

# HEADING TOWARD HOMELESSNESS: ISSUES IN RESIDENTIAL HEALTH CARE FACILITIES



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## **HEADING TOWARD HOMELESSNESS: ISSUES IN RESIDENTIAL HEALTH CARE FACILITIES**

### **Introduction**

New Jersey's affordable housing crisis has been well documented.<sup>1</sup> The lack of safe, affordable housing presents a serious challenge for a large segment of New Jersey's population, but those residents who subsist on very low incomes face the greatest challenges.

Low income residents who also require some assistance in order to live independently, such as nursing care or social services even at a minimal level, have even fewer options. They may not yet qualify for nursing home care because of their medical needs, but cannot afford costly assisted living facilities. This population includes older adults and those with chronic, though manageable, mental illnesses. Residential health care facilities (RHCFs), which provide minimal supports such as medication management and meals, are often the only viable option for these New Jersey residents. As part of our Department's ongoing investigation into affordable housing issues, we explored the system of RHCFs in New Jersey.

Our goal was to be able to make informed recommendations regarding the quality of RHCFs that are currently available, assess how such housing meets the needs of low-income New Jersey residents, and measure the availability and viability of alternatives to RHCF living. The Department of Community Affairs (DCA) regularly monitors RHCFs for compliance with health and safety regulations. We undertook a comprehensive and independent examination of the housing and services provided by RHCFs and sought to determine whether RHCF residents were experiencing satisfactory quality of life and with what aspects of RHCF living such satisfaction is correlated.

RHCFs have been closing their doors at a rapid rate. Preliminary results from our examination suggest that this development should be viewed with alarm by those who advocate on behalf of the elderly and mental health consumers. Although RHCFs are only one housing option, they remain critical for these populations. Many elderly and mental health consumers live independently or in group homes, transitional houses, supportive apartments, assisted living facility or nursing homes. However, without the financial resources to pay for these costlier options, RHCFs are one of a limited number of affordable alternatives available for those who do not require or qualify for facilities that provide a greater level of supports.

RHCFs also should be considered a valuable resource in meeting the community housing needs, at least on a transitional basis, for individuals who are languishing in state and county psychiatric hospitals, cleared for release but awaiting placement. Psychiatric hospitals are the costliest treatment setting for these individuals. In addition, once these individuals enter far less costly community placements, they are eligible for federal assistance under the Supplemental Security Income (SSI) and Medicaid programs.

Apart from the fact that the state will save money by using RHCFs to transition mental health consumers into community living arrangements, there are compelling moral and legal reasons to expedite the transition of individuals from hospital settings to community placements. There are currently about 1,000 people in psychiatric hospitals throughout New Jersey who have been deemed ready for discharge, but are nevertheless being involuntarily held in hospitals awaiting a community placement (known as "conditional extension pending placement" or "CEPP").

Although the vast majority of patients on CEPP status are discharged within one year, some patients have remained on CEPP status for over five years.<sup>2</sup>

<sup>1</sup> *Affordable Housing in New Jersey: Reviving the Promise*, Department of the Public Advocate, Division of Public Interest Advocacy, October 25,

<sup>2</sup> Home to Recovery – CEPP Plan. DHS/DMHS, January 2008. Please note that some of the patients on CEPP for very long periods of time include those whose special circumstances make it difficult for them to access community placement, such as sex offenders.

Even those patients who are released from a hospital within one year of being cleared for discharge are being denied their freedom for a significant period of time. Under state law, these individuals have a legal right to live in the least restrictive setting possible,<sup>3</sup> and for many of them, an RHCf would provide the level of support they need to lead successful lives in the community. We cannot ignore the rights and the needs of the CEPP population any longer.

Because those who live in RHCfs tend to have few resources and live on fixed incomes, they are often marginalized within our society. Yet for the more than 2,400 individuals who live in RHCfs throughout the state, having an address is the very thing that indicates that they are very much a part of their communities. Many of the individuals in RHCfs have neither the ability nor the desire to live elsewhere. With affordable housing so lacking, it is unlikely that these individuals would be able to continue living in their communities of choice should their RHCf close down. Nevertheless, however crucial RHCfs may be, our examination has revealed that improvements could and should be made in order to improve residents' quality of life.

## **Background:**

### **The History of Residential Health Care Facilities**

RHCfs have been part of a loosely regulated system of housing in New Jersey for about forty years. Originally designed as homes for aging citizens, RHCfs began to house large numbers of mental health consumers following the deinstitutionalization movement that began in the late 1960s and peaked in the early 1980s. Sadly, large numbers of consumers affected by deinstitutionalization did not receive the services and supports that they needed to live productively within the community. As a result, many mental health consumers became homeless while others, who received mental health treatment but had few housing options

because of their limited financial resources, began living in RHCfs.

Older adults who need little nursing care or other services utilized RHCfs as an inexpensive community-based housing option, which allowed them to maintain more independence than living in a nursing home or other facility. For some older adults, living in an RHCf is preferable to living alone, which can be difficult to manage and lonely. While someone living alone could go days without speaking to anyone else, those living in RHCfs need to speak to their roommate, staff, or other residents on a daily basis. Meeting with a nurse for a short time each week also increases the likelihood that any developing health problems are addressed before they worsen.

Under New Jersey's administrative code, RHCfs are licensed long term care providers that provide "food, shelter, supervised health care and related services, in a homelike setting, to four or more persons 18 years of age or older who are unrelated to the owner or administrator."<sup>4</sup> Residents must be ambulatory and be able to self care with respect to incontinence, be without the need of 24-hour skilled nursing care, and able to perform most activities<sup>5</sup> of daily living (i.e., bathing, dressing, and grooming) with little or no assistance. The facilities must provide 24-hour supervision, laundry service, staff supervision or assistance for residents taking their medication, transportation, and recreational activities.<sup>5</sup> In addition, a registered nurse must be available at all times, either in person or on call, and the nurse is responsible for directing health maintenance and monitoring services. The registered professional nurse must provide a minimum of .20 hours – or twelve minutes – of nursing care per resident per week.<sup>6</sup>

<sup>4</sup> N.J.S.A. 30:11A-1; N.J.A.C. 8:43-1.3

<sup>5</sup> RHCfs must provide: transportation (N.J.A.C. 8:43-4.7); Personal care - bathing, oral hygiene, hair care, manicuring and pedicuring, and shaving) as needed to maintain acceptable personal hygiene (N.J.A.C. 8:43-7.1); laundry (N.J.A.C. 8:43-15.8); meals (N.J.A.C. 8:43-8.1); The facility shall arrange for health services to be provided to residents as needed (N.J.A.C. 8:43-9.2); medicine supervision/assistance (N.J.A.C. 8:43-10.1); recreational activities (N.J.A.C. 8:43-11.1); housekeeping (N.J.A.C. 8:43-15.1).

<sup>6</sup> N.J.A.C. 8:43-9.1

<sup>3</sup> See N.J.S.A. 30:4-24.2; In re S.L., 94 N.J. 128 (1983).

RHCFs are licensed by the DEA and are subject to the rules of DCA and the Department of Health and Senior Services (DHSS).<sup>7</sup>

Housing coupled with these services allows people with mental illnesses or older adults with few resources a practical way to continue living somewhat independently and in the community. In conducting our field work, we saw that for many residents of RHCFs, having just these supports in place makes the difference between remaining in the community or being homeless or unnecessarily confined to an institution.

Economic shifts, smaller hospitals, more expensive nursing homes, and fewer group homes have all added to the decrease in housing available to the elderly or people with mental illnesses. RHCFs have, in many ways, provided a safe haven for individuals who might otherwise have chosen one of these options. Yet RHCFs are closing quickly, which means that one more housing option may no longer be available to these populations. At the time Governor Codey's Mental Health Task Force issued its report in 2005, there were 144 freestanding RHCFs. Currently, only 82 of these remain. One owner observed:

*"I remember being here in '89, and I can tell you that we are going to have another homelessness crisis like that. Closing these houses down means these people are once again heading toward homelessness."*

- RHCF Owner/Administrator  
Essex County

Since 2005, RHCFs have been licensed by the Department of Community Affairs (DCA).<sup>8</sup> Prior to 2005, the DHSS inspected and licensed all RHCFs.

<sup>7</sup> N.J.A.C. 8:43-2.2. The specific rules governing RHCFs can be found at N.J.A.C. 8:43-1.1 to 8:43-16.6. These rules cover physical plant requirements (N.J.A.C. 8:43-3.1 to 8:43-3A.11); staffing and administrative requirements (N.J.A.C. 8:43-4.1 to 8:43-5.2); resident care (N.J.A.C. 8:43-6.1 to 8:43-10.3); record keeping (N.J.A.C. 8:43-13.1); resident rights (N.J.A.C. 8:43-14.1 to 8:43-14.2) and more.

<sup>8</sup> According to the New Jersey Register, 37 *N.J.R.* 1105(a), DCA assumed responsibility for licensing RHCF's became effective on May 13, 2005.

Following recommendations made by Governor Codey's Task Force, this responsibility was switched to DCA due to that agency's extensive experience with housing. If abuse or neglect of residents age 60 or older is suspected, the Public Advocate's Office of the Ombudsman for the Institutionalized Elderly is empowered to investigate RHCFs. However, for those residents under age 60, there is no agency with this authority. Adult Protective Services may investigate complaints of abuse and neglect if it is reported and they believe such investigation is warranted. Adult Protective Services agencies visit RHCFs only if there is a complaint.

