Adult Homes Serving Residents with Mental Illness:
A Study of Conditions, Services, and Regulation

A Report

by the New York State Commission on Quality of Care
for the Mentally Disabled
and the Mental Hygiene Medical Review Board

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PREFACE

Adult homes licensed by the Department of Social Services (DSS) are the largest single congregate residential option in the community for people with mental illness. With approximately 9,000 of the 25,000 beds in adult homes serving this population, they play a larger role than residential programs certified by the Office of Mental Health (OMH) like supervised community residences (3,881 beds), Residential Care Centers for Adults (620 beds), supported apartments (1,794 beds), and family care homes (2,828 beds).

Although intended primarily to provide residential services, personal care and supervision for the frail elderly, adult homes have also served patients discharged from psychiatric hospitals, many of whom are also frail and elderly. In recent years, a greater number of younger patients discharged from psychiatric hosptials in urban areas have been placed in adult homes, usually because other housing alternatives, including OMH-sponsored community residences and apartments, are not available to them.

Such placements have occurred as psychiatric hospitals struggle to avoid overcrowding by discharging patients who have been stabilized. The pressure under which psychiatric hospitals operate, and the high demands for admission,* prompt discharges into adult homes, often with insufficient scrutiny of whether such homes are "adequate and appropriate" settings (MHL Sec. 29.15) in which to meet the needs of the discharged patient for safe housing, personal care, supervision, and access to ongoing treatment and psychiatric rehabilitation.

This study of adult homes serving significant numbers of residents with mental illness was requested by the legislature to examine not only the conditions in such homes but also whether laws governing the regulation and inspection of these homes by DSS and OMH, enacted a decade ago, are being appropriately implemented.

As documented in this report, in the course of the study the Commission found many adult homes that provided adequate and, at times, exemplary care and supervision for their residents, at a modest cost (19 homes serving 21 percent of the sample population). At the same time, we found a significant number of homes (14 homes serving 45 percent of the sample population) with seriously deficient conditions that adversely affected the day-to-day living conditions, safety, supervision and health of the residents.

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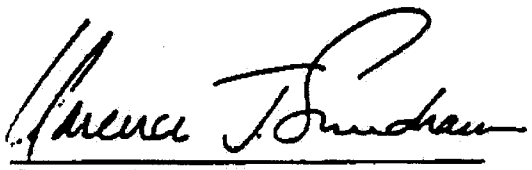
*_Admission and Discharge Practices of Psychiatric Hospitals: A Report to the New York State Legislature Pursuant to Chapter 50 of the Laws of 1987_, NYS Commission on Quality of Care, April 1988.

As this latter part of the adult home industry exists at present, it does not serve the interests of the residents who live in deplorable conditions. These residents, often suffering from mental illness and other infirmities, are too afraid of jeopardizing their "home" to complain, and often lack advocates to forcefully and effectively press their concerns. They must rely upon state regulatory agencies to ensure that operators provide them with care and services that meet minimum standards. However, as the Commission found, the existing regulatory structure does not consistently provide such an assurance. In many instances, the seriously deficient conditions observed by Commission staff had existed for some time and had been cited by DSS inspectors during their visits, but had remained uncorrected or had recurred repeatedly.

The conditions in these homes will not change without a significant change in the effectiveness of enforcement of the laws and regulations already on the books. The Commission believes that this requires a strong commitment from both OMH and DSS to the correction of entrenched problems that have persisted in the decade since the enactment of the legal reforms. In particular, the Commission believes that the long-term viability of adult homes serving significant numbers of residents with mental illness is contingent upon more consistent assurances that the needs of patients discharged from psychiatric hospitals can be met with the level of care provided by adult homes. Equally important, appropriate and effective outpatient mental health services must be available to meet their needs for treatment and psychiatric rehabilitation.

The Commission is gratified to note that, following the circulation of a draft of this report to OMH and DSS, a Task Force on Enforcement, convened and chaired by the Deputy Secretary to the Governor for Human Services, has been formed to coordinate agency efforts to correct the deficient conditions at the adult homes with the most serious problems. The Commission will be participating actively with OMH and DSS in this effort.

The findings, conclusions and recommendations contained in this report represent the unanimous opinions of the members of the Commission. A draft of this report has been reviewed by DSS, OMH and the State Office for the Aging. Their responses to our recommendations are appended to the report.



