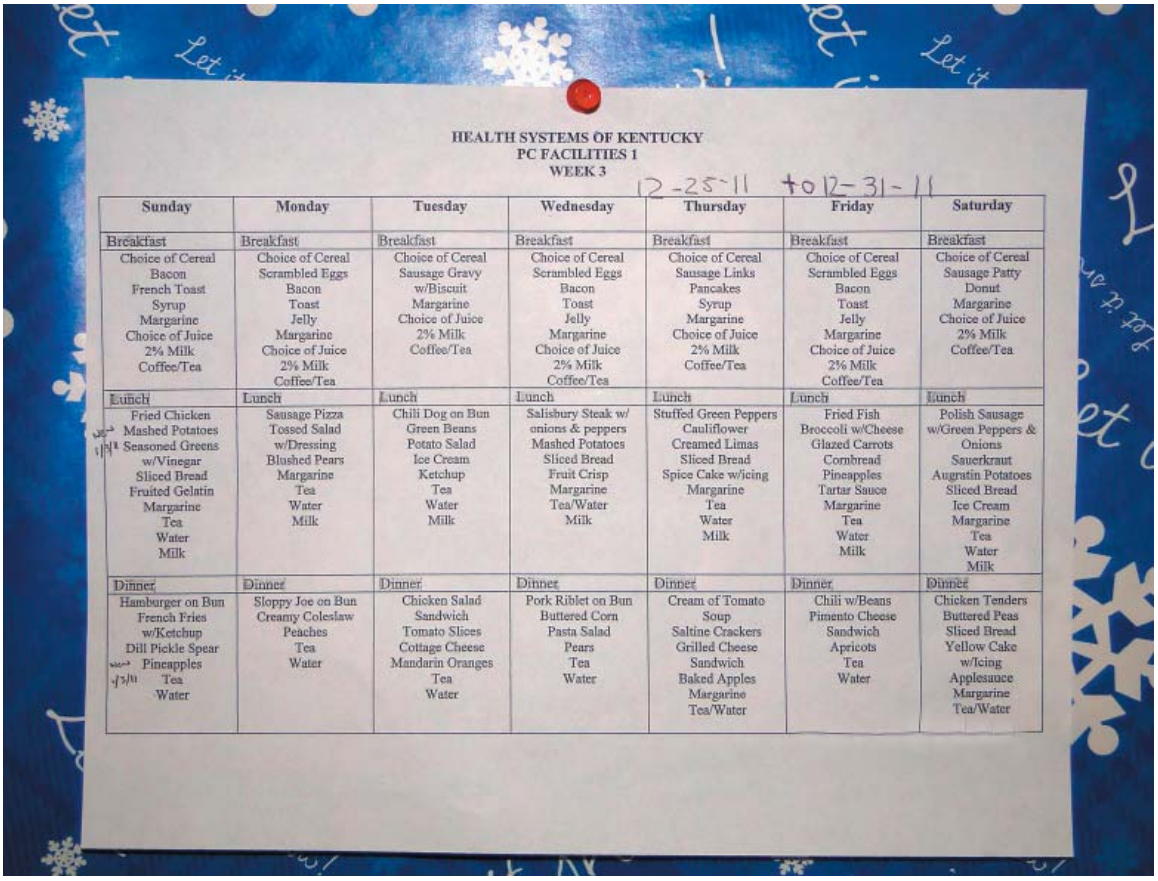
Most residents stated that they are not allowed to cook, do laundry, or clean their rooms. They stated that staff performs these tasks (Tables 24, 25, and 26). Some residents indicated staff buys their clothing for them out of their personal allowance. Many residents stated that one of the activities they would enjoy would be to go shopping for themselves. A complaint by the residents was that they do not like the clothing that the staff selects (Table 27).