## **Study Design & Administration**

Our project began in summer of 2007 with an analysis of data provided by the DCA gathered in the course of its routine inspections to enforce compliance with health and safety regulations. The DCA inspections illustrate the range of differences among RHCFs throughout New Jersey; several facilities did not have any regulatory violations, while others had upwards of one hundred citations for infractions. The range of violations was zero to 112 with the median average being 56 and these citations ranged from fairly minor problems, such as failure to post a copy of the facility's current license, to egregious issues such as vermin and other unsanitary conditions. We were concerned that so many facilities had several dozen violations and we were, therefore, interested in seeing these facilities in particular and learning from the residents themselves whether they felt the conditions in which they lived were substandard.

Prior to developing the data collection tools, we knew that there were some basic areas that we needed to explore, so we kept the following questions in mind:

- Who comprises the population of RHCFs and what are their perceptions about living in these facilities?
- Are RHCFs a viable option for the two target populations that we serve?
- Why are RHCFs closing?

- What are some feasible ways in which to make RHCFS better places for people with mental illnesses and older adults to live?
- Are current funding levels adequate?

In order to answer these questions, and to determine some of the “best practices” that are being applied in RHCFS across the state, we selected survey instruments that had been widely used by social scientists researching similar projects.<sup>9</sup> The instruments included: (1) a lengthy survey to be administered to the owner or administrator; (2) a shorter survey to be administered to a sample of willing residents; and (3) an environmental assessment to be completed by project staff. Ultimately, these tools were selected and modified so that we could determine which aspects of RHCFS living most impacted the residents’ stated degree of satisfaction.

The owner/administrator survey was adapted from the “Multiphasic Environmental Procedure (MEAP),”<sup>10</sup> a tested research tool that was designed to identify the population within each facility and to examine the policies and practices of each facility. Thus, it includes questions about the number of residents, their demographics as well as staff response to various behaviors, and admission criteria. This survey also includes questions about activities offered at the facility, whether residents regularly attend psychiatric day programs or senior centers, the level of family involvement in residents’ care, and other factors which might increase the quality of care that residents receive.

The resident survey was designed by researchers at Scripps Gerontology Center at Miami University, located in Ohio,<sup>11</sup> to determine resident satisfaction with their RHCFS and other information. The survey asks residents to rate their satisfaction in various areas: employees and administrators; the quality of care and services they receive; the

quality of communication between residents and administrators; the quality of the activities provided; laundry services and food; and the physical environment. Because RHCFS are closing, we supplemented the survey with open-ended questions asking where participants would like to live if they had the means and opportunity to live elsewhere. We included another set of open-ended questions regarding the interactions they have with relatives, friends, and neighbors to get a sense of the level of personnel engagement or isolation they experience.

The neighborhood and physical assessment was designed to gauge the environment in which RHCFS residents live.<sup>12</sup> It asks whether the facility was in a rural, suburban, or urban neighborhood, and whether services that might be important to residents, such as hospitals, transportation, or recreation were available in the immediate area.

The assessment also includes questions about the facility itself, including whether or not there were such features as air conditioning, outdoor space, and communal space.

In September of 2007, RHCFS owners, operators, and administrators were formally contacted by letter requesting their cooperation.<sup>13</sup> For the most part, RHCFS owners and operators were enthusiastic about speaking to us. They wanted to explain deficiencies in their facilities and discuss changes they would make with additional resources. A limited number of owners were not eager to speak to us, but they ultimately provided a minimal amount of information to us and allowed us to interview residents when we visited them unannounced.

11 Straker, J. (2007). Residential Care Facility Satisfaction Tool. Developed for the Ohio Department of Aging. Scripps Gerontology Center, The University of Miami: Miami, OH.

12 This assessment also was taken from the MEAP.

13 Following the analysis of DCA’s inspection data, the Department of the Public Advocate instituted an Internal Review Board [IRB] in July 2007. The IRB, comprised of staff not working on the project, as well as counsel and members outside State government, was established to insure the confidentiality and protection of all subjects. While we are not aware of any complaints that had been made by either owner/operators or residents with whom we spoke, the IRB gives them a forum through which to confidentially voice their concerns.

9 The Department of the Public Advocate received permission from the developers of each survey to use these tools in our study.

10 Moos, R., & Lemke, S. (1996). *Evaluating Residential Facilities: The Multiphasic Environmental Assessment Procedure*. NY, NY: Sage, Inc.

Between September and December of 2007, staff visited all 82 RHCf facilities currently licensed by the State of New Jersey. At each visit, the staff administered the surveys and completed the assessments. The Office of the Ombudsman for the Institutionalized Elderly, which has some jurisdiction over these facilities as part of its statutory responsibility for investigating abuse or neglect of the elderly, visited those facilities that refused to cooperate. At the conclusion of the visits, staff entered the collected answers into the SPSS™ program and conducted analyses.<sup>14</sup> There are 2,462 individuals living in RHCfs throughout New Jersey. During the study, we interviewed 238 residents and all 82 facility owners or operators.

## Funding Residential Health Care

Individuals living in RHCfs often rely on a number of funding sources to cover their healthcare and living expenses. These include Medicaid, Medicare, SSI, Veterans Affairs, state optional supplemental security, and private funds. Unlike nursing homes and assisted living facilities, RHCfs do not directly provide healthcare services, but instead “assist [residents] in obtaining health services” from healthcare providers.<sup>15</sup> As a result, the cost of living at an RHCf and the costs of medical care are allocated separately.

### Payment of Room and Board

RHCfs remain a housing option largely because they are an affordable option for those on a fixed income. Most of the residents of RHCfs receive SSI or Social Security Disability (SSD), or a combination of the two.

SSI is a federal income assistance program for the aged, blind, and disabled.<sup>16</sup>

Each month, SSI beneficiaries receive their “benefit rate,” which was set at \$623.00 for the year 2007.<sup>17</sup> In New Jersey, SSI is supplemented by the state’s “optional supplemental security” (OSS) program.<sup>18</sup> For persons living alone or with others in a household, the supplement is \$31.23, for a total benefit of \$654.23. For persons living in RHCfs, New Jersey’s benefit rate is \$210.50, for a total benefit of \$833.50. While there are no “eligibility criteria” for this heightened supplement, individuals may not be admitted into RHCfs unless admission is appropriate. Under the licensure rules, RHCfs may admit individuals only if they have the certification of a physician, advanced practice nurse, or physician assistant that the individual is suitable for admission.<sup>19</sup>

Many residents of RHCfs use the SSI and state funds to pay for the cost of room and board. However, operators cannot utilize the entire \$833.50 because the state withholds a \$102.50 per month “personal needs allowance” for use by the resident.<sup>20</sup> Thus, operators receive only \$731 per month, which works out to a per diem rate of about \$24 per day for room and board. When a person is ineligible for SSI, or their SSI does not cover the cost of the facility, they must pay out of private funds or supplement their payment with private funds. Some facilities, however, accept only private pay residents. RHCfs can charge these private pay residents whatever the market will allow, and our survey found that monthly costs typically range from \$1,100 to \$3,000. Some RHCfs have a mix of SSI and private pay residents, although most RHCfs provide services solely to residents who receive SSI or a combination of residents who receive SSI and SSD.

14 Formerly known as the Statistical Package for the Social Sciences. The Division of Elder Advocacy used the SPSS™ program to analyze and present the collected data because it is an appropriate quantitative analysis tool for a study of this size.

15 While RHCfs do have a nurse on staff, this is merely to supervise and monitor the residents’ health and administration of medications. N.J.S.A. 30:11A-1; N.J.A.C. 10:38-1.4. Additional healthcare services provided by a staff nurse, although acceptable, are not included in the RHCf price and would have to be billed separately to the proper medical funding source.

16 42 U.S.C. 1381-1381a.

17 42 U.S.C. 1382(f) (federal benefit rate to be updated in Federal Register); 71 F.R. 62636 (federal benefit rate for 2007 will be \$623.00 for a single individual).

18 N.J.S.A. 44:7-86 (supplement available, to be increased to adjust for cost of living).

19 N.J.A.C. 8:43-4.12; N.J.A.C. 8:43-13.1.

20 Ibid.; N.J.A.C. 10:123-3.4 (PNA for RHCf is currently \$92.50 but an extra \$10 per month was added in the state budget).

## Payment for Health Care Services

Medicaid funds provide the bulk of payment for health services provided to residents of RHCFS. Medicaid is a federal- and state-funded health insurance program. The eligibility requirements and benefits vary by state.<sup>21</sup> In New Jersey, an individual is eligible for Medicaid if they are both low-income and are either: (1) aged, blind or permanently disabled; (2) pregnant; (3) a child; or (4) the parent of a child.<sup>22</sup> While individuals must be “low-income,” certain higher income individuals can become eligible if they become “medically needy” due to the cost of treating their illness or disability.<sup>23</sup> Medicaid covers the cost of long term care, but will not do so if pre-admission screening shows that the placement is not necessary or advisable.

Most RHCFS residents have a low income and are aged or disabled, but do not qualify for nursing home services because they do not meet the clinical level of need for Medicaid long-term care services. Assisted living facilities typically provide less nursing care than nursing homes. Some RHCFS residents might qualify for receiving that level of care, but may not want to live in such a facility because they are more highly structured, typically limited to elderly residents and more isolated from the community. An RHCFS, however, provides greater opportunity for an individual to remain in their own community and age in place.