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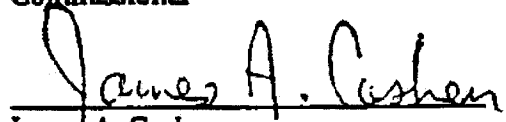

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ACKNOWLEDGEMENTS

The assistance of many persons and agencies were critical to the Commission's completion of this study. Throughout the course of the study, the Commission received the cooperation of the Division of Adult Services of the Department of Social Services. The Division made available information that was requested by the Commission, entered into a memorandum of understanding to facilitate the gathering of data directly from the homes, and interceded promptly to resolve the few problems with access to the homes as they arose.

The Commission is also grateful to the operators, staff, and residents of adult homes who accommodated our visits, answered our questions, and generally helped us to understand both the strengths and the limitations of adult homes serving persons with mental illness. The Commission would especially like to thank the number of long-time advocates for persons in adult homes, including representatives of the Coalition for the Institutionalized Aged and Disabled and Mobilization for Youth Legal Services, for their insights and for their assistance in arranging informal forums for the Commission with residents of adult homes.

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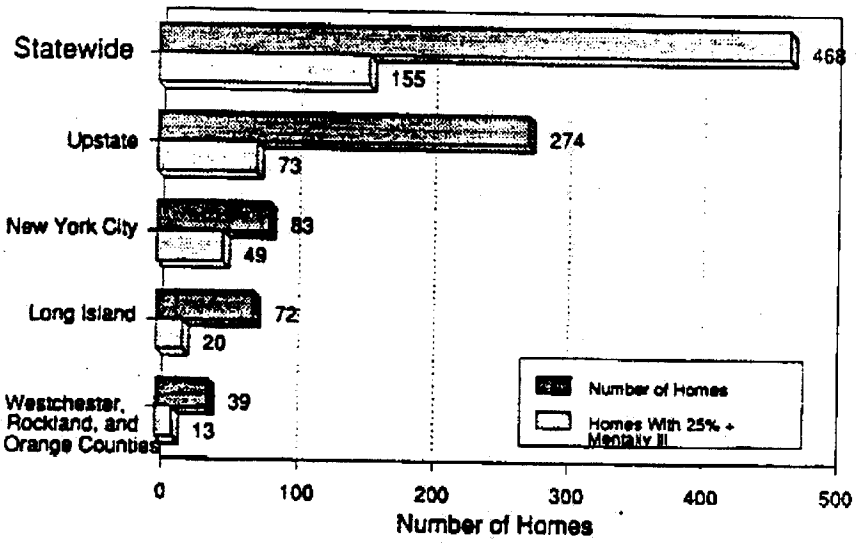
Introduction

In the wake of reports by Special Prosecutor Charles Hynes on conditions in adult homes,* the Legislature enacted Chapter 669 of the Laws of 1977. Recognizing the special needs of the residents with mental disabilities in these homes, this law requires the joint visitation and inspection by both the Department of Social Services and the then Department of Mental Hygiene of adult homes in which a significant number of residents have a mental disability. It also allows the Department of Mental Hygiene to propose supplementary standards for these homes. In September 1978, the Department of Social Services promulgated regulations (18 NYCRR §485.5) which further authorized the Offices of the Department of Mental Hygiene, including the Office of Mental Health, to carry out these responsibilities.

In the spring of 1989, the Legislature asked the Commission to review such adult homes and the effectiveness of the implementation of this program of joint visitation and inspection by the Department of Social Services and the Office of Mental Health in regulating and monitoring these programs. As a backdrop to this request, it is important to point out that adult homes are a major supervised housing resource for persons with mental illness in New York State. (Figure 1) As of July 1989, approximately 155 of the 468 adult homes statewide report that at least 25 percent of their resident population have a significant mental illness.**

Figure 1: Number of Adult Homes in NYS Serving Many Persons With Mental Illness



*_Private Proprietary Homes for Adults, An Interim Report_, Charles J. Hynes, Deputy Attorney General, March 31, 1977.