Table 24: Are you allowed to cook for yourself? *		
	Number of Responders	Percent
Yes	14	6.5
No	194	89.4
Sometimes	6	2.8
Unsure	3	1.4
Total:	217	100.0
*Excludes missing data		

Table 25: Who Cleans your Room?		
	Number of Responders	Percent
Staff	188	86.2
Me	28	12.8
Other	2	.9
Total:	218	100.0

Table 26: Who Cleans your Laundry?*		
	Number of Responders	Percent
Staff	202	92.7
Me	16	7.3
Total:	218	100.0

Table 27: Who buys your clothing*		
	Number of Responders	Percent
Staff	51	23.7
Me	80	37.2
Guardian	33	15.3
Other	12	5.6
Family Member	39	18.1
Total:	215	100.0
*Excludes missing data		



HEALTH SYSTEMS OF KENTUCKY
PC FACILITIES 1
WEEK 3
12-25-11 to 12-31-11

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast
Choice of Cereal Bacon French Toast Syrup Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Scrambled Eggs Bacon Toast Jelly Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Sausage Gravy w/Biscuit Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Scrambled Eggs Bacon Toast Jelly Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Sausage Links Pancakes Syrup Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Scrambled Eggs Bacon Toast Jelly Margarine Choice of Juice 2% Milk Coffee/Tea	Choice of Cereal Sausage Patty Donut Margarine Choice of Juice 2% Milk Coffee/Tea
Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
Fried Chicken Mashed Potatoes Seasoned Greens w/Vinegar Sliced Bread Fruited Gelatin Margarine Tea Water Milk	Sausage Pizza Tossed Salad w/Dressing Blushed Pears Margarine Tea Water Milk	Chili Dog on Bun Green Beans Potato Salad Ice Cream Ketchup Tea Water Milk	Salisbury Steak w/ onions & peppers Mashed Potatoes Sliced Bread Fruit Crisp Margarine Tea/Water Milk	Stuffed Green Peppers Cauliflower Creamed Limas Sliced Bread Spice Cake w/icing Margarine Tea Water Milk	Fried Fish Broccoli w/Cheese Glazed Carrots Cornbread Pineapples Tartar Sauce Margarine Tea Water Milk	Polish Sausage w/Green Peppers & Onions Sauerkraut Augratin Potatoes Sliced Bread Ice Cream Margarine Tea Water Milk
Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner
Hamburger on Bun French Fries w/Ketchup Dill Pickle Spear Pineapples Tea Water	Sloppy Joe on Bun Creamy Coleslaw Peaches Tea Water	Chicken Salad Sandwich Tomato Slices Cottage Cheese Mandarin Oranges Tea Water	Pork Riblet on Bun Buttered Corn Pasta Salad Pears Tea Water	Cream of Tomato Soup Saltine Crackers Grilled Cheese Sandwich Baked Apples Margarine Tea/Water	Chili w/Beans Pimento Cheese Sandwich Apricots Tea Water	Chicken Tenders Buttered Peas Sliced Bread Yellow Cake w/Icing Applesauce Margarine Tea/Water

LACK OF CHOICE

Most of the time individuals do not choose to live in a personal care homes (Table 28), and often times are placed at PCHs directly from a psychiatric hospital. Rarely does the individual visit the PCH before placement. Very often the patient leaves the hospital for a "10 day home visit" and if there are no problems, the patient is then discharged from the hospital. Many individuals residing at the PCH have lived in multiple PCHs and have had multiple hospitalizations. One resident stated that the "facility is a dump and I did not want to live here after I saw it." Another resident stated that she had a home already and did not understand why she had to live in a homeless shelter. It was reported that staff at a psychiatric hospital told one resident that they would petition the court for state guardianship for him if he did not live at the PCH. Some residents said it was better than living on the streets and others said, "It is not my home." There are few housing options for individuals who have had multiple admissions to a psychiatric hospital. The lack of housing limits the choice for the individual and/or the guardian. Residents were asked if they enjoy living at the personal care home. Over 50% said they did enjoy living there. Residents were also asked if they had any complaints about living in a PCH (Table 29). Forty five percent (45%) stated they had a complaint. The complaints identified by residents were: loneliness and not having anything do, residents fighting and stealing from each other, food concerns (quality of food and not enough food), and concerns about the staff (Table 30). Residents stated they do not have any choice over the food served at the facilities. One resident stated "I eat what I am given".