RHCFS also can bill Medicare for medication monitoring and other medical expenses for those residents who receive Medicare. Medicare Part A is a federally-funded health insurance program.<sup>24</sup> To be eligible, an individual must generally be over 65 years old.<sup>25</sup> In certain circumstances, where a person is disabled and has been receiving SSD for two years, they may be deemed eligible although they are not yet 65.<sup>26</sup> Medicare Part A mostly covers inpatient hospital care.<sup>27</sup> Medicare Part B is funded through the federal government, as

well as monthly premiums and deductibles contributed by the beneficiary.<sup>28</sup> Medicare Part B has the same eligibility requirements as Part A and covers outpatient care, including doctor’s visits and nursing care.

Medicare Part D provides prescription drug coverage, which is administered through a host of private insurance plans.<sup>29</sup> Depending on which plan an individual chooses, he or she may have to pay monthly or yearly premiums and co-pays.<sup>30</sup> For those individuals eligible for Medicare *and* Medicaid, prescription drug coverage is provided through Medicare Part D.<sup>31</sup> In New Jersey, the Part D benefit is supplemented for senior citizens through the Pharmaceutical Assistance to the Disabled (PAAD) program.<sup>32</sup> Under PAAD, the federal government is the primary payer of prescription drugs for seniors, and PAAD pays all other costs in excess of the \$5 per prescription co-payment for covered medications.<sup>33</sup>

## **Analysis of DCA Violation Reports**

Our research included analysis of data provided by the New Jersey Department of Community Affairs, Division of Codes and Standards, Bureau of Rooming and Boarding House Standards. The data were extracted from notice of licensure violations and deficiencies completed by DCA’s investigators during their routine visits to each RHCFS.<sup>34</sup>

We used the data to rate the quality and performance of each investigated RHCFS between December 2006 to April 2007, using the number of violations and the type of violations as determining factors.<sup>35</sup>

28 42 U.S.C. 1395(j).

29 42 U.S.C. 1395w-101 to 116.

30 42 U.S.C. 1395w-101.

31 42 U.S.C. 1395w-101(b)(3)(D).

32 N.J.S.A. 30:4D-20 to 20:4D-35.5.

33 *Ibid.* Most residents of RHCFS take at least one prescribed medication, with many residents taking several medications. Residents must pay for medication insurance co-pays out of their personal needs allowance. Operators indicated that failure to take prescribed medication could be a reason to be evicted from an RHCFS. For this reason, having Medicaid, Medicare D, or some other form of insurance is essential in order to live in an RHCFS.

34 Not all of the RHCFS were investigated between December 2006 to April 2007—only the 67 of the 82 we subsequently visited.

35 The RHCFS were divided according to their locations. The northern region consisted of Sussex, Passaic, Bergen, Essex, Hudson, Union and Warren. The central counties included Hunterdon, Somerset, Middlesex, Monmouth, Mercer, Ocean and Burlington. The southern region was comprised of Gloucester, Camden, Atlantic, Cape May, Cumberland and Salem.

21 42 U.S.C. 1396a to -1396v. See *A.K. v. Division of Medical Assistance and Health Services*, 350 N.J. Super. 175, 178 (App. Div. 2002).

22 N.J.S.A. 30:4D-3(i). Those receiving SSI are automatically eligible.

23 *Ibid.*

24 42 U.S.C. 426.

25 *Ibid.*

26 *Ibid.*

27 *Ibid.*

The range of violations was zero to 112 and we categorized those with zero to three violations as good performers, those with 4 to 21 violations as average, and facilities with 22 or more violations as the poor performers.

#### Northern Residential Health Care Facilities Performance

There were 23 RHCs in the northern part of the state investigated by DCA during the five-month period studied, more than any other region. Out of these 23 RHCs there were two best performers that incurred zero violations during this time period. In our survey, however, we found that these two facilities were not among the better facilities in terms of resident satisfaction, and were more institutional than home-like in their atmosphere. Of the 23 northern facilities examined, nine qualified as good performers (including the two best performers), and three RHCs were rated as average performers. Twelve of the 23 northern RHCs, however, were poor performers. The worst performers for this region incurred 41 and 51 violations.

#### Central Residential Health Care Facilities Performance

There were 18 RHCs in the central part of the state investigated during the study period. Of these 18 facilities, six qualified as good performers. Only one facility ranked as a best performer because it incurred no violations during the study period. Again, however, while this facility was clean and the building met objective standards, this facility was not among the better facilities in terms of resident satisfaction. Four RHCs in the central region were rated poor performers, and eight qualified as average performers. The worst performer for this region, and for the entire state, incurred 112 violations in the time period studied.

#### Southern Residential Health Care Facilities Performance

There were 14 RHCs in the southern part of the state that were subject to DCA investigations during the time period studied.

Of these 14 RHCs, there were two best performers that incurred zero violations during the time period studied. Upon our survey, however, one of these facilities was not among the better facilities in terms of resident satisfaction. The other had a highly institutional atmosphere, was a bleak and dreary facility, and resident satisfaction ranked very low. Three of the 14 facilities received average ratings, and nine were poor performers. The worst performer in the southern region incurred 111 violations.

Analyzing the information from DCA provided us with an overview of how the facilities were perceived by the agency that issues their licenses. DCA looks primarily at housing and health/safety violations, however, and many of the operators that we interviewed were forthcoming about the fact that their facilities are in need of physical upgrades. Furthermore, until only recently, RHC administrators were accustomed to DHSS regulations and many indicated they were not prepared for the DCA emphasis on physical plant.<sup>36</sup> Therefore, the high amount of violations could reflect the unanticipated requirements that DCA would impose. For example, many administrators volunteered that they were shocked to learn that they would be cited for not having a proper hood over their kitchen stove and complained about the significant expense they incurred to correct that error. On the other hand, many facility administrators noted that they believe that DCA and its inspectors are easy to work with because they “get it” and work with the administrators while they correct their errors.

Ultimately, however, the DCA data did not correlate with how satisfied residents are with regard to their living situations. This suggests that DCA has valuable expertise in examining facilities that were lacking while under the oversight of DHSS, but DCA investigators are not trained to evaluate the conditions which lead residents to be satisfied or dissatisfied with their living arrangement. For example, while DCA inspectors did an excellent job in

<sup>36</sup> DCA assumed responsibility for licensing RHCs effective on May 13, 2005.



determining whether or not a diet was nutritionally sound, they did not ask residents about whether or not they like the food served, or about the variety of food provided. One resident of a facility in the southern region told us, "Sometimes I would just really like a piece of cake." These types of subtle quality of life issues are difficult to measure, and not well suited to the types of inspections DCA conducts.

It is important for the health and safety of residents of RHCFS that DCA examine the temperature in the refrigerator, the conditions under which food is prepared, and the ventilation system in each building. It is likely that the rapid rate at which RHCFS closed in recent years can be attributed in large part to the more rigorous standards DCA imposed on facilities that may well have been substandard. The lack of correlation between DCA's data and resident satisfaction, however, indicates that measuring the quality of life in an RHCFS is a more difficult task than measuring code compliance.

## **Preliminary Report of Our Findings:**

### **The Residents**

#### Nina, age 83

*Nina is an 83-year-old-woman who lives in a large old house in Montclair. The house belongs to a church and is a RHCFS for older women. She first learned about the facility when she came here more than 30 years ago to visit her aunt. Nina worked at a low wage job for many years, and didn't have a lot of choices about where to go when she retired. She could no longer afford the garden apartment she rented in Essex County because her pension and Social Security did not keep pace with rent increases. She did not want to go to a nursing home, and knew she did not need that level of care.*

*Eleven years ago, Nina moved here. She can afford to stay here only because the facility is subsidized by an endowment. In most RHCFS, the resident receives a personal needs allowance of \$102.50 each month and*

*the remainder of the resident's income goes to the operator. Typically, the operator receives about \$730 a month for the housing and meals that the resident receives. In Nina's case, however, Nina receives an allowance of about \$300 per month, which is half of her income, with the remainder of her pension and Social Security going to the RHCFS. This financial arrangement works solely because of the endowment. She meets with a nurse every week to monitor her medications, and when she needs to see her doctor, transportation is provided by the facility. She hopes to remain here for the rest of her life.*

#### James, age 46

*James grew up in Plainfield, and except for time he spent in the hospital, he has always lived within 10 miles of his childhood house. James was an only child and his parents are long deceased. He says he has no family anymore. Although only in his forties, he looks much older. He says he looks older than his years because he lived on the streets for a time and got into some fights. He now believes those troubles were because he did not always take the medication that his doctor wanted him to take, and instead indulged in street drugs. James was first hospitalized when he was 23, and spent several years at Marlboro Psychiatric Hospital, which has since closed. James' case manager helped him find this RHCFS when he was released from Trinitas Hospital two years ago. He has tried living in a group home but did not like all the rules and regulations. In his current home, James is able to follow the rules because there are few. He goes to a psychiatric day program almost every day, taking an occasional day off if he's just not feeling well. He says he'd like to get his own apartment someday, but doesn't know how he'll ever afford it. For now, James calls this his home.*

#### Robert, age 34

*"The beach is beautiful," Robert told us when we talked to him about why he lives at a RHCFS in Atlantic City. Along with 25 other residents, Robert lives in an old but well kept building across the street from the boardwalk, just a short walk to the beach. Robert came to*

Atlantic City after dropping out of college and worked sporadically at the casinos for a number of years. He says that he realized he had a mental illness when he was in his late 20s, but avoided treatment because he didn't want people to think of him as "another crazy person." He has found a medication that seems to work for him, and has not been in a hospital in almost three years. He doesn't attend a day program, preferring to work at odd jobs or just walk around town in the daytime. He does take his medication, though, "because they make me," referring to the staff of the RHCf. Robert is not sure what the future is going to hold for him, but for now he is content with his living situation.

The stories of Nina, James, and Robert are similar to the stories of many residents that we met with over the past several months.