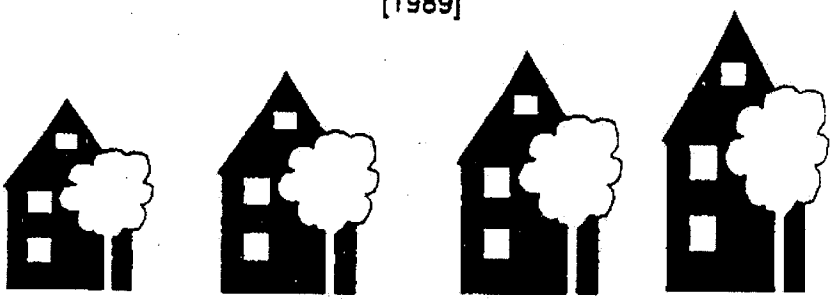
Private Proprietary Homes for Adults, Charles J. Hynes, Deputy Attorney General, March 31, 1979.

**The July 1989 _DSS Congregate Care Facility Directory_ identifies 155 adult homes whose resident population includes at least 25 percent persons with mental illness. In 1988 DSS reported data indicating that 150 adult homes statewide met this criteria. As most fiscal data presented in the report covers the period 1986-1988, the most recent period for which financial data were available, these sections of the report focus on these 150 homes, and especially the 147 of these homes where financial statements were available.

From another perspective, the nearly 9,000 persons with mental illness living in adult homes statewide comprise over one-third (36 percent) of the total 25,000 residents of adult homes. By comparison, approximately 9,500 persons with mental illness are afforded supervised residential care in the Office of Mental Health's community residence, apartment, and family care programs.

It is also important to note that funding for adult homes, limited to the residents' Supplemental Security Income (SSI), Social Security Disability (SSD), Home Relief (HR), and Social Security Assistance (SSA) payments, is markedly lower than for other publicly subsidized supervised facilities, like nursing homes, health related facilities, and the Office of Mental Health community residences. The standard SSI amount for the support of a resident in an adult home for one year is approximately $8,500;* for a resident in a community residence for the mentally ill for a year, public funding is approximately $24,300. The public costs of care in health related facilities and skilled nursing facilities are even higher at approximately $27,800 and $43,000 annually per resident, respectively. (Figure 2) While many adult homes serving persons with mental illness often have few private-pay residents, the Department of Social Services' data indicate that only 10 percent of the residents in these homes are private-pay residents.

Figure 2: Average Annual Per Resident Public Funding to Supervised Residential Care Settings*
[1989]



*Public funding excludes residents' personal allowance.

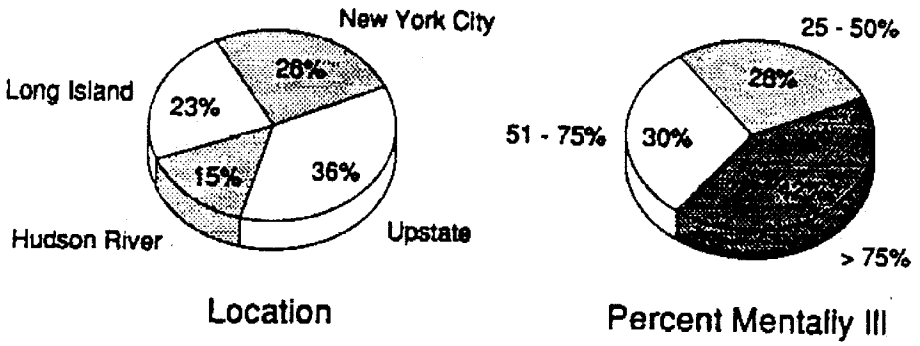
*As of January 1, 1990, an individual residing in an adult home in New York City, Nassau, Suffolk and Westchester Counties is entitled to a yearly Supplemental Security Income (SSI) benefit of $9,852, and in the rest of the State, $9,492. Of these respective amounts, the adult home operator receives $8,832, or $8,472 for residential care, and the resident receives $1,020 ($85 per month) allowance for his/her personal needs. The public portion of SSI payments may be reduced by "countable income" received by a recipient during any calendar quarter from earnings or unearned sources (e.g., public or private pensions), but the home receives such income up to the standard SSI amount. Homes may also receive payments above the SSI amount from "private-pay" residents who have income or resources that make them ineligible for SSI benefits.

Methods

Consistent with their lower level of public funding, the expectations and requirements imposed upon adult homes are different and generally less demanding than upon facilities with higher levels of reimbursement. Unlike skilled nursing facilities, health related facilities and community residences, adult homes are not a treatment facility and are required neither to have a professional staff (e.g., nurses, psychologists, therapists, etc.), nor to provide nursing, medical, or habilitative services. Rather, they are expected to provide room and board, limited personal care, case management and supervision, and assistance to residents in attending to their own needs and in accessing and using appropriate community services.