Table 28: Who chose for you to live at the PCH?*		
	Number of Responders	Percent
Me	41	19.1
Guardian	39	18.1
Team	48	22.3
Case Manager	12	5.6
Family	47	21.9
Unsure	9	4.2
Other	19	8.8
Total:	215	100.0
*Excludes missing data		

Table 29: Do you have any complaints about living here?*		
	Number of Responders	Percent
Yes	99	45.6
No	111	51.2
Unsure	7	3.2
Total:	217	100.0
*Excludes missing data		

Table 30: What is your biggest complaint about living at the PCH?		
	Number of Responders	Percent
Nothing to Do/Lonely	23	20.0
Staff Concerns	14	12.2
Food Concerns	11	9.6
Facility is in Disrepair	4	3.5
Resident's or Staff Steal	12	10.4
Resident's Fighting	16	13.9
Money Concerns	6	5.2
Other	29	25.2
Total:	115	100.0
*Excludes missing data		

Many residents who did not have a guardian stated that they would like to live in the community (59 percent) (Table 31). However, they indicated staff was not available to assist them because they were too busy. The majority of individuals living in a personal care home have previously lived independently (Table 32). Sixty-seven percent of the residents stated they would like to participate in more activities in the community (Table 33). About one third of the residents stated that they would like to have a job (Table 34). Very few residents stated they go out for fun (15%) (Table 35). Over half of the residents stated that they rarely or never go out for fun. Over a third of the residents stated they cannot refuse medications (Table 36). They stated if they refused, they are threatened with having to go to a psychiatric hospital.

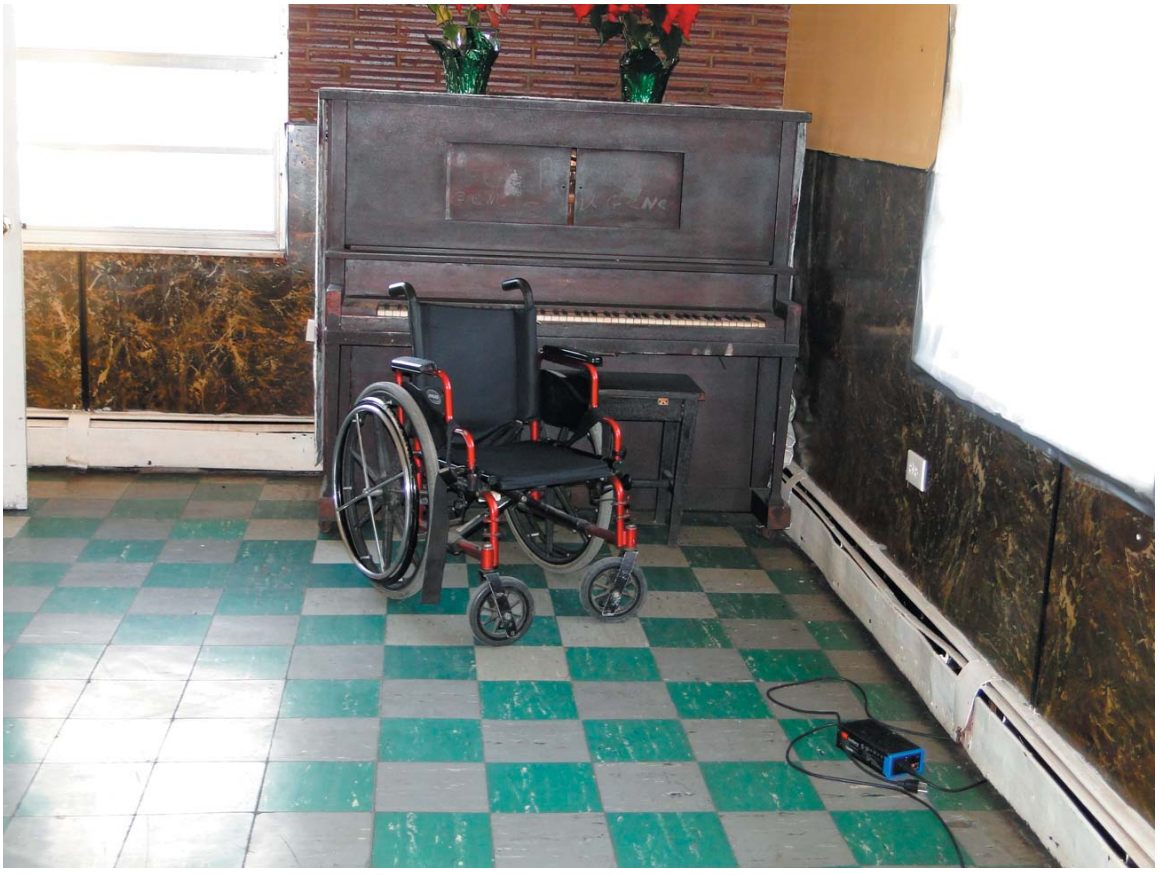
Table 31: Do you want to live in the community?		
	Number of Responders	Percent
Yes	129	59.2
No	67	30.7
Sometimes	9	4.1
Unsure	13	6.0
Total:	218	100.0