Our study revealed some interesting facts regarding the demographics of people who live in RHCfs statewide. Almost two-thirds of the 2,462 residents were men (62% male, 38% female) and almost half of the residents (49%) have lived in the same facility for five years or more (see tables 1 and 2 for an illustration of gender and length of stay).

**Table 1: Resident Gender Demographics as Described by Owners or Administrators**

| Gender  | Number | Percentage |
|---|--------|------------|
| Female  | 929    | 38         |
| Male  | 1533   | 62         |
| Total number of residents between September and December, 2007: 2,462 |        |            |

Seven of the administrators noted that at one or two of their residents have lived in their respective facility for 20 or more years, and three people have lived in their respective facility for at least 30 years. One administrator noted that all of her residents have lived there for 15 years. Thus, for many of the residents, the RHCf is their home.

**Table 2: Resident Length of Stay Demographics as Described by Owners or Administrators**

| Length of Stay  | Number | Percentage |
|---|--------|------------|
| Less Than 1 Year  | 342    | 14         |
| 1 to 5 Years  | 775    | 32         |
| More Than 5 Years   | 1211   | 49         |
| Total number of residents between September and December, 2007: 2,462 |        |            |

The ethnicities represented by residents seemed to reflect the population in the community where the facility was located.

We found that of the total number of residents, 71% were White, 23% were African American, 4% were Hispanic, and 1% each were Asian/Asian American or a combination of any of the above (see Table 3 for a complete demographic description).<sup>37</sup>

**Table 3: Resident Race and Ethnicity Demographics as Described by Owners or Administrators<sup>38</sup>**

| Ethnicity   | Number | Percentage |
|---|--------|------------|
| African American  | 570    | 23         |
| Asian (Asian American)  | 23     | 1          |
| Hispanic  | 105    | 4          |
| White   | 1723   | 71         |
| Other/Combination   | 16     | 1          |
| Total number of residents between September and December, 2007: 2,462 |        |            |

<sup>37</sup> New Jersey's RHCf population differs from the broader NJ population mostly in terms of the African American and Hispanic populations. According to the 2006 US Census, 13.6% of NJ's population is African American and according to the 2000 US Census 13.2% of NJ's population is Hispanic. Therefore, RHCfs have a greater disproportionate percentage of African Americans, and a lesser disproportionate share of Hispanics.

<sup>38</sup> In two of the residences, the administrators gave us minimal information that lacked most of these demographic details and many of the administrators provided us with estimates of their numbers, especially with payment sources other than SSI and private pay as well as length of stay. As a result not all of the percentages add up to 100%. Also, numerous administrators noted that some of their residents had double sources of payment such as SSI and SSD or SSI and SSA. The reported numbers reflect the best estimates that the administrators could give us.

**Table 4: Resident Age Demographics as Described by Owners or Administrators**

| Age Group   | Number | Percentage |
|---|--------|------------|
| Under 50  | 698    | 28         |
| Between 50 and 59   | 865    | 35         |
| 60 and Above  | 809    | 33         |
| Total number of residents between September and December, 2007: 2,462 |        |            |

The age span of residents at RHCs was somewhat surprising. Since RHCs had originally housed older residents, we expected a larger cohort of older adults, and a mix of adults with mental illness or addiction issues. In some homes, one group – either elderly or individuals with mental illness – predominated. In an aggregate look at the ages of residents at all facilities, however, 28% are under age 50, 35% are between 50 and 59 years of age, and 33% are over 60 years of age (see Table 4). Even in those facilities that housed mostly elderly residents, we did see older adults with mental illnesses, typically depression. Of those facilities which had a mix of elderly residents and those with mental illness, about 65% were people with mental illnesses.

Although one third of all facilities have at least one resident who privately pays for their room, board, and services, Table 5 shows that a large majority of RHC residents are supported by SSI (see Appendix 1, which provides the distribution of payment sources used by residents in each facility).

**Table 5: Resident Age Demographics as Described by Owners or Administrators**

| Source of Payment   | Number | Percentage |
|---|--------|------------|
| SSI   | 1495   | 61         |
| SSD   | 298    | 12         |
| Social Security Retirement Benefits                                   | 97     | 4          |
| Veterans Administration   | 69     | 3          |
| Private Pay   | 207    | 8          |
| Total number of residents between September and December, 2007: 2,462 |        |            |

Elderly residents with relatives who were involved in their lives were able to afford better places. In addition to a resident's Social Security and pension, these families were willing and able to subsidize their monthly expenses with as much as \$2,000 or \$3,000 more per month. Not surprisingly, RHCs which primarily took such "private pay" residents offered a notably more pleasant environment and more services than other facilities. Of the 82 residences we visited, seven houses catered only to private pay older adults.

For those residents who are mentally ill and who may have other problems, such as developmental disabilities or alcohol or drug problems, the RHCs tended to provide accommodations that were much more spare and utilitarian. Many factors contribute to this. Because those with severe and persistent mental illnesses are usually diagnosed in their 20s, they have less of a work history and are less likely to get reasonable disability benefits. Families of people with mental illnesses may not be as willing or as able as those with elderly relatives to assist in funding the individual's housing. In fact, many people with mental illnesses may be estranged from their families.<sup>39</sup>

Because this group has fewer resources, these individuals have fewer choices about where to live. Even within the universe of RHCs, people for whom mental illness is their primary presenting issue tended to be relegated to spaces that were less well-appointed. Nevertheless, it is noteworthy that the overwhelming number of all residents are prescribed psychotropic medication (Table 6). This is significant because within the general population of elderly people, psychotropic medications are not so heavily relied upon for individuals who do not have serious and persistent mental illness. This anomaly suggests that psychotropic medications may

<sup>39</sup> There is ample evidence indicating that persons with mental illnesses are often alienated from their families. Sources include "Beside the Golden Door: Policy, Politics, and the Homeless", J. Wright, B. Rubin, J. Devine (Aldine Transaction, 1998); "Evidence based practices for services to families of people with psychiatric disabilities," L. Dixon, W. McFarlane, A. Lucksted, published in *Psychiatric Services*, July 2001, 52(7):903-10.

be overutilized within RHCfs and the care of these individuals may require closer review.

**Table 6: Residents taking Medications as Described by Owners or Administrators**

| Medication  | Number | Percentage |
|---|--------|------------|
| Residents Who Take Medication   | 2380   | 97         |
| Residents who Take Psychotropic Medication                            | 2208   | 90         |
| Total number of residents between September and December, 2007: 2,462 |        |            |

Younger residents who take psychotropic medications, however, were found to have serious and persistent mental illnesses. Many of these residents had histories of hospitalization and were currently utilizing the public mental health system.

They may live with mental illnesses, or they may have some health problems related to a chronic condition or to aging. What most residents have in common, though, is that they have low incomes and few housing options because of their low income.

An adult living in New Jersey, with an income of approximately \$830 per month has very few housing options. Rental assistance lists are closed in many counties because the need for housing assistance far outstrips the funds available to provide it. Group homes and supervised apartments for people with mental illnesses are scarce, particularly at this time as state hospitals are again downsizing. As the population of state hospitals decreases, patients from those institutions are in need of secure, supervised community settings. Those patients are often given a preference for mental health community residential beds over those who are already in the community, who are in danger of homelessness, or who may be in short term institutions, such as community or county hospitals.

Cost is the primary reason that people choose to live in RHCfs as opposed to other settings.

Residents placed a high value on having their own bed, an address for receiving mail, and a place to keep their possessions, even if they shared the bedroom with three others people and shared the bathroom with five others. Residents also valued a setting where they receive three meals each day and someone reminds them to take their medication. For these New Jerseyans, there is no way to secure supportive and safe housing on an income as low as \$830 a month. Even some RHCfs are not willing to take residents with incomes at such a low level and accept only private pay residents who can afford much higher monthly rates.

Beyond having little to pay for room and board, the personal needs allowance of \$102.50 that residents receive leaves little for the other expenses of daily living. The personal needs allowance must cover toiletries, recreational activities, clothing, and all other expenses.

### The Facilities

What we learned from our visits to RHCfs was that even with a well run RHCf, aging facilities combined with low reimbursement rates leave virtually no financial margin for error.

We visited all 82 RHCfs that were open during the time of our data collection, and saw some houses that had leaky roofs or insect infestation. Most, however, did not have such serious problems. Generally, we saw facilities that were kept in at least minimally satisfactory condition, and certainly as well as they could be given the financial constraints under which most RHCfs operate. For example, in one facility a common room had been closed off because of a leaking roof which the owner had not yet been able to afford to repair. The loss of the room, however, meant the loss of the residents' "quiet lounge" without a television. When facilities had violations potentially posing health or safety problems, we immediately reported these violations to the Office of the Ombudsman for the Institutionalized Elderly or DCA, as appropriate. Some of the violations that we encountered included medication left on a table in an unlocked office, unsanitary conditions, and a resident with an open wound.

There are no maximum limits on the number of residents a licensed RHCf may house. Some RHCfs have as few as six residents, while one is licensed for 255 people. The services, surroundings, and care that is provided in each facility have a similarly broad range. A few of the facilities were built specifically to serve as RHCfs, but most are simply old houses that have been retrofitted with fire alarms, sprinkler systems and additional bathrooms in order to function as RHCfs.

Smaller facilities also offered more privacy than larger facilities and were less likely to have multiple roommates or dormitory style rooms. Residents with more than one roommate or those who lived in dormitory style rooms complained about a lack of privacy and theft of personal items more frequently than those who had private rooms or who had only one roommate. Additionally, in smaller facilities it is more likely that residents will get to know one another and form interpersonal bonds. This is less likely in a large facility, where the residents were more likely to indicate that they felt they were living among strangers.