The Commission made unannounced inspections to 47 of the 155 adult homes which serve many residents with mental illness. This sample of 47 adult homes represented a diverse group of small, medium, and large homes, and homes located in cities, in suburban neighborhoods, and in rural areas. The Commission also shaped its sample to be geographically representative, including more homes downstate, where adult homes serving the largest numbers of persons with mental illness are located. We also visited homes which almost exclusively served persons with mental illness and others which served a more integrated population. (Figure 3) During these inspections, Commission staff reviewed living conditions and services for residents. Photographs were taken to document observations and, where appropriate, the consent of residents was obtained. Additionally, written reports of the Commission's findings for each adult home studied were prepared and sent to the appropriate officials within the Department of Social Services and the Office of Mental Health, as well as to the adult home operators.

Figure 3: Characteristics of Adult Homes Visited [N=47]



During the on-site visits, the Commission also interviewed 144 mentally ill residents in these homes and reviewed their records, a random sample assuring a 90 percent statistical confidence level. Data related to the medical and mental health services afforded to these residents, as well as their daily living skills and social rehabilitation needs, were also obtained from interviews with the adult home administrator and/or other responsible staff persons in the homes.

From a fiscal perspective, financial statements for homes serving many residents with mental illness were requested, and available reports from 147 of these homes were obtained to examine the profitability, costs, and staffing of adult homes. The Commission also analyzed balance sheets for 20 of these homes to obtain a fuller understanding of the "profitability" of adult home operations with particular attention to the equity the operators had invested in the homes.* Additionally, fiscal staff conducted on-site reviews of financial records at ten adult homes to determine the reliability of the financial reports submitted.

Who Lives in Adult Homes?

The Commission recognized that fundamental to assessing the performance of adult homes serving many persons with mental illness was an understanding of the level of assistance, supervision, and services these individuals require. State regulations for adult homes, as well as public funding levels for these homes, assume that their residents are in need of basic custodial care, some assistance with personal care, moderate supervision and the support of appropriate community services, but that they are not in need of the more intensive services provided by the more expensive supervised models of care offered by the state, including mental health community residences, health related facilities, and skilled nursing facilities.

The Commission's sample of 144 persons with mental illness living in adult homes revealed that, while a diversity of men and women with mental illness reside in adult homes, both young and old, a significant percentage of these persons were substantially dependent on staff to perform daily living tasks and to obtain needed medical and mental health services.

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*Pursuant to New York Social Services Law, §461-e, financial statements setting forth information pertaining to the operations of adult homes, including revenues, expenditures and other data, must be submitted each year to the Department of Social Services. Of the 150 homes whose resident population in 1988 included at least 25 percent persons with mental illness, three homes failed to submit financial statements during the three-year period. Balance sheets recording homes' assets, liabilities and operators' equity are not required to be filed, but the Commission requested these statements from the 47 homes in the site visit sample. Twenty (20) of the operators complied with this request.

SELECTED RESIDENTS* OF THE ADULT HOMES

Jack Canter is 62 years old, and he has been a resident of an adult home for eight years. Prior to this admission, Mr. Canter had been hospitalized in a state psychiatric center for approximately four years. Mr. Canter has a psychiatric diagnosis of schizophrenia, paranoid, chronic with acute exacerbations, and currently he is being treated with the psychotropic medication Moban. Reportedly, Mr. Canter has a fixed delusional system which causes him to be disoriented to time and place. Additionally, Mr. Canter suffers from several medical conditions including seizures, ulcerated legs, and arteriosclerotic heart disease. Due to his medical conditions, at times, Mr. Canter requires staff assistance to ambulate. According to adult home staff, Mr. Canter can be verbally abusive toward others. Adult home staff also reported that Mr. Canter has been awaiting placement in an HRF/SNF since February 1989.

Mildred Johnson is 82 years old and she has been a resident of an adult home for nine years. Prior to this admission, Ms. Johnson had been hospitalized in a state psychiatric center for over 35 years. Ms. Johnson is diagnosed as having schizophrenia, catatonic, in remission, and currently she is not being treated with psychotropic medication; however, she does attend a geriatric mental health program. Medically, Ms. Johnson suffers from anemia and hypertension.