Table 32: Have you ever lived independently?		
	Number of Responders	Percent
Yes	163	74.8
No	54	24.8
Unsure	1	.5
Total:	218	100.0

Table: 33 Do you want to do more out in the community? *		
	Number of Responders	Percent
Yes	145	67.1
No	71	32.9
Total:	216	100.0
*Excludes missing data		

Table 34: If you do not have a job, do you want a job?		
	Number of Responders	Percent
Yes	75	37.3
No	109	54.2
Unsure	17	8.5
Total:	201	100.0
*Excludes missing data		

Table 35: How often do you go out for fun?		
	Number of Responders	Percent
Always	18	8.3
Often	17	7.8
Sometimes	62	28.4
Rarely	49	22.5
Never	72	33.0
Total:	218	100.0



Tables 36: Medications		
Can you refuse to take your medicine? *		
	Number of Responders	Percent
Yes	95	43.8
No	83	38.2
Sometimes	6	2.8
Unsure	33	15.2
Total:	217	100.0
		What happens if you refuse your medicines?
You go to the hospital	42	20.4
Staff encourage me to take it	25	12.1
Threatened or have to leave the PCH	7	3.4
Nothing happens	30	14.6
Restrictions are placed on you like smoking	6	2.9
Other	54	26.2
I never refuse medications or I am not sure since I don't refuse	38	18.4
They force you to take your medications	4	1.9
Total:	206	100.0
*Excludes missing data		

FACILITY OBSERVATIONS

All but one of the PCHs visited by P&A are located in small towns and/or rural areas (Table 37). With the exception of the PCH located in an urban area, public transportation is not available to the residents of personal care homes. Many of the PCHs were observed to be located within walking distance to stores and restaurants; however, many were convenience stores/gas stations, fast food restaurants and/or dollar stores (Table 38). This is the only interaction that many residents have with the community.

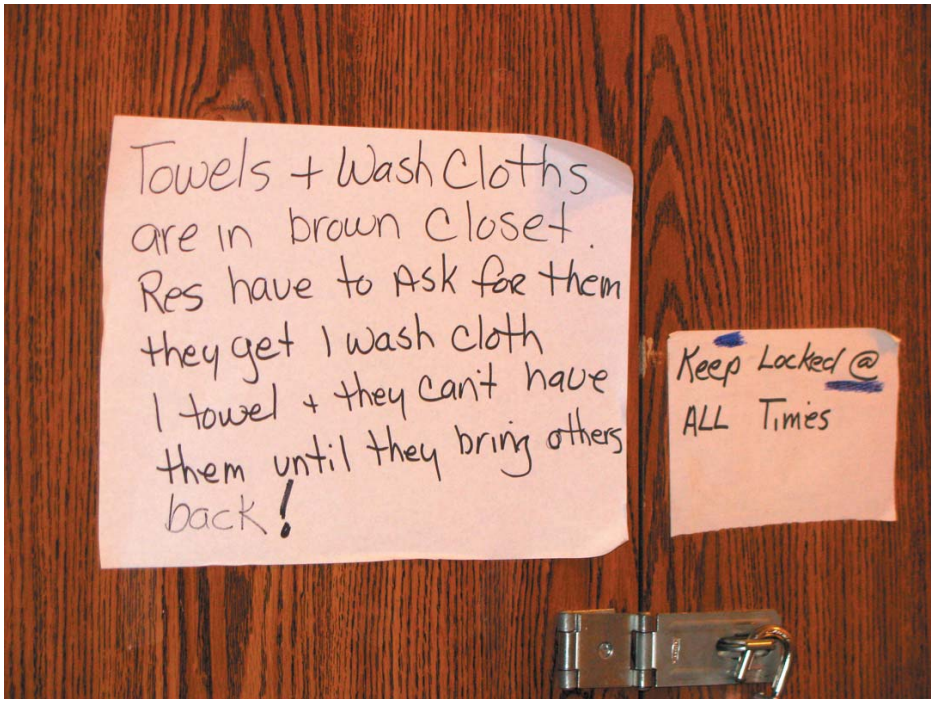

Towels + Wash Cloths
are in brown Closet.
Res have to ask for them
they get 1 wash cloth
1 towel + they can't have
them until they bring others
back!
Keep Locked @
ALL Times