Of those RHCfs that were mainly geared toward older adults, we typically saw a more pleasant physical setting: clean, bright rooms, pictures of family that indicated involvement by family members, and better quality furniture and furnishings. This is partly due to the fact that some RHCfs which cater only to older adults did not accept SSI or SSD, and all residents were private pay. All facilities have a private pay rate, but at facilities that accept only private pay residents, the monthly fee was typically about \$3,750 per month, which is about one-half to two-thirds less than an assisted living facility. This is almost \$3,000 more per month than the amount received by operators of facilities that have mainly low-income residents, and so it made sense that the physical surroundings were generally more pleasant and comfortable, the quality of the food was better, and the residents had more privacy (single or double rooms only). Operators noted that there was typically a lot of family involvement in “private pay” facilities, as

the families sometimes paid the resident’s fee and often came to visit.

In those RHCfs that catered primarily to residents with mental illnesses, the physical plant generally was not as pleasant or as clean. In most cases, it was apparent that this was just an issue of funding. In rare cases, however, operators indicated that they provided a less welcoming environment because people with mental illnesses deserved less. One operator went so far as to tell us that she did not really believe that the residents she was paid to care for were truly ill, but rather that they had a “laziness disease.” In settings like this, people with mental illnesses are stigmatized even by those who make their own living by housing them. Although this facility ranked as a good performer by DCA standards, clearly this operator should not be working with vulnerable individuals.

Given that RHCfs are essentially health care facilities that predominantly serve people with mental illnesses and the elderly, it is surprising that there is no requirement for air conditioning. Mental health consumers who take psychotropic medications, particularly antipsychotics or major tranquilizers, have difficulty regulating their body temperatures and are at high risk of heat stroke and seizure. Older adults are also at a higher risk of heat related disorders. In some instances, due to the age of the facilities and concerns about fire hazards, residents are prohibited from having an air conditioner or a fan, even if they are willing to pay extra to subsidize this cost. Given the needs of the population served, a regulation requiring RHCfs to provide air conditioning is strongly advised.

Unlike group homes and some nursing homes, most RHCfs are for-profit ventures. As we were told by one operator, “for-profit” is their tax status, even if it is not always the bottom line reality of running such a facility.

## **Owners & Operators**

Over the course of our project, we noted certain patterns among those who own and

operate RHCFs. Some facilities are owned by families and employ family members almost exclusively. Facilities of this type typically offered little in the way of staff training or orientation. Other facilities are owned by small corporations, and function in a more businesslike manner. Some owners and operators were jaded, but most said they did this work because they felt it was important.

We also found that the type of owner or operator at each facility has an effect on the satisfaction of its residents. Some operators function as “house mothers,” and are very involved in each aspect of their residents’ lives. At one facility in Atlantic County, a resident credited the operator of the RHCF in which he lived with helping him to stop using alcohol because alcohol use is not tolerated at the facility. He realized that he would rather live at the facility than continue abusing alcohol, and appreciated the support that he received from the RHCF operator.

In an interview of one operator, we asked him about other operators we had met who expressed unhappiness with their work and indicated they were trying to get out of their businesses. He had this to say:

*“I would bet that the people who don’t care, who hate their jobs, they’re the ones who have been doing this 20, 30 years. They’ve heard the promises from this governor, that senator, about how we’re going to help you. I’ve been in this business for 4 years now, and I’ve heard these stories. I still have some hope that things are going to get better, though, because if they don’t, the state’s not going to be able to build hospitals big enough or nursing homes big enough for all these people who live here. If we weren’t here, where would they go?”*

- Joe

RHCF Owner, Middlesex County

This owner’s statement presents a stark prediction. If RHCFs continue to close, where are these elderly individuals and mental health consumers going to go? RHCFs serve the needs of elderly individuals who need some

support and access to nursing care in order to remain independent, but who do not need the level of care provided in a nursing home and who cannot afford more expensive options such as assisted living. RHCFs also are a critical resource for mental health consumers who need some structure and support in their daily living and some nursing care, but who cannot tolerate the highly structured environment of a group home or other community care setting. In an RHCF, these New Jerseyans can maintain their independence while living in the community.

## **Findings and Recommendations**

From our data and study we have concluded that it is essential to keep RHCFs viable and to better support them as an important resource for housing vulnerable individuals who have some care needs as a result of age or mental illness. These facilities provide the only supportive housing option for many low income elderly.

For mental health consumers, RHCFs must be recognized as a critically important resource in addressing the serious challenge of finding community placement options for more than 1,000 individuals who have been cleared for discharge from state psychiatric hospitals and who remain hospitalized, awaiting placement. Our study clearly indicated that residents and operators of RHCFs would benefit by instituting additional wraparound services such as life skills coaching, case management, help learning to navigate public transportation, and assistance in finding vocational training. These types of services assist individuals in making the transition from living in a psychiatric facility to more independent living situations in the community.

There is both a legal and moral imperative to provide community housing alternatives for individuals at state psychiatric hospitals who are cleared for discharge but awaiting placement in the community, and better utilizing RHCFs provides an important tool in meeting that need. But there is a stark economic reality as well. According to figures

released by the New Jersey Department of Human Services, Division of Mental Health Services (DMHS), the state spends \$472 million to maintain five state psychiatric hospitals. According to the NJ State Budget, the average combined census in those hospitals is 2166, bringing the cost per patient to about \$218,000 per patient. Based on the DMHS figures, the state pays \$277.4 million for the state hospitals. Other sources, including federal uncompensated care funds, pay for the balance, about \$194.9 million.

Currently, the state funded portion of an individual's stay in state psychiatric hospitals is about \$128,000 annually. But the fiscal picture is not that simple. By failing to support an adequate network of community programs, New Jersey is effectively choosing to devote far more than \$128,000 per patient to keep these individuals unnecessarily hospitalized.

DMHS reports that the state receives a total of \$139.3 million in federal uncompensated care funds to support the five state psychiatric hospitals. The amount of federal funds the state receives for uncompensated care is capped, however, and thus is not tied to the actual per capita cost of operating New Jersey's psychiatric hospitals. As a result, a reduction in the census at the state hospitals would likely *not result in a reduction in these critically needed federal funds*. Moreover, because these federal funds flow directly into the state general fund and are unrestricted, reducing the census at state hospitals, and the cost of operating those hospitals, would free these federal funds so they could be redirected to support mental health services in the community, where they are most needed, further alleviating the state burden of supporting these programs.

Furthermore, once placed in a community setting, a large number of these individuals become eligible to receive other federally-supported benefits, including SSI and individual Medicaid coverage. By keeping these individuals unnecessarily hospitalized,

New Jersey *also* is failing to draw down these essential federal funds to support community placements.

In short, by choosing to keep a large number of patients unnecessarily hospitalized, rather than supporting more appropriate and cost effective community programs, New Jersey is squandering large amounts of both federal and state resources that would be more efficiently spent on community alternatives. Furthermore, by perpetuating a system of overcrowded hospitals that contain hundreds of individuals who are ready to be discharged into community placements, New Jersey is failing to draw down *additional* federal funds that would provide further support for these individuals in community placements.

As a result, the *actual* cost to state taxpayers of keeping patients unnecessarily hospitalized is far greater than \$128,000 per year. And the cost to those patients who are involuntarily and unnecessarily hospitalized, rather than living productive lives in the community, is immeasurable.

The DCA began oversight of RHCs following recommendations made by Governor Codey's Mental Health Task Force in 2005. This has proven to be a positive change, as DCA representatives have a much better grasp of safety codes, and are better able to inspect for health and safety regulations. Also, since DCA has been the licensing agency for RHCs, 62 facilities have closed their doors. This may be due in part to more stringent oversight from DCA, thereby making it more difficult for substandard operators to continue doing "business as usual."

In addition to recommending a change in agency oversight, from DHSS to DCA, Governor Codey's Mental Health Task Force noted that creating a maintenance fund for RHCs and expanding training for operators in areas such as substance abuse and first aid would help to improve the services provided to these vulnerable residents.

The Task Force also recommended increasing funding for operators, and it is apparent that this is very much needed.

Building and strengthening this network of housing will require a commitment and effort on the part of DMHS. Merely releasing mental health consumers from hospitals without investing in community services will have predictable disastrous results. RHCfs cannot become a dumping ground for mental health consumers, nor should they be a permanent solution for most of those who need housing. They are a valuable transition tool, however, and a mental health consumer living in an RHCf with the proper supports can gain the skills needed to transition to a supported apartment.

Many patients may want to wait for a supervised apartment or more desirable placement. These individuals, however, should be presented with the choice to enter an RHCf on a transitional basis, not a permanent basis. Currently, consumers who live in RHCfs are less likely to receive supportive housing, because there is a preference that such housing slots go first to people within the state hospital system. This structural problem would need to be addressed so that those who are released from psychiatric hospitals to RHCfs may someday be given the resources to move on, if they are otherwise able to do so.

Certainly, RHCfs are not an ideal type of housing for everyone. Nonetheless, they tend to be affordable, which is one reason that they appeal to people with mental illnesses, older adults, or others on a very limited fixed income. For those individuals who need the level of care provided at an RHCf, they may be a good option, especially if other social services can be provided to assist RHCf residents to transition from congregate living into other settings, or for those people who wish to permanently remain in RHCfs. RHCf operators and the mental health community need to collaborate on creative solutions to ensure access to high quality RHCfs for people with mental illnesses and the elderly.