George Edwards is a 57-year-old mildly retarded man and he has been a resident of an adult home for six years. Prior to this admission, Mr. Edwards lived at home with his mother. Since his admission to an adult home, Mr. Edwards had to be hospitalized in a state psychiatric center for a period of 35 days and was diagnosed as having atypical psychosis. Currently, Mr. Edwards is being treated with the psychotropic medication, Mellaril; however, adult home staff report that Mr. Edwards frequently refuses to take his medication. Reportedly, Mr. Edwards has poor personal hygiene skills, is assaultive toward others, and exposes himself. Mr. Edwards' careless smoking habits also reportedly pose a fire hazard to the home's residents and staff. At the time of the Commission's review, Mr. Edwards was being referred to a community residence. If this referral was not successful, the adult home administrator stated that he may be evicted from the home.

Joanne Day is 50 years old and she has been a resident of an adult home for approximately four years. Prior to this admission, Ms. Day lived with her husband in their own home. Ms. Day is diagnosed as having schizophrenia, paranoid type, and she is being treated with the psychotropic medication, Haldol. Reportedly, Ms. Day participates in both on-site and off-site recreational/leisure activities, and she regularly receives mental health services from the on-site mental health program. According to adult home staff, Ms. Day is fairly independent; however, she requires assistance with her personal hygiene care.

Daryl Tucker is 28 years old, and he has been a resident of an adult home for approximately four years. Mr. Tucker carries a joint diagnosis of schizotypal personality disorder and attention deficit disorder, and he is being treated with the psychotropic medications, Mellaril and Klonopin. Reportedly, Mr. Tucker has poor personal hygiene skills, exhibits bizarre and ritualistic behavior, and is an episodic alcohol abuser. According to adult home staff, several agencies have been involved in attempts to assist Mr. Tucker with his problems without success.

Arlene Davis is a 50-year-old articulate woman, and she has been a resident of an adult home for approximately two years. Prior to this admission, Ms. Davis lived independently in her own apartment. Ms. Davis has a psychiatric history of chronic depression and recurring psychosis, and she periodically hallucinates and evidences delusional thinking. Ms. Davis is currently being treated with the psychotropic medication, Haldol, and she attends off-site mental health clinic services. According to adult home staff, Ms. Davis spends her entire day in the home, but she will participate in several on-site groups during the week.

*All resident names have been changed to protect their confidentiality. Residents reflect a cross section of the residents in the Commission's sample.

Approximately two-thirds of the population was over 55 years of age, although the significant minority of younger residents under 35 (8 percent) often stood out to the casual visitor. Additionally, residents with mental illness in downstate homes tended to be significantly younger than residents of upstate homes. Whereas 39 percent of these residents in downstate homes were under 55, only 18 percent of these residents in upstate homes were under 55.

Almost all residents in the sample carried a major psychiatric diagnosis, and while few had signs or symptoms of acute psychiatric illness (e.g., a recent suicide attempt, dangerous or bizarre behavior, hallucinations, etc.) at the time of the Commission's review, more than one in three residents had been hospitalized for a psychiatric condition in the past two years. Additionally, all but a few residents were receiving at least one psychotropic medication and some outpatient mental health services to treat their ongoing mental illness. (Figure 4)

Nearly three-fourths of the residents (72 percent) in the sample also had a concomitant medical condition, including hypertension, heart disease, respiratory disease, diabetes, and genitourinary/gastrointestinal disorders. Most of these residents were scheduled to see a physician at least monthly, and the majority were also receiving medications for their medical condition(s). In contrast, reportedly only 5 percent of the residents in the sample currently had an alcohol or drug abuse problem, largely because most operators of adult homes refused admission to individuals with such problems.