Table 37: The location of the facility.		
	Number of Responders	Percent
In-Town	7	35.0
Residential	7	35.0
Country or Rural	6	30.0
Total:	20	100.0

Table 38: Are there stores or restaurants in walking distance of PCH?		
	Number of Responders	Percent
Yes	14	70.0
No	6	30.0
Total:	20	100.0

The majority of the PCHs appeared institutional (Table 39). Most of the PCHs were former nursing homes, hospitals or roadside motels. The buildings have long halls that extend from the center, where the residents' rooms are located. One of the PCHs is a two story building, but does not have an elevator. The bedrooms of the residents house anywhere between one and four people (84% of the residents have at least one roommate). They are crowded and the furniture is in disrepair and looks institutional (metal beds) (Table 40). The mattresses are old and stained, and few beds had appropriate bed linens (mattress pads, sheets, blanket and bedspread) although this is a regulatory requirement. One individual who has an intellectual disability and a physical disability sleeps in a bed that resembles a crib. He stated that he wanted a bed like the other residents. This same PCH had eight people sleeping in one room using short room partitions for privacy. Over half of the rooms of the PCHs did not have privacy curtains. Several of the administrators stated the residents did not want privacy curtains. The majority of the PCHs had an odor of strong cleaning products, urine and/or cigarette smoke. Some of the PCHs either did not have accessible signage into the building or did not have an accessible entrance to the building (Table 41). Three-fourths of the PCHs did not have accessible parking available (Table 42). Most of the PCHs have a recreation area and this is usually either a smoking area and/or picnic tables. When P&A staff arrived at the PCHs, they found 20% of the PCHs' doors were locked (Table 43). Three of the PCHs were enclosed with a fence. One of the PCHs keeps the fence locked at all times.

Table 39: What does the facility look like?		
	Number of Responders	Percent
Institutional	16	80.0
Homelike	1	5.5
Motel	3	15.0
Total:	20	100.0

Table 40: What do residents rooms look like?		
	Number of Responders	Percent
Home Like	5	25.0
Institutional	13	65.0
Crowded	2	10.0
Total:	20	100.0

Table 41: Is there an accessible entrance with signage?		
	Number of Responders	Percent
Yes	10	50.0
Yes, but no signage	6	30.0
No	4	20.0
Total:	20	100.0

Table 42: Is there accessible parking with van space and vertical signage visible above parking spot?		
	Number of Responders	Percent
Yes	5	25.0
No	15	75.0
Total:	20	100.0

Table 43: Were the doors un- locked upon arrival at the PCH?		
	Number of Responders	Percent
Yes	18	80.0
No	2	20.0
Total:	20	100.0

Activity calendars were posted in all but one of the PCHs. Activities included bingo, coloring, movies, and exercise. In some cases, activities involve people from the community (Table 44). In most cases this was a church group and either a religious service was conducted or the group provided activities. Very few PCHs organized activities in the community. For those that did organize activities, few participated in them because the PCH did not have vans that could transport more than five to six residents. Other activities were contingent on the climate, depending on the temperature in the summer and winter. In several PCHs, community groups conducted cookouts for the residents living there.