We recognize that recommendations similar to ours have been made in the past, notably by the Mental Health Task Force. But even years before the work of the Mental Health Task Force, studies found that RHCfs were not being adequately funded, and this would eventually cause the loss of housing that benefits older adults and people with mental illnesses. New Jersey cannot afford to continue losing this essential housing resource.

### **Recommendation 1: Make Quality Wrap Around Services Available**

RHCf operators and the mental health community should partner together to broaden wrap around services. Right now, there is a service gap for RHCf residents. DMHS should direct providers who offer state-funded case management services to do outreach to clients in RHCfs to close that service gap.

One example of such a partnership can be seen at an RHCf in Essex County. Within this facility, 20 of the 24 residents are members of the University of Medicine and Dentistry's (UMDNJ) PATH Program.<sup>40</sup> PATH, a federally subsidized program through HUD, is an acronym for "Projects for Assistance in Transition from Homelessness." PATH clients are eligible for services such as case management, medication monitoring, and life skills coaching, which may include help with learning transportation systems or help in applying for vocational training. These additional services, sometimes called "wrap around" services, help to meet the needs of mental health consumers who wish to live independently but need to learn the skills to do so.

This sort of partnership between the facility and DMHS, which contracts for the case management services for residents, creates

40 PATH, a federally-funded housing/case management program, is well established and has had excellent outcomes. Some sources include "Strategies for Preventing Homelessness", M. Burt, C. Pearson, A. Montgomery, HUD (2005); "Homeless Outreach: On the Road to Pretreatment Alternatives", J. Levy, Journal of Contemporary Social Sciences, 2002; "Homeless in New Jersey: Why Does it Happen?", G. Kirkland, Ph.D., Bloomfield College, January 2006.



badly needed opportunities for individuals with mental illnesses to live in their communities of choice. This federally-funded program used to exist in several RHCFS, but now only exists in the Essex program discussed above, and is about to be phased out because PATH services are not available to individuals who are no longer homeless or at risk of homelessness. There are other case management services, however, through which these services may be provided, and supportive services like these can make the difference between success and failure for psychiatric patients who are transitioning into the community. Certainly not all public/private partnerships will work, but in our research, we spoke to operators, mental health staff who provide services, and residents who received case management services, and all said that such programs are effective in keeping people out of the hospital.

Other types of support services, such as Residential Intensive Support Teams (RIST) should also be expanded to meet the needs of consumers in RHCFS. RIST programs provide whatever supportive services are needed, including case management, training in how to use public transportation, referrals and linkages to mental health services, and self-help services. Currently, there are RISTs in nine counties in New Jersey, and these have been very successful in helping consumers become comfortable living independently. RISTs tend to be fairly inexpensive to fund because they are typically staffed with paraprofessionals who have certifications or bachelor degrees and training in case management. RISTs are also often staffed by peer counselors, who have experienced RHCFS living themselves, and so are well equipped to assist other consumers in a self help system.

RHCFS living, combined with enhanced services for mental health consumers, could serve as a way to transition individuals from New Jersey's overcrowded state psychiatric hospitals at a much lower cost than keeping people in the hospital. This is both fiscally responsible and clinically appropriate, as it allows individuals to be treated in the community, which is a far less

restrictive setting than a hospital. Consumers then have the opportunity to learn the skills they need and make the supportive relationships they need to live successfully in a community setting. This can be achieved without creating more housing but by shoring up the housing stock that is now available.

**Recommendation 2: Screen RHCFS residents for Medicaid waiver home and community based services.**

RHCFS operators and the state's Office of Community Choice Options (OCCO) should partner together to identify eligible residents who are at risk of nursing home placement because of greater need for assistance with the activities of daily living (toileting, eating, bathing, bed mobility, transfer, locomotion, and dressing) for enrollment in one of the state's Medicaid waiver home and community based services programs.<sup>41</sup> DHSS, through its regional OCCOs, should do outreach to each RHCFS so that eligible residents can receive the services necessary to allow them to remain in their homes as their care needs increase.

The Caregiver Assistance Program (CAP) and the Community Care Program of the Elderly and Disabled (CCPED) are two of the Medicaid waiver programs administered by DHSS which can provide services for eligible applicants in their own homes, including RHCFS. Available services differ slightly, but include care management, home health aide and chore aide services, and some transportation to medical appointments.

**Recommendation 3: Use RHCFS placement for nursing home residents who are being transitioned back into the community under the DHSS Global Options – Nursing Facility Transition program as a source of affordable housing.**

<sup>41</sup> Eligibility for a DHSS administered Medicaid waiver for home and community based services requires that the applicant be 65 and over, or between the ages of 18 and 64 and disabled. In addition, the applicant must be financially eligible for the institutional Medicaid Only program as well as clinically eligible, requiring a nursing facility level of care.

Global Options – Nursing Facility Transition (GO-NFT) is a DHSS program which optimizes all DHSS Medicaid waiver programs to custom design supportive services in the community to facilitate the transition of nursing home residents back into their own communities where appropriate. Currently, a major obstacle to transitioning nursing home residents who are clinically appropriate for GO-NFT is the lack of affordable housing in the community. RHCFS should be better utilized for this purpose, both for short-term placement while residents wait for other subsidized housing to become available, and for long-term placement for residents who prefer the communal aspect of RHCFS living.

GO-NFT would provide these RHCFS residents with an array of services, including care management, home health aide and chore aide services, environmental accessibility adaptations, and transportation, which would allow them to live successfully in RHCFS without increasing the burden on RHCFS operators.

#### **Recommendation 4: Increase State SSI Supplement for RHCFS Residents**

RHCFS operators and the mental health community should partner together to advocate for increasing the state supplement to SSI payments. Governor Codey's Task Force recommended that funding for RHCFS by \$50 per month per resident by increasing the state supplement. Not surprisingly, the operators with whom we spoke believe that a larger increase is necessary. Operators advised us that even an increase to a total \$40 per diem would make a significant difference and would allow most facilities to remain open and continue serving the consumers and elderly residents who depend on them.

In order to give operators more resources to improve services in the RHCFS, the Public Advocate recommends increasing the state SSI/SSD supplement by \$16 a day, or \$5,900 a year, which would make the total state/federal daily reimbursement \$40 a day, or \$14,600 a

year per consumer with a total state share being \$8,390.

Ultimately, such an approach would save the state money because decent and effective community placement alternatives help consumers avoid costly hospitalizations. Keeping with the FY '08 state budget estimates noted above, a consumer in a state psychiatric hospital costs the State of New Jersey about \$75,000. By supporting a person in an RHCFS rather than a state or county psychiatric hospital, the state would ultimately save about \$60,000 per year per individual. The cost of wrap around services in the community would consume only a fraction of those savings.

This would require shifting DMHS funds currently used to subsidize hospitals and community programs. This could be achieved through closing down units within large psychiatric hospitals in order to reduce the census, reducing overtime costs by better utilizing staff, and moving individuals who are ready to leave into community settings. While representing a savings for the state, this would also alleviate some of the problems currently caused by overcrowding in the state hospital system. Most importantly, such a shift would be a huge benefit for consumers who would no longer be involuntarily held at these hospitals.

#### **Recommendation 5: Develop Networks to Improve the Quality of RHCFS**

RHCFS operators and the mental health community must become partners to improve RHCFS quality. Clearly, inadequate funding is responsible in large part for quality issues at the RHCFS. However, our examination revealed that other factors are at play in the quality equation. Some RHCFS simply had better policies and practices, and thus able to run more effective operations. For example, one RHCFS administrator did not know how to bill Medicaid, while most others did. Another administrator had learned through years of trial and error that a particular response to resident theft was effective, while others continuously struggled with the problem.

Establishing and supporting both formal and informal networks to encourage operators to share information about their own experiences and best practices would be a cost effective way to improve quality within RHCs. Certainly, RHC administrators are not the only actors that could share in this process. Family members, mental health professionals, and other stakeholders could also add to the conversation.

## **Conclusion**

*“New Jersey has, by failure to act, determined that the board and care industry and its residents therein have little value. This critical statement is not baseless, evidenced by over twenty-five years of evaluation through task forces, committees, scholarly literature and legislative hearings that have resulted in absolutely no action. As a result, vulnerable, disenfranchised residents face a multitude of issues ranging from quality of life to life and death on a daily basis. When New Jersey’s economy was stronger, no money was made available. The existing silo structure of State agencies could not work together. Politics interfered with human lives. As a result, this industry has been fated to face extinction, and those that survive, survive at the expense of residents.”*

-Governor Codey’s  
Mental Health Task Force Report  
(2005)

Since those words were written, there has been some positive action taken by the state but more must be done to ensure the survival of this critical housing option.

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Appendix 1.