Figure 4: Clinical Characteristics of Persons With Mental Illness Living in Adult Homes [N=144]

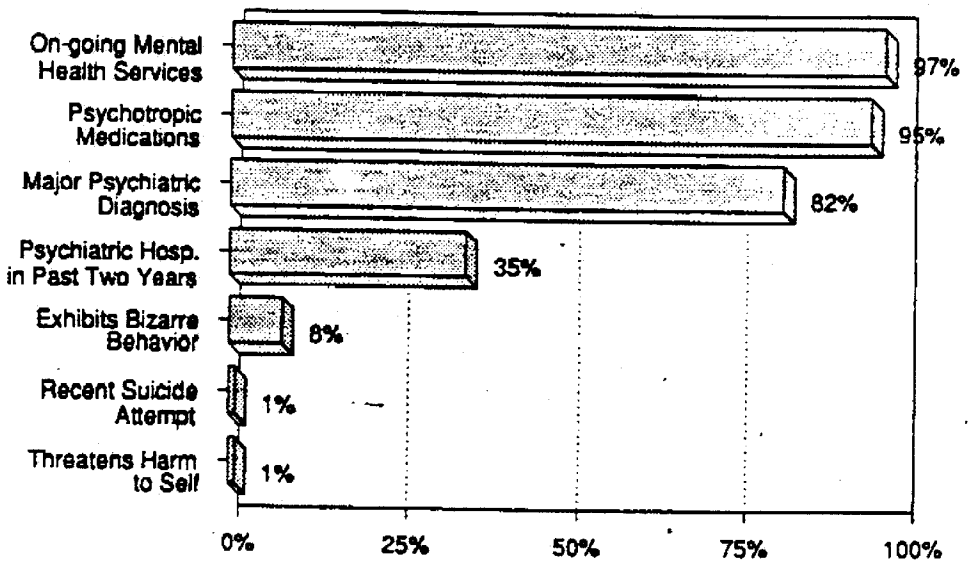
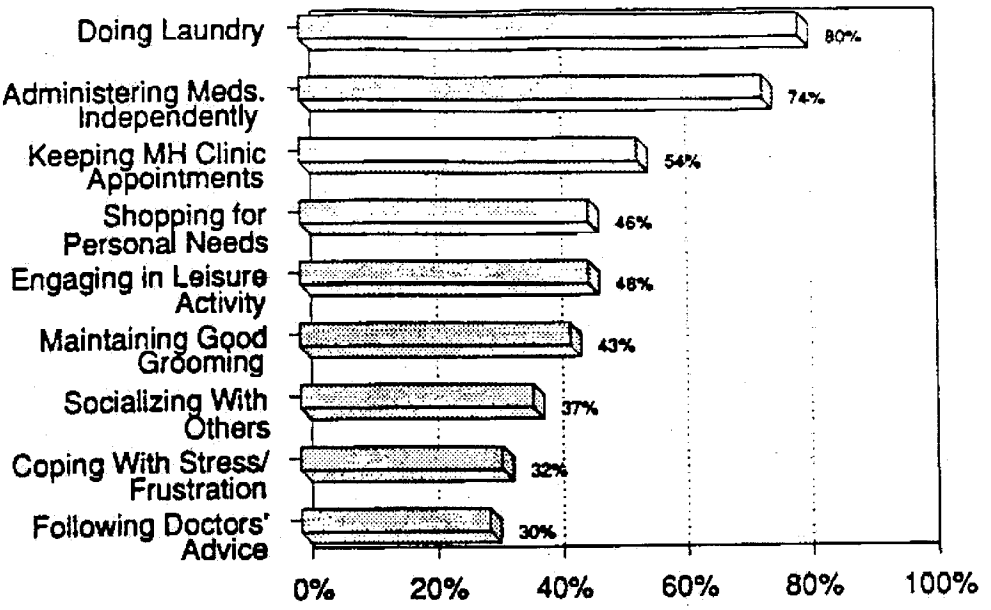


Figure 5: Skill Deficits of Persons With Mental Illness Living in Adult Homes [N=144]



The data also showed that most persons with mental illness living in adult homes had not lived independently for a number of years. Overall, 69 percent of the residents sampled had lived in the adult home for at least three years, and only 6 percent of the residents had resided independently immediately prior to moving to the adult home. More than half of the sample (54 percent) had previously been on an inpatient psychiatric unit, while another 27 percent had previously lived in another supervised care setting, like another adult home, a family care home, a community residence, or a health care facility.