EXIT

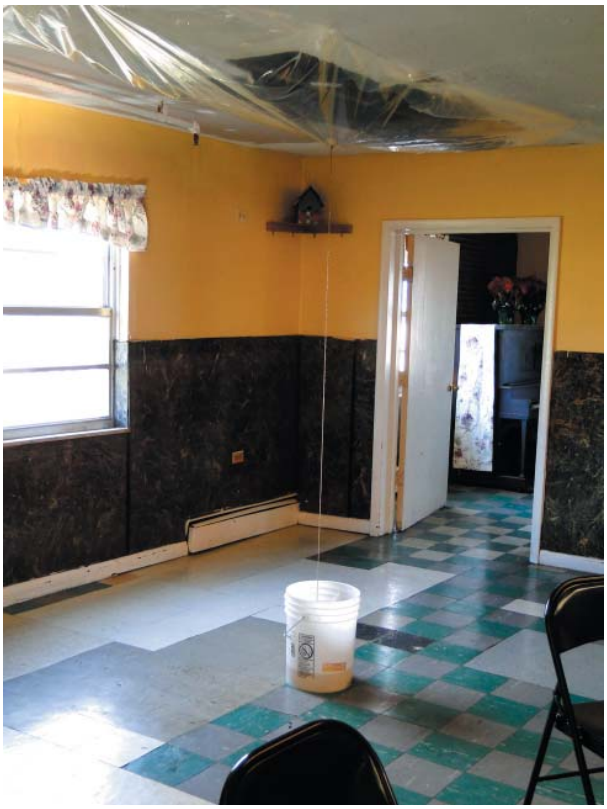


Table 44: Are there activities that involve people from the community?		
	Number of Responders	Percent
Yes	18	90.0
No	2	10.0
Total:	20	100.0

With the exception of one PCH that offered activities to help individuals develop skills to live in a more integrated setting, there was very little difference noted in the activities offered by the other PCHs. Most of the facilities do not have a staff member whose sole responsibility is to provide activities. Often staff assume this role along with their other duties. The staff at the PCH attends training on mental illness and intellectual disability. The Department of Behavioral Health and Developmental and Intellectual Disabilities provide this training and it is held in the state psychiatric hospitals. One administrator stated that they have not sent anyone to the training in six years due to cost (Table 45).

Table 45: How frequent is BH/IDD training? *		
	Number of Responders	Percent
Annually	4	40.0
Bi-Annually	1	10.0
Quarterly	2	20.0
Every 3 Years	1	10.0
Every 6 Years	2	20.0
Total:	10	100.0
*Excludes missing data		

OFFICE OF INSPECTOR GENERAL (OIG)

The Division of Health Care within the Office of Inspector General is responsible for inspecting, monitoring, licensing and certifying all health care facilities and is responsible for investigating complaints against health care facilities, reviews facility plans and developing regulations. The division recommends various long-term care facilities for certification to receive Medicaid and Medicare funds through contracts with the Health Care Financing Administration of the U.S. Department of Health and Human Services.

There are four regional offices of the Division of Health Care. The regional offices are responsible for conducting on-site visits of all health care facilities in the state to determine compliance with applicable licensing regulations and Medicare/Medicaid certification requirements. Complaints concerning these facilities are investigated by regional office staff.

When P&A found violations at PCHs, those violations were reported to the Office of the Inspector General. An example of a violation reported:

Upon arriving at the Personal Care Home in July 2011, P&A staff noticed a chain link fence surrounding the PCH with a padlock. The fence was not locked. When P&A staff entered the facility, a staff from PCH stated the fence must have been unlocked and proceeded to lock it. Residents confirmed that the fence is usually locked and they often jump it to leave the PCH to go to the the store nearby. The PCH is located about a mile from the town and there are few stores or restaurants close to the PCH. Residents stated that they can only leave if the administrator is at the PCH. They stated that he often does not come to the PCH for several days. There was not a current activities calendar posted. The last one posted was from November 2010. Residents stated that the only activities that the PCH offers are when members from a local church visit on Wednesday evenings and on Sundays. A report was made to the OIG, detailing these issues. Prior to a follow-up visit to the PCH, P&A called the OIG to inquire about the result of its investigation. P&A was informed that due to lack of staff, the OIG had not been able to investigate the complaints reported in July 2011; however P&A was informed that the OIG would initiate the investigation immediately. In October 2011, the OIG cited the PCH for having a locked fence surrounding the facility, not posting a menu and other violations.