Distribution of Payment Sources in Facilities across the Counties<sup>1</sup>

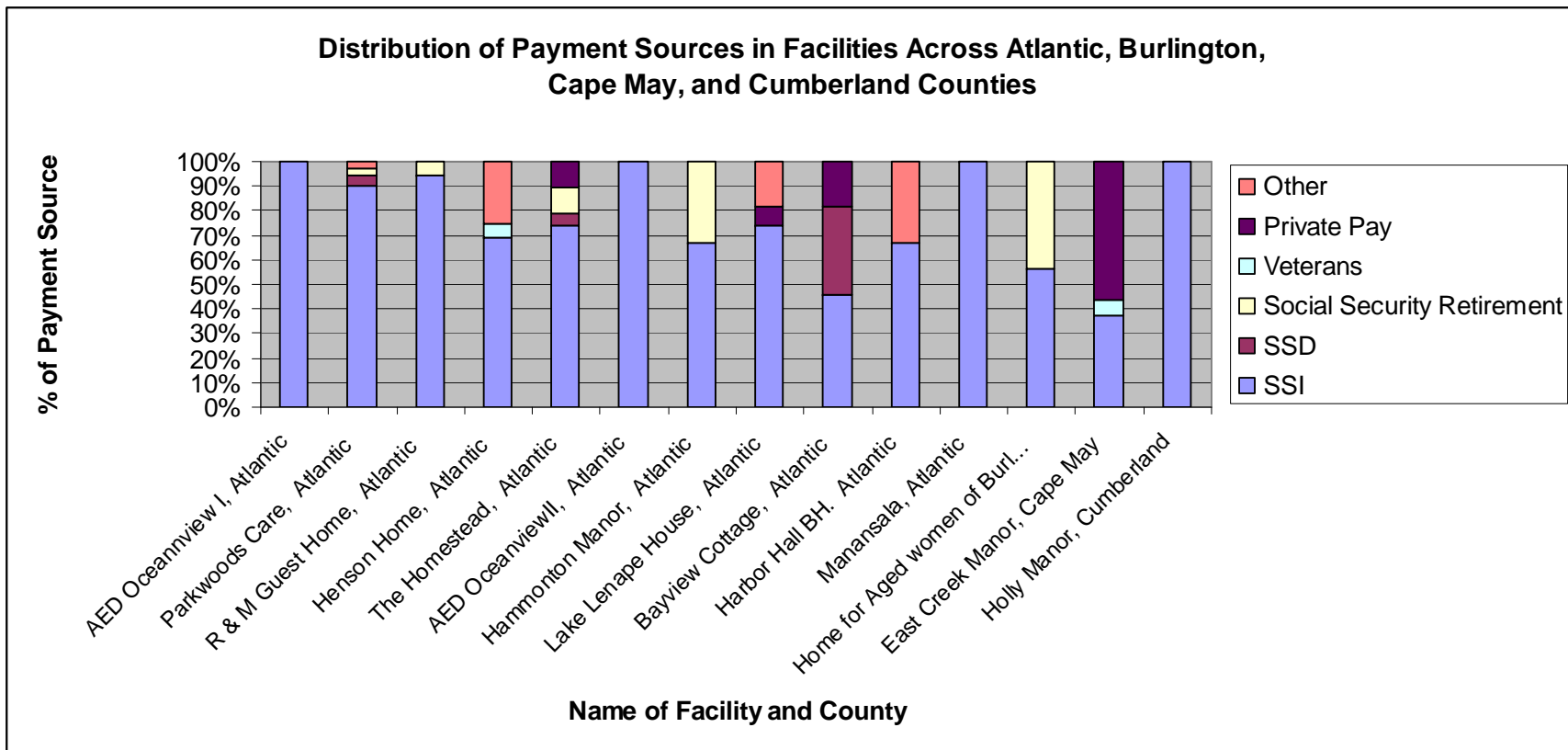


Figure 1. Distribution of Payment Source Across Facilities in Atlantic, Burlington, Cape May, and Cumberland Counties

<sup>1</sup> "Many of the administrators gave us an estimate of the payment sources and not a complete response of the payment sources for their residents. The "Other" category can be any of the sources already noted such as SSI or SSD but in two cases "Other" also signifies general assistance before SSI kicks in and two cases it stands for a non-profit organization."

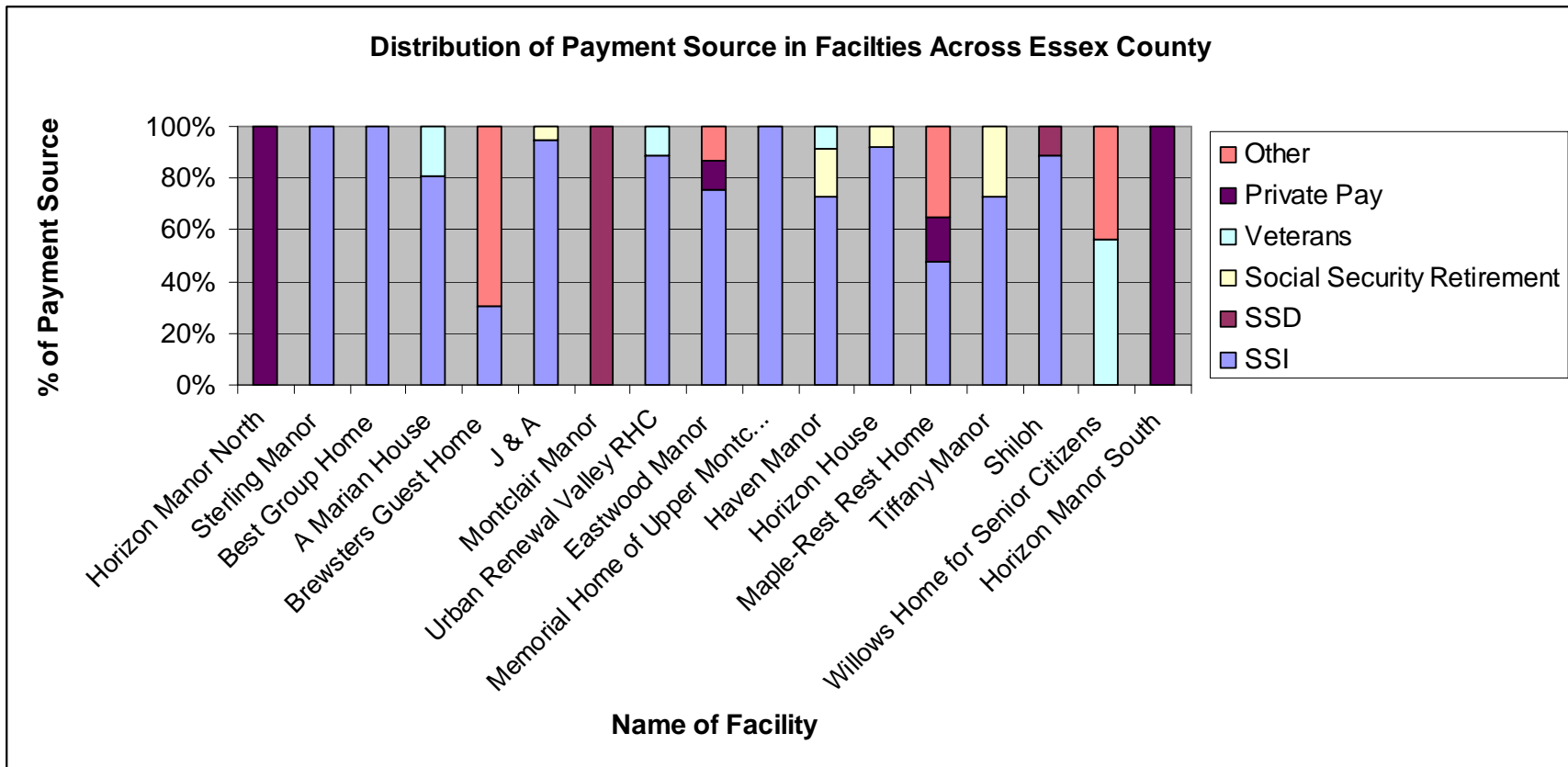


Figure 2. Distribution of Payment Source Across Facilities in Essex County

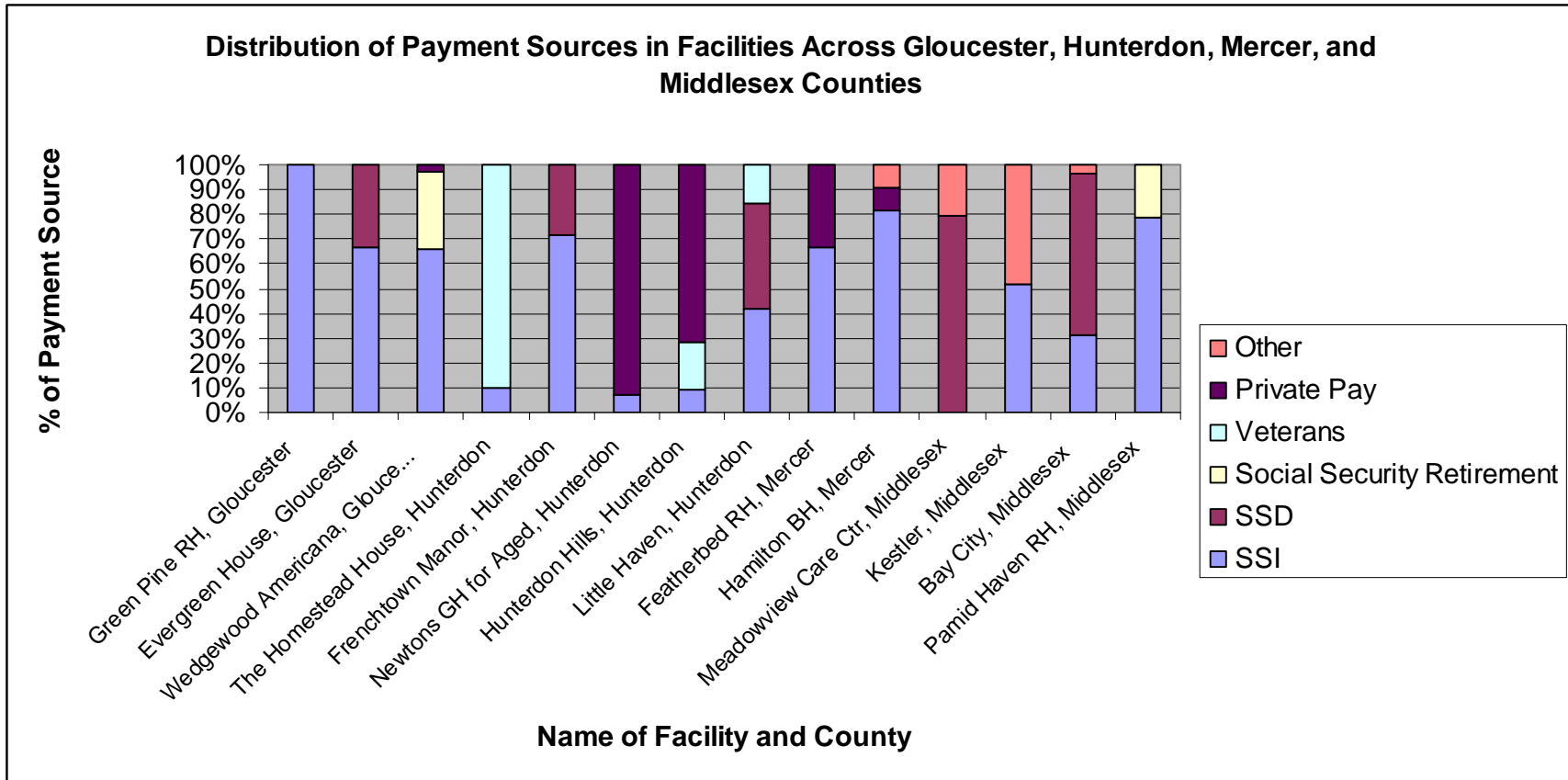


Figure 3. Distribution of Payment Source Across Facilities in Gloucester, Hunterdon, Mercer, and Middlesex Counties

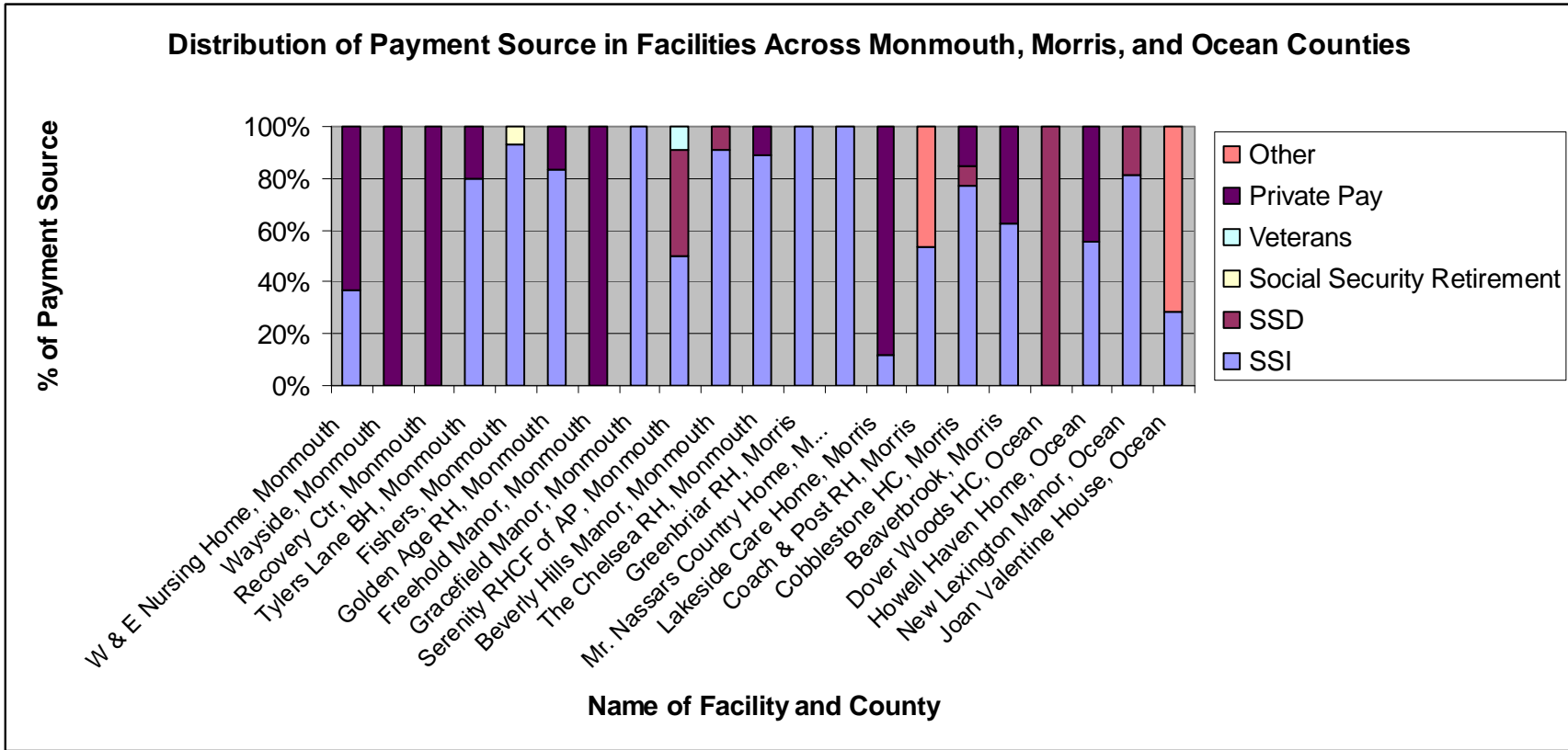


Figure 4. Distribution of Payment Source Across Facilities in Monmouth, Morris, and Ocean Counties

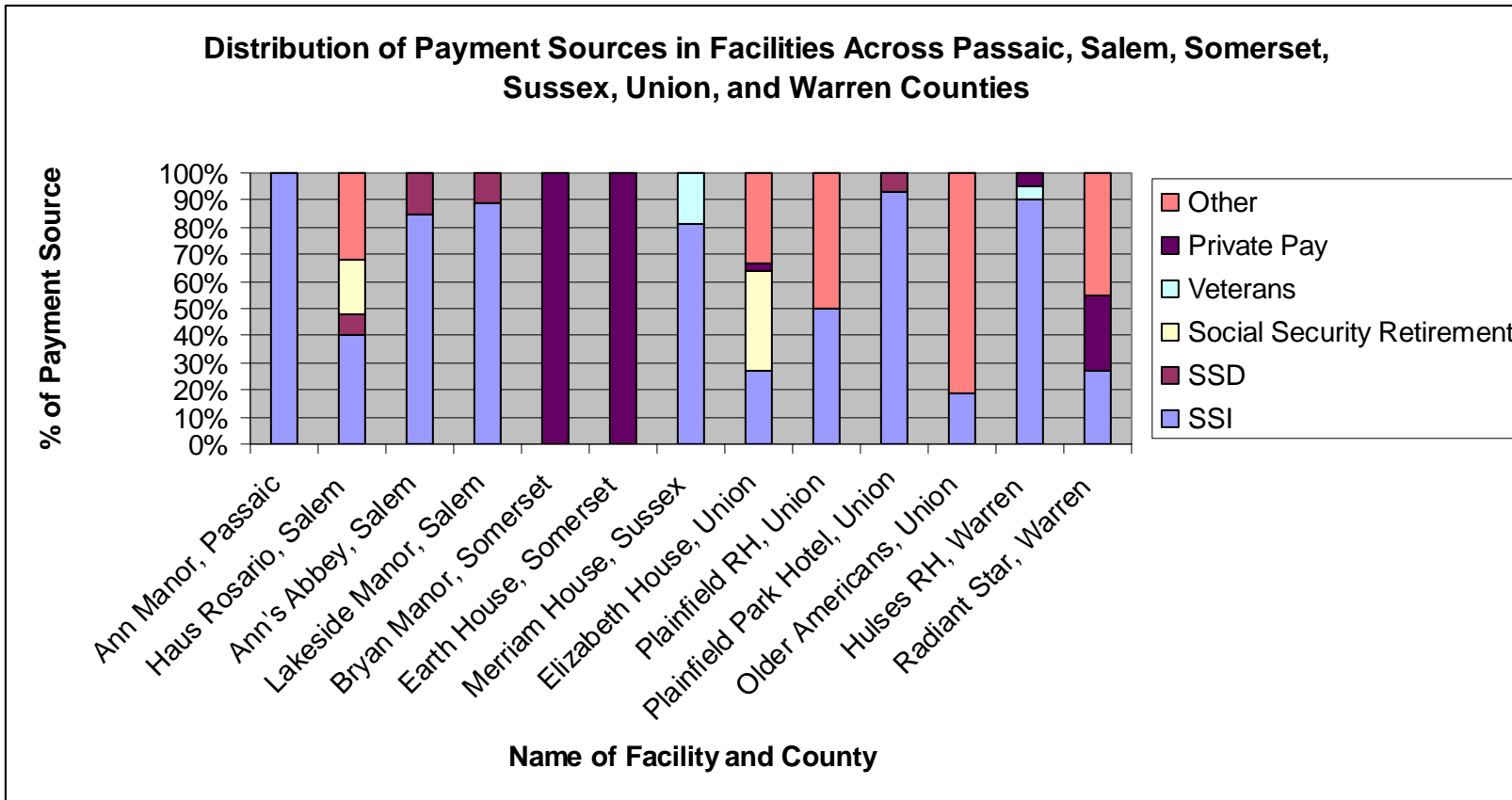


Figure 5. Distribution of Payment Source Across Facilities in Passaic, Salem, Somerset, Sussex, Union, and Warren Counties