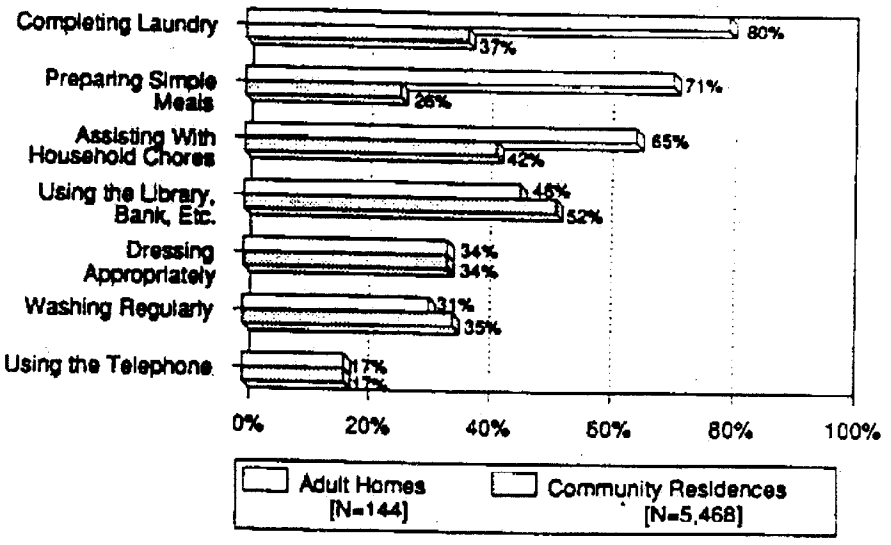
According to adult home staff, many of the residents in the sample also had deficits in basic personal care skills, like doing laundry, shopping for personal needs, and maintaining a good personal appearance. Over one-third of the residents were also described as having problems using community resources, managing their money, and advocating for their own needs. Most residents also required assistance with administering their own medications, keeping their mental health clinic appointments, and/or following through on doctors' advice. Many also had difficulty engaging in leisure activities, socializing with others, or coping with stress or frustration. Notably, in some cases it was not possible to determine whether the residents' difficulties in these areas were perpetuated because they had little opportunity to utilize these skills in the adult homes where they lived. (Figure 5)

By design, a part of the Commission survey tool used to review the 144 adult home residents with mental illness mirrored a portion of an Office of Mental Health's instrument, the Client Characteristic and Needs Survey, used by the agency to assess persons living in its community residence programs. Data from this section of the survey tool were used to compare the profile of residents with mental illness living in adult homes with residents living in the mental health community residence programs.

As shown in Figure 6, this analysis showed that residents of adult homes tend to be less likely to have signs of acute mental illness than residents of community residences. Simultaneously, however, residents of adult homes were more likely to evidence the debilitating signs of chronic mental illness, including significant deficits in basic daily living skills. For example, residents of adult homes were more likely than residents of community residences to be assessed by home/residence staff as unable to do their own laundry, assume responsibility for household chores, and prepare simple meals. In other basic skill areas, like washing regularly, dressing appropriately, and using the telephone correctly, the profile of adult home residents was remarkably comparable to that of community residence clients.

Other significant differences between residents of the two types of care facilities included age and length of stay. The sampled residents of adult homes were more likely to be over 55 (67 vs. 10 percent) and to have resided two years or longer in the adult home (69 vs. 24 percent) than their counterparts in community residences.

Figure 6: Skill Deficits of Persons With Mental Illness in Adult Homes vs. Community Residences



Inside Adult Homes

Homes with "Good" Conditions

As described earlier, the Commission's sample of 47 homes represented a geographically diverse array of homes of different sizes and resident composition. The diversity of the sample, however, hardly prepared us for the extent of variation in conditions we witnessed. (Figure 7) (See also Appendix A.) In 19 of the 47 homes, or 40 percent, conditions were very good, with few significant deficiencies, and 11 of these homes had no significant deficiencies in any of the areas reviewed. From their exterior maintenance to their inside environments, these homes evidenced the care and attention of their owners and staff. Furnishings were well maintained, comfortable, and attractive; housekeeping was outstanding; and staff conscientiously attended to fire and safety precautions. These homes were equally impressive in their attention to residents' personal care needs for proper hygiene, grooming, and dress, and in their attention to appropriate medication administration practices.

These homes also provided a variety of activities for residents and encouraged residents to use community resources. Most importantly, staff showed respect for residents, not only in ensuring basic residents' rights, but more obviously in their ongoing interactions with the people who lived in their home. These homes provided examples of the potential of adult homes to provide a safe, comfortable residence at a reasonable cost. Notably, they represented a cross section of homes across the state.

Figure 7: Conditions in Adult Homes Visited [N=47]