CONCLUSION

As a result of visiting twenty personal care homes throughout the state and interviewing twenty percent of the resident population (218 individuals), P&A concludes that personal care homes are congregate settings that segregate persons with disabilities from the community. In the case of Olmstead v. L.C. , the United States Supreme Court ruled that "[u]njustified isolation . . . is properly regarded as discrimination based on disability." [10]

The Preamble of the ADA defines the most integrated setting as one that meets the needs of individuals with disabilities to interact with non-disabled persons to the fullest extent possible.[11] Discrimination includes keeping people in institutions separate and alone. Personal Care Homes in Kentucky are institutions. Personal Care Homes fail to integrate persons with disabilities into the social mainstream, fail to promote equality of opportunity, and fail to maximize individual choice. They restrict community and integration and interactions with individuals who do not have a disability

In Kentucky, there is a revolving door between state psychiatric hospitals and personal care homes. The community infrastructure is lacking and little available and affordable housing, public transportation or crisis services. Individuals living in PCHs have the right to have lives that look similar to people without disabilities.

Residents living in a PCH are:

- segregated from the community, limiting family relations, social contacts, economic independence, and cultural enrichment.

- restricted from accessing the community due to the location of the PCH and lack of transportation.

- subjected to regimented meal times often with assigned seating, medication, smoke breaks, curfews and bedtimes.

- not able to have private phone conversations based on the location of the phone. They are limited to phone time due to the number of individuals using the phone.

- not always able to refuse medication. They are threatened with hospitalization or having to leave the PCH if they refuse.

- not able to choose their roommate and often have multiple roommates. Residents have virtually no privacy.

- subjected to loss of personal property due to theft. Residents are not able to lock their own bedrooms.

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- restricted from accessing the local community mental health centers.

- subjected to activities (or lack of activities) in the PCH that for some is demeaning and meaningless. Activities such as coloring, puzzles, board games, bingo and bowling with plastic pins become mundane day after day and are not age appropriate. The majority of the PCH do not plan activities in the community.

- discouraged from seeking employment because they are not able to keep wages earned.

- not able to shop for the clothes they would like to wear.

- not able to choose the food they would like to eat for meals, often times not getting enough food to eat and not having fresh vegetables and fruits.

- not provided alternative living options other than homeless shelters or the streets.

The physical settings of PCHs look like institutions. Long halls are lined with bedrooms. Individuals share bathrooms. In some instances, the day rooms are not large enough to accommodate all of the residents, nor do they have comfortable seating available to all residents. The furniture in the majority of the homes is old, filthy and in disrepair. The mattresses are old, stained and many beds do not have adequate linens. The physical structures of the PCHs are in disrepair. There are leaking roofs, peeling paint, holes in the ceiling,

exposed cables, uneven flooring, moldy bathrooms with tiles missing, and in some cases, bathrooms that are not accessible. More often than not an unpleasant odor was present throughout the PCH. Residents either line up at the medication room or their name is called out over a paging system in order to receive medication. Sign-out sheets are used when a resident leaves the facility. Some PCHs enforce a curfew which results in entry doors being locked as a specific time. Three PCHs have fences that enclose the property. In one instance the fence is locked by a padlock and only staff can unlock it, restricting the residents from leaving the PCH.

While the above mentioned, such as room accommodations, disrepair of the physical structure, inadequate bed linens, and inaccessibility are issues, the greater issue remains the continued placement of persons with mental health diagnoses, intellectual, developmental, and other disabilities in congregate and segregated settings. The placement of persons who have a mental illness or intellectual disability in a personal care home "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." [12] The state of Kentucky perpetuates this assumption by not developing recovery-oriented services and housing alternatives to help individuals with mental illness to achieve greater independence. Instead, the state continues to subsidize PCHs, relying on these institutions to provide housing for individuals with mental illness. By continuing to do so, the state continues to segregate individuals who have a disability from the rest of the community, violating their civil rights.

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[1] 902 KAR 20:036 §2
[2] 902 KAR 20:036 §4
[3] KRS 216.515(5)
[4] KRS 216.515
[5] 42 USC § 10805(a)(6)
[6] Ibid
[7] 921 KAR 2:015 §14
[8] *Olmstead v. L.C.*, 527 U.S. 581, 592, (1999)
[9] Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. http://www.ada.gov/olmstead/q&a_olmstead.htm (last accessed on 3/14/12)
[10] *Olmstead*, 527 U.S. at 597
[11] 28 CFR pt. 35, App. A, p. 450 (1998)
[12] *Olmstead*, 527 U.S. at 592